Living in Norfolk with Dementia: A Health and Wellbeing Needs Assessment

Full report

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With thanks to HealthWatch Norfolk and the Dementia Needs Assessment Steering Group

Date: July 2014
Dear family and friends
Please try to understand
What I am now, not think of me
   As I was.
I am alone, shut in
   With my fears
My frustrations
My forgetfulness.
Forgive me if I strike out at you.
   Why do I do that?
What has happened to me?
I cannot cope with this alien world.
I feel threatened. I am frightened.
Speak softly, approach slowly.
Repeat again and again what you want of me.
Those twisted tangles in my brain
   Have messed up my world.
Be patient, for I do love you,
And I need your help and love,
   So very, very much.
Your Alzheimer Patient.
   Joy Glenner
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Dementia needs assessment for Norfolk, 2014

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Executive summary

Dementia currently affects 800,000 people in the UK (equivalent to the population of Newcastle and Sunderland) and it will rise to 1 million by 2021. It costs the UK society an estimated £23 billion per year. However the statistics miss the unique life stories of individuals, carers, family and friends. Each with their own journey, challenges, good times and bad. Over the past 10 years in Norfolk, dementia has come a long way but there is still much to be done. The momentum that has been built from the many achievements to-date now needs concrete progress as Norfolk strives to become a Dementia Friendly county.

This report describes the needs of people with dementia and their carers in Norfolk and makes recommendations to further improve services. The aim is to systematically review the health issues facing individuals with dementia and their wider social network, leading to actions that will improve diagnosis and care for individuals with dementia and their carers. It is aimed at commissioners, providers, voluntary organisations, strategic bodies, people with dementia and their carers.

The report has been produced by 1) reviewing data, 2) evaluating research, strategies, national documents and examples from other areas and 3) speaking to people with dementia, carers and professionals, in addition to visiting a number of different organisations along the dementia pathway.

Key facts include
- An estimated 16,400 people in Norfolk have dementia (either diagnosed or undiagnosed). Equivalent to 1 in every 53 people in Norfolk or the populations of Cromer, Hunstanton and Holt combined.
- Great Yarmouth and Waveney Clinical Commissioning Group (CCG) has the highest number of people with dementia reflecting its larger population.
- North Norfolk CCG has the highest proportion of people with dementia.
- There are about 26 new cases of dementia per year per 1000 population of over 65s in Norfolk (diagnosed or undiagnosed). That equivalent to about 78 new people getting dementia in Wymondham per year.
- The incidence of dementia increases as age increases, but is not a natural part of ageing.
- Just over half of people with dementia have mild dementia and remaining have moderate or severe disease.
- About two thirds of people with dementia live in the community compared to long term care.
- Over the next 20 years there will be an estimated additional 9,000 people with dementia. That is equivalent to the whole population of Downham Market. The greatest growth will be in people over 90 years old.

Community Development

People with dementia find it hard to feel part of, and participate in, their community. In Norfolk, the first town to take part in the Dementia Friendly Communities programme was Wymondham followed by Swaffham and Diss with plans developing for other towns. Other important communities were identified including social networks (e.g. friends and family), support groups (e.g. day services and dementia cafes), community groups or clubs, workplaces and ethnic, cultural or faith communities. The community of carers is equally important.
People with dementia and their carers identified several attributes they wanted from their community which included awareness, support groups, clearer information, a supportive physical environment, activities at the right level, good transport and local amenities. A mapping exercise showed where services are distributed throughout Norfolk.

**Timely diagnosis**

Feedback from people with dementia and carers suggest that they would like to know their diagnosis. Diagnosis is not an end in itself, but a gateway to allow people with dementia and their carers to make informed decisions about the future. Nationally the average person waits three years from the onset of symptoms to receiving a diagnosis.

The diagnosis rate in Norfolk and Waveney 2012/13 was 43.2%, meaning that 56.8% of people with dementia remained undiagnosed. Great Yarmouth and Waveney CCG has the highest diagnosis rate (49.6%) and West Norfolk CCG has the lowest (35.3%). Across the county diagnosis rates vary from 13% to 123% (23% more diagnoses than estimated cases). Only 6% of practices diagnose more than two thirds of people with dementia and 30% of practices diagnose less than one third. There needs to be a step change in the diagnosis rate if the national NHS England target of 67% is to be reached.

There appears to be no relationship between living in a rural area or being deprived and having a diagnosis of dementia.

Barriers to diagnosis include a perceived lack of support, the absence of a cure, lack of understanding among GPs about the diagnostic pathway and a lack of an accepted diagnostic tool.

A literature search found a lack of evidence based solutions to improving diagnosis. One study found that improving quality of coding in GP practices resulted in dementia recorded diagnosis increasing by 8.8% and it took practices on average 4.7 hours.

**Support for people with dementia and their carers**

Support is necessary for both the person with dementia and their carer to prepare for a diagnosis, come to terms with the condition and manage the progression of symptoms. With good support a person with dementia is able to maintain their unique sense of identity and self-worth.

A recent evaluation of the Admiral Nurses pilot in mid-Norfolk showed positive results with potential benefits to health and social care.

The National Institute of Health and Care Excellence recommend cognitive stimulation for all people with dementia. However there are only a limited number of groups in Norfolk.

In general slightly less than one in eight people in Norfolk provided unpaid care for someone else in 2012/13. North Norfolk is the area with the highest proportion of unpaid carers. Only one in 16 of these carers undergo a carer’s assessment.

End of life care is an important part of someone’s dementia journey. A number of community health services provide end of life care. Discussion with hospital staff revealed a lack of capacity
within community services to allow expedited discharge for people with dementia to allow them to die at home.

Discussion with people with dementia and their carers suggests a lack of knowledge and information about legal support.

Generally people with dementia and their carers felt the quality of services when received was good, but that there remain capacity issues. Gaps identified were in relation to accessible information, services targeted to specific stages of dementia, variation in provision, care needs of the carer, respite, support from GPs, personal care services, home carers, Accident and Emergency (A+E) services, out of hours services, support for people who are employed and lack of a central point of contact.

People with dementia often have other medical problems or a dual diagnosis (e.g. dementia in Parkinson’s disease). These need to be incorporated into the service delivery of person centre care.

Data from Norfolk Constabulary suggest that the number of victims of crime and non-crime events relating to domestic abuse is increasing in over 65 year olds. Anecdotal evidence suggests that this may be due to dementia; either a true increase or an increase in reporting.

Primary and community healthcare services

There has been a change in community mental health services over the past few years. The establishment of the Dementia Intensive Support Teams (DIST) has aimed to provide community health care closer to a person’s home. The formation of the DIST has resulted in more episodes of patient management compared to mental health hospital admissions. However there remain questions about whether the DIST currently have sufficient capacity, is consistently delivered across the county and if the current number of dementia assessment beds is right.

Staff identified the following issues with current service provision; lack of age and stage specific services, more proactive services, lack of information, lack of continuity of care, lack of understanding around the diagnostic pathway, lack of overnight services and more training for GPs.

Focus group discussions revealed high satisfaction with the quality of service received from the ambulance service.

The number of people over 65 years old who have been reported missing has increased in the past 2 years. The estimated cost of missing people because of dementia is £136,000 in 2012/13 and £176,800 in 2013/14. A number of assistive technologies have come to market to help prevent missing persons.

People with dementia and their carers expressed a desire to have a single point of contact, rather than contacting multiple different agencies. A dementia adviser, dementia support worker or Admiral Nurse, or similar, may be able to provide this single point of contact and help to provide a joined up integrated service.
Secondary healthcare services

About 1 in 3 to 1 in 5 people in hospital have dementia. The proportion of emergency admissions for those aged 65 years and older with dementia recorded as a co-morbidity has increased over the past decade. West Norfolk CCG has a significantly higher rate of such hospital admissions compared with other CCGs.

Some people with dementia stay in hospital for longer than they should. Possible reasons for delayed discharges include delays in organising social care, Continuing Health Care Assessments, cancelled home care, lack of community services and lack of service provision over the weekend. There were positive and negative themes about hospital admission. Areas for improvement included reducing frequent moves between wards, inappropriate admissions, access to specialist support and Accident and Emergency departments. The FAIR CQUIN (also known as memory matters) was generally felt to be a good scheme.

There are between 400 and 550 referrals each month for the DIST and Community Mental Health Teams. About half of referrals are in the central Norfolk region, a quarter in west and a quarter in east. Approximately 73% of people who attend a memory assessment centre in Norfolk received a positive diagnosis. There are currently 15 dementia assessment beds located in Norwich for the whole county. Roughly three are reserved for west Norfolk patients, three for east Norfolk and nine for central Norfolk.

Medicines management and prescribing

There are currently four drugs which are recommended as options for managing Alzheimer’s disease. All four drugs are used across Norfolk. There is over £1000 difference in 1 year’s treatment cost between the cheapest (donepezil tablets) and the most expensive (galantamine modified release capsules). There appears to be a larger use of rivastigmine in West Norfolk CCG compared to other CCGs. West Norfolk CCG spends the most per patient (£204 per patient) compared. North Norfolk CCG spends the least (£125 per patient). Improvements appear to have been made in the prescribing of antipsychotics.

The Medicines Use Review service is under-utilised and often not accessed by those who need it the most. Reports from pharmacists suggest that people with dementia are often discharged by acute hospitals without enough information. Another issue highlighted was the lack of information and processes for pharmacists to signpost to other services.

Social care and housing, including care homes

Often unpaid caring is a 24 hours a day, seven days a week, 356 days a year job with little respite. It is estimated that unpaid carers of people with dementia save the UK government £8 billion every year.

Discussions with professionals identified a number of issues with current social care system. These include lack of information and advice at an early enough stage (especially for self-funders), lack of funding, strict eligibility criteria, lack of appropriate respite, long waiting times, lack of community services and lack of integration.
North Norfolk CCG has the highest number of people with dementia in care homes. Many people with dementia do not have an opportunity to visit the care home before admission. 40.8% of people self-fund nursing or residential care.

A fifth of care homes in Norfolk which cater for people with dementia did not meet the Care Quality Commission standards from March 2013 to July 2014. Common areas of concern for dementia care homes in Norfolk were 1) caring for people safely and protecting them from harm, 2) staffing, 3) quality and suitability of management and 4) providing care, treatment and support that meets people’s needs. Feedback from professionals highlighted the following areas for improvement include stigma, variation in quality, involvement of community mental health teams, activities, quality of staff and respite.

Housing reports suggest that good housing for people with dementia can reduce or delay demand for health and social care services, can improve diagnosis rates and can improve health and social care outcomes. Norwich City Council is considering a Dementia Adaptations Scheme which would improve housing for people with dementia.

**Workforce**

There are multiple different levels of specialist dementia staff including, Dementia Care Coaches, Admiral Nurses, dementia advisers, dementia support workers and dementia leads.

A survey by the University of East Anglia found that 92% of hospital staff felt that they had insufficient training overall in relation to dementia. Particular deficiencies were reported in appropriate communication skills, assessing cognition, dealing with aggressive behaviours and recognising pain. Knowledge of the Mental Capacity Act (2005) was identified as a gap by the majority of respondents.

Discussion with professionals identified the following issues, workforce development is key, care home staff and domiciliary carers need more training, recruitment is important, there is a need to get the timing of training sessions correct and there should be a focus on training outcomes rather than numbers.

Health Education England is likely to commission a ‘tiered approach’ to training with differential levels of competence achieved. Norfolk and Suffolk Dementia Alliance have locally developed the Dementia Care Coaches model. The interactive programme trains individuals to a high standard of competence in order for them to train other people in their organisation and their ‘sphere of influence’.

A tiered approach to workforce is also required to provide a comprehensive service across Norfolk. This may include a combination of dementia advisers, dementia support workers and Admiral Nurses, or similar.

**Inequalities**

The quality and extent of services provided to people with dementia depend on who they are and where they live. There are also certain groups who receive a poor service because they have a dual diagnosis. Unfortunately dementia services do not appear to regularly collect ethnicity, sexual identity, disability or religion information.
There does not appear to be an association between having dementia and being deprived.

In Norfolk 1 in 44 over 65 year olds are non-white British. There is some evidence that people from black, Asian and minority ethnic groups (BAME) suffer dementia at a younger age and generally are less likely to access statutory services.

The number of older people from lesbian, gay, bisexual or transgender (LGBT) communities is likely to increase in the future. Older LGBT people are more likely to be single and live on their own compared to heterosexual people.

Approximately 15,000 people over 65 years attend a church in Norfolk. The 2011 census suggest that the majority of people in Norfolk consider themselves to be either Christian or have no religion. There are examples of dementia friendly faith groups.

Feedback from discussion with professionals and stakeholders identified other groups who are at risk of inequalities including self-funders, people who live in rural areas, those with co-morbidities and those without social support.

**Recommendations**

Based on the above assessment the following recommendations have been made.

1. Information and support for people with dementia and their carers
   a. Within the first 6 months of diagnosis comprehensive information and advice should be given to people with dementia and carers about current and future services, including likely eligibility thresholds.
   b. Clinical Commissioning Groups should ensure that GPs are aware of available support. For example using a web-based road map or information sheet located in each consultation room.
   c. Web and print directory of dementia services that allows users and providers to contribute should be produced by commissioners. This should be a new partnership county-wide website produced jointly with Norfolk County Council care directory, Heron database, Norfolk and Suffolk Dementia Alliance and Clinical Commissioning Groups.
   d. Norfolk County Council and Clinical Commissioning Groups should ensure that people with dementia and carers who self-fund are able to access the same high quality information and advice as those who are eligible for social care support.

2. Support
   a. Dementia advisors, dementia support workers and Admiral Nurses, or similar, should be jointly commissioned by health and social care. Their scope and case load should be well defined. One of their key roles should be providing integrated comprehensive health and social care information during the first 6 months after diagnosis.
   b. Clinical Commissioning Groups should ensure that GP practices sign up to the GOLD driving scheme and GPs should encourage people with dementia to participate.
   c. The support and services offered by Independence Matters are currently under-utilised and should be promoted by commissioners and providers to people with dementia and their carers.
   d. Commissioners should consider a buddying-type scheme to match newly diagnosed people and carers with those who have been diagnosed for longer and carers.
e. GPs should be encouraged to refer people with dementia and carers to the Medicines Use Review service.

f. People with dementia who do not have an advocate should be given additional support from dementia advisors/support workers/Admiral Nurses, or similar.

g. Carers should be encouraged to undertake carers training after diagnosis

h. More carers should be encouraged to have a carer’s assessment.

i. Norfolk County Council, Clinical Commissioning Groups, providers and voluntary organisations should work together with Parkinson’s Pathway Group to agree a common carer’s pathway.

j. Commissioners and providers should work together to help more people with dementia die in their place of choice.

3. Making Norfolk Dementia Friendly

a. All pharmacies, libraries and transport providers should become Dementia Friendly.

b. Dementia Friendly Communities should extend to non-geographical communities.

c. Efforts should be made to ensure that the Dementia Friendly Communities programme does not increase variation and inequalities.

d. Norfolk County Council should encourage dementia teaching in schools and identify a local school to be a dementia champion.

4. Timely diagnosis

a. Clinical Commissioning Groups should assist GP practices to standardise dementia coding and undertaking coding audits.

b. Clinical Commissioning Groups should use the Dementia Partnership principles to improve timely diagnosis.

c. Clinical Commissioning Groups and mental health providers should explore primary care based assessment clinics.

5. Planning services

a. Norfolk County Council, Clinical Commissioning Groups and providers should adopt a co-production model of accessible service design and delivery.

b. Norfolk County Council and Clinical Commissioning Groups, providers and voluntary organisations should use the dementia prevalence map to plan health, social care and transport services.

c. Norfolk County Council and Clinical Commissioning Groups should ensure that there are services tailored to the age and stage of dementia.

d. Commissioners and providers should work together to ensure more cognitive stimulation is provided, including continuation groups afterwards.

e. Commissioners and providers should work together to ensure people with a dual diagnosis do not fall between services.

f. Norfolk County Council should commission more respite which is flexible, offers choice and includes expansion of domiciliary respite. Commissioners and providers should work together to make respite more affordable.

g. Norfolk County Council and Clinical Commissioning Groups should commission more activity-based groups for people with dementia.

h. Commissioners and providers should ensure that current and future services are accessible to service users and carers of different ethnic groups, religions and lesbian, gay, bisexual and transgender communities.

i. Commissioners and providers should collect information about users in accordance with the Equality Act 2010 to ensure services are equitable.
6. Training
   a. Training provided should focus on the outcome of successfully delivering person-centred care, rather than numbers attending training.
   b. Providers, especially acute hospitals, community healthcare, care homes and domiciliary care organisations, should include essential dementia skills and knowledge in their job specifications when recruiting staff.
   c. Providers and commissioners should work with the Norfolk and Suffolk Dementia Alliance in order to develop their workforce in accordance with the “dementia dozen”.
   d. Providers should use the Dementia Care Coaches model for workforce development.
   e. Providers should ensure that staff are sufficiently knowledgeable about the Mental Capacity Act (2005) and Mental Health Act (1983 amended 2007).
   f. Providers should ensure that frontline health and social care staff are trained in cultural competence.
   g. Commissioners and providers should not consider Dementia Friends training as sufficient for health and social care staff.

7. Integration
   a. Commissioners and all providers throughout the dementia pathway should work together to develop joint referral pathways and where appropriate agree tools. This approach should be county-wide, but modifiable for local differences. This should include review of the shared care agreements.
   b. Acute trusts should share learning, examples of good practice and expertise in older people’s medicine across the county.
   c. Norfolk Constabulary, health services and adult social care should work together to identify people at risk of going missing and intervene early within integrated pathways.

8. Secondary care
   a. In 2015 an independent review should take place of the current provision of dementia assessment beds, including comparison with other comparable areas and localities, to assess if the current provision is adequate.
   b. Acute hospitals should adopt the King’s Fund principles for Enhancing the Healing Environment for wards looking after people with dementia and specific areas within A+E and acute assessment units.
   c. People with dementia admitted to an acute hospital as an emergency should receive a comprehensive multi-disciplinary team review including social work and consultant involvement within 24 hours and make every effort to ensure that the patient goes to the right ward first time.
   d. All patients with dementia should have their nutritional needs assessed and immediate action taken where appropriate.
   e. Acute hospitals should ensure that discharge letters of people with dementia accurately reflect medications on discharge and any reasons for medication changes.
   f. People diagnosed in neurology or older people’s medicine should be referred to mental health memory services for further support requirements.

9. Personal care and housing
   a. Norfolk County Council should commission a comprehensive Flexible Dementia Support Service for people with dementia who have a crisis which is free at the point of use and also provide more night sitters.
   b. Care First system should have a section to record dementia.
c. Clinical Commissioning Groups and Norfolk County Council should support the pilot of the Dementia Adaptations Housing Scheme. If successful it should be rolled out throughout the county.

10. Home carers
   a. The role of paid home carers should not be undervalued. Commissioners and providers should ensure they receive adequate dementia training and information, especially in relation to difficult behaviour.
   b. Providers of home carers should make every effort to ensure consistency of staff.

11. Care homes
   a. Care homes should be encouraged to conduct outreach in the community to destigmatise dementia, improve the image of care homes and help make Norfolk a dementia friendly county.
   b. Commissioners and supporting organisations should focus on improving the culture and leadership in care homes that have residents with dementia. Good examples of high quality dementia care and best practice in care homes should be shared.
   c. Care homes should be encouraged to sign the Dementia Pledge.
   d. All care homes with residents with dementia should agree to the Herbert Protocol.
### Abbreviations

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<th>Abbreviation</th>
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<tbody>
<tr>
<td>A+E</td>
<td>Accident and Emergency</td>
</tr>
<tr>
<td>BME</td>
<td>Black and minority ethnic</td>
</tr>
<tr>
<td>BAME</td>
<td>Black, Asian and minority ethnic</td>
</tr>
<tr>
<td>CCG</td>
<td>Clinical Commissioning Group</td>
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<tr>
<td>CQUIN</td>
<td>Commissioning for Quality and Innovation</td>
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<td>DH</td>
<td>Department of Health</td>
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<td>DIST</td>
<td>Dementia Intensive Support Team</td>
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<tr>
<td>DSR</td>
<td>Directly age standardised rate</td>
</tr>
<tr>
<td>ERPHO</td>
<td>East Region Public Health Observatory</td>
</tr>
<tr>
<td>ESRC</td>
<td>Economic and Social Research Council</td>
</tr>
<tr>
<td>FAIR</td>
<td>Find, Assess and Investigate, Refer</td>
</tr>
<tr>
<td>GP</td>
<td>General practice/General practitioners</td>
</tr>
<tr>
<td>GYW</td>
<td>Great Yarmouth and Waveney</td>
</tr>
<tr>
<td>GY</td>
<td>Great Yarmouth</td>
</tr>
<tr>
<td>HES</td>
<td>Hospital Episode Statistics</td>
</tr>
<tr>
<td>IC</td>
<td>Information Centre</td>
</tr>
<tr>
<td>ICD</td>
<td>International Classification of Disease</td>
</tr>
<tr>
<td>IMD</td>
<td>Index of Multiple Deprivation</td>
</tr>
<tr>
<td>JSNA</td>
<td>Joint Strategic Needs Assessment</td>
</tr>
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</tr>
<tr>
<td>LSOA</td>
<td>Lower super output area</td>
</tr>
<tr>
<td>MSOA</td>
<td>Middle super output area</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute for Health and Care Excellence</td>
</tr>
<tr>
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<td>National Institute for Health Research</td>
</tr>
<tr>
<td>NSF</td>
<td>National Service Framework</td>
</tr>
<tr>
<td>NSFT</td>
<td>Norfolk and Suffolk Foundation Trust</td>
</tr>
<tr>
<td>ONS</td>
<td>Office for National Statistics</td>
</tr>
<tr>
<td>PANSI</td>
<td>Projecting Adult Needs and Service Information System</td>
</tr>
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<td>PCT</td>
<td>Primary Care Trust</td>
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<tr>
<td>POPPI</td>
<td>Projecting Older People Population Information</td>
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<tr>
<td>QOF</td>
<td>Quality and Outcomes Framework</td>
</tr>
<tr>
<td>UL</td>
<td>Upper limit of confidence interval</td>
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I. Introduction

Dementia currently affects 800,000 people in the UK and it will rise to 1 million by 2021.¹ A third of people with dementia live in the community. One third of people over 95 years old have dementia. There are currently 670,000 carers of people with dementia in the UK. Dementia costs the UK society an estimated £23 billion per year.¹

However the statistics miss the individual life stories of individuals, carers, family and friends. Each with their own journey, challenges, good times and bad. One person with dementia and their carer who contributed to this report have overcome challenges with employment, diagnosis, attitudes of professionals, accessing information and advice and navigating through the system. There are over 16,000 people with dementia in Norfolk. Many of these will have similar experiences yet all different in their own way.

Dementia has come a long way over the past 10 years. There are a number of visionary and enthusiastic people and organisations driving the dementia agenda forward and much has been achieved. The Norfolk Dementia Strategy was launched in 2009 and ends in 2014.² This echoes the 17 principles of the national strategy, Living Well with Dementia.³ In 2012 the Norfolk and Suffolk Dementia Alliance was established to bring senior decision makers from organisations across the dementia pathway together. The Norfolk Health and Wellbeing Board, established in April 2013, chose dementia as one of its three priority areas alongside obesity and under-fives. The formation of five Clinical Commissioning Groups (CCGs) across Norfolk in April 2013 has established a new type of commissioner. This adds to the complexity of the health and social care landscape in Norfolk, with CCGs joined by seven district councils, one county council, three acute trusts, one mental health trust for both Norfolk and Suffolk and two community health providers.

There is still much work to be done in Norfolk. The number of people, carers, friends and family affected by dementia will increase substantially over the next 20 years. There is not a comprehensive service across Norfolk at the moment and services are only going to become more stretched. Dementia does not discriminate against where a person lives and who they are and their cultural diversity. However this does affect the service a person and their carer will receive.

Dementia has reached a crucial point in Norfolk. Considerable momentum has been built over the past few years, but concrete progress is now needed to work towards the comprehensive equitable service provision that people with dementia and their carers need and deserve. Through the collective efforts of commissioners, providers, voluntary organisations, businesses, communities and residents Norfolk can truly achieve its aim to become Dementia Friendly.

The aim of this report is to build on the Dementia Needs Assessment 2010 to systematically review the health issues facing individuals with dementia and their wider social network, leading to recommended actions that will improve prevention, diagnosis and care for individuals with dementia and their carers. It is aimed at commissioners, providers, voluntary organisations, strategic bodies, people with dementia and their carers. This report describes the needs of people with dementia and their carers in Norfolk and makes recommendations to improve services.

II. What is a needs assessment and how is it produced?

A needs assessment is a systematic method for reviewing the health issues facing a population, leading to agreed priorities and resource allocation that will improve health and reduce inequalities. Needs assessments are:

- A recommended public health tool to provide evidence about a population on which to plan services and address health inequalities
- Able to provide an opportunity to engage with specific populations and enable them to contribute to targeted service planning and resource allocation.
- Able to provide an opportunity for cross-sectorial partnership working and developing creative and effective interventions

Potential benefits subsequent to undertaking needs assessment are:

- Strengthened community involvement in decision making
- Improved team and partnership working
- Improved communication with other agencies and the public
- Encourage better use of resources

The challenges of undertaking a needs assessment include:

- Developing a shared language between sectors
- Obtaining commitment from ‘the top’
- Accessing relevant data
- Accessing the target population
- Maintaining team impetus and commitment
- Translating findings into effective action

Approaches to health assessments are:

- Epidemiological - focuses on the quantitative needs of the population in line with the available evidence base
- Comparative - compares services available locally with those described in the literature and in other areas of the country
- Corporate - gathering the views of interest groups including health organisations, health professionals, social care professionals, voluntary organisations, older people’s groups, users and carers

This needs assessment was produce by 1) reviewing data from a number of different sources, 2) evaluating the published research, strategies, national documents and examples from other areas and 3) speaking to people with dementia, their carers and professionals in addition to visiting a number of different organisations along the dementia pathway. Sources of data are shown in Appendix 2.

Dementia was divided into 10 domains covering a wide range of topics such as timely diagnosis, secondary care and inequalities. This allowed a “deep dive” into these topics. Each domain contains several questions that were agreed during a scoping period. This work was supported by a steering group made up of commissioners, providers, voluntary organisations and older people representatives. HealthWatch Norfolk undertook focus groups with people with dementia and their carers. Their report is provided in Appendix 5.

Services were identified through a mapping exercise as shown in Appendix 1. This involved triangulating information from the Heron database, Carer’s directory, Alzheimer’s Society, Age UK,
stakeholders and internet searches. Two maps were produced one from an organisational perspective (labelled “System”) and one from a person with dementia and their carers perspective (labelled “Mr and Mrs Smith”). While every effort was made to include all services, some services may not have been identified. The purpose was not to create a directory of services but to show the known services in order to identify gaps.

This needs assessment is concerned with Norfolk, including Great Yarmouth but not Waveney. A Suffolk dementia needs assessment published last year included Waveney. However there are several instances where the data has necessitated the inclusion of Waveney.

Throughout the report there are text boxes that contain direct quotes from people with dementia or carers who have contributed to the report either through a focus group or discussion during a visit to an organisation.

Recommendations are presented at the end of the report.

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III. What the data tells us

Norfolk in General

- Life expectancy: 83 yrs for men, 79 yrs for women.
- 859,400 people in Norfolk, 1 in 5 are >65, 1 in 10 are >75.
- England's 6th most rural county.
- In the next twenty-five years, over 85s will increase by 174%.
Norfolk's population was estimated to be 859,400 in mid-2011; an increase of 60,800 (7.6%) since mid-2001, compared to an 8.6% rise in the East of England. Population density in 2011 was 1.6 people per hectare, the sixth lowest of the 27 English counties.

Over this ten year period:

In terms of broad age groups, the number of children (aged 0-14 years) fell marginally whereas numbers of working age adults (aged 15-64 years) increased by 35,900, and older people (aged 65 years and over) increased by 27,300. The most significant change was the rising number of 60-64 and 65-69 year olds.

Estimates for mid-2011 confirm that Norfolk’s population has a much older age profile than England as a whole. 21.7% of Norfolk's population in 2011 were aged 65 and over and 10.4% were aged 75 and over, compared with 16.4% and 7.8% in England respectively. The current peak is seen in the 60-64 year olds in Norfolk (due to the post-war baby boom in the late-1940s and net migration) and to a lesser extent in 45-49 year olds, largely due to the high birth rate years of the 1960s.

These changes would have a significant impact on local demand for health and social services as the prevalence of conditions such as dementia and disabling life events, such as heart attack and stroke, increase with age. The total number of older people with dementia in Norfolk is therefore expected to increase significantly.

The 2008-2010 three-year rolling average life expectancy at birth in Norfolk is 79.5 years for men and 83.3 years for women. The comparative rates for the region are 77.6 years and 83.2 years, whilst for England they are 78.6 and 82.6 respectively.

Where people who are over 75 years old live is shown in Figure 1. This shows that the North Norfolk has the largest proportion of people who are over 75 years old.5

Figure 1: Map showing the percentage of people who are over 75 years

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Dementia in Norfolk

GP practice prevalence rates vary hugely: from 1 dementia patient for every 625 patients to 1 every 24

Estimated total prevalence in Norfolk & Waveney 16,400

Diagnosed prevalence has risen by 35% in last 5 years

57% remain undiagnosed

72.3%

...are living in the community

46% have severe or moderate disease

Mild (55%)
Moderate (33%)
Severe (13%)

New dementia cases in Norfolk every year
3,885
Incidence

Incidence is the number of new cases of disease within a given population over a specified period of time.

There are about 26 new cases of dementia per year per 1000 population in Norfolk (diagnosed or undiagnosed).

Table 1 below shows the incidence for each Clinical Commissioning Group (CCG) split by age noting that the incidence for those less than 65 years old is not available. Table 1 shows that the number of new cases per year is highest in Great Yarmouth and Waveney CCG with over 1000 additional people with dementia per year. This reflects the larger population in Great Yarmouth and Waveney compared to other CCGs. The lowest is Norwich. The incidence of dementia increases as age increases. The incidence rates of dementia in adults aged 65 years or over are shown in Table 2 and Figures 2 and 3. This is based on data from the Medical Research Council Cognitive Function and Ageing Study\(^6\) in 2005 and POPPI estimates\(^7\).

Table 1: Estimated incidence (new cases) of Dementia among persons by CCG, and age band for Norfolk and Waveney per year, April 2013

<table>
<thead>
<tr>
<th>CCG</th>
<th>65-69</th>
<th>70-74</th>
<th>75-79</th>
<th>80-84</th>
<th>85+</th>
<th>Total 65+</th>
</tr>
</thead>
<tbody>
<tr>
<td>GYW</td>
<td>115</td>
<td>125</td>
<td>142</td>
<td>202</td>
<td>503</td>
<td>1,086</td>
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<tr>
<td>North Norfolk</td>
<td>97</td>
<td>107</td>
<td>128</td>
<td>177</td>
<td>445</td>
<td>954</td>
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<td>Norwich</td>
<td>69</td>
<td>76</td>
<td>96</td>
<td>142</td>
<td>370</td>
<td>753</td>
</tr>
<tr>
<td>South Norfolk</td>
<td>102</td>
<td>112</td>
<td>128</td>
<td>173</td>
<td>424</td>
<td>939</td>
</tr>
<tr>
<td>West Norfolk</td>
<td>83</td>
<td>97</td>
<td>111</td>
<td>154</td>
<td>368</td>
<td>812</td>
</tr>
<tr>
<td>Norfolk &amp; Waveney</td>
<td>466</td>
<td>517</td>
<td>604</td>
<td>848</td>
<td>2111</td>
<td>4545</td>
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<tr>
<td>Norfolk</td>
<td>400</td>
<td>444</td>
<td>518</td>
<td>726</td>
<td>1797</td>
<td>3885</td>
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<td>48</td>
<td>52</td>
<td>56</td>
<td>80</td>
<td>190</td>
<td>426</td>
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</table>

Table 2: Incidence rate (per year) of dementia by gender for those aged 65+ years per 1000 population with 95% confidence intervals

<table>
<thead>
<tr>
<th>Age band</th>
<th>Males</th>
<th></th>
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<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Rate</td>
<td>LL 95%CI</td>
<td>UL 95%CI</td>
<td>Rate</td>
<td>LL 95%CI</td>
<td>UL 95%CI</td>
<td>Rate</td>
</tr>
<tr>
<td>65-69</td>
<td>6.9</td>
<td>3.3</td>
<td>14.5</td>
<td>6.3</td>
<td>2.9</td>
<td>15.6</td>
<td>6.7</td>
</tr>
<tr>
<td>70-74</td>
<td>14.5</td>
<td>7.4</td>
<td>34.1</td>
<td>6.1</td>
<td>2.8</td>
<td>12.6</td>
<td>10.3</td>
</tr>
<tr>
<td>75-79</td>
<td>14.2</td>
<td>6.7</td>
<td>25.1</td>
<td>14.8</td>
<td>8.5</td>
<td>25.1</td>
<td>14.5</td>
</tr>
<tr>
<td>80-84</td>
<td>17.0</td>
<td>6.7</td>
<td>34.1</td>
<td>31.2</td>
<td>21.2</td>
<td>34.1</td>
<td>26.5</td>
</tr>
<tr>
<td>85+</td>
<td>58.4</td>
<td>27.3</td>
<td>96.7</td>
<td>71.7</td>
<td>52.0</td>
<td>96.7</td>
<td>68.5</td>
</tr>
</tbody>
</table>

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Figure 2: Incidence of dementia by age band

![Graph showing incidence of dementia by age band.]

Figure 3: Incidence of dementia by age band and CCG

![Graph showing incidence of dementia by age band and CCG.]
Prevalence

Prevalence is the number or proportion of a population with a certain condition at any given time.

Diagnosed prevalence of dementia

General Practices (GP) started maintaining registers of people with dementia under the Quality Outcomes Framework (QOF) in 2006/7. The proportion of people with diagnosed dementia by CCG as recorded on the GP QOF register is shown in Table 3 and the number of people with a diagnosis is shown in Table 4. Great Yarmouth and Waveney, North Norfolk, and South Norfolk CCGs have higher prevalence of 0.8%-0.9% than England average rate 0.6%, while Norwich and West Norfolk CCGs have lower or equal rates to England average rate. The proportion of people diagnosed has increased in all CCGs over time.

Table 3: Prevalence (%) of dementia (all ages) according to the GP’s QOF registers by CCG, for 2007/08 to 2012/13

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>Great Yarmouth &amp; Waveney</td>
<td>0.6</td>
<td>0.6</td>
<td>0.7</td>
<td>0.7</td>
<td>0.8</td>
<td>0.8</td>
</tr>
<tr>
<td>North</td>
<td>0.5</td>
<td>0.5</td>
<td>0.6</td>
<td>0.7</td>
<td>0.8</td>
<td>0.9</td>
</tr>
<tr>
<td>Norwich</td>
<td>0.4</td>
<td>0.5</td>
<td>0.5</td>
<td>0.5</td>
<td>0.5</td>
<td>0.5</td>
</tr>
<tr>
<td>South</td>
<td>0.5</td>
<td>0.6</td>
<td>0.6</td>
<td>0.6</td>
<td>0.6</td>
<td>0.7</td>
</tr>
<tr>
<td>West</td>
<td>0.5</td>
<td>0.5</td>
<td>0.5</td>
<td>0.5</td>
<td>0.6</td>
<td>0.6</td>
</tr>
<tr>
<td>Norfolk &amp; Waveney</td>
<td>0.5</td>
<td>0.5</td>
<td>0.6</td>
<td>0.6</td>
<td>0.7</td>
<td>0.7</td>
</tr>
</tbody>
</table>

Table 4: Prevalence (numbers) of dementia (all ages) according to the GP’s QOF registers by CCG, for 2007/08 to 2012/13

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Great Yarmouth &amp; Waveney</td>
<td>1,417</td>
<td>1,557</td>
<td>1,703</td>
<td>1,864</td>
<td>1,907</td>
</tr>
<tr>
<td>North</td>
<td>962</td>
<td>1,009</td>
<td>1,167</td>
<td>1,335</td>
<td>1,542</td>
</tr>
<tr>
<td>Norwich</td>
<td>910</td>
<td>1,138</td>
<td>986</td>
<td>1,048</td>
<td>1,090</td>
</tr>
<tr>
<td>South</td>
<td>1,160</td>
<td>1,049</td>
<td>1,275</td>
<td>1,393</td>
<td>1,517</td>
</tr>
<tr>
<td>West</td>
<td>787</td>
<td>917</td>
<td>879</td>
<td>926</td>
<td>1,020</td>
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<tr>
<td>Norfolk &amp; Waveney</td>
<td>5,236</td>
<td>5,670</td>
<td>6,010</td>
<td>6,566</td>
<td>7,076</td>
</tr>
</tbody>
</table>

These tables show the aggregated results for all practices within a CCG. However the number and percentage of patients on the register varies between the General Practices (Figure 4). The smallest proportions had rates of between >0 to 0.1% patients registered. The highest proportion was a practice in West Norfolk CCG that had just over 2% patients registered.

As with all data on from the Quality Management and Analysis System (QMAS) from which an extract is taken at the end of March to form the QOF, information cannot generated by age band, gender or disease severity.
Figure 4: Distribution of GP practices according to QOF dementia prevalence in Norfolk and Waveney using QOF registers for the 2012/13

Diagnosed and Undiagnosed Prevalence of Dementia

Approximately 1 in every 53 people in Norfolk has dementia (either diagnosed or undiagnosed).

The recently published National Dementia Prevalence Calculator Version 3.2 aims to provide a reliable estimate of all people living with dementia, from the mildest to the most severe cases, be they diagnosed or not. It does this by using the most recently available GP practice QOF registers, the national dementia prevalence rate and care home data from the Care Quality Commission. The Exeter database provides age-gender specific population data for each medical practice, enabling an estimate of dementia prevalence for men and women within each age group. There is no adjustment for ethnicity, deprivation or other factors.

Table 5 summarises findings for the CCGs in Norfolk and Waveney. In 2012/13 there were 7,076 people with diagnosed dementia on the GP QOF disease registers. There are an estimated 16,400 people with diagnosed or undiagnosed dementia. Great Yarmouth and Waveney CCG have the highest number of people with dementia because it has the largest population. North Norfolk CCG has the highest proportion of people with dementia. It is estimated that 43.2% of people with dementia are currently diagnosed in Norfolk. The diagnosis rate varies from 35.3% in West Norfolk CCG to 49.6% in Great Yarmouth and Waveney CCG.

Table 5: Current (GP practice QOF) and estimated number of people with dementia by CCG for Norfolk and Waveney, 2012/13

<table>
<thead>
<tr>
<th>CCG</th>
<th>Population</th>
<th>QOF Dementia Register</th>
<th>Estimated number of people with dementia</th>
<th>Dementia Gap Number</th>
<th>Dementia Diagnosis Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>GYW</td>
<td>231,986</td>
<td>1,907</td>
<td>3,844</td>
<td>1,937</td>
<td>49.6</td>
</tr>
<tr>
<td>North</td>
<td>168310</td>
<td>1,542</td>
<td>3,588</td>
<td>2,046</td>
<td>43.0</td>
</tr>
<tr>
<td>Norwich</td>
<td>193,608</td>
<td>1,090</td>
<td>2,659</td>
<td>1,569</td>
<td>41.0</td>
</tr>
<tr>
<td>South</td>
<td>222990</td>
<td>1,517</td>
<td>3,419</td>
<td>1,902</td>
<td>44.4</td>
</tr>
<tr>
<td>West</td>
<td>165867</td>
<td>1,020</td>
<td>2,889</td>
<td>1,869</td>
<td>35.3</td>
</tr>
<tr>
<td>Norfolk &amp; Waveney</td>
<td>982,761</td>
<td>7,076</td>
<td>16,400</td>
<td>9,324</td>
<td>43.2</td>
</tr>
<tr>
<td>East Anglia Local Area Team</td>
<td>2,484,235</td>
<td>15,846</td>
<td>4,297</td>
<td>19,964</td>
<td>44.3</td>
</tr>
<tr>
<td>Midlands and East of England Region</td>
<td>16,696,617</td>
<td>95,881</td>
<td>24,569</td>
<td>108,858</td>
<td>46.8</td>
</tr>
</tbody>
</table>

In general when models are produced, the model is based on research undertaken elsewhere in the UK examining the prevalence of diagnosed disease in the community, which has then been modelled and applied to different populations such as those living in a particular CCG area. Therefore, how accurate the estimates are, depends on the quality of the initial research and the modelling itself. If, for example, the original research did not involve very deprived areas, the model would not be accurate if applied to very deprived areas within Great Yarmouth, Waveney, King’s Lynn, Thetford or parts of Norwich.

There are many reasons why dementia prevalence could differ between practices; just because a practice may have a particularly low recorded prevalence or a relatively large undiagnosed prevalence, it does not necessarily mean that it is performing worse than other practices. A comparison of the modelled prevalence and the actual practice list register is only a starting point for investigation. Practices with a low prevalence of diagnosed cases or a relatively large difference between the model and the register prevalence can be examined further and considered in relation to patient characteristics using local knowledge.

It is noted that the estimates from the Dementia Calculator are higher than previous estimates, used at the time of first publication of the National Dementia Strategy. At this time there was no adjustment for age and gender and national prevalence was assumed to be 1.1%, which applied to the population of Norfolk and Waveney, predicted 10,000 to 11 000 people.

Table 6 shows the expected number of people with dementia at different levels of severity based on Dementia Calculator estimates. Just over half of people with dementia have mild dementia and remaining people have moderate or severe disease. Moderate and severe cases are more likely to be captured on GP dementia registers. This differentiation between mild, moderate and severe is

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10 The Alzheimer’s Society report, Dementia UK 2007 estimates that there were 683,597 people with dementia in the UK at that time. This represented one person in every 88 (1.1%) of the entire UK population and conceded that this was is probably a very slight underestimate as it may not have comprehensively included people with learning disabilities or people with dementia in NHS continuing care facilities.
slightly arbitrary since it does not reflect how challenging an individual’s behaviour may be or ability to undertake normal day to day activities.

**Table 6: Estimated number of people with dementia by severity and CCG for Norfolk and Waveney, 2012/13**

<table>
<thead>
<tr>
<th>CCG</th>
<th>Mild Dementia</th>
<th>Moderate Dementia</th>
<th>Severe Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>GYW</td>
<td>2,114</td>
<td>1,269</td>
<td>461</td>
</tr>
<tr>
<td>North</td>
<td>1,974</td>
<td>1,184</td>
<td>431</td>
</tr>
<tr>
<td>Norwich</td>
<td>1,463</td>
<td>878</td>
<td>319</td>
</tr>
<tr>
<td>South</td>
<td>1,881</td>
<td>1,128</td>
<td>410</td>
</tr>
<tr>
<td>West</td>
<td>1,589</td>
<td>953</td>
<td>347</td>
</tr>
<tr>
<td>Norfolk &amp; Waveney</td>
<td>9,020</td>
<td>5,412</td>
<td>1,968</td>
</tr>
<tr>
<td>East Anglia Local Area Team</td>
<td>19,695</td>
<td>11,817</td>
<td>4,297</td>
</tr>
<tr>
<td>Midlands and East Of England Region</td>
<td>112,607</td>
<td>67,564</td>
<td>24,569</td>
</tr>
</tbody>
</table>

Table 7 shows that about two thirds of people with dementia live in the community compared to long-term care.

**Table 7: Estimated number of people with dementia and place of residents by CCG for Norfolk and Waveney, 2012/13**

<table>
<thead>
<tr>
<th>CCG</th>
<th>Community</th>
<th>Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>GYW</td>
<td>2,809</td>
<td>1,035</td>
</tr>
<tr>
<td>North</td>
<td>2,415</td>
<td>1,174</td>
</tr>
<tr>
<td>Norwich</td>
<td>1,993</td>
<td>666</td>
</tr>
<tr>
<td>South</td>
<td>2,510</td>
<td>910</td>
</tr>
<tr>
<td>West</td>
<td>2,125</td>
<td>764</td>
</tr>
<tr>
<td>Norfolk &amp; Waveney</td>
<td>11,850</td>
<td>4,550</td>
</tr>
<tr>
<td>East Anglia Local Area Team</td>
<td>26,401</td>
<td>9,408</td>
</tr>
<tr>
<td>Midlands and East Of England Region</td>
<td>158,063</td>
<td>46,677</td>
</tr>
</tbody>
</table>

Figure 5 below shows where people with dementia live across Norfolk and Waveney. This shows that there are a significant number of people with dementia in North Norfolk, the Norwich area and west-central Norfolk.

Additional data are shown in Appendix 3.
Population Projections

Table 8 shows the estimated projected number of people with diagnosed or undiagnosed dementia in Norfolk based on data from POPPI\(^\text{11}\). Over the next 20 years there will be an estimated additional 9,000 people with dementia. The greatest growth will be in the over 90 year olds.

Table 9 shows the estimated projected number of people with diagnosed or undiagnosed dementia by CCG based on data from the prevalence calculator\(^\text{12}\).

\[\text{\textsuperscript{11}}\text{Projecting Older People Population Information (POPPI). Available at } \text{http://www.poppi.org.uk/} \text{ Accessed on 23 June 2014.}\]

\[\text{\textsuperscript{12}}\text{Dementia Calculator (2012/13, Dementia Partnerships). Available at } \text{http://www.dementiapartnerships.org.uk/diagnosis/dementia-prevalence-calculator/} \text{ Accessed on 23 June 2014.}\]
### Table 8: Estimated projected number of people with dementia over the next 20 years in Norfolk using POPPI

<table>
<thead>
<tr>
<th></th>
<th>2014</th>
<th>2018</th>
<th>2022</th>
<th>2026</th>
<th>2030</th>
<th>2034</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 65 years</td>
<td>242</td>
<td>254</td>
<td>267</td>
<td>280</td>
<td>292</td>
<td>304</td>
</tr>
<tr>
<td>65-69 years</td>
<td>705</td>
<td>683.3</td>
<td>607</td>
<td>562</td>
<td>506</td>
<td>453</td>
</tr>
<tr>
<td>70-74 years</td>
<td>1,644</td>
<td>1,839</td>
<td>2098</td>
<td>2358</td>
<td>2603</td>
<td>2864</td>
</tr>
<tr>
<td>75-79 years</td>
<td>2,391</td>
<td>2,674</td>
<td>2962</td>
<td>3196</td>
<td>3471</td>
<td>3718</td>
</tr>
<tr>
<td>80-84 years</td>
<td>3,740</td>
<td>3,999</td>
<td>4309</td>
<td>4581</td>
<td>4871</td>
<td>5153</td>
</tr>
<tr>
<td>85-89 years</td>
<td>4,039</td>
<td>4,442</td>
<td>4848</td>
<td>5257</td>
<td>5660</td>
<td>6066</td>
</tr>
<tr>
<td>&gt; 90 years</td>
<td>3,753</td>
<td>4,404</td>
<td>5059</td>
<td>5678</td>
<td>6325</td>
<td>6953</td>
</tr>
<tr>
<td><strong>Total population</strong></td>
<td>16,514</td>
<td>18,295</td>
<td>20,150</td>
<td>21,911</td>
<td>23,728</td>
<td>25,512</td>
</tr>
</tbody>
</table>

### Table 9: Estimated projected number of people with dementia over the next 5 years by CCG using dementia prevalence calculator

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>GYW</td>
<td>2661</td>
<td>2788</td>
<td>2915</td>
<td>2987</td>
<td>3114</td>
<td>3214</td>
<td>3313</td>
</tr>
<tr>
<td>North</td>
<td>3844</td>
<td>4028</td>
<td>4223</td>
<td>4343</td>
<td>4533</td>
<td>4690</td>
<td>4845</td>
</tr>
<tr>
<td>Norwich</td>
<td>3588</td>
<td>3763</td>
<td>3942</td>
<td>4059</td>
<td>4235</td>
<td>4383</td>
<td>4530</td>
</tr>
<tr>
<td>South</td>
<td>3419</td>
<td>3599</td>
<td>3792</td>
<td>3917</td>
<td>4103</td>
<td>4263</td>
<td>4418</td>
</tr>
<tr>
<td>West</td>
<td>2889</td>
<td>3082</td>
<td>3233</td>
<td>3350</td>
<td>3522</td>
<td>3656</td>
<td>3801</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>16401</strong></td>
<td><strong>17260</strong></td>
<td><strong>18105</strong></td>
<td><strong>18656</strong></td>
<td><strong>19507</strong></td>
<td><strong>20206</strong></td>
<td><strong>20907</strong></td>
</tr>
</tbody>
</table>
Mortality

This chapter presents information on mortality where the primary diagnosis was a mental illness (ICD10 F00 – F99) obtained from Office for National Statistics (ONS). International Classification Diagnosis descriptions are shown in Appendix 4.

The number of people who are classified as dying with a dementia condition as the primary diagnosis (ICD 10 codes F00-F03) depends on the doctor stating dementia as the primary diagnosis on the death certificate. Someone dying with dementia may often have death attributed to a different cause, e.g. heart disease, diabetes; these deaths are not included in the data presented here.

There were 1,678 deaths in the years 2010-2012 recorded due to dementia. This was 5.5% of all the 30,324 deaths registered among residents of Norfolk and Waveney. This gives an average of 559 deaths per year.

Table 10 shows the dementia directly age standardised mortality rate per 100,000 European standard population by CCG and gender during 2010-2012.

Table 10: Directly age standardised mortality rate (DSR) per 100,000 residents from dementia by gender and CCG for Norfolk and Waveney, 2010-2012

<table>
<thead>
<tr>
<th></th>
<th>Males</th>
<th></th>
<th>Females</th>
<th></th>
<th>Persons</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>DSR</td>
<td>Number</td>
<td>DSR</td>
<td>Number</td>
<td>DSR</td>
</tr>
<tr>
<td>GYW</td>
<td>137</td>
<td>17.2</td>
<td>319</td>
<td>24.7</td>
<td>456</td>
<td>21.9</td>
</tr>
<tr>
<td>North Norfolk</td>
<td>125</td>
<td>18.0</td>
<td>230</td>
<td>19.9</td>
<td>355</td>
<td>19.2</td>
</tr>
<tr>
<td>Norwich</td>
<td>69</td>
<td>12.5</td>
<td>162</td>
<td>16.5</td>
<td>231</td>
<td>15.2</td>
</tr>
<tr>
<td>South Norfolk</td>
<td>109</td>
<td>15.5</td>
<td>252</td>
<td>23.3</td>
<td>361</td>
<td>20.3</td>
</tr>
<tr>
<td>West Norfolk</td>
<td>88</td>
<td>14.5</td>
<td>187</td>
<td>20.5</td>
<td>275</td>
<td>18.2</td>
</tr>
<tr>
<td><strong>Norfolk and Waveney</strong></td>
<td><strong>528</strong></td>
<td><strong>15.7</strong></td>
<td><strong>1,150</strong></td>
<td><strong>21.2</strong></td>
<td><strong>1,678</strong></td>
<td><strong>19.2</strong></td>
</tr>
</tbody>
</table>
Mortality rates by MOSAIC social group

MOSAIC is a geo-demographic segmentation system developed by Experian and marketed in over twenty countries worldwide. Each of the nearly one-quarter million block groups was classified into sixty segments on the basis of a wide range of demographic characteristics. The basic premise of geo-demographic segmentation is that people tend to gravitate towards communities with other people of similar backgrounds, interests, and means. A number of geo-demographic segmentation tools are available; of which Norfolk County Council currently hold a licence for the MOSAIC software, from which MOSAIC and Health MOSAIC classifications may be produced.

Mosaic Public Sector classifies all consumers in the United Kingdom by allocating them to one of 7 super groups, 15 groups and 69 types. These paint a rich picture of UK citizens in terms of their socio-economic and socio-cultural behaviour. The super groups have been created to provide a high level overview of an area and are constructed by combining together the relevant groups.

Figure 6 shows the social backgrounds for those who had mortality from dementia for 2010-2012 after applying the mortality data to MOSIAC. Out of the 1,678 dementia deaths MOSAIC can only recognise 1,612 residents for the analysis due to postcodes related issues. This shows that the ‘Rural and small town inhabitants’ and ‘Elderly occupants’ are most likely to have dementia mentioned as cause of death.

Figure 6: MOSIAC Public Sector Super groups for dementia mortality for Norfolk and Waveney, 2010-2012

Figure 7 shows more detailed groups. This graph shows that the following four groups are most likely to dementia documented on their death certificate.

- Residents of small and mid-sized towns with strong local roots
- Active elderly people living in pleasant retirement locations
- Residents of isolated rural communities
- Elderly people reliant on state support
MOSAIC data allows for key features and communication preferences for each of these groups. Group B are receptive to face-to-face information, local papers and magazines, but non-receptive to internet, text messages, national papers and interactive TV. Group L are receptive to local papers and face-to-face information, but non-receptive to internet information, telephone communication, text message, national papers and interactive TV.
Cost of dementia

It is estimated that dementia costs the UK society £23 billion a year.13 This is estimated to grow to £27 billion by 2018. In Norfolk the cost is estimated to be £296 million per year based on cost of healthcare £23.6 million, cost of accommodation of £121.2 million, cost of social services £44.3 million and cost of informal care of £106.4 million.

The cost depends on the stage of disease and where the person with dementia lives. 2007 estimated costs were14:

- People in the community with mild dementia - £14,540
- People in the community with moderate dementia - £20,355
- People in the community with severe dementia - £28,527
- People in care homes - £31,263

There is also a significant cost to people with dementia and carers. 670,000 people in the UK act as primary carers for people with dementia, which saves the state £8 billion per year.13

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IV. Gold standards

Several key documents have described the qualities of good services for people with dementia and their carers. This section highlights some of the key documents.

Supporting people with dementia and their carers in health and social care 2006

In 2006 the National Institute for Health and Care Excellence (NICE) published guidelines on dementia. This is based on a review of the published literature and extensive work with stakeholders within the Guideline Development Group. It identifies the following priority areas:

1. People with dementia should not be excluded from services
2. Health and social care staff should always seek valid consent
3. Carers should have an assessment of needs and if appropriate offered psychological therapy
4. Health and social care managers should co-ordinate and integrate working across all agencies
5. Memory assessment services should be the single point of referral for all people with a possible diagnosis of dementia
6. Structural imaging should be used to assess people with suspected dementia
7. People with dementia who develop non-cognitive symptoms that cause them significant distress should be assessed early
8. Health and social care staff should have access to dementia-care training
9. Acute and general hospital trusts should provide services that address the specific personal and social care needs

Living Well with Dementia: A National Dementia Strategy 2009

In 2009 the Department of Health (DH) published their national strategy. It was based on over 50 stakeholder events. It outlined 17 strategic objectives as shown below.

1. Improving public and professional awareness and understanding of dementia
2. Good-quality early diagnosis and intervention for all
3. Good-quality information for those with diagnosed dementia and their carers
4. Enabling easy access to care, support and advice following diagnosis
5. Development of structured peer support and learning networks
6. Improved community personal support services
7. Implementing the Carers’ Strategy
8. Improved quality of care for people with dementia in general hospitals
9. Improved intermediate care for people with dementia
10. Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers
11. Living well with dementia in care homes

Each objective was aimed at one of the four following themes 1) raising awareness and understanding, 2) early diagnosis and support, 3) living well with dementia or 4) cross cutting. The objectives were accompanied with practical advice about how each one could be delivered.

The national strategy was followed five months subsequently with an implementation plan which outlined a five year plan to achieve the strategic objectives. The implementation plan did not include direct outcomes.

Living well with Dementia: Transforming the quality and experience of dementia care for the people of Norfolk. A joint commissioning strategy 2009-14

Following the publication of the national strategy Norfolk developed a joint commissioning strategy. This document, developed after full public consultation, described how the national strategy would be implemented locally. It uses 14 of the national objectives which were applicable locally. It begins with setting out 11 fundamental principles:

1. Integrated
2. Patient/person-centred
3. Family-orientated
4. Recognition for all services
5. Housed well
6. Offering help and prevention
7. Targeted
8. Knowledgeable workers
9. Enough workers
10. Equal
11. Meets national standards

It identifies three key areas for improvement which are 1) improved awareness, 2) early diagnosis and intervention and 3) higher quality of care. Each recommendation was linked with planned actions, milestones, lead agency and outcome measures. The strategy expires in 2014.

17 Living well with dementia: A National Dementia Strategy Implementation Plan, Department of Health, 22 July 2009
Quality outcomes for people with dementia: building on the work of the National Dementia Strategy

In 2010, a year after the dementia strategy, the Department of Health published quality outcomes for people with dementia.\(^{19}\) The aim of the document was to present a revised implementation plan with key quality outcomes. It aimed that, by 2014, all people living with dementia in England should be able to say:

1. I was diagnosed early
2. I understand, so I make good decisions and provide for future decision making
3. I get the treatment and support which are best for my dementia, and my life
4. I am treated with dignity and respect
5. I know what I can do to help myself and who else can help me
6. Those around me and looking after me are well supported
7. I can enjoy life
8. I feel part of a community and I'm inspired to give something back
9. I am confident my end of life wishes will be respected. I can expect a good death

It is expected that these are the outcomes that service provision in Norfolk will be measured against.

NICE Dementia Quality Standards

Simultaneously in 2010 the National Institute of Health and Care Institute (NICE) published 10 quality standards for dementia.\(^{20}\) This contributes to the NICE dementia pathway. The quality standards are:

1. People with dementia receive care from staff appropriately trained in dementia care.
2. People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.
3. People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.
4. People with dementia have an assessment and an on-going personalised care plan, agreed across health and social care that identifies a named care coordinator and addresses their individual needs.
5. People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of:
   a. Advance statements
   b. Advance decisions to refuse treatment
   c. Lasting Power of Attorney
   d. Preferred Priorities of Care
6. Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.
7. People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early


opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan.

8. People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health.

9. People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.

10. Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.

Prime Minister’s Challenge on Dementia – Delivering major improvements in dementia care and research by 2015

In 2012 the Prime Minister’s Challenge was published\(^2\)\(^1\). It established three champion groups to progress dementia services by 2015

1. Driving improvements in health and care
   a. Increased diagnosis rates through regular checks of over 65’s
   b. Financial rewards for hospitals offering quality dementia care
   c. An Innovation Challenge Prize of £1m
   d. Dementia Care and Support Compact signed by leading care homes and home care providers
   e. Promoting local information on dementia services

2. Creating dementia friendly communities that understand how to help
   a. Dementia-friendly communities across the country
   b. Support from leading businesses for the PM’s Challenge on Dementia
   c. Awareness-raising campaign
   d. A major event over the summer, bringing together UK leaders from industry, academia and the public sector

3. Better research
   a. More than doubling overall funding for dementia research to over £66m by 2015
   b. Major investment in brain scanning
   c. £13m funding for social science research on dementia (NIHR/ESRC)
   d. £36m funding over 5 years for a new NIHR dementia translational research collaboration to pull discoveries into real benefits for patients
   e. Participation in high quality research

In 2014 Norfolk’s Health and Wellbeing Board has produced a Norfolk dementia strategy. This will replace the 2009-14 strategy. The intention is that this will be a “living document” which will respond to changing priorities. Currently there are 18 strategic objectives that are:

1. Ensure that a comprehensive needs assessment is included in the Joint Strategic Needs Assessment (JSNA) and informs this full strategic plan.
2. Ensure that the needs of hard to reach groups, such as homeless people, BME groups, people who are socially or geographically isolated, are recognised and addressed. A review of transport will assess how older people and their carers access health and wellbeing services including services within GP practices.

3. Encourage and support multi-disciplinary working across clinical and organisational boundaries to ensure people are not inappropriately admitted to acute hospitals and to enable timely discharge from acute hospitals.

4. Evaluate new services including measures of satisfaction of the older people with dementia and their carers who receive the services (monitor outcomes not just outputs) and, if effective, fund long-term.

5. Improve the awareness and understanding of dementia.

6. Promote and support dementia friendly communities.

7. Ensure the public, independent and voluntary sector workforce supporting older people are required to have appropriate levels of dementia training.

8. People with dementia and their carers must be included from the start and through the whole process to implementation and monitoring (co-production).

9. Improve the rate of timely diagnosis of dementia and provide information and support in GP practices. The ‘family GP’ model is the best for patient-centred care.

10. Improve post diagnosis support and ensure continuity of care through a care manager approach so that relevant agencies co-ordinate support for older people with dementia and their carers from diagnosis until the end of life.

11. Ensure appropriate support is available in the community post diagnosis, both professional support e.g. Admiral Nurses and in the community, e.g. Pabulum Cafés, aids and adaptations, assistive technology.

12. All acute hospitals must have a dementia strategy, a dementia lead and have an holistic view of the care of people with dementia and other long term conditions, and coordinate treatment provided by different specialists.

13. Develop and agree a specific end of life approach for people with dementia and their carers.

14. Establish sustainable low level generic preventative services which help all older people to remain living independently, including information, advice and advocacy.

15. Identify and assess the ongoing health and wellbeing needs of carers of people with dementia and encourage and enable carers, including older carers, to recognise they are carers.

16. Identify in local development plans how homes for meeting the aspirations and needs of older people, including those with dementia and their carers, can be provided, and ensure the provision of housing information and advice.

17. Improve the take-up of attendance allowance and other benefits

18. Improve quality of care for those unable to maintain independent living.

19. Ensure residential care and nursing homes have the highest quality of care for their residents.
Domain 1: Community Development

Dementia often scares people who do not know or understand the condition. For a person with dementia having bad experiences when they are out and about can lead to a fear of leaving their house. These experiences are usually because people in the community, shops, business and public services misunderstand dementia. This can lead to a cycle were people with dementia and their carers find it difficult to contribute and feel part of their community and therefore become increasingly isolated. So it is hardly surprising that people with dementia are kept in the shadows of society, further adding to the sigma and fear.

In order to make people with dementia and their carers feel valued and participate in their communities, those communities need to understand, accept, adapt and become dementia friendly.

In 2012, the Prime Minister launched the Dementia Challenge. One of three champion groups established was around creating dementia friendly communities. The Alzheimer’s Society and Dementia Action Alliance have been responsible nationally for driving the dementia friendly communities’ agenda forward.

Why are dementia friendly communities important?

Building dementia-friendly communities: A priority for everyone (2013) published by the Alzheimer’s Society highlighted the difficulties people with dementia face and why making communities more dementia friendly is so important. The report is based on a survey of 500 people with dementia and 2,200 of the general public. Key findings include:

- 42% of people with dementia and 73% of the general public do not think their area is geared up to help them live well with dementia
- Only 47% of people with dementia feel part of their community
- 35% of people with dementia go out once a week or less and 10% once a month or less
- One in ten people with dementia had to stop all the things they used to do
- 97% of the general public felt that people with dementia have something to offer their communities
- Half of the general public feel that dementia friendly areas would be nicer places for everyone to live
- Most common barriers to people with dementia doing more in their communities are:
  - Lack of confidence (69%)
  - Worry about becoming confused (68%)
  - Worry about getting lost (60%)
  - Mobility issues (59%) and physical health issues (59%)
  - Not wanting to be a burden to others (44%)
  - Lack of appropriate transport (33%)

Figure 8, from the aforementioned report, shows why dementia friendly communities are important.

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What is a dementia friendly community?

The Alzheimer’s Society defines a dementia friendly community as one “in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them.”

The Joseph Rowntree Foundation states that being dementia friendly is about “recognising that people with dementia want to carry on living their lives. This requires businesses, organisations, statutory agencies to think of the person first, as a citizen, member, participant, client, customer in their own right but with particular needs because of their dementia.”

According to the Alzheimer’s Society this should focus on the following 10 areas:

- People with dementia should be involved in their communities
- Stigma should be challenged and understanding built
- Community activities which are accessible and sensitive to people with dementia
- People with dementia should feel confident about the positive contribution they can make in their community
- Ensure access to early diagnosis and post-diagnostic support
- Ensure that people with dementia are given practical support to help them engage in community life
- People with dementia should be supported to live in their communities, from maintaining independence to inclusive, high quality care homes
- Transport should be consistent, reliable and responsive to their needs

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Physical environments should be easy to navigate for people with dementia
Business and services should be respectful and responsive to people with dementia

The Joseph Rowntree Foundation has a four year programme aimed at making the UK a good place for people with dementia called “Dementia without Walls”.\(^{26}\) It has three strands, one of which is supporting dementia friendly communities.

Worldwide Minnesota has pioneered Dementia Capable Communities in the United States.\(^{27}\) Their initiative is called “ACT on Alzheimer’s”. It is a partnership of private and public organisations across the state. There are five key aims:

- Raising awareness and reducing stigma
- Identifying and investing in new initiatives
- Increased detection and improved care
- Sustaining caregivers
- Equipping communities

It has developed an online toolkit to help communities to become dementia friendly. This is based on a four stage process.

- **Convene** – bringing key community leaders and residents together to form an Action Team
- **Assess** – review the strengths and gaps in dementia using a pre-specified community assessment tool
- **Analyse** – consider the community needs and determine the issues that stakeholders are motivated to act on, then set goals
- **ACT Together** – establish an implementation plan for action and evaluation

There are currently 19 communities across the state which have engaged with the project.

Innovation in Dementia undertook a survey and focus groups of people with dementia in 2011 around what makes a community dementia friendly.\(^{28}\) Their recommendations were:

- People with dementia should advise on planning and access issues in order to make the physical environment more dementia friendly.
- Service providers should be made aware that many people with dementia are covered by The Equality Act 2010.
- People with dementia and their advocates should be made aware of their rights under The Equality Act 2010.
- People with dementia should be supported and encourage to develop a role in raising awareness and training.
- Buddy schemes to support people with dementia in the community should be developed.
- Organisations responsible for providing support and information to people with dementia and their carers should ensure that the information they provide is informed by a social as well as a medical model of dementia.
- Public awareness campaigns should reflect a rights-based approach to dementia.
- Awareness campaigns nationally and locally should be supported.
- Development of a role for people with dementia in raising awareness of dementia.


 Guidance enables service providers to produce information which is accessible people with dementia.

 Guidance enables service providers to produce information which is accessible people with dementia.

 The applicability of the Equality Act 2010 to people with dementia should be investigated.

 What communities are important to people with dementia and their carers?

 The Dementia Friendly Communities programme has primarily focused on geographical communities. In Norfolk the first town to take part in the Dementia Friendly Community programme was Wymondham followed by Swaffham and Diss with plans being developed for other towns.

 Other important communities were identified through discussion with people with dementia and their carers. These include social networks (e.g. friends and family), support groups (e.g. day services and dementia cafes), community groups or clubs, workplaces and ethnic, cultural or faith communities. Many of these are not confined to a geographical location. For example a person from Eastern Europe may feel more part of their Eastern European community than a specific geographical area. Or a person with early onset of dementia who is employed may feel a stronger attachment to the community of work colleagues rather than a specific town.

 The community of carers is equally important. A diagnosis of dementia can change the communities and social networks that a carer identifies with and as dementia progresses the community of a carer becomes increasingly important.

 Participant (carer, female): After [my husband] was diagnosed, we lost contact with many local friends and neighbours because they found it difficult. We always kept in touch with long term friends, but we ended up spending more and more time with other people with dementia.

 What proportions of people with dementia live at home?

 In Norfolk 72.3% (approximately 11,850) of people with dementia live in the community. One third of people with dementia in the community live alone (approximately 3,950 people across Norfolk). The remaining 27.7% live in long-term care facilities.

 What support do people with dementia want from their community?

 The support that people want from their community, based on discussion with people with dementia and their carers and review of the literature, falls into seven key themes:

 Awareness – this was the strongest theme. Most people with dementia and their carers want members of the community to have a basic understanding of what dementia is and how it affects people.
Support groups – these are hugely valued by people with dementia and their carers. Many people spoke of the invaluable support provided. This was especially useful in terms of sharing information, experiences and learning.

Clear information – navigating services in the community for people with dementia and their carers is challenging. Simple changes such as making signage dementia friendly and bus timetables easier to read could make a significant difference. The following advice has been suggested by Innovations in Dementia:29

- Signs should be clear, in bold face with good contrast between text and background.
- There should be a contrast between the sign and the surface it is mounted on.
- Signs should be fixed to the doors they refer to – not on adjacent surfaces.
- Signs should be at eye level and well-lit.
- The use of highly stylized or abstract images or icons as representations on signage should be avoided.
- Think about placing signs at key decision points for someone who is trying to navigate your premises for the first time.
- Signs for toilets and exits are particularly important.
- Ensure that glass doors are clearly marked.

Physical environment – the ability to easily get outside. For example having suitable parking facilities.

Activities at the right level – people with dementia, especially wanted to be able to do activities, such as singing or walking in the community. For example, the Dementia Adventure offers activity based short breaks for people with dementia and their carers. It is important that these are at the right level. People with mild dementia wanted to be able to undertake activities with others at a similar stage and not people with advanced disease. There is also a need for more activities in care homes. One study found that people in care homes with dementia spent less than 12 minutes in everyday undertaking constructive activities other than watching television.30 Examples of activities include social stimuli (e.g. real or stimulated pet), music or art.31 These concerns were echoed by health and social care professionals.

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Transport – communities need public transport which is accessible and supported by helpful staff. The ability to access and use services in a community often depends on good transport links.

Local facilities – people with dementia and their carers rely more than most on local amenities.

**What is the current community service provision?**

Services were identified through a mapping exercise that is shown in Appendix 1. This involved triangulating information from the Heron database, Carer’s directory, Alzheimer’s Society, Age UK Norfolk, stakeholders and internet search.

The mapping exercise shows there are a number of community services available. Many of these are provided by voluntary organisations. Currently community services provided by voluntary organisations could be more joined up. While everyone with dementia has access to county-wide services, such as advice service from Alzheimer’s Society, disparities in provision exist.

Figures 11 to 15 show maps services available in the community. While every effort was made to include all services, some services may not have been identified.
Figure 10: Map of day centres that cater for older people or people with dementia

Courtesy of the Guild
Figure 11: Map of pharmacies
Figure 12: Map of travel time to pharmacy within 20 minutes
Figure 13: Map of libraries

Courtesy of Library Service
Figure 14: Map of mobile libraries
Figure 15: Map of bus routes
What good examples of dementia friendly community development do we have from the literature or other areas?

The Joseph Rowntree Foundation has produced a report of 20 examples of grassroots dementia friendly work from communities across Yorkshire. These case studies include:

- Making York Railway Station and Airedale General Hospital dementia friendly
- Working with Trading Standards to prevent doorstep crime by providing befriending services, arranging family reconciliations, helping change locks and undertake home safety checks
- Working with supermarkets and department shops to ensure signage is clear and staff understand dementia
- Working with the South Asian community to combat preconceptions and link people with dementia and carers with services
- Promoting dementia resources within libraries
- Reminiscence groups in church halls and memory cafes
- Teaching children in schools about dementia
- Working with York Museums Trust to develop arts-based activities for people with dementia
- Working with the leisure centres to develop an inclusive environment so that people with dementia can mix with other users
- Helping solicitors to develop dementia friendly processes to give people with dementia legal advice

Bruges, Belgium, has been hailed a leading example of a dementia friendly city. This includes local dementia choirs, dementia friendly “safe havens” (shops and businesses where people with dementia and carers can stay if in distress), specialist dementia counsellors and a database for police to track vulnerable dementia sufferers.

Hampshire has promoted the use of a help cards scheme. This allows people with dementia to give a card to anyone they come into contact with which explains their conditions and any specific individual needs. It is part of a wider scheme called Communication Awareness Care.

The Alzheimer’s Society has published guidance for the financial sector about how to become dementia friendly. The document calls for financial services to sign up to the dementia friendly financial services charter and meet a number of stated commitments.

The Health and Social Care Partnership has developed a Dementia Resource Suite for Schools.

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friendly generation. The resource suite provides information for schools about how to communicate the key messages about dementia education in schools.
Domain 2: Timely diagnosis

Researcher: Looking back to the beginning, was there a point when you thought to yourself something’s not quite right?
Participant (carer, female): I can pinpoint it very precisely. [My husband] used to do my accounts, I was treasurer and I can’t count so he used to do my accounts for [a charitable organisation] and he kept saying ‘there’s something wrong with the calculator’ and he took a week and he couldn’t finish it. And then I discovered we hadn’t got any car insurance and we hadn’t had any for two years. So I realised there was something wrong.

Diagnosis is not an end in itself, but a gateway to allow people with dementia and their carers to make informed decisions about the future. The benefits of timely diagnosis are considerable. Unfortunately the average person waits three years from the onset of symptoms to receiving a diagnosis. People with dementia and their carers are usually aware that something is not right. If this is combined with misunderstanding about the disease or coping strategies it can lead to significant anxiety and detrimental care. The timing of the diagnosis is crucial. For some people it may take months for them to be ready to receive a diagnosis. For example 64% of carers report being in denial about the problem before diagnosis. Across dementia services the terminology has changed from “early diagnosis” to “timely diagnosis”.

Not only is the timing important but the manner in which the diagnosis is shared and support available afterwards. Receiving a diagnosis of dementia is life changing. For some people it is unexpected and others it confirms their fears or relieves uncertainty. The diagnosis should be delivered in a sensitive manner. Following a diagnosis people with dementia and their carers should have access to advice, information and support. These are covered in chapters 3 and 4.

The Prime Minister’s Challenge on Dementia described a target of achieving 67% diagnosis rate with appropriate diagnostic support by 2015. The current national average is 45%. This target will be a considerable challenge for Clinical Commissioning Groups in Norfolk.

What are the current diagnoses rates across Norfolk and how accurate are they likely to be?

The Dementia Prevalence Calculator provides estimates of diagnosis rates. Version 3 has just been released. Using Dementia UK (2007) and Health Social Care Information Centre data the prevalence of dementia is calculated by applying these figures to a GP practice populations, adjusted for age, gender and proportion of people in a care home. It can estimate the number of people with mild, moderate or severe disease. The data can then by aggregated to Clinical Commissioning Group or Area Team level.

The analysis is reviewed by an independent consultancy company. A literature search could not find any evaluation or validation of the estimations.

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Table 11 below shows the diagnosis rate for each Clinical Commissioning Group. The diagnosis rate in Norfolk and Waveney is 43.2%, meaning that 56.8% of people with dementia remain undiagnosed. Great Yarmouth and Waveney CCG has the highest diagnosis rate (49.6%) and West Norfolk CCG has the lowest (35.3%).

**Table 11: Diagnosis of dementia by Clinical Commissioning Group**

<table>
<thead>
<tr>
<th>CCG</th>
<th>Population</th>
<th>Number of people with diagnosis</th>
<th>Estimated number of people with dementia</th>
<th>Percentage of people with dementia diagnosed</th>
</tr>
</thead>
<tbody>
<tr>
<td>GYW</td>
<td>231,986</td>
<td>1,907</td>
<td>3,844</td>
<td>49.6</td>
</tr>
<tr>
<td>North</td>
<td>168,310</td>
<td>1,542</td>
<td>3,588</td>
<td>43.0</td>
</tr>
<tr>
<td>Norwich</td>
<td>193,608</td>
<td>1,090</td>
<td>2,659</td>
<td>41.0</td>
</tr>
<tr>
<td>South</td>
<td>222,990</td>
<td>1,517</td>
<td>3,419</td>
<td>44.4</td>
</tr>
<tr>
<td>West</td>
<td>165,867</td>
<td>1,020</td>
<td>2,889</td>
<td>35.3</td>
</tr>
<tr>
<td>Norfolk &amp; Waveney</td>
<td>982,761</td>
<td>7,076</td>
<td>16,400</td>
<td>43.2</td>
</tr>
<tr>
<td>East Anglia Local Area Team</td>
<td>2,484,235</td>
<td>15,846</td>
<td>4,297</td>
<td>44.3</td>
</tr>
</tbody>
</table>

Figure 16 shows the trends over the previous four years and predicted trend over the next five years, assuming all things remain the same. This highlights the need for a step change in the diagnosis rate if the number of people with diagnosed dementia is going to reach the target of 67%.
What variation exists across the county?

The diagnosis rate for a Clinical Commissioning Group reflects the average throughout all practices. However there is considerable variation within each CCG. Across the county diagnosis rates vary from 13% to 123% (23% more diagnoses than estimated cases). Only 6% of practices diagnose more than two thirds of people with dementia and 30% of practices diagnose less than one third.

The figures below illustrate the variation across Norfolk and for each individual CCG. This shows that:

- 17 practices in Norfolk and Waveney perform significantly better than others and 27 perform significantly worse
- 2 practices in Great Yarmouth and Waveney CCG perform significantly better than others and 7 perform significantly worse
- 2 practices in North Norfolk CCG perform significantly better than others and 3 perform significantly worse
- 4 practices in Norwich CCG perform significantly better than others and 3 perform significantly worse
- 1 practice in South Norfolk CCG perform significantly better than others and 4 perform significantly worse
- 3 practices in West Norfolk CCG perform significantly better than others and 6 perform significantly worse
Figure 17: Variation in dementia diagnoses in Norfolk and Waveney

![Dementia prevalence for Norfolk and Waveney](image)

Source: GP practice QOF disease registries 2012/13

Figure 18: Variation in dementia diagnoses in Great Yarmouth and Waveney CCG

![Dementia diagnosis for Great Yarmouth and Waveney CCG](image)

Source: GP practice QOF disease registries 2012/13
Figure 19: Variation in dementia diagnosis for North Norfolk CCG

![Diagram showing variation in dementia diagnosis for North Norfolk CCG.](image)

Source: GP practice QOF disease registries 2012/13

Figure 20: Variation in dementia diagnosis for Norwich CCG

![Diagram showing variation in dementia diagnosis for Norwich CCG.](image)

Source: GP practice QOF disease registries 2012/13
Figure 21: Variation in dementia diagnosis for South Norfolk CCG

Figure 22: Variation in dementia diagnosis for West Norfolk CCG
Table 12 shows the relationship between rurality and likelihood of having a diagnosis. There is no clear relationship between living in a rural area and having a diagnosis of dementia.

**Table 12: Diagnosis by rural group**

<table>
<thead>
<tr>
<th>Rural Group</th>
<th>Population</th>
<th>Diagnosed dementia</th>
<th>Prevalence (%)</th>
<th>Expected numbers</th>
<th>Diagnostic rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hamlet and isolated dwelling - less sparse</td>
<td>7,033</td>
<td>80</td>
<td>1.1</td>
<td>159</td>
<td>50.4</td>
</tr>
<tr>
<td>Village - sparse</td>
<td>17538</td>
<td>116</td>
<td>0.7</td>
<td>386</td>
<td>30.1</td>
</tr>
<tr>
<td>Village – less sparse</td>
<td>83,904</td>
<td>618</td>
<td>0.7</td>
<td>1,432</td>
<td>43.1</td>
</tr>
<tr>
<td>Town and fringe - sparse</td>
<td>57851</td>
<td>563</td>
<td>1.0</td>
<td>1,353</td>
<td>41.6</td>
</tr>
<tr>
<td>Town and fringe - less sparse</td>
<td>249,210</td>
<td>2,040</td>
<td>0.8</td>
<td>4,753</td>
<td>42.9</td>
</tr>
<tr>
<td>Urban &gt;10k - less sparse</td>
<td>563,812</td>
<td>3,644</td>
<td>0.6</td>
<td>8,271</td>
<td>44.1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>979,348</strong></td>
<td><strong>7,061</strong></td>
<td><strong>0.7</strong></td>
<td><strong>16,354</strong></td>
<td><strong>43.2</strong></td>
</tr>
</tbody>
</table>

Equally there does not appear to be an association between the likelihood of being diagnosed and deprivation as shown in figure 23.

**Figure 23: Association between diagnosis and deprivation**
To what extent do people with dementia want to know about a diagnosis of dementia?

Published evidence suggested that the majority of people with mild dementia wish to know their diagnosis. However if the diagnosis is disclosed at the wrong time or in the wrong manner there can be negative consequences. Some researchers advocate that diagnosis should be disclosed in all situations where the person with dementia shows both the desire and ability to know.

The above three studies describe several benefits to sharing a diagnosis which include:

– confirming suspicions and ending uncertainty
– increasing understanding of problems
– giving access to support
– promoting positive coping strategies
– facilitating planning and fulfilment of short term goals

Feedback from people with dementia and carers suggest that they would like to know their diagnosis.

participant (carer, female): It easier to deal with when you’ve got a diagnosis. You’ve got a label you can put on it and it’s easier to cope with because people with dementia do all sorts of funny things and if you’ve got a label it’s easier to deal with.

There were several examples where a diagnosis was given in an insensitive manner or without appropriate follow-up. This is a particular risk when the diagnosis is made in neurology or older people’s medicine outpatient clinic.

One focus group participant was convinced of the diagnosis and only wanted a diagnosis if it gave access to treatment or services.

participant (carer, female): The test, oh yes… I mean I was sure long before his actual diagnosis, I had no doubts it was Alzheimer’s and um, what happened in the end was, we were referred to Addenbrookes because I said to the GP ‘Look, this is absolute nonsense, I know he has Alzheimer’s but I just want to know if we should be doing anything, or if he should be on any medication’. So when we were referred to Addenbrookes they were terrific there, absolutely terrific and they said ‘Of course he has Alzheimer’s, no doubt about it’ you know and ‘We’re sorry you’ve had all this carry on to get it diagnosed’.

38 G Pinner et al. What should we tell people about dementia? Advances in Psychiatric Treatment 2003:9: 335-341
40 R Pratt A Psychosocial Model of Understanding the Experience of Receiving a Diagnosis of Dementia. Dementia 2003:2:181-199
What are the barriers and drivers of increasing diagnoses?

In 2013 the University of East Anglia undertook a survey for the Norfolk and Suffolk Dementia Alliance of GPs to identify the barriers to diagnosing. Results are shown in Figure 23. This shows that GPs feel that a diagnosis would benefit patients and families and they have the skills. It also shows that people with dementia and families would like to know as early as possible. Most GPs felt that memory services were adequate, 39% of GPs felt that there was little point in diagnosing dementia because there were no services to support people with dementia and their carers.

**Figure 23: GP Survey of barriers to diagnosis**

![Figure 23: GP Survey of barriers to diagnosis](image)

Information from people with dementia, their carers, health professionals and stakeholders has been collated. The main drivers and barriers are shown in Figure 24. Perceived lack of support and the absent of a cure were strong themes. Generally speaking GPs did not understand the diagnostic pathway and did not feel like they participated in the diagnosis. The lack of an accepted tool to use was also highlighted as a barrier. The main drivers were financial, either the Directed Enhanced Service or Quality Outcome Framework. In particular circumstances, such as drug treatment or concern from the patient or relatives, the GP would be more likely to refer for diagnosis.

Directed Enhanced Service and Quality Outcomes Framework are described in Domain 5.
Some focus group members suggested that a diagnosis of dementia may be undesirable because it would restrict the services which someone would be eligible for. For example some care homes “don’t take people with dementia”. However this was disputed by others. It is unclear if this is a true barrier to diagnosis.

Many health or social care staff miss opportunities to intervene in order to refer for diagnosis and subsequently improve access to services.

**Participant (carer, female):** …things had been difficult for some time. [My husband] had started to miss things like his GP appointments. He would telephone the surgery and make the appointment, then forget he had done it. This happened several times and there were about five or so missed appointments but no-one from the surgery had called to ask why or to check up and see if he was OK. If [my husband] did make his appointment, he would occasionally be ten minutes late as he would forget something or get distracted along the way. When he arrived at the surgery he would be told that he was late and the GP could no longer fit him in. This happened about five or six times. In all that time - about a year I think it was - not a single NHS person called to check up on him or ask why it was happening. It was about that time when I was diagnosed with severe depression and was admitted into [a local hospital]. I actually was kept in for a couple of months. [My husband] lived at home, completely alone, with no help for his dementia at all. No-one checked up, or called in. He got into quite a bad state. It was only on my insistence as I began to get a bit better myself in hospital…that a social worker was asked to call in on him and check all was well. All was not well. He hadn’t been eating, hadn’t cleaned the house, not washed himself or his clothes, had not tended the garden or put the rubbish out for two months.
What interventions are successful in improving diagnoses, either from literature or other examples of good practice?

A literature search found a lack of evidence based solutions to improving diagnosis.

A systematic review of widespread population screening did not find enough evidence to support its use.41

One randomised controlled trial compared usual practice with a combination of electronic tutorial (from a CD rom), decision support software (built into electronic medical records to prompt diagnosis) and practice-based workshops.42 Thirty-six practices participated in the study. The authors found that decision support software and practice based workshops significantly improved detection rates. The electronic tutorial did not improve diagnosis rates.

One study distributed guidance about coding of dementia to 23 practices in London.43 The guidance involved a simple five point process.

- Identify commonly used Read Codes for dementia/memory concerns
- Obtain practice's QOF dementia register
- Run searches to generate lists of patients who may have dementia
- Compare search results with QOF dementia register
- Discuss with patients for further review

As a result of the guidance the proportion of people diagnosed with dementia increased on average by 8.8% per practice and took on average 4.7 hours per practice.

Prof Alistair Burns visited seventeen different Clinical Commissioning Groups to learn lessons about commissioners who were successful in increasing dementia diagnoses.44 Key themes were extracted from CCGs which were making greatest progress, these were:

- The local health and care community has a coherent, focused, and clearly led plan of work to improve dementia care
- Commissioners and clinical leaders are active and visible in this pursuit, knowledgeable about what works, and proactively delivering a comprehensive strategy and action plan; working relationships are positive, and it appears that values and ambitions are shared
- Work is proactive, systematic and sustained, rather than reactive and piecemeal
- Dementia care is being mainstreamed within existing health and care services, rather than being framed as something associated with memory services alone
- Ambitions to improve diagnosis are being progressed within the wider context of raising awareness about dementia; improving knowledge and skills of health and care staff; understanding the role of primary care in dementia care, including care of patients living in care homes

41 Boustani et al. Screening for Dementia. Systematic Evidence Reviews 2003 No. 20
Voluntary and community sector organisations are key partners in the development of strategic plans and as service providers. Investments in this sector are key components of local dementia strategies.

Interventions which were used in successful CCGs were:
- High levels of Enhanced Service for Dementia (DES) amongst GPs
- Coding reconciliation exercises and monitoring of QOF performance
- Commissioning dementia adviser services to support timely diagnosis and post-diagnostic support
- Training of health care professionals
- Training for carers
- Advance care planning
- Access to respite care

North Norfolk CCG piloted the CANTABmobile technology. The technology is a computer based tool that is marketed as a five to seven minute test for cognitive impairment. 5-10% of those individuals who get an amber or red light on the test will progress over the next year to dementia. After five years this rises to 50%. The evaluation from North Norfolk CCG is still awaited but initial discussions suggest that the CCG will not be progressing with it. Although the practices found it easy to use, none of them felt it provided sufficient benefit over paper-based tools to justify cost of investment in system.

Dementia Partnerships is a specialist knowledge portal that brings together networks, organisations, groups and individuals to share knowledge and learning in the field of dementia. It is sponsored by NHS England. The Partnership has published a resource which details 10 key steps to improving timely diagnosis. These are:
- Understand demand
  - Describe prevalence, incidence, diagnosis rates and population projections
- Improve access to memory assessment
  - Ensure that supply matches demand. There needs to be sufficient memory assessment services to allow the diagnostic pathway to operate efficiently. An inefficient process is likely to disincentivise referral
- Build capacity and support in the community
  - Strong local leadership, good support, appropriate treatment, skilled workforce and timely and accessible information
- Drive improvement; monitor and review
  - Use incentives and performance manage
- Ensure transparency about access and standards
  - Provide up-to-date data, information and intelligence to practitioners about performance
- Educate; promote
  - Primary care staff about the prevalence, diagnosis rates, diagnostic pathway and support available
- Recognise; assess; refer
  - Proactive, responsive primary care services
- Find cases

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Opportunistic case finding, especially with complex cases and care home residents
  - Check coding
    - Accurate coding on the GP Quality Outcomes Framework dementia register
  - Review prescribing
    - Ensure appropriate prescribing of anti-dementia drugs and anti-psychotics

The southwest have designed a Dementia Roadmap. It aims to provide high quality information about the dementia journey alongside local information about services, support groups and care pathways to assist primary care staff to more effectively support people with dementia and cognitive impairment, their families and carers. The main audience is staff working in primary care, including GPs, nurses and practice managers.

Improving diagnosis rates is likely to follow the innovation curve as shown in Figure 25. The diagram shows that for any behaviour change, such as improving dementia diagnoses among GPs, there will be innovators who lead the way with the new service. These tend to be individuals who are enthusiastic about all new services. The early adopters are amenable to change, but usually wait for other people to do it first. This group are open to new services. The important group in the whole curve is the early majority. This group represents a large proportion of the workforce and need good evidence to change behaviour. The late majority start to change behaviour only after they see everyone else changing. Laggards are resistant to most innovations.

In Norfolk it is crucial that changing the behaviour of GPs moves quickly from the innovators and early adopters to the early majority. After the early majority have changed their practice then the late majority will follow and eventually the laggards.

Figure 25: Innovation curve

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Arguably one of the most important components of the journey for someone with dementia is the support they receive. Support is necessary for both the person with dementia and their carer to prepare for a diagnosis, come to terms with the condition and manage the progression of symptoms. With good support a person with dementia is able to maintain their unique sense of identity and self-worth. The physical and mental health of carers is significantly at risk with many reporting declines in mental health and long-term health problems.

Dementia affects people in different ways. Support therefore needs to be flexible and person-centred. Delivering person-centred care in a health and social care system that is organisationally-based is challenging. This chapter explores the support needs for people with dementia and their carers.

What support services are currently available for people with diagnosed or undiagnosed dementia and their carers?

The dementia pathway is shown in Figure 26. It illustrates the pathway from primary prevention through to end of life care. Easy access to information, advice, advocacy and support are important in the early stages. In order to live well with dementia there needs to be supportive social services, community agencies, specialists, housing teams and care homes. Planning early for the end of life is key. The four aims of the dementia pathway are reducing stigma, supporting everyone, making wellbeing a priority and dying in the right place. These can be measured by the nine national outcomes as shown in the diagram.

Figure 27 shows the draft carers’ pathway which is currently being developed. This is shown for illustrative purposes only since it is still a work in progress. It is being developed by the Parkinson’s Pathway Development Group.
Figure 26: Norfolk Dementia Pathway

Raising Public Awareness & Understanding
Health Living Choices

Dementia Suspected

Timely Diagnosis and Intervention
Easy Access to Information, Advice and Advocacy, and to Support & Care
Community Support

Ongoing Wellbeing

Living Well with Dementia

Personal Support Services
Community Support
Carer Support
Care in Acute and Specialist Hospitals
Housing Support and Telecare
Living Well with Dementia in Care Homes

Patient & Carer Planning
Improved End of Life Care

Palliative Stage

Making the Change
- Good quality Information & advice for patients and carers
- An informed and effective workforce for people with dementia
- A Joint local commissioning strategy for dementia

Reduced Stigma
Everyone Supported
Wellbeing a Priority
Choice of Place

Aims

National Outcomes
People with dementia:
1. Are diagnosed in a timely way
2. Can enjoy their life
3. Get right information and advice
4. Can make decisions about their future
5. Get the right treatment and support
6. Are treated with dignity and respect
7. Feel part of the community
8. Have carers who are well supported
9. Know their end of life wishes are

Courtesy of Norfolk Older People’s Strategic Partnership
Figure 27: Draft carers' pathway

- **Specialist outpatients**
  - Specialist nurse triage

- **Occupation and physio**

- **Hospital support services**
  - "Home from hospital (Red Cross)"

- **Neurologist / OPM**

- **Palliative**

- **Community care team**
  - *Neurological specialist nurse*
  - *Community nursing*
  - *Dietician*
  - *Occupational Therapy*

- **Mental Health Access and Assessment Team (AAT)**

- **Dementia & Complexity in Later Life (DCLL)**

- **Improving Access to Psychological Therapies (IAPT)**

- **Recovery**

- **Hospital**

- **Carers**
  - Carers assessment
  - Information and/or services
  - Carers Helpline Triage / info signpost
  - Onward referral if

- **Services for Cared-for**

- **Other resources (including e-resources)**
  - *Grants:*
    - short breaks
    - carers learning grant
  - *Locality support for:*
    - one-to-one support

- **Services for Cared-for community**

- **Carers Agency Partnership (CAP)**

- **Palliative**

- **Social care**

- **Services**

**Courtesy of Kevin Vaughan**
It is important to note that support services are accessed by people with and without a diagnosis. If a person does not have a diagnosis they should not be denied support services. However diagnosis should be a gateway to accessing these services appropriately. This is important because diagnosis can sometimes be difficult to make and it is important to exclude other causes of cognitive impairment. Therefore the GP is a key to ensuring that a person with dementia has access to the right support.

A mapping exercise in Norfolk was undertaken to collate details of the services currently available (Appendix 1). Most support for people with dementia and their carers was provided by voluntary organisations. There were a number of dementia cafes, but fewer activity based groups or groups that were age and stage specific. Appropriate and flexible respite was identified as a gap.

Admiral Nurses, dementia support workers and dementia advisers are an important source of support for people with dementia and their carers.

An evaluation of the Admiral Nurses pilot in mid-Norfolk has recently been compiled by Zena Aldridge, Admiral Nurse Lead and Nicola Findlay, Occupational Therapist, and edited by Kate Rudkin, Head of Development and Operations, Age UK Norfolk. The evaluation used a mixed method technique. The qualitative component used interviews from 23 spouses, 11 offspring and one grandchild. The quantitative component used questionnaires from 28 professionals including GPs, social workers and nurses (28% response rate from 100 questionnaires). Between June 2013 and April 2014 there were over 230 referrals; the highest proportion was self-referrals. The evaluation shows that people with dementia, carers and professionals were very positive about the service. The Admiral Nurses supported 12 people to seek a diagnosis. The evaluation suggested that Admiral Nurses reduced the contact time between other services and avoided eight mental health bed admissions. It was estimated that the Admiral Nurse pilot resulted in savings of £426,601 to health and social care over the period from June 2013 and April 2014.

Participant (carer, female): The GP suggested an Admiral Nurse and she is just amazing. There are days when [my husband] drives me absolutely bonkers. The nurse can give us a bit of respite and really helpful practical advice. The main thing was that [the Admiral Nurse] understands what it’s like to live with someone with dementia and when you have feelings like you are really at the end of your tether that they tell you that they are normal.

Dementia advisers have not been fully evaluated locally but an annual report has highlighted that the services are valued by those using the services. A national evaluation found that dementia adviser services were able to successfully meet the needs people with dementia and their carers.48 The authors collectively evaluated activity across 40 demonstration sites and then explored eight case studies in-depth. The report stated that the “Dementia Adviser and Peer Support Network services had a significant role in enabling people with dementia and carers to re-narrate their lives, finding a new life which, though different from life prior to dementia, had meaning, value and purpose and in signposting people with dementia and carers to appropriate other services and support.” This concept of enabling people with dementia and their carers to re-narrate their lives is

an important part of helping people come to terms with dementia. Dementia advisers were also found to help raise awareness of dementia and tackle stigma.

NICE guidance states “People with mild-to-moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme. This should be commissioned and provided by a range of health and social care staff with appropriate training and supervision, and offered irrespective of any drug prescribed for the treatment of cognitive symptoms of dementia.” Cognitive stimulation includes activities that involve cognitive processing; usually group-based with an emphasis on enjoyment of activities. The programme usually lasts for several weeks. There can be a need for continuation meetings after the formal group has finished ensuring that the benefits last.

Norfolk and Suffolk Foundation Trust currently have two groups based in Norwich and have another group planned. Aylsham Care Trust has recently set up a group for people who live within 10 miles of their site in Aylsham. Worstead Day Care Centre offers cognitive stimulation therapy as part of their general day services. The Forget-Me-Nots is a charity which offers a number of cognitive stimulation therapy groups. Groups have been initiated in Doughty’s Hospital, Martineau Hall, Dell Rose Court and Norwich Prison.

**Carers’ support**

Slightly less than one in eight people in Norfolk provide unpaid care for someone else in 2012/13. Figure 28 shows that most is 1 to 19 hours per week. The highest proportion of unpaid carers was aged 50 to 64 years.

**Figure 28: Unpaid carers across Norfolk**

North Norfolk is the area with the highest proportion of unpaid carers and Norwich is the area with the lowest proportion as shown in figure 29.

**Figure 29: Geographical variation in unpaid carers**

![Bar chart showing percentage of population providing different hours of unpaid care in various areas of Norfolk](image)

There were about 6,000 carer’s assessments in Norfolk in 2012/13. The majority of these were for non-mental health related problems as shown in figure 30. This shows that only one in 16 carers undergo a carer’s assessment.
There are several organisations and services that support carers. Most organisations supported all types of carers, not just dementia carers. Some combined a carers group with a cared for group.

There are a number of different ways in which carers access support. The main sources were professionals, voluntary organisations and word of mouth via support groups. Other sources include county-wide publicity and community events.

The Care Act 2014 will hopefully provide impetus for significantly more support for people with dementia and their carers. It covers a number of different areas which will impact on the lives of people with dementia. For example part of the Care Act states that local authorities must give information and advice to everyone, not just people who are eligible for state support.

**What support is available for end of life care?**

End of life care is an important part of someone’s dementia journey. People with dementia do not often die because of the complications of end-stage dementia but usually because of another illness, such as heart attack. At the end-stage of dementia people can often have difficulty eating, leading to de-conditioning or aspiration pneumonia. There are a number of end of life services available for people with dementia. None of them are specific for dementia but they do include dementia alongside other terminal conditions.
The End of Life Care Strategy\textsuperscript{50} outlines what should be regarded as a “good death”. The report suggests the following for components.

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

These provide a good measure of how to deliver high quality end of life care in dementia.

Norfolk and Suffolk Palliative Care Academy, a collaborative group of individuals and organisations, has set up the Be Ready For It campaign.\textsuperscript{51} This encourages people to talk openly about death and dying. It provides practical help to allow people and their carers plan for death.

A number of community health services provide end of life care. These include community nursing teams, care home facilitators and specialist palliative care nurses. GPs have a pivotal role in providing high quality end of life care for people with dementia.

Norfolk and Suffolk Foundation Trust will provide some expert mental health advice for complex cases at the end of life. However the majority of their work is focused on diagnosis and treatment, rather than end of life.

Some community health services have started using Yellow Folders. Yellow Folders are given to people with any life-limiting condition to be a personal record of their preferred care plan. It therefore gives an opportunity for people with dementia and their carers to document their story and choices. This will hopefully reduce the number of times a person with dementia or their carer has to retell their story and also assists with future decision making.

Discussion with hospital staff revealed a lack of capacity within community services to allow expedited discharge for people with dementia who are at the end of life to allow them to die at their place of choosing.

\textbf{Do people with dementia understand and know how to access legal support, such as power of attorney and wills?}

If someone has dementia it is important that they organise their legal and financial affairs before there are any issues relating to their mental capacity. Furthermore as dementia progresses people often find it increasingly difficult to make decisions.

Making the correct legal and financial choices is important because it helps carers and public services make decisions which would be consistent with what the person with dementia would have wanted. Legal services include wills, lasting power of attorney and enduring power of attorney (both components 1. property and financial affairs and 2. health and welfare).


Unfortunately some people with dementia lose capacity before making a will or arranging a lasting power of attorney. This can have significant consequences. For example, a person with dementia may receive more hospital treatment than they would have previously chosen.

Discussion with people with dementia and their carers suggests a lack of knowledge and information about legal support. For some people it is not perceived as a priority, while other people believe that it is enough to verbally tell their carer their wishers.

**Carer** “You don’t know what you don’t know”

There is a need to provide people with dementia and their carers with comprehensive advice and information shortly after diagnosis, in order to allow them to make informed decisions.

**What do people with dementia and their carers think about the current level of support and where are the gaps?**

There were several positive aspects about the level of care for people with dementia and their carers. These included:

- **Quality of services is largely good**
  - Feedback from focus groups was generally positive about the quality of services. Capacity within services was not always felt to be adequate, but the quality of care when received was thought to be good.

- **Support groups**
  - Both people with dementia and their carers spoke highly of support groups. Sharing experiences, learning, information and knowledge proved invaluable to people with dementia and their carers.

- **Relationship with GP**
  - Some people with dementia and their carers spoke about how great a benefit it was to have a good relationship with their GP. High quality person-centred, holistic care when provided by a GP was a significant source of support.

- **Ambulance services**
  - Generally speaking people with dementia and their carers were complimentary about the quality of service provided by ambulance staff.

- **Attitudes and personalities of home carers**
  - Whilst people with dementia and their carers felt that there was improvements needed in relation to home carers, most were complimentary about the attitude and personalities of individual home carers.

- **Dementia Friends Campaign**
  - The Dementia Friends Campaign was felt to be an important step in increasing awareness and reducing stigma in the general population.

Several gaps were identified by people with dementia and their carers. These included:

- **Lack of information**
  - The primary gap identified was a lack of information about dementia services. This resulted in people with dementia and their carers spending considerable time finding out about what services are available. People with
dementia and their carers were keen to share their acquired knowledge with other people with dementia and their carers.

Participant (male, carer): I have found it difficult to get information on the types of help and support and services that are available. There is just nothing out there. Telephoning the doctors surgery, or the district nurse, or social services can be a nightmare. All the systems are automated and this is extremely upsetting for someone with dementia who cannot manage to keep track of the questions they are being asked, there are no steps ‘to go back’ if you think you have made a mistake. Health and social care services should have help lines and appointment booking systems that are ‘speaking to people the old-fashioned way’. It is all very impersonal, very technical and there is no human or social interaction.

Participant (carer, female): There is a real need for carers to have a place or space for information sharing, learning about what’s on for people with dementia and their carers, to get information about important issues such as financial help, finding and securing good respite care or domiciliary care or companionship care.

Researcher: Did you get any help from your GP or the social worker with finding a carer for your wife?

Participant (carer, male): (laughing) We didn’t get any help with that whatsoever. The social worker did mention to me that I could arrange help this way, I mean, to just do it myself so I did. I looked on the internet and I ordered brochures and I called Age UK and...Dementia UK and the Alzheimer’s Society I think, to get advice.

Participant (carer, female): Something has occurred to me…I don’t know if there are forums for us, or forums or whatever you call it, on the website, on the web, that people would know about, where people can have a dementia chat with somebody else. Do you know what I mean? Where they can, if they want to go on and chat to somebody and go ‘I’ve had a really rotten day’. But of course there’s all sorts of security issues and worries about doing things like that. I do wonder whether something like that might be, particularly, particularly, as this isn’t going to go away. Erm, it’s going to affect people, people like me, later on, hopefully not me but why not me, in a sense, people who actually, their families will be totally digital, totally online so their first thought will probably be what I find on there to tell me about it, what can I find for help so I think getting as much as possible online and setting up networks and things, particularly where people for various reasons can’t get people to day centres and different things. The information is there, people can use it or not, and people can do a kind of chat thing, where they just kind of vent their frustrations and then carry on with their lives.

- Services targeted at the right age and stage of dementia
  - People with dementia wanted to attend services with others who had similar experiences. Some people with mild dementia had been put off certain services because of the people who attended had advanced disease with complex behavioural problems. Equally younger people with dementia (e.g. less than 60 year old) may not want to attend services which are predominately accessed by and for very elderly people.

- Variation across the county
  - There is considerable variation in service provision across the county. The mapping exercise highlighted a number of issues. For example currently Admiral Nurses are only provided in mid-Norfolk. Cognitive stimulation therapy sessions are mainly concentrated around the Norwich area.
Care needs of the carer
  o Carers often spoke about how services were organised around the person with dementia and the needs of the carer were overlooked. Ignoring the needs of the carer can lead to ‘burn out’ and/or crisis.

Respite
  o Lack of flexible respite was identified as an important issue. Respite came in a number of different ways. For example, some carers reported that having an Admiral Nurse visit provided respite. Some carers wanted only a few hours of respite to, for example, go shopping. Carers found respite very expensive and this was a disincentive to use it. Some carers reported a two week stay could cost as much as £1500 which most carers found too expensive and completely unaffordable.

Participant (carer, female): So day to day, a hard thing is finding time for yourselves...does there comes a point where day to day things start to get too difficult and you'd like more help just to be able to go to the shops or take your husband shopping and more personal care like washing...

Participant (carer, female): But I thought, oh dear, is this going to happen on a more regular basis, one's not going to be able to cope and everyone sparked very quickly from ringing social services at Norfolk County Council and the Social Worker came out two days later and she said – our son came – and she spent two hours and took quite a lot of trouble in listening to [my husband] in what he could say and what he could understand and what he couldn't and she said ‘Well I suggest you and your son decide on two care home that you think are the best’, meanwhile we tried one or two including [a care home] for short period, ‘Choose the two you think are the best and let me know which one you think would be good and I’ll try and arrange respite care that will then probably need to go into permanent care and so we choose the one he’s actually in and um, he was in there for two weeks and then they said ‘Well look, we are having a room coming empty, just after [my husband] was due to come home and we have people wanting to come in there but do you want [your husband] to stay? Because if so you’d better stake a claim now otherwise we don’t know when they’ll be another one’. So I think we decided it was better to continue because he seemed fairly happy and settled and that’s what happened in fact.

Participant (carer, female): Its fourteen pounds an hour to go out.

Role of the GP
  o While some people were positive about the support given by GPs, some felt disappointed. Some people felt that their GP only looked at the physical problems without understanding the wider social and psychological issues. Other people complained that their GP had little or inaccurate information about dementia services. Some carers felt excluded from GP consultations.

Personal care services
  o Carers especially felt that there was a lack of personal care services which was compounded with misunderstanding. This resulted in carers feeling overwhelmed at times with the personal care needs of the person with dementia. People with dementia and their carers reported spending considerable amounts of time trying to find out about the social care process and then chasing professionals in the system to find out the progress of
assessments. This was especially an issue for people who were just above (outside) the eligibility threshold.

<table>
<thead>
<tr>
<th>Coping with the following day to day activities was identified by carers as the most important</th>
</tr>
</thead>
<tbody>
<tr>
<td>• help with buying and preparing meals</td>
</tr>
<tr>
<td>• ensuring the person with dementia drinks and eats regularly</td>
</tr>
<tr>
<td>• ensuring any prescription medication is taken in the correct quantity at the right times of day</td>
</tr>
<tr>
<td>• ensuring the person has a daily wash or bath and puts on clean clothing appropriate to the temperature/weather</td>
</tr>
<tr>
<td>• ensuring that electrical and gas appliances are off or on safely</td>
</tr>
<tr>
<td>• ensuring the building is safe and secure</td>
</tr>
<tr>
<td>• protecting people from rogue traders and postal/telephone scams</td>
</tr>
<tr>
<td>• ensuring the person with dementia has access to the money that they need but also that their finances are protected.</td>
</tr>
</tbody>
</table>

➢ Home carers
  o Whilst the attitude and personality of home carers was identified as a positive experience, people with dementia and their carers highlighted a lack of training, inconsistency of staff and an inability to deal with challenging behaviour as areas for improvement.

**Participant (carer, female):** *I didn’t always feel satisfied with the calibre of the home carers. I know that home carers do not get paid very well, have long distances to travel in between client visits and receive very little training. I felt that home carers need more training about dementia awareness. It wasn’t really their fault. You can’t blame them, but the standard of home care could be very much improved. For example, the carers really needed to look in my father’s fridge every day to keep an eye on the best before dates and eat-by dates on the food items. I would often visit to find spoiled and rotting food items in his fridge and occasionally find he had eaten spoiled or rotten food items because they had not been removed and he could no longer realise that these could be at best unpleasant and at worst, harmful. I was absolutely heart broken. I then decided to buy ready meals for him as a means for him to have a hot meal easily twice a day. Sadly though, and I wasn’t around, his friends and neighbours did not like the concept of ready meals and encouraged my father not to eat them. This meant he would not eat, become hungry, thirsty, confused and subsequently become under the weather or even fall as a result of dizziness.*

**Participant (carer, male):** *It can be expensive and it’s very difficult to get good quality help. We have had one or two awful experiences with a couple of agencies, sending people at the wrong time or, just simply sending the wrong sort of person because not everybody is predisposed to caring or nursing others. I do sometimes worry about the level of training some of these people have because so many of them seem so very young and I don’t quite see how they can have gained all the right experience.*

➢ Out of hours services
  o Many people with dementia and their carers did not know which services were available out of hours and how to access them. There was a general opinion that services stopped at 5pm, but the behaviour of people with
dementia often worsens in the evening or overnight leaving carers feeling unsupported.

- **Accident and Emergency services**
  - People with dementia and their carers did not feel that A+E services were good for people with dementia. A+E was often seen as a noisy, busy, frightening place.

- **Support for carers who are employed**
  - There are significant numbers of people under 65 years old who are unpaid carers. Carers UK estimated that 2.3 million carers had to stop work because of caring duties and 3 million reduced their hours. This has a significant impact on a carer’s income, but can also affect physical and mental health. A Department of Health report found that employment generally meets important psychosocial needs in society and it is central to an individual’s identity, social roles and social status. It is therefore not surprising that in some cases giving up work can be detrimental to a carer’s mental and physical health. Employers need to be more flexible about the working arrangements of carers with dementia.

- **Central point of contact**
  - Carers and people with dementia felt that it would be helpful to have a single point of contact, instead of having to ask multiple different people.

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**Participant (carer, female):** The other thing would be and I don’t know if this is do-able, but obviously people with dementia have a GP practice and I’m thinking if there could be somebody who works a bit like the district or community nurses, but not a community nurse, not necessarily medically trained, someone who supported a group of practices, who knows and who could get a picture of all the people, you know, just how many families were affected erm in the area, could monitor them and could act as a liaison and could make occasional phone contact or email contact to say ‘How you doing? I know you’re there, you haven’t dropped off the end of the world. We’re having a so-and-so day in your area would you like to bring mum along it’s just an informal coffee morning type thing’. The occasional thing rather than a commitment thing that might actually be quite helpful. Someone who was in contact, could feed back, could be an intermediary, could contact families and just do a little bit of support like that, maybe just an email or phone call occasionally. But at the same time, could feed data back up through the chain, so they could see groupings for example ‘there’s quite a few families in just this little area of villages here, I wonder if they’d like to put in touch with other, so they can arrange, you know how people arrange their own toddler mornings because they know each other they could arrange their own stuff. That is, if there was some money to fund it, that would I think, could be very valuable.

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**Co-morbidities**

People with dementia usually have other medical problems. For example, with vascular dementia people are more likely to have other vascular problems, such as heart disease and diabetes. In order to provide person-centred care is it vital to take a holistic approach

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to a person’s care which includes their co-morbidities. Unfortunately people with dementia who have co-morbidities are at risk of receiving worse care because of the complexity of their situation. Co-morbidities provide an opportunity for integration between services.

**Participant (carer, male):** …my wife needs insulin injections four times a day but the District Nurse can only come once a day to give her the insulin. How is that meant to help? What is meant to happen on the other three occasions? Not all carers can administer insulin and administering insulin to someone with dementia can be hugely difficult if the person does not want the injection…or has lost a lot of weight, has very little muscle on them, even on their stomach area.

Many people with Parkinson’s disease have dementia. The point prevalence of dementia in Parkinson’s disease is estimated to be 30%\(^54\). That means that at any one time about one in three people with Parkinson’s disease will have dementia. The cumulative prevalence rises to 75% for people who have had Parkinson’s disease for more than 10 years. This means that 3 in every 4 people with Parkinson’s disease for more than 10 years will have dementia. 3.6% of people with dementia are likely to have dementia and Parkinson’s disease.\(^55\) This is equivalent to about 590 people across Norfolk with dementia and Parkinson’s disease. The true number of people with dementia in Parkinson’s disease is likely to be higher than this because of the Norfolk demographics.

People with dementia are four to five times more likely to experience falls than older people without similar significant impairment.\(^56\) People with dementia have physical and mental changes which makes them more likely to have falls. The Falls Needs Assessment recommended “Dementia pathways and the specific needs of people with dementia need to be considered when developing falls prevention interventions and services – and equally appropriate falls prevention advice and interventions needs to be considered for people diagnosed with dementia.”\(^57\)

**Participant (carer, male):** [My wife] had had a fall and cut herself quite badly. She had needed an ambulance to take her to hospital as it was suspected that she had also had a head injury of some nature. She found the hospital stay terribly distressing from beginning to end. She constantly asked where she was, when she was going home and so on. She could not keep still in the bed or even sit still and was constantly getting up and moving around. She had a fall in hospital again which was upsetting because her carer thought ‘at least in hospital, she’ll be safe, someone will be around twenty-four seven to keep an eye on her’. She had quite a deep laceration on her thigh from falling at home and whilst in hospital, this developed an infection which needed to treated with antibiotics. The hospital staff found it difficult to encourage her to swallow her antibiotics and her husband finds it near on impossible to get her to take her antibiotics. She needed to go back to her surgery but as a carer it is very difficult to get to speak to any health professionals on her behalf.

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Sight loss is also common in dementia. It is estimated that 123,000 people in the UK have both dementia and serious sight loss.\(^{58}\) That is equivalent to approximately 1600 people in Norfolk with both dementia and sight loss.

Incontinence is another significant co-morbidity that is common in dementia. People with dementia, compared to those who do not have dementia, are three times more likely to have urinary incontinence and four times more likely to have faecal incontinence.\(^{59}\)

**Participant (Carer, male):** I have to get up with [my wife] in the night or rather I tend to wake [my wife] up several times a night because otherwise you know she might be incontinent and she'll wet the bed because often I can't get her to the toilet on time and it all happens so quickly.

### Domestic abuse

Obtaining good quality data on domestic abuse is difficult. Data from Norfolk Constabulary suggests that the number of victims of crime and non-crime events relating to domestic abuse is increasing over 65 years olds (Figure 30 and 31). Anecdotal evidence suggests that this may be due to dementia; either a true increase or an increase in reporting.

**Figure 30: Crime and non-crime victim domestic abuse events in Norfolk**

![Bar chart showing the number of victim events by age and year.](chart.png)

- **Note:** A *victim event* is defined as *either* an instance of a victim in a ‘believed domestic’ crime *or* an instance of a domestic party who was also a complainant in a non-crime domestic abuse incident.

- Domestic abuse is defined as any incident or pattern of incidents of controlling, coercive or threatening behaviour, violence or abuse between those aged 16 or over who are or have been intimate partners or family members regardless of gender or sexuality.

\(^{58}\) Access Economics 2009. Future Sight Loss UK 1: Economic Impact of Partial Sight and Blindness in the UK adult population. RNIB

\(^{59}\) Grant L et al. First Diagnosis and Management of Incontinence in Older People with and without Dementia in Primary Care: A Cohort Study Using The Health Improvement Network Primary Care Database. PLOS Medicine DOI: 10.1371/journal.pmed.100150
Figure 31: Crime and non-crime perpetrator events in Norfolk

Note: A perpetrator event is defined as *either* an instance of an offender, suspect or person of interest in a ‘believed domestic’ crime or an instance of a domestic party in a non-crime domestic abuse incident where another domestic party was the complainant.
Domain 5: Primary and community healthcare services

Remaining independent at home in their community is a primary concern for many people with dementia. High quality, person-centred community services are vital.

Over the past 20 years health service planners have tried to shift healthcare from reactive acute care to proactive community care. The benefits of high quality community care are obvious; people with dementia are able to receive flexible healthcare closer to home, people are more likely to stay at home for longer, deconditioning is prevented in acute hospitals and the cost of expensive inappropriate hospital stays is reduced.

However there is a risk that if community services do not have adequate resources and capacity then patients are left with less access to appropriate healthcare. Paramount to the delivery of high quality community care is the role of the GP. S/he can be the gateway to services and can influence the support a person with dementia and their carer receive. In addition, community nurses, community matrons, case managers, physiotherapists, occupational therapists, ambulance staff and pharmacists all have an important role to play.

One of the biggest challenges for community services is delivering joined up, or integrated, healthcare. Arguably services have become more fragmented over the past few years making this task more difficult. Integrated healthcare is important for two main reasons. Firstly it allows services to work with each other to ensure people with dementia receive high quality healthcare. Secondly integrated services can be more efficient by sharing expertise and learning and reducing duplication.

This chapter considers the needs of people with dementia in relation to primary and community healthcare.

What dementia specific services are available in primary and community health care?

Cognitive stimulation therapy is covered in Domains 3 and 4.

Admiral Nurses and Dementia Advisers are covered in Domains 3, 4 and 9.

There has been a change in community mental health services over the past few years. The establishment of the Dementia Intensive Support Teams (DIST) has aimed to provide community health care closer to a person’s home. The number of acute mental health assessment beds has been reduced to release resources for DIST. The DIST are separate from the community dementia diagnostic and treatment services. There are three DISTs in Norfolk: west, central and east. The DIST consist of specially trained nurses and support workers that visit people with dementia in their homes or care homes during periods of crisis to prevent further decline. There is no age restriction. The Norfolk and Norwich University Hospital and Queen Elizabeth Hospital work closely with DIST to identify and intervene with patients whose admission was primarily caused by a dementia crisis. Capacity within DIST is still an issue. During a visit to the Queen Elizabeth Hospital to collect data for this report, the DIST had closed to referrals because it had reached its maximum caseload. The role of the DIST in the James Paget University Hospital is
unclear. DIST staff based in the hospital have been withdrawn and the new referral pathways are currently being resolved.

An evaluation of the DIST in west Norfolk was undertaken in April 2014 by Norfolk and Suffolk Mental Health Foundation Trust. Over a six month period, before the establishment of DIST, between August 2012 and January 2013 there were 38 admissions to Chatterton House with an average length of stay of 37 days. The 12 dementia assessment beds in Chatterton House were closed and three beds were made available in the Julian Hospital (Norwich) for west Norfolk patients. Financial support for carers travelling was made available. Over an eight-month period between August 2013 and April 2014 there was an average of 27 referrals per month and active caseload of 33. In total there were 3,238 contacts, 97% of these were for assessment and treatment. Over this period there were 18 people admitted to Blickling Ward and 12 people admitted to Sandringham Ward. Therefore it can be estimated that over a 1 year period there would have been approximately 76 admissions to assessment beds, compared with 324 episodes of patient management in the community (assuming all referrals result in patient contact). It is clear that the formation of the DIST has resulted in more episodes of patient management compared to mental health hospital admissions. However there remain questions about whether the DIST currently have sufficient capacity and if the number of dementia assessment beds is right.

What do GPs, case managers, community matrons, case managers, ambulance staff and pharmacy staff think about service provision?

Focus groups and semi-structured interviews were held with a number of different health professionals. The following themes about current service provision emerged:

- **Dementia Intensive Support Teams (DIST)**
  - Overall DIST have been a good development. It allows for a greater number of people to benefit from community services. The reduction in acute assessment beds and centralisation of the beds in Norwich was highlighted as an issue. This requires families and friends to travel from across Norfolk to assessment beds in Norwich. The role of the DIST supporting acute hospitals, especially the James Paget University Hospital, was unclear.

- **Services need to be age and stage specific**
  - Professionals felt that there was a lack of services targeted at specific ages and stages, for example young men with early-stage dementia.

- **Need to move to a more proactive approach**
  - Currently many people with dementia and their carers are left unsupported until a crisis. A more proactive approach with early information and advice would prevent many crises.

- **No agreed tool for identify people with suspected dementia in primary care**
  - A lack of an agreed tool made it difficult for GPs. There appears to be several different tools in use.

- **Lack of information to people with dementia and carers**
  - Health professionals felt that they were not aware of the services available to people with dementia and their carers in order to advise patients.

- **Lack of support for people with dementia once discharged to GP**
  - Patients are discharged back to the care of their GP after mental health services involvement. Professionals felt that this was often a “falling off a cliff” experience for people with dementia and their carers.
➢ Lack of continuity of care
  o Health professionals stated that people with dementia and their carers would benefit from greater continuity of care. There was often a need for people with dementia and their carers to re-tell their story to multiple different professionals. This is especially important because the challenges that each individual person with dementia will face is different.

➢ Lack of understanding around the diagnostic pathway
  o GPs felt that they did not fully understand the pathway through mental health services. This meant that there was sometimes a reluctance to refer because they were not familiar with the process.

➢ Lack of overnight services
  o Overnight services were felt to be particularly important because the behaviour of people with dementia often worsened overnight. Therefore services need to be flexible to be able to manage increased needs overnight.

➢ Need for more training for GPs
  o Health professionals felt that the role of the GP was important in delivering high quality care and ensuring that people with dementia and their carers felt supported. There was large variation in the ability of GP to meet the needs of people with dementia and their carers. Therefore more training is need.

➢ Care homes
  o The quality of care for people with dementia was highlighted as a particular issue. There are often multiple GPs covering one care home and healthcare provided is often reactive rather than proactive.

➢ Alcohol related dementias
  o Professionals felt that alcohol-related dementia was a significant gap and more information was needed about current service provision. However it was felt that alcohol-related dementia should be considered separately to other types of dementia.

What are the challenges for the ambulance service?

The East of England ambulance service does not routinely collect data on the number of people with dementia. However a search through the Patient Care Report over the period from 12th May 2013 to 18th April 2014 identified 105 people in Norfolk with dementia reported from either the patient or carer. However this is likely to be significantly under-reported.

Most emergency calls for people with dementia are not specifically for a dementia crisis, but for another associated problem, such as a fall. It can often be difficult for ambulance staff to assess if a person with a fall who has dementia is more confused than usual. Increased confusion in someone who has fallen can indicate serious pathology. This results in more conveyances to hospital for assessment.

Ambulance staff do not currently have any simple process for making a referral to a GP if they suspected undiagnosed dementia. It appears that some ambulance staff would try to contact their GP to highlight the issue, but this could take several hours. There are no specific links with the Dementia Intensive Support Teams (DIST). Therefore ambulance staff would need to go through the GP to access DIST.
Recent mandatory professional update programmes from the ambulance trust have included sessions on dementia awareness and mental capacity act training. Four members of the ambulance staff in Norfolk and Suffolk have undertaken the Dementia Care Coach training provided by Norfolk and Suffolk Dementia Alliance in order to become local champions.

A regional CQUIN (excluding Norfolk) for 2013/14 aimed to establish more referral pathways in collaboration with acute trusts to improve care of people with dementia. This resulted in an additional 256 people with dementia being referred.

Focus group discussions revealed high satisfaction with the quality of service received from the ambulance service. One participant commented on the wait for an ambulance to arrive, but did not feel that it was unnecessarily long.

**What is the impact of missing persons?**

Norfolk Constabulary do not collect data if missing persons have dementia. Generally speaking the number of people over 65 years old who have been reported missing has increased as shown in Figure 32.

**Figure 32: Number of people over 65 years going missing**

![Figure 32: Number of people over 65 years going missing](Courtesy of Norfolk Constabulary)

Figure 33 below shows the proportion of these individuals who were classified as high or medium risk. Most people with dementia would be classified as high risk.
Most people over 65 years old who go missing are from home; however 1 in 8 people who go missing are from long-term care facilities as shown in figure 34.

Assuming that the number of people with dementia who are reported missing is equal to the number of over 65 year olds classified as high risk, this would mean that the estimated cost of missing people because of dementia would be £136,000 in 2012/13 and £176,800 in 2013/14. This is based on cost estimations from the Centre for the Study of Missing Persons using £3400 per high risk person who goes missing.\(^6\)

A number of assistive technologies have come to market to help prevent missing persons. These include reminder messages (recording when a person enters or leaves home), alarms and light sensors (for example if a person gets up overnight or enters a certain room), trigger response systems (activated if the front door is opened at certain times of the day) and tracking devices (fitted with GPS to identify people who go missing). Some

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people with dementia will be eligible for these technologies from public services, however many will require self-funding.

A person with dementia who is reported missing will probably have displayed early warning signs. It is important the carers and relatives intervene at this stage to prevent the person going missing and potentially coming to harm.

**What Directed Enhanced Service/Locally Enhanced Service/Quality Outcomes Framework exist and what impact have they had on dementia care?**

The Quality Outcomes Framework (QOF) for dementia, remunerates GP practices for meeting the following criteria: 1) keeping a register of people with dementia, 2) undertaking an annual review of people with dementia and 3) ensuring that people who are newly diagnosed have had the appropriate investigations.

The Directed Enhanced Service (2014/15) requires GPs to undertake opportunistic assessments of at risk patients with some basic memory questions followed by more detailed questioning if concerns found. Where appropriate patients should then be referred onwards, offered care planning, undertake a health check of carers and records kept up-to-date. GPs will be paid £0.37 per patient for signing up to the service (equivalent to £2,587 for an average sized practice) and then the total national budget available for the service will be divided among the practices depending on activity.

No locally enhanced services specifically for dementia were identified.

All practices participate in the national Quality Outcomes Framework and most practices across Norfolk have signed up to the national Directed Enhanced Service (2014/15). No evaluation of the impact of the Quality Outcomes Framework or Directed Enhanced Service was identified. The impact that these services have had on dementia care is therefore unknown.

Table 12 below shows the performance of organisations in Norfolk against the Quality Outcomes Framework target to undertake a care review of patients with dementia. It shows good achievement of the target, but does not demonstrate if this resulted in improved care for people with dementia and their carers.

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Table 12: Performance of Norfolk organisations against the Quality Outcomes Framework dementia indicator

<table>
<thead>
<tr>
<th>Area</th>
<th>Number of people with dementia on GP register</th>
<th>Number of people meeting QOF target</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2012-13</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Midlands and East of England</td>
<td>88,427</td>
<td>73,050</td>
<td>82.61</td>
</tr>
<tr>
<td>NHS Great Yarmouth &amp; Waveney</td>
<td>1,767</td>
<td>1,465</td>
<td>82.91</td>
</tr>
<tr>
<td>NHS North Norfolk</td>
<td>1,397</td>
<td>1,161</td>
<td>83.11</td>
</tr>
<tr>
<td>NHS Norwich</td>
<td>990</td>
<td>811</td>
<td>81.92</td>
</tr>
<tr>
<td>NHS South Norfolk</td>
<td>1,385</td>
<td>1,153</td>
<td>83.25</td>
</tr>
<tr>
<td>NHS West Norfolk</td>
<td>939</td>
<td>783</td>
<td>83.39</td>
</tr>
<tr>
<td><strong>2011-12</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Norfolk PCT</td>
<td>4326</td>
<td>3432</td>
<td>79.33</td>
</tr>
<tr>
<td>Great Yarmouth and Waveney PCT</td>
<td>1699</td>
<td>1238</td>
<td>72.87</td>
</tr>
</tbody>
</table>

How can community, primary care and secondary care services be delivered in an integrated way for the benefit if people with dementia and their carers?

Delivering joined up, integrated services has been identified as a priority by people with dementia, their carers and professionals. There is a need to integrate health services as well as health and social care services. From discussions with health professionals it is evident that many of the individual contacts between frontline staff have been lost. For example, a community mental health nurse may have lost contact with district nursing colleagues. This makes it difficult for organisations to work together for the benefit of the person with dementia and their carer.

In addition there is a lack of understanding of the different services offered by each organisation. Therefore professionals cannot advise people with dementia and their carers about which other services they would benefit from most.

People with dementia and their carers expressed a desire to have a single point of contact, rather than multiple, different agencies.
A dementia adviser, dementia support worker or Admiral Nurse, or similar, may be able to provide this single point of contact and help to provide a joined up integrated service for people with dementia. The staff would need to be commissioned jointly by health and social care and have a detailed knowledge of services available.
Domain 6: Secondary healthcare services

Almost every person who has a diagnosis of dementia will have been through the memory assessment service and, if suitable for treatment, the memory treatment service. The memory service is where the person with dementia and their carer have first contract with specialists to discuss the diagnosis, treatments, and services available and their possible future needs.

Most people with dementia and their carers have some experience of being admitted into hospital or seen in Accident and Emergency departments. Admission into acute hospital for people with dementia is not usually a good outcome. There are often mostly negative consequences for people with dementia who are admitted, including a lack of person-centred care. Hospital admission is often the time in a person’s journey when life changing decisions are made. Care needs are usually re-assessed and it may result in a move from their home to a long-term care facility. Ensuring that this episode of care is of high quality and that the person with dementia, their carer and their family feel supported in making difficult decisions is vital.

Unfortunately this is often not the case. Assessment in Accident and Emergency departments can be frightening. People with dementia can be moved between several wards. Organising personal care can take weeks, resulting in extended admissions and the inevitable associated risks.

How many dementia people with dementia are seen in secondary care?

Between 1 in 3 to 1 in 5 people in hospital have dementia. Table 13 below shows the point prevalence of dementia in the Norfolk and Norwich University Hospital over a four year period.

Table 13: Point prevalence of dementia in the Norfolk and Norwich University Hospital

<table>
<thead>
<tr>
<th>Year</th>
<th>Point prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>21.6%</td>
</tr>
<tr>
<td>2010</td>
<td>25%</td>
</tr>
<tr>
<td>2011</td>
<td>28.55%</td>
</tr>
<tr>
<td>2012</td>
<td>29.2%</td>
</tr>
</tbody>
</table>

Inpatient hospital admissions rates reported through Hospital Episodes Statistics (HES), due to mental and behavioural disorders, provide useful information on use of acute hospital services (i.e. excluding the mental health trust). Numbers of admissions to these services are likely to be affected by how willing people are to make use of routine care for their mental health condition that would reduce the risk of an acute admission. Rates could also be affected by differences in referral patterns and practices within primary and secondary care across Norfolk and Waveney.

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62 Dewing et al. hat is the current state of care for older people with dementia in general hospitals? A literature review. Dementia 2014 [epub ahead of print]
Data are presented on all Norfolk and Waveney residents who have been admitted to a District General Hospital over three financial years 2010/11 - 2012/13. Admissions are defined as spells, and a person could be admitted more than once.

Table 14 shows the number of admissions during the time period. In Norfolk and Waveney there were approximately 117 people with dementia admitted per 100,000 residents over these 3 years. West Norfolk CCG has a significantly higher rate of hospital admissions compared with other CCGs, both in males and females. The reason for this is not clear. It could be an issue with coding and recording of dementia or it could reflect difference in service provision.

Table 14: Directly age standardised Dementia all hospital admissions rate (DSR) per 100,000 residents by gender and CCG for Norfolk and Waveney, April 2010- March 2013

<table>
<thead>
<tr>
<th>CCG</th>
<th>Males Number</th>
<th>DSR</th>
<th>Females Number</th>
<th>DSR</th>
<th>Persons Number</th>
<th>DSR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Great Yarmouth and Waveney</td>
<td>397</td>
<td>113.3</td>
<td>343</td>
<td>97.2</td>
<td>740</td>
<td>104.6</td>
</tr>
<tr>
<td>North Norfolk</td>
<td>277</td>
<td>104.0</td>
<td>241</td>
<td>88.0</td>
<td>518</td>
<td>94.8</td>
</tr>
<tr>
<td>Norwich</td>
<td>346</td>
<td>117.4</td>
<td>249</td>
<td>81.6</td>
<td>595</td>
<td>98.5</td>
</tr>
<tr>
<td>South Norfolk</td>
<td>334</td>
<td>101.8</td>
<td>349</td>
<td>99.9</td>
<td>683</td>
<td>100.5</td>
</tr>
<tr>
<td>West Norfolk</td>
<td>544</td>
<td>218.6</td>
<td>498</td>
<td>188.2</td>
<td>1,042</td>
<td>201.9</td>
</tr>
<tr>
<td>Norfolk and Waveney</td>
<td>1,898</td>
<td>128.5</td>
<td>1,680</td>
<td>108.2</td>
<td>3,578</td>
<td>117.5</td>
</tr>
</tbody>
</table>

The proportion of emergency admissions for those aged 65 years and older with dementia recorded as a co-morbidity has increased over the past decade. Figure 35 shows that in Norfolk and Waveney the proportion of emergency admissions with dementia as a recorded co-morbidity has increased from 2.5% to 10% between 2000/01 and 2011/12.

Figure 35: Percentage of all emergency admissions for those aged over 65 years with dementia as a co-morbidity
Figure 36 shows dementia related admission in 2009/10. This shows that the majority of admissions come from Norwich, King’s Lynn and Cromer/Sheringham. The darker areas of the map show area with higher admission.

Figure 36: Dementia related admissions in 2009/10 by type of admission

The National Dementia Audit collects data on patients with dementia admitted into hospital. The Norfolk and Norwich University Hospital and Queen Elizabeth Hospital submit data. Length of stay and discharge information are shown in Table 15. The sample of cases shows that the median length of stay was shorter in the Norfolk and Norwich University Hospital and that more people at the Queen Elizabeth Hospital were given less than 24 hours’ notice of discharge.

Table 15: National Dementia Audit data

<table>
<thead>
<tr>
<th>Hospital</th>
<th>NNUH</th>
<th>QEH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients sampled</td>
<td>40</td>
<td>41</td>
</tr>
<tr>
<td>Range length stay (days)</td>
<td>4-78</td>
<td>5-75</td>
</tr>
<tr>
<td>Median length stay (days)</td>
<td>8</td>
<td>14</td>
</tr>
<tr>
<td>Discharge planning initiated within 24 hours (%)</td>
<td>59</td>
<td>6</td>
</tr>
<tr>
<td>Notice of discharge: Less than 24 hours (%)</td>
<td>9</td>
<td>23</td>
</tr>
<tr>
<td>Notice of discharge: 24 hours (%)</td>
<td>13</td>
<td>0</td>
</tr>
<tr>
<td>Notice of discharge: 24-48 hours (%)</td>
<td>47</td>
<td>43</td>
</tr>
<tr>
<td>Notice of discharge: More than 48 hours (%)</td>
<td>16</td>
<td>9</td>
</tr>
</tbody>
</table>

Activity in Norfolk and Suffolk Foundation Trust from 2013 is shown in Table 16 based on data from the Access and Assessment Team for both Dementia Intensive Support Teams
and Community Mental Health Teams. This shows that there are between 400 and 550 referrals each month, except for June when there was a peak at 751. About half of referrals are in the central Norfolk region, a quarter in west locality and a quarter in east.

**Table 16: Mental health service activity over seven month period in 2013**

<table>
<thead>
<tr>
<th>Month</th>
<th>April</th>
<th>May</th>
<th>June</th>
<th>July</th>
<th>August</th>
<th>September</th>
<th>October</th>
</tr>
</thead>
<tbody>
<tr>
<td>Locality</td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>West</td>
<td>74</td>
<td>18</td>
<td>73</td>
<td>16</td>
<td>100</td>
<td>13.5</td>
<td>85</td>
</tr>
<tr>
<td>Central</td>
<td>209*</td>
<td>52*</td>
<td>235</td>
<td>52</td>
<td>536</td>
<td>71</td>
<td>248</td>
</tr>
<tr>
<td>GYW</td>
<td>135</td>
<td>30</td>
<td>144</td>
<td>32</td>
<td>115</td>
<td>15.5</td>
<td>135</td>
</tr>
<tr>
<td>Total</td>
<td>418</td>
<td>100</td>
<td>422</td>
<td>100</td>
<td>751</td>
<td>100</td>
<td>468</td>
</tr>
</tbody>
</table>

* April numbers not available, so used May referrals % as an approximation.
** October numbers not available, so repeated September referral % as an approximation.

Figure 37 shows referrals to the Norfolk and Suffolk Foundation Trust (NSFT) between April 2012 and September 2013. This shows that referrals in the west increased in the last three months.

**Figure 37: Numbers of referrals to NSFT by locality**

![Figure 37: Numbers of referrals to NSFT by locality](Courtesy of NSFT)

Figures 38, 39 and 40 show the split by need. (C18 = cognitive impairment (low need), C19 = cognitive impairment or dementia complicated (moderate need), C20 = cognitive impairment or dementia (high need) and C21 = cognitive impairment or dementia (high physical or engagement need). This shows that the increase in referrals has mainly been in those with low or moderate need.
In 2009/10, 1337 people attended a memory assessment centre in Norfolk, of whom 73% received a positive diagnosis. No up-to-date information is available, but is expected that the proportion diagnosed will be similar in 2013/14.
What are the reasons for delayed discharge for people with dementia?

Discussion with people with dementia, carers and health and social care professionals identified a number of possible reasons for delayed discharges from acute hospitals. These include:

- **Delays in organising social care**
  - Hospital staff reported that there is often a delay because of delays in organising social care. Patients may have recovered from their acute medical problem and considered “medically fit”, but could remain in hospital for several additional days or weeks while social care is organised.

- **Continuing Healthcare Assessments and appeals**
  - These were highlighted as a significant source of delays, often for weeks. There were occasional reports of people with dementia being able to move to planning beds while this process was complete. However planning beds were in short supply and added an additional move for the person with dementia.

- **Cancelled home care**
  - A few examples were given where home care had been cancelled on admission. This meant that when the person was ready to be discharged home there was no home care available. This was a particular problem over the weekend.

- **Lack of community services**
  - Professionals felt that length of stay in acute hospital could be reduced if there were more community services. They expressed concerns that people with dementia often felt like they were “falling off a cliff” when leaving hospital. Examples of community services that would help include more intermediate care beds, facilitating intravenous treatments in care homes and intensive palliative care support.

- **Lack of services over the weekend**
  - Hospital staff suggested that more services over the weekend would help to reduce the length of stay for people with dementia.

Are people with dementia appropriately managed in hospitals?

There were several positive themes which emerged about hospital care for people with dementia. These included:

- **Dementia friendly environments**
  - Elsing Ward at the Norfolk and Norwich University Hospital was a good environment for people with dementia. In addition, small modifications which had been made to an older people’s medicine ward at the Queen Elizabeth Hospital had made a positive difference.

- **Carers involvement**
  - The carers involvement in the James Paget University Hospital was a good example of facilitating carers to be involved in the episode of care. Carers are encouraged to contribute to the care provided to their loved one where appropriate. Carers are also given a carers pack and the hospital has the Louise Hamilton Centre on site which provides a relaxing environment for carers and hosts a dementia café.

- **Dementia Support Workers**
Dementia Support Workers at the Norfolk and Norwich University Hospital and Queen Elizabeth Hospital provide support for people with dementia and carers during admission.

Find, Access, Refer CQUIN
- The find, access, refer CQUIN was seen as a good way to ensure that people admitted into hospital with cognitive impairment are appropriately referred.

There were several areas of improvement highlighted, including:

- **Examples of care not being person-centred**
  - There were simple examples of process which could have made a person’s experience in hospital considerably better. For example one professional reported that a person with dementia who was undergoing a day procedure was seventh on the list and therefore was not operated on until late in the afternoon. This resulted in considerable agitation and could have been easily resolved by giving the patient higher priority on the operating list.

- **Frequent hospital moves**
  - People with dementia, carers and professionals identified frequent hospital moves as an issue. A person with dementia would often move around several different wards. For example A+E, short stay ward, medical assessment unit, outlying medical ward and finally an older people’s medicine ward. This can add to the disorientation and confusion for people with dementia.

- **Inappropriate admissions**
  - Hospital professionals highlighted that some people with dementia could have been prevented from admission. There were reports of people with dementia being admitted because of a social reasons or because a carer has become unwell. Professionals felt that some people were inappropriately admitted from A+E where community services could have been arranged to prevent inpatient admission.

- **Communication between commissioners and frontline staff**
  - There were instances where frontline staff did not know commissioning decisions which had been made or future plans. This resulted in anxiety among staff and difficulties in planning services. Better communication between commissioners, mental health services and acute hospitals was needed.

- **Night time care**
  - People with dementia often become more agitated or confused overnight. Non-pharmacological treatments should be tried first. However these are labour intensive. Professionals highlighted the need for better awareness and policies for preventing and managing agitation overnight.

- **Specialist support in acute hospitals**
  - The Queen Elizabeth Hospital does not have any older people’s medicine consultants and the James Paget University Hospital only have two older people’s medicine consultants who are currently absorbed in stroke services. A lack of older people’s medicine experts advocating for better dementia care in these hospitals risks weakening the drive to improve dementia services.

- **Hospital environments**
  - Hospital wards which were modified to be dementia friendly helped to improve dementia care.

- **Accident and Emergency Departments**
Most A+E departments were not dementia friendly. The Queen Elizabeth Hospital were making their A+E department more dementia friendly.

<table>
<thead>
<tr>
<th>Carer: A+E is no place for someone with dementia.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer: Being admitted via the accident and emergency department is a terrible experience, the discomfort and noise levels are both seriously bad.</td>
</tr>
<tr>
<td>Carer: the brusqueness of the staff was unpalatable at two in the morning.</td>
</tr>
</tbody>
</table>

- **Nutrition**
  - Some professionals felt that ensuring adequate nutrition was often overlooked during admission. Staying hydrated and ensuring a good intake of nutrients is important to prevent increased confusion and help the recovery process.

- **End of life services**
  - There was frustration amongst health professionals about not being able to discharge people with dementia who were terminally ill because of a lack of community palliative care services. This often resulted in people with dementia dying in hospital, rather than at home.

- **Care home relationships**
  - There were a number of examples of how relationships with care homes could be improved. A+E staff reported often having little or no information about the person with dementia from care homes. Ward staff reported that care homes usually request a re-assessment and occasionally would refuse to accept the person back.

- **Rehabilitation beds**
  - More rehabilitation beds are needed for people with dementia. Staff reported that occasionally people with dementia were given a lower priority for rehabilitation because they had “less potential to benefit”.

Falls in hospital were not identified as an issue by professionals or people with dementia and their carers. Data from the Norfolk and Norwich University Hospital suggests that out of the 2,682 falls in 2013/14 about 1 in 4 (22.5%) were in people with dementia.

The Carers’ Audit provided a useful source of information about the experience of people with dementia in hospital. Themes that emerged were:

- More communication from senior medical staff to family is needed.
- Staff are busy and difficult to access either in person or by telephone.
- Families know the person with dementia best, and are particularly helpful in recognising signs of pain.
- There is a need for more stimulation during inpatient stays.
- Families would like to know how long they will have to wait in A+E.
What dementia services are provided in acute hospitals?

Each hospital in Norfolk has different dementia provision.

The Norfolk and Norwich University Hospital has an Older People’s Medicine consultant lead for dementia and a dementia service project manager. The Dementia Intensive Support Team visits the hospital daily and provides support. The hospital has four dementia support workers that help people with dementia on the wards. There is also a mental health liaison service. One older people’s medicine ward (Elsing Ward) has been made a dementia friendly ward in accordance with the Kings Fund Enhancing the Healing Environment principles. Modifications include colour coded bays and toilets, improved signage, contrasting designs and easy to read clocks with dates and times.

The James Paget University Hospital, near Great Yarmouth, has a gastroenterology consultant lead for dementia and a dementia care project manager. It also has a dementia care liaison nurse and mental health liaison service. Previously there were members of the Dementia Intensive Support Team based in the hospital, however they have been withdrawn. The links between the hospital and community mental health services are still being resolved.

The Queen Elizabeth Hospital, King’s Lynn, has a nurse lead for dementia. The hospital has 2.5 dementia support workers and a mental health liaison service. The Dementia Intensive Support Team undertakes in-reach into the hospital. However during the visit to the hospital to gather information for this report, the DIST was closed to referrals because it had reached capacity. There have been some modifications made to a ward for older people’s medicine to make it more dementia friendly.

What inpatient beds for dementia exist?

The reconfiguration of the community mental health services has resulted in the creation of the Dementia Intensive Support Team (DIST) with closure of beds for dementia assessment. There are currently 15 dementia assessment beds located in Norwich for the whole county. Roughly three are reserved for west Norfolk patients, three for east Norfolk and nine for central Norfolk. This means that patients and families have to travel from throughout the county to Norwich for these beds.

NICE guidance suggests that admission should be avoided wherever possible.“As far as possible, dementia care services should be community-based, but psychiatric inpatient admission may be considered in certain circumstances, including if:

- the person with dementia is severely disturbed and needs to be contained for his or her own health and safety and/or the safety of others (in some cases, this might include those liable to be detained under the Mental Health Act 1983)
- assessment in a community setting is not possible, for example if a person with dementia has complex physical and psychiatric problems”

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Professionals identified the need for a balance between centres of specialised expertise and providing services close to a person’s homes. It is unclear whether the number of assessment beds in Norfolk is right. This will depend on the success of the DIST to proactively prevent admissions. Since the DIST are still establishing themselves in Norfolk it is difficult to draw conclusions about the number of beds.

Currently no patients have required out of the county placement for a dementia bed. However this does not necessarily mean that the supply is meeting demand. Faced with the prospect of having to send a patient to another part of the country, local professionals are likely to exhaust all other options.

In 2012 the number of dementia assessment beds in Lancaster was reduced. There are about 17,000 people with dementia in Lancaster. In 2012 the number of beds was reduced from 65 to 30 beds. It is very difficult to draw comparisons between sites because health service provision varies considerably between regions and the proportion of people with advanced disease also varies.

What impact have CQUINs had on dementia care?

Commissioning for Quality and Innovation (CQUIN) payments enable commissioners to link a proportion of a provider’s income to the achievement of local goals. Some CQUINs are nationally agreed, while others are agreed locally.

In 2013/14 there was a national dementia CQUIN which incentivised the identification of patients with suspected dementia when in hospital to ensure prompt referral. This includes finding people with dementia, assessing and investigating their symptoms and referring for support (aka FAIR) as shown in Figure 41. The funding is divided into three parts:

1. 60% of the funding is granted for case finding suspected dementia in patients over 75 years old who have been admitted as an emergency for more than 72 hours and ensuring they are appropriately assessed and referred.
2. 10% of funding is granted for ensuring sufficient clinical leadership of dementia and appropriate training of staff
3. 30% of funding is granted for ensuring carers of people with dementia feel adequately supported.

The third part of this must include a monthly audit of carers of people with dementia and report the findings to their Board at least twice per year. The content of this audit is for local determination but must include a question on whether carers of people with dementia feel adequately supported. Data from the carers’ audits have been included above.

This CQUIN will continue in 2014/15. The terminology has changed to include delirium as well as dementia.

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Figure 41: Diagram illustrating the FAIR CQUIN

All emergency admissions aged over 75

Table 17 shows the achievement of the CQUIN in the Norfolk and Norwich University Hospital, James Paget University Hospital and Queen Elizabeth Hospital from January to March 2014. It demonstrates that the all three hospitals have met the 90% target.

Table 17: Achievement of the FAIR CQUIN

<table>
<thead>
<tr>
<th></th>
<th>NNUH</th>
<th>JPUH</th>
<th>QEH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of cases identified</td>
<td>1802</td>
<td>849</td>
<td>708</td>
</tr>
<tr>
<td>Number of emergency admissions</td>
<td>1942</td>
<td>922</td>
<td>752</td>
</tr>
<tr>
<td>Percentage of cases identified</td>
<td>93%</td>
<td>92%</td>
<td>94%</td>
</tr>
<tr>
<td>Number of cases with diagnostic assessment</td>
<td>148</td>
<td>112</td>
<td>122</td>
</tr>
<tr>
<td>Number of cases with positive case finding question</td>
<td>153</td>
<td>122</td>
<td>122</td>
</tr>
<tr>
<td>Percentage of cases further assessed</td>
<td>97%</td>
<td>92%</td>
<td>100%</td>
</tr>
<tr>
<td>Number of cases referred</td>
<td>148</td>
<td>52</td>
<td>122</td>
</tr>
<tr>
<td>Number of cases with positive or inconclusive diagnostic assessment</td>
<td>148</td>
<td>52</td>
<td>122</td>
</tr>
<tr>
<td>Percentage of cases referred</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

The Norfolk and Norwich University Hospital provided data on their FAIR CQUIN over a six-month period. Of approximately 4000 patients screened, 330 were referred (8.25%) of which 193 (58.5%) were given a diagnosis.

Several dementia CQUINs finished during the 2013/14 year for community health services, ambulance trust and mental health trust. Evaluations of these were not available.

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Domain 7: Medicines management and prescribing

There are currently four drugs licensed for dementia. However most people with dementia take a number of other medicines for their other long-term conditions. For someone whose memory is impaired, making sure medicines are taken at the right time, in the right way and watching out for side effects can be challenging. For carers managing medications, in addition to organising finances, bills and utilities, can be challenging especially if the person with dementia has challenging behaviour. If medicines are not taken appropriately then this can lead to deterioration in health and worsening of symptoms.

Doctors need to be sure that they are prescribing the most appropriate drug in the best formulation while considering the cost-effectiveness. For example some people with dementia are happy to take tablets, while others manage much better with a patch. There are also drugs which doctors should limit in people with dementia. The anti-psychotic drugs are the most well-known drugs which should be limited in people with dementia. They are often used to manage challenging behaviour and agitation, but have been found to increase the risk of stroke.  

What drugs are prescribed to improve or stabilise cognition?

There are currently four drugs which are recommended as options for managing Alzheimer’s disease. Donepezil, galantamine and rivastigmine (all are acetylcholinesterase inhibitors) are recommended by NICE as options for managing mild to moderate Alzheimer’s disease under specific conditions. Memantine is recommended as an option for managing Alzheimer’s disease for people with severe Alzheimer’s disease or moderate disease who are intolerant or have a contraindication to acetylcholinesterase inhibitors. Not all people with dementia benefit from these drugs and NICE only recommends continuation where there is ongoing benefit. It should also be noted that NICE recommend a number of non-drug treatments such as cognitive stimulation.

NICE did not specify which drug is the most cost-effective. The guidance states it is impossible to say whether one acetylcholinesterase inhibitor is better than another at treating Alzheimer’s disease. There is also new evidence on the effectiveness of memantine, although it remains less supportive of this drug’s use. All four drugs are used across Norfolk. NICE found very little difference in the cost-effectiveness of the drugs but the patent of some of these drugs has now expired.

Table 18 shows the cost of one year’s treatment with each drug. There is over £1000 difference between the cheapest (donepezil tablets) and the most expensive (galantamine

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modified release capsules). The formulation of the drug makes a significant difference as well. Galatin XL (galantamine 24mg prolonged release capsules) cost half the price of galantamine 24mg modified release capsules.

**Table 18: Cost of 1 year's treatment for dementia drugs**

<table>
<thead>
<tr>
<th>Drug</th>
<th>Cost of 1 year's treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Galantamine 24mg Modified Release Capsules</td>
<td>£1,037.40</td>
</tr>
<tr>
<td>Galantamine 12mg tablets</td>
<td>£963.30</td>
</tr>
<tr>
<td>Rivastigmine 4.6mg/24 hours patches</td>
<td>£946.04</td>
</tr>
<tr>
<td>Rivastigmine 9.5mg/24 hours patches</td>
<td>£946.04</td>
</tr>
<tr>
<td>Memantine hydrochloride 5mg/acuation oral solution</td>
<td>£897.04</td>
</tr>
<tr>
<td>Galantamine 16mg modified release capsules</td>
<td>£843.70</td>
</tr>
<tr>
<td>Galantamine 8mg tablets</td>
<td>£770.77</td>
</tr>
<tr>
<td>Galantamine prolonged release 24mg capsules</td>
<td>£518.70</td>
</tr>
<tr>
<td>Rivastigmine 6mg capsules</td>
<td>£435.76</td>
</tr>
<tr>
<td>Galantamine prolonged release 16mg capsules</td>
<td>£421.85</td>
</tr>
<tr>
<td>Memantine 20mg tablets</td>
<td>£375.05</td>
</tr>
<tr>
<td>Donepezil 10mg orodispersible tablets</td>
<td>£173.03</td>
</tr>
<tr>
<td>Donepezil 5mg orodispersible tablets</td>
<td>£129.61</td>
</tr>
<tr>
<td>Rivastigmine 3mg capsules</td>
<td>£88.40</td>
</tr>
<tr>
<td>Donepezil 10mg tablets</td>
<td>£20.80</td>
</tr>
<tr>
<td>Donepezil 5mg tablets</td>
<td>£15.60</td>
</tr>
</tbody>
</table>

Figure 42 shows the amount spent on each drug between March 2012 and February 2013 in Norfolk. It shows that most is spent on galantamine, memantine and rivastigmine. It is not possible to break this down into individual treatments because some prescriptions cover more than one treatment.
Figure 43 shows the cost by Clinical Commissioning Group for a 12 month period from March 2012 and February 2013. This shows that Great Yarmouth and Waveney CCG spend the most on dementia drugs. This is in keeping with the higher prevalence and diagnosis rates in Great Yarmouth and Waveney CCG. There appears to be a larger use of rivastigmine in West Norfolk CCG and the reason for this is unclear.
Figure 43: Total cost per drug by Clinical Commissioning Group

Figure 44 shows the average cost per patient. This has been calculated by dividing the total cost of each drug by the total number of people with a diagnosis of dementia. Comparing this assumes that all areas have a comparable proportion of people with dementia who are eligible for treatment. This shows that West Norfolk CCG spends more per patient (£204 per patient) compared to all others. North Norfolk CCG spends the least (£125 per patient). This may be because of the higher use of rivastigmine in West Norfolk CCG or that more people in West Norfolk CCG are eligible for treatment.
What is the current use of long-term anti-psychotics therapies and is it appropriate?

NICE guidance gives clear advice about when antipsychotics should be used.\textsuperscript{71} It states that people with non-cognitive symptoms should not be prescribed antipsychotics and gives the following criteria for use of antipsychotics drugs.

“People with Alzheimer's disease, vascular dementia, mixed dementias or DLB with severe non-cognitive symptoms (psychosis and/or agitated behavior causing significant distress) may be offered treatment with an antipsychotic drug after the following conditions have been met.

- There should be a full discussion with the person with dementia and/or carers about the possible benefits and risks of treatment. In particular, cerebrovascular risk factors should be assessed and the possible increased risk of stroke/transient ischaemic attack and possible adverse effects on cognition discussed.
- Changes in cognition should be assessed and recorded at regular intervals.
- Alternative medication should be considered if necessary.
- Target symptoms should be identified, quantified and documented.
- Changes in target symptoms should be assessed and recorded at regular intervals.
- The effect of co-morbid conditions, such as depression, should be considered.
- The choice of antipsychotic should be made after an individual risk–benefit analysis.
- The dose should be low initially and then titrated upwards.
- Treatment should be time limited and regularly reviewed (every 3 months or according to clinical need).”

In 2013-14 Anglia Commissioning Support Unit reviewed 1,717 care home residents with dementia as shown in Table 19. Of these 566 had a diagnosis of dementia, and of those

with dementia 113 (just under 20%) were taking an antipsychotic. The appropriateness of all antipsychotics were reviewed and stopped in seven cases (6.2%).

Table 19: Review of antipsychotic prescribing in care home residents in Norfolk

<table>
<thead>
<tr>
<th>Antipsychotics</th>
<th>Number with dementia</th>
<th>Number taking antipsychotics</th>
<th>Number whose antipsychotic has been stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total for City</td>
<td>71</td>
<td>20</td>
<td>3</td>
</tr>
<tr>
<td>Total for North</td>
<td>146</td>
<td>31</td>
<td>2</td>
</tr>
<tr>
<td>Total for Southern</td>
<td>259</td>
<td>38</td>
<td>0</td>
</tr>
<tr>
<td>Total for West</td>
<td>90</td>
<td>24</td>
<td>2</td>
</tr>
<tr>
<td>Total for Norfolk</td>
<td>566</td>
<td>113</td>
<td>7</td>
</tr>
</tbody>
</table>

The National Dementia Audit also collects data on antipsychotic use. Table 20 shows the results for Norfolk and Norwich University Hospital and Queen Elizabeth Hospital. James Paget University Hospital does not submit data to the national audit. This shows that between 17 to 20% of people with dementia were prescribed an antipsychotic during admission. At the NNUH 21% of these were due to an existing prescription, whereas at the QEH this figure was only 8%. However this data does not show the appropriateness of the prescribing.

Table 20: Antipsychotic prescribing in acute hospitals

<table>
<thead>
<tr>
<th></th>
<th>NNUH</th>
<th>QEH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antipsychotic drugs during admission (%)</td>
<td>23</td>
<td>17</td>
</tr>
<tr>
<td>Antipsychotics due to an existing prescription (%)</td>
<td>21</td>
<td>8</td>
</tr>
<tr>
<td>regular prescription</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A PRN prescription for antipsychotics in place (%)</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>If PRN in place, it was administered during the admission (% route from previous question)</td>
<td>50</td>
<td>100</td>
</tr>
<tr>
<td>A new or additional prescription of antipsychotic (%)</td>
<td>5</td>
<td>12</td>
</tr>
</tbody>
</table>

No data was available for the use of antipsychotics in the community or acute mental health beds.

What access to advice/support in managing their medications do people with dementia have?

Participant (carer, male): Some days it’s a bit of a fight to get her to take her medicine.

There are several community services available to help people with dementia and their carers manage medications. The Medicines Use Review service is a free service offered by pharmacists. It enables people with dementia and/or their carer to discuss with a pharmacist their medications. The pharmacist is able to offer advice and support about taking the medication. This might include the use of aids, such as dosette boxes. Part of the pharmacists duty is sometimes to undertake a Equality Act 2010 assessment. This allows people with physical or mental disability, of which dementia would be part, to have a
“reasonable adjustment” to their medicine services. The nature of the reasonable adjustment depends on the needs of the person with dementia and their carer.

Norfolk Medicines Support Service gives medicine support for those who do not meet eligibility criteria. There is also a pharmacy delivery service which is offers free delivery for those who are housebound, elderly or have difficulty getting to a pharmacy.

Medicines are also reviewed in primary care. The Quality Outcomes Framework (QOF) offers remuneration for a practice achieving 80% of patients with a repeat prescription having a medication review in the past 15 months. This could be done by a GP or practice pharmacist.

Discussion with professionals revealed that the Medicines Use Review service is underutilised and often not accessed by those who need it the most. Discharge from hospital was highlighted as a particularly important period. Anecdotal reports from pharmacists suggest that people with dementia are often discharged without enough information. For example, changes have been made to doses, or medications, or drugs stopped without a clear reason. This is especially important for people with memory problems who rely on good communication between professionals.

Another issue highlighted was the lack of signposting facilities. Pharmacists often come into contact with a range of vulnerable people and may be the first health professional to suspect memory loss. There is no easy referral pathway and pharmacists can only advise someone to see their GP. Better communication and referral pathways are needed to ensure that if a health professional in any part of the system suspects memory loss or need for more support, they are in a position to discuss it with the individual and refer or signpost to the correct service.
Domain 8: Social care and housing, including care homes

Living at home independently with dementia or caring for someone with dementia at home can be incredibly challenging. For carers this is often 24 hours a day, seven days a week, 356 days a year job with little respite. The needs of each person with dementia are different. Some people need help with very personal and private tasks such as washing, dressing and toileting, others with eating. Understandably this sort of personal care can be difficult for carers and is a common source of daily anxiety. Support with personal care is provided by the local authority depending on an assessment of need and eligibility. Social care support is needed to help with personal care and to give carers some respite during the day. Without this support carers are likely to burn out in a short space of time, and unfortunately many do. It is estimated that unpaid carers of people with dementia save the UK government £8 billion every year.72

Appropriate housing is important. Simple modifications to a house can make the environment more dementia friendly, helping both the person with dementia and their carer. These may include aids and adaptations from an occupational therapist or physiotherapist, contrasting colours for crockery, cutlery or bathroom suites, additional lightening or handrails for people with mobility problems.

Care homes, residential or nursing, provide long-term care for people who can no longer live independently in the community. Often this is decided during or after admission to hospital. It is estimated that up to 80% of residents living in care homes have dementia or significant memory problems.73 Many people with dementia do not have an opportunity to visit the care home before admission. Care home admission can also be associated with considerable worry and guilt on the behalf of carers. There are several good and bad examples of dementia provision in care homes. The Alzheimer’s Society produced a report on care homes called Low Expectations.73 In the report they surveyed members of the public and found that people have low expectation of the quality of care provided in care homes and the quality of life for residents. The report argues that expectations need to increase to improve care.

How many people have dementia in social care settings?

The Dementia Prevalence Calculator estimates the number of people who have dementia in long-term care.74 Table 21 shows that North Norfolk CCG has the highest number of people with dementia in care homes (1174) compared with Norwich CCG which has the lowest (666). Overall there are approximately 4549 people with dementia in care homes in Norfolk and Waveney which is equivalent to one in three people with dementia being in a care home.

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Table 21: Number of people with dementia in care homes

<table>
<thead>
<tr>
<th></th>
<th>Number of people in the community</th>
<th>Number of people in care homes</th>
<th>Percentage in care homes</th>
</tr>
</thead>
<tbody>
<tr>
<td>North Norfolk CCG</td>
<td>2415</td>
<td>1174</td>
<td>48.6%</td>
</tr>
<tr>
<td>South Norfolk CCG</td>
<td>2510</td>
<td>910</td>
<td>36.2%</td>
</tr>
<tr>
<td>Norwich CCG</td>
<td>1995</td>
<td>666</td>
<td>33.4%</td>
</tr>
<tr>
<td>West Norfolk CCG</td>
<td>2125</td>
<td>764</td>
<td>36.0%</td>
</tr>
<tr>
<td>Great Yarmouth &amp; Waveney CCG</td>
<td>2809</td>
<td>1035</td>
<td>36.9%</td>
</tr>
<tr>
<td>Norfolk and Waveney</td>
<td>11854</td>
<td>4549</td>
<td>38.4%</td>
</tr>
</tbody>
</table>

What is the current social care provision for people with dementia with dementia?

People with dementia undergo an assessment of their needs and finances. Based on these two components a person with dementia may be eligible for free or part-funded personal care. This funding comes in the form of a personal budget. This allows recipients to choose how their funding is spent. This requires providers, such as day centres, to compete for clients. Personal budgets have been welcomed as part of a person-centred approach to providing personal care. However there remains significant challenges in the social care system, namely lack of funding and strict eligibility criteria. Policies for these are set nationally and enacted locally. Some social services are not means tested but provided at the point of need.

Figure 45 shows national data about funding of care home places. It shows that about 33% of care home places for dementia are self-funded and about 47% are provided without top-up by the local authority. The remaining 20% are either provided by the local authority with top up or by NHS Continuing Healthcare.
Figure 45: Funding sources of care home places

Figure 46 shows the funding source of care homes places in Norfolk in 2012/13, although this is not specific to dementia. It shows that 40.8% of people self-fund nursing or residential care. This is slightly higher than the estimated national average and would be in keeping with the socio-economic status of Norfolk.

Figure 46: Funding source of care homes in Norfolk
Figure 47 shows how social care support is divided between different conditions in Norfolk. It shows that most people who receive support have a physical disability. There were only 2,000 people with dementia who received support in Norfolk (of 7,000 people with a diagnosis). However dementia is likely to be underestimated because of a lack of recording since social care assessments are based on need rather than diagnosis.

**Figure 47: Clients receiving support in Norfolk**

![Bar chart showing the distribution of social care support across different conditions and service types in Norfolk.]

During a crisis there several services available. Norfolk Swift Response is a free service which provides 24-hour help and support for people with an urgent, unplanned need at home which does not require emergency services. For example if a carer is taken into hospital. Norfolk First Support provides intensive support in a person’s home for up to six weeks. For example it may be used for people who have returned home after a hospital stay. The service is free to those who meet the eligibility criteria. In 2012 Suffolk introduced a Flexible Dementia Service which is provided by Care UK. The service can provide support for up to six weeks for people with dementia who are in crisis. This is similar to the Norfolk Swift Responses and Norfolk First Response but specialises in supporting people with dementia and is free at the point of need (unlike Norfolk First Response).

Attendance Allowance a weekly cash payment paid by the government to individuals aged 65 or over in the UK who need help with personal care or have difficulties with activities of daily living because they are physically or mentally disabled. It paid based on a person’s disability and is not means tested. Feedback from stakeholders suggest that the uptake of Attendance Allowance among people with dementia is poor.

Discussions with professionals suggest that generally people with dementia and their carers are not given information and advice at an early enough stage. Therefore carers do

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not seek help until a crisis. If information and advice was given earlier crises could be avoided and people with dementia would be more likely to stay in the community for longer.

What is the quality of care for people with dementia with dementia in nursing and residential homes?

The Care Quality Commission (CQC) has inspected 174 care homes in Norfolk that care for people with dementia. Of these 137 met all standards, 35 did not meet all standards and 2 required enforcement action. Nine care homes that did not meet standards or required enforcement action are no longer registered with the CQC. Table 22 shows the areas of concern for each domain of the care homes that remain registered with CQC. This shows that caring for people safely and protecting them from harm was the commonest area of concern, followed by staffing, quality and suitability of management and providing care, treatment and support that meets people’s needs.

Table 22: Care Quality Commission areas of concern for registered care homes of people with dementia that did not meet standards or required enforcement action

<table>
<thead>
<tr>
<th>Inspection area</th>
<th>Number of times highlighted as area of concern</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treating people with respect and involving them in their care</td>
<td>4</td>
</tr>
<tr>
<td>Providing care, treatment and support that meets people’s needs</td>
<td>10</td>
</tr>
<tr>
<td>Caring for people safely and protecting them from harm</td>
<td>15</td>
</tr>
<tr>
<td>Staffing</td>
<td>12</td>
</tr>
<tr>
<td>Quality and suitability of management</td>
<td>11</td>
</tr>
</tbody>
</table>

Discussions were held with professionals and a number of visits were undertaken to care homes. Several good examples were highlighted. These included:

- People with dementia being matched with care home based on facilities, other residents and needs.
- Care homes divided into small groups of 5-7 people who share similar interests
- Environments that have been modified to be dementia friendly
- Signing up to the Dementia Pledge or Butterfly approach

Areas for improvement included:

- Stigma – there remains a considerable amount of stigma about care homes. This leads to low expectations and can be a self-fulfilling prophecy (i.e. clients and staff do not have high expectations of care homes and therefore are not motivated to improve standards).
- Variation – there is considerable variation in the quality of care homes for people with dementia. The greatest variation is the extent to which leadership and management in care homes appreciated dementia. There was also variation in the standard of accommodation, however there were examples of care homes that had a lower standard of accommodation but nevertheless were able to provide high quality dementia care.
Support from community mental health teams – care home staff did not feel that they had good access to support from community mental health teams. This was particularly needed if a person with dementia was displaying challenging behaviour.

- Respite in care home – respite in care homes was often considered to be poor. There was a lack of capacity and people with dementia were often distressed and agitated during periods of respite. Furthermore there were a number of reports of people with dementia going into a care home for respite and not returning home.

Participant (carer, female): But I thought, oh dear, is this going to happen on a more regular basis, one’s not going to be able to cope and everyone sparked very quickly from ringing social services at Norfolk County Council and the Social Worker came out two days later and she said – our son came – and she spent two hours and took quite a lot of trouble in listening to [my husband] in what he could say and what he could understand and what he couldn’t and she said ‘Well I suggest you and your son decide on two care home that you think are the best’, meanwhile we tried one or two including [a care home] for short period, ‘Choose the two you think are the best and let me know which one you think would be good and I’ll try and arrange respite care that will then probably need to go into permanent care and so we choose the one he’s actually in and um, he was in there for two weeks and then they said ‘Well look, we are having a room coming empty, just after [my husband] was due to come home and we have people wanting to come in there but do you want [your husband] to stay? Because if so you’d better stake a claim now otherwise we don’t know when they’ll be another one’. So I think we decided it was better to continue because he seemed fairly happy and settled and that’s what happened in fact.

Lack of community nursing support – some residential home managers felt that with more community nursing support some people with dementia could have been prevented for being admitted to hospital. For example by administering intravenous treatments in the community.

Lack of activities – a number of people raised concerns about a lack of activities for people with dementia in care homes. This is especially important for people with dementia who would benefit from cognitive stimulation.

Quality of staff – the ability of staff to be able to deliver high quality care to a person with dementia varies considerably. This is a combination of selecting the right people to be carers and giving them the appropriate training and mentorship.

The issue of safeguarding was raised. The safeguarding incidents that were reported were usually resident on resident incidents. Due to time constraints this report has not been able to full explore safeguarding issues.

What are the housing needs of people with dementia and how could they be improved (both existing and proposed housing)?

Figure 48 shows the number of households where the reference person is over 65 years old. This shows that most over 65 year olds live around about Norwich with pockets throughout Norfolk.
Figure 48: Number of households where the reference person is 65 years old or over

Figures 49 and 50 show social care housing for those who are over 65. Some district councils still provide their own social housing while others are provided by housing associations. This shows that Norwich, Great Yarmouth and west central Norfolk have the greatest areas of social housing for over 65 year olds.

Figure 49: Percentage of people living in social housing provided by the local authority
While no data exists which shows the tenure of people with dementia, information from housing enquires is available from West Norfolk District Council. From 5,681 client enquiries, 352 (6.2%) declared a dementia. Of these 352, 331 (94%) were over 65 years, 149 (42%) were over 85 years and 302 (86%) had another chronic disease. This shows that the housing needs of people with dementia are usually associated with needs of other chronic conditions.

There are currently 14 Norse housing with care schemes in Norfolk. Four of these have specialist dementia units. Figure 51 shows all the housing with care schemes in Norfolk and Figure 52 shows the ones with specialist dementia units.
Figure 51: Housing with care schemes in Norfolk

Figure 52: Housing with care schemes with specialist dementia units
Housing reports suggest that for people with dementia good housing can reduce or delay demand for health and social care services, improve diagnosis rates and improve health and social care outcomes, although there remains a lack of robust data. The University of Stirling has produced good practice guidelines for designs. This gives advice about colours and contrasts, lighting, fixtures, kitchens, bathrooms, entrances and exits and outdoor spaces.

An 88-bed specialist dementia home has recently been opened in Gorleston. This includes a number of facilities including fitness, wellbeing and activity room, treatment rooms, hairdressing salon, safe garden, assistive technologies and a number of quiet rooms. An 80-bed dementia care home and 92 apartment housing with care scheme is planned at Bowthorpe, Norwich. This is due to be completed in 2016.

Whilst there is no specific housing support for people with dementia, the Disabled Facilities Grants are designed to meet the needs of people with physical or mental disabilities. There is likely to be a bias towards physical disabilities because of their well-recognised disparity of esteem. Norwich City Council is considering a Dementia Adaptations Scheme. This would be a two year pilot that offers training to case officers, a package of adaptations not covered by the Disabled Facilities Grant or social care for people on low incomes and signposting for people with dementia by case officers to other services.

Nationally, other areas have piloted schemes to help people with dementia living in housing with care schemes. For example, Housing 21 in Bristol have piloted a Portable Care scheme where staff from the housing with care scheme undertake formal visits to hospital during a person’s admission to give housing context and to advocate for them. From 22 admissions, 42 visits took place for a total of 92 social care hours. It was estimated that this saved 33 bed days through quicker discharge (£11,715 saving) and 95 bed days through managed readmission (£33,725 saving).

What are the gaps in the social care system?

Discussion with health and social care professionals, people with dementia and carers highlighted a number of issues and gaps within the social care system. These include:

- Lack of funding – the limited budget within social care and subsequent cuts was highlighted as an issue. This is not specific to dementia, but undoubtedly has an impact.
- Eligibility criteria – eligibility criteria means that people who are just about the threshold and therefore not entitled to any publicly funded services often find support, personal care and finances challenging.

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Lack of information – people with dementia and carers did not understand the social care process and did not know how to access support.

Respite – appropriate, flexible respite was identified as a significant gap. There is a lack of appropriate care home capacity for respite. This is compounded by a lack of information for carers about flexible respite options. If self-funded, respite was seen as too expensive.

Self-funders – it was felt that self-funders got a poorer service than people who met the eligibility criteria. People who were eligible for services were given lots of support to help them choose the right services, however self-funders had to find out all the information themselves.

Targeted services to age and stage – there was a lack of social care services which were targeted to a particular age or stage of dementia.

Long waiting times - several carers reported spending considerable amounts of time trying to find out what was happening with their social care application.

Home carers – many carers appreciated the attitude and personality of paid home carers, but felt that they needed more training especially in managing challenging behaviour. Professionals felt that the work of home carers had been undervalued and this had resulted in poor staff morale and motivation.

Participant (carer, female): I needed to sell our home in order to be able to pay for care for [my husband] through getting somewhere a lot smaller. I was absolutely horrified to find out what it would cost for care. I was too afraid to pay that sort of money. Very quickly I worked out I would be left with very little indeed. At least at that point, with nothing, I would be entitled to get some help from the NHS and social services. Why should we be penalised for having worked all our lives, for having saved and gone without, and brought up our children, to then learn we were not entitled to any help at all? We did go through this…er…financial assessment…to see what help we were entitled to. Because we had sold the house we were told we had the money to pay for [my husband’s] care. I argued that the money was there to enable us to buy a smaller house. We are now having to rent a house. I am trying to keep the money from the sale of the house to one side and not use it. I cannot really work these days because [my husband] requires so much care from me.

Participant (carer, female): So day to day, a hard thing is finding time for yourselves…does there come a point where day to day things start to get too difficult and you’d like more help just to be able to go to the shops or take your husband shopping and more personal care like washing…”

Participant (carer, female): Its fourteen pounds an hour to go out.

Participant (carer, female): But what about the needs of self-funders? Often it feels as if these.
Lack of consistency – there appears to be a lack of consistency for people with dementia and their carers. Carers reported having to repeat their stories to multiple different social workers. Furthermore there is a different social care team during hospital admission.

Lack of community services – social care staff wanted more community-based services for people with dementia, both to provide support in a crisis but also day-to-day activity-based services. For example there are only three night sitters for people with dementia in Norfolk.

Lack of flexibility – Professionals felt that current services are not sufficiently flexible to allow care to be more person-centred. For example provision of additional care in times of crisis in their own home.

Integration with health – social workers reported a lack of communication between health and social care. For example a community mental health team would visit a person with dementia and the social worker had no means of finding the outcome of the visit or future plans.

Flexible respite was highlighted as an issue by carers and professionals. The National Institute for Health Research (NIHR) Service Delivery and Organisation (SDO) funded the University of York to review different models of respite care. They proposed eight different models including:

1. Day care
2. Home day care (in the home of a volunteer or care worker)
3. Clubs, interests or activity groups (day opportunities)
4. Home-based support (including sitting services)
5. Host-family respite (also known as adult placement schemes)
6. Overnight respite in specialist facilities
7. Overnight respite in non-specialist facilities (where one or two beds within a residential or nursing home or hospital ward are available for respite)
8. Holidays

One type of respite, such as dementia respite beds in a care home, will not be appropriate for everyone, therefore there needs to be choice and options within the system to allow a person-centred approach.

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Domain 9: Workforce

People with dementia and their carers interact with a wide range of professionals from both health and social care. Most of these people are non-specialist frontline staff that look after people with a range of health and social problem. For example in a typical week a person with dementia and their carer might interact with the GP receptionist to book an appointment, pharmacists to collect medications, home carers for personal care and a social worker to organise social care. If admitted a person with dementia will meet lots of people as they journey through the hospital, from ambulance staff to discharge team. If one or two of these individuals do not understand dementia and make wrong decisions about how to communicate, the best time for an appointment or even which bay to go into in A+E, then it can impact the rest of that person’s passage through the system. Wrongly some staff assume that because something works for a person without dementia, it will automatically work for person with dementia.

The need for workforce development is not new. In the National Dementia Strategy aimed to develop an “informed and effective workforce for people with dementia”. As the number of people with dementia increases, the need for a workforce that is able to deliver high quality care to people with dementia is going to grow.

While training staff specifically in dementia is needed, there are wider benefits too. A professional who gets it right for someone with dementia, is likely to get it right for other vulnerable people.

What levels of specialist staff and volunteers exist?

There are multiple different levels of specialist staff. These include

- Dementia organisational leads – usually responsible for the management and strategic direction of an organisation. Dementia project managers usually support them.
- Dementia care coaches - coaches act to coach, mentor and role model within an organisation.
- Dementia specialist nurses – registered nurses who have taken advanced training in dementia care
- Admiral Nurses – specialist nurses that work with carers and people with dementia and they were developed by Dementia UK. An evaluation of the Admiral Nurse pilot is described in Domains 3 and 4.
- Dementia Support Workers – work with people with dementia and their carers to support them either in the community or hospital. In practice this role may provide more information and advice rather than support
- Dementia Advisers – provide information and advice to people with dementia and their carers and signpost them to appropriate services. A national evaluation of dementia advisers is described in Domain 3 and 4.
- Dementia friends – non-specialist who have undertaken a short training session. This is organised by the Alzheimer’s Society and part of the Prime Minister’s Challenge. The ambition is to have 1 million people who have become Dementia Friends by 2015.

Accessed 23 June 2014
Dementia Friends Champions – non-specialists who have undertaken a one-day training session in order to deliver dementia friends training.

What is the level of understanding among non-specialist health and social care staff?

The University of East Anglia undertook a survey in 2011 for the Norfolk and Suffolk Health Innovation Education Cluster (HIEC). It surveyed 293 people from all acute hospitals in Norfolk. Two thirds of staff were working at bands 5, 6 or 7 and over half were registered nurses. The survey found that 92% of respondents felt that they had insufficient training overall in relation to dementia. The majority of the staff reported insufficient training in person-centred care, basic awareness and skills for care of people with dementia. Particular deficiencies were reported in communication skills, assessing cognition, dealing with aggressive behaviours and recognising pain. Knowledge of the Mental Capacity Act 2005 was identified as a gap by the majority of respondents. 40% of respondents felt that they had peer support and access to reflective groups to improve their capacity to deliver care to people with dementia.

The following themes were identified from discussion with professionals

- Workforce development must be a priority – there was wide recognition among all professionals that workforce development was key to improving dementia care across the county.
- Care home staff and domiciliary carers – this group was identified as needing focused training. Care home managers felt that the best way to train staff was through one-to-one training in the care homes, augmented with a limited number of formal training sessions. Domiciliary care workers were highlighted as being a particularly challenging group because of their lone working situation. Therefore there was not the same opportunity for peer support, feedback, mentoring and reflection.
- Importance of recruitment – ensuring that the correct people are recruited in the first instance was felt to be important as some people naturally find it easier to care for people with dementia than others.
- Morale among staff – some professionals felt that the low paid nature of frontline care staff, negative media coverage and high staff turnover resulted in poor morale. This had the potential to reduce motivation to improve their services.
- Difficulties with timing training sessions – certain organisations have dementia awareness training as part of a busy induction package whereas others have bespoke sessions. Benefits and drawbacks of both were highlighted; induction ensured that everyone is present but the ability of staff to retain the knowledge during a full induction programme was questioned. Bespoke training had the difficulty of ensuring all staff were present. The staff who attend bespoke generally had an interest in dementia and were not the people who needed more training. Making training mandatory annually was felt to be important. Enabling staff to undertake the Dementia Care Coach training was challenging because of the time commitments involved.
- Mental Capacity Act 2005 and Mental Health Act 1983 amended 2007 – there appeared to be significant confusion about the Mental Capacity Act and Mental

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Health Act, especially among doctors. The lack of understanding meant that these pieces of legislation were not being used to the benefit of people with dementia.

- Quality versus quantity – The quality and outcome of training was highlighted as being more important that the number of people attending training sessions.
- Health Education England – several professionals felt that a national approach to dementia training was useful, but there was uncertainty about the intentions of Health Education England.

What current training is provided?

There are a number of levels of training currently provided. The Norfolk and Suffolk Dementia Alliance have a directory of training on their website which details 102 learning resources.81 This includes face-to-face sessions, distance learning, e-learning, videos, podcasts and publications.

Norfolk and Suffolk Dementia Alliance has developed 12 competencies that are needed to provide high quality of care for people with dementia.82 The twelve competencies are:

1. Explain what is meant by the term dementia and identify the primary causes of dementia.
2. Recognise the key characteristics of dementia including the early signs of dementia and appreciate that these signs can be associated with other medical conditions and/or changes to the person’s general circumstances.
3. Understand the definition and significance of delirium and depression and how each differs from dementia.
4. Recognise the differences between irreversible and reversible dementia.
5. Describe how brain changes affect the way a person functions and behaves.
6. Know the current research findings into cause, prevention and recommended diagnostic procedures.
7. Discuss why it is important to personalise the care you provide to someone with dementia.
8. Demonstrate that you understand the use, effects, side effects and undesirable effects of medication used to manage symptoms of dementia.
9. Demonstrate a knowledge and understanding when caring for people with dementia.
10. Recognise that there are different ways of thinking about dementia.
11. Demonstrate an understanding of the legal and ethical issues involved in caring for people with dementia and designed to protect people with dementia.
12. Understand why a person with dementia may be more vulnerable to abuse and neglect.

Most providers include some kind of dementia awareness training for their staff. This varies in depth and format. However there is a need for training to match an individual’s level of need based upon their role in their organisation. Staff who have high direct contact with people with dementia and are involved with delivery of care will need significantly more training than staff who have infrequent or indirect contact.


Health Education England (HEE) has begun a tiered approach to training. Tier 1 training is already in place. Tier 1 is training to familiarise staff with recognising and understanding dementia, interacting with those with dementia, and being able to signpost people with dementia and carers to appropriate support. HEE has set learning outcomes. There is an e-learning tool available, although face-to-face training could be used. In 2013/14 it is estimated that 100,000 NHS staff received tier 1 training and HEE is aiming to train a further 250,000 health and care staff by March 2015.

It is likely that HEE will commission Tiers 2 and 3. Tier 2 training would be in-depth training for all staff that work regularly with people with dementia. Tier 3 would be to prepare key staff to lead in transforming care.

This approach to training is consistent with matching training with need. However there is a risk that this approach to training focuses on numbers rather than outcome.

The Norfolk and Suffolk Dementia Alliance have locally developed the Dementia Care Coaches model that has a particular interest in home, residential and primary care. The programme trains individuals to a high standard in order for them to train other people in their organisation. This model relies on the employing organisation choosing an appropriate person to undertake the training. This should ideally be someone who has the ability to influence others in the organisation; not necessarily because of their position but their personality and function. In management terminology, this model has the potential for organisational transformation through a “change agent”. There are currently 140 Dementia Care Coaches in Norfolk who are set to complete.

It is likely that both of these models will work simultaneously. Consideration needs to be given to how these training models complement each other.

Dementia Friends training has been part of the Prime Minister’s Challenge. It aims to deliver Dementia Friends training to 1 million people by 2015. People with dementia and their carers felt that the Dementia Friends initiative was a positive step forward, especially in terms of raising awareness and reducing stigma among the public. Professionals felt that Dementia Friends training was good for members of the public, but not sufficient for frontline staff.

The University of East Anglia has a number of qualifications in dementia care, including a Higher Education Certificate, Post-Graduate Certificate and Masters. City College Norwich also offers Dementia care and pathway diplomas and certificates.

Dementia Toolkit for Effective Communication produced by the Dementia Training and Education Community (DEMTEC) is a well-recognised toolkit that aims to help staff and carers to improve communication of staff with people with dementia. It is particularly suited for health and care staff.

Organisations that sign the Dementia Pledge commit to providing training that meets the needs of people with dementia.

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What workforce is needed for the future?

The national dementia CQUIN for acute hospitals requires each organisation to have a dementia lead. Many other organisations, such as general practices or pharmacies have members of staff who have been trained in dementia care.

While there is a need for a tiered approach to training, as detailed above, there is also a need for a tiered approach to staff who provide specialist support for people with dementia and their carers. This will allow people with dementia and their carers to get an appropriate level of support and ensure that highly skilled professionals are not providing basic levels of support and vice versa.

The local Admiral Nurse Evaluation and national dementia adviser evaluation have shown positive results. There is no national guidance on the number of dementia specialist needed.

The Admiral Nurse model (as described by Dementia UK) has not been compared to other specialist dementia nurses. This model has been chosen because of positive results from the local pilot. A similar tiered approach is required but commissioners may wish to explore other models of specialists.

Provisional numbers of staff needed have been estimated based on feedback from people with dementia, carers and stakeholders in order to provide a comprehensive service across Norfolk as shown in Table 23.

Table 23: Estimated indicative number of dementia advisers, dementia support workers and Admiral Nurses, or similar, required

<table>
<thead>
<tr>
<th>CCG</th>
<th>Number of newly diagnosed cases in the community each year</th>
<th>Number of sessions required for ave of 3 sessions for each new case</th>
<th>Number of current people with dementia in the community</th>
<th>Number of sessions required for ave of 2 sessions per year</th>
<th>Dementia adviser</th>
<th>Dementia Support Worker</th>
<th>Admiral Nurse or similar</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>North Norfolk CCG</td>
<td>497</td>
<td>1988</td>
<td>1373</td>
<td>2746</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>South Norfolk CCG</td>
<td>529</td>
<td>2116</td>
<td>1110</td>
<td>2220</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Norwich NCCG</td>
<td>378</td>
<td>1512</td>
<td>785</td>
<td>1570</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>West Norfolk CCG</td>
<td>443</td>
<td>1772</td>
<td>1092</td>
<td>2184</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Great Yarmouth &amp; Waveney CCG</td>
<td>583</td>
<td>2332</td>
<td>734</td>
<td>1469</td>
<td>6</td>
<td>4</td>
<td>2</td>
<td>12</td>
</tr>
</tbody>
</table>
This has been calculated based on 15 newly diagnosed cases per 1000 per year, of which 72% are in the community. Each newly diagnosed person in the community would receive on average 3 sessions with a dementia adviser, dementia support worker or Admiral Nurse or similar. Each currently diagnosed person in the community would receive on average 2 sessions per year with a dementia adviser, dementia support worker or Admiral Nurse, or similar.
Domain 10: Inequalities

Sadly the quality and extent of services provided to people with dementia depend on who they are and where they live. There is wide variation in the services provided across the county. If someone is from a marginalised group, such as black, Asian and minority ethnic or learning disabilities, they are likely to find it more difficult to access services. Having a strong advocate who understands the system appears to be important in receiving a good service. So for people with dementia who live alone and/or do not have an advocate or people for marginalised groups who find it difficult to navigate the complex health and social system it can be very difficult to access the appropriate support that they need.

There are also certain groups that get a poor service because they have a dual diagnosis. For example a person with Parkinson’s disease or Down’s syndrome also with dementia, may not get the best of both worlds but instead may fall between services because neither is set up for them.

One of the aims of the national strategy for dementia was to provide a strategic framework to “address health inequalities relating to dementia”. However the strategy did not have any objectives which were directly related to reducing inequalities. The 2009 Norfolk Dementia Strategy highlighted equality as a key principle.

One of the key challenges of looking at dementia and inequalities is a lack of good quality data. Providers of dementia services do not appear to regularly collect ethnicity, sexual identity, disability or religion information. Therefore drawing conclusions about the equitability of services is difficult.

Do inequalities exist in service provision or health outcomes in the following groups?

In March 2011 the Department for Communities and Local Government (CLG) published the English Indices of Deprivation 2010 (ID 2010). This includes county and district summary measures and other measures at the level of Lower Super Output Area (LSOA). An estimated 47,400 people in Norfolk (5.6% of the area’s population) were living in the most deprived ten per cent of LSOAs in England. This amounted to 29 LSOAs out of the 530 in Norfolk.

People who live in the most deprived areas generally have the poorest health and wellbeing outcomes. On average lower socio-economic and marginalised groups, have poorer health and access to healthcare than people who live in affluent areas and from higher socio-economic groups. There are hidden pockets of deprivation scattered across some of the smaller towns and the more rural parts of Norfolk.

There does not appear to be an association between having dementia and being deprived as shown in Figure 53.
The county’s ethnic composition has changed significantly since the 2001 Census, which recorded a minority ethnic population of 30,000 (3.8%). By 2011, this is estimated to have risen to 64,800 (7.6%). Similarly, numbers in ethnic groups other than white rose from 1.5% of the population in 2001 to around 3.5% in 2011. This shows that the Norfolk is becoming more diverse.

The 2011 census showed the following distribution of non-white British older people.

- In Norfolk 1 in 44 over 65 year olds are non-white British
- In Norwich 1 in 30 over 65 year olds are non-white British
- In Breckland 1 in 39 over 65 year olds are non-white British
- In King’s Lynn and West 1 in 40 over 65 year olds are non-white British
- In Great Yarmouth 1 in 44 over 65 year olds are non-white British
- In South Norfolk 1 in 51 over 65 year olds are non-white British
- In Broadland 1 in 55 over 65 year olds are non-white British
- In North Norfolk 1 in 58 over 65 year olds are non-white British

For the over 80 years old group in Norfolk, 1 in 51 people are non-white British.

There is some evidence that people from black, Asian and minority ethnic groups (BAME) suffer dementia at a younger age. The Alzheimer’s Society estimate that the proportion of people from BAME groups who have early onset dementia is 6.1% compared to 2.2% in the general population.  

A report by the Social Care Institute for Excellence found that in black and minority ethnic (BME) communities there were lower levels of awareness and increased stigma about

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dementia. This may explain why people from BME groups are under-represented in current service provision. Furthermore the study found that carers in BME groups may be reluctant to ask for help because of cultural reasons.

Discussions with stakeholders and professionals revealed that dementia services in Norfolk are generally accessed by mainly white British people.

A study in Bradford looked at barriers to dementia services for people from south Asian communities. The report identified the following barriers:

1. Community or family expectations
2. Access to services
3. Assessment
4. Use of interpreters
5. Lack of referral

The All Party Parliamentary Group on Dementia published “Dementia Does not Discriminate” and made the following recommendation “Health and wellbeing boards (HWBs) should encourage local joint working between BAME community groups and dementia services from the health, social care and voluntary sectors. HWBs should facilitate forums for sharing expertise between these groups to improve the ability/confidence of mainstream dementia services to deliver culturally sensitive services and enable community groups to better support people with dementia. These forums should include representatives from housing associations, domiciliary care providers and care homes, to ensure they provide people with dementia from BAME communities with good support.”

The number of older people from lesbian, gay, bisexual or transgender (LGBT) communities is likely to increase in the future. Older LGBT people are more likely to be single and live on their own compared to heterosexual people. They are also considerably less likely to have children or family members who are able to provide social support. Therefore this group are particularly vulnerable to inequalities.

Approximately 15,000 people over 65 years attend a church in Norfolk. The 2011 census suggest that the majority of people in Norfolk consider themselves to be either Christian or have no religion, as shown in Figure 54.

There are examples of churches and gurudwaras who have become dementia friendly.

Feedback from discussion with professionals and stakeholders identified other groups who are at risk of inequalities.

- **Self-funders** – many professionals felt that self-funders were often left to sort out care themselves whereas people who were eligible for social care were provided with help and advice. This was especially important for people who were just above the eligibility threshold and faced financial challenges. It is hoped that the Care Act 2014 will go some way to improving this situation.
- **Rural areas** – people with dementia and their carers living in rural areas were identified as being at risk of inequalities. This was particularly important if public transport links were poor or the individual lived alone. Services were fewer and more limited in scope in rural areas.
- **Those without social support/advocate** – the importance of having an advocate to ensure that a person with dementia receives the care that they need was identified. Therefore people with dementia who live alone and do not have someone to advocate for them were at risk of a poorer service.
- **Co-morbidities** – people with dementia and a co-morbidity were highlighted as at particular risk of a poor service. This was especially important for people with dementia and Parkinson’s disease, learning difficulty, Down’s syndrome or a mental health problem. Services were often not able to manage people with a dual diagnosis and were reluctant to take ownership of their care. This resulted in people falling between services.

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**Figure 54: Pie chart of religion in Norfolk**

There are examples of churches and gurudwaras who have become dementia friendly.

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V. Recommendations

1. Information and support for people with dementia and their carers
   a. Within the first 6 months of diagnosis comprehensive information and advice should be given to people with dementia and carers about current and future services, including likely eligibility thresholds.
   b. Clinical Commissioning Groups should ensure that GPs are aware of available support. For example using a web-based road map or information sheet located in each consultation room.
   c. Web and print directory of dementia services that allows users and providers to contribute should be produced by commissioners. This should be a new partnership county-wide website produced jointly with Norfolk County Council care directory, Heron database, Norfolk and Suffolk Dementia Alliance and Clinical Commissioning Groups.
   d. Norfolk County Council and Clinical Commissioning Groups should ensure that people with dementia and carers who self-fund are able to access the same high quality information and advice as those who are eligible for social care support.

2. Support
   a. Dementia advisors, dementia support workers and Admiral Nurses, or similar, should be jointly commissioned by health and social care. Their scope and case load should be well defined. One of their key roles should be providing integrated comprehensive health and social care information during the first 6 months after diagnosis.
   b. Clinical Commissioning Groups should ensure that GP practices sign up to the GOLD driving scheme and GPs should encourage people with dementia to participate.
   c. The support and services offered by Independence Matters are currently under-utilised and should be promoted by commissioners and providers to people with dementia and their carers.
   d. Commissioners should consider a buddying-type scheme to match newly diagnosed people and carers with those who have been diagnosed for longer and carers.
   e. GPs should be encouraged to refer people with dementia and carers to the Medicines Use Review service.
   f. People with dementia who do not have an advocate should be given additional support from dementia advisors/support workers/Admiral Nurses, or similar.
   g. Carers should be encouraged to undertake carers training after diagnosis
   h. More carers should be encouraged to have a carer’s assessment.
   i. Norfolk County Council, Clinical Commissioning Groups, providers and voluntary organisations should work together with Parkinson’s Pathway Group to agree a common carer’s pathway.
   j. Commissioners and providers should work together to help more people with dementia die in their place of choice.

3. Making Norfolk Dementia Friendly
   a. All pharmacies, libraries and transport providers should become Dementia Friendly.
   b. Dementia Friendly Communities should extend to non-geographical communities.
c. Efforts should be made to ensure that the Dementia Friendly Communities programme does not increase variation and inequalities.
d. Norfolk County Council should encourage dementia teaching in schools and identify a local school to be a dementia champion.

4. **Timely diagnosis**
a. Clinical Commissioning Groups should assist GP practices to standardise dementia coding and undertaking coding audits.
b. Clinical Commissioning Groups should use the Dementia Partnership principles to improve timely diagnosis.
c. Clinical Commissioning Groups and mental health providers should explore primary care based assessment clinics.

5. **Planning services**
a. Norfolk County Council, Clinical Commissioning Groups and providers should adopt a co-production model of accessible service design and delivery.
b. Norfolk County Council and Clinical Commissioning Groups, providers and voluntary organisations should use the dementia prevalence map to plan health, social care and transport services.
c. Norfolk County Council and Clinical Commissioning Groups should ensure that there are services tailored to the age and stage of dementia.
d. Commissioners and providers should work together to ensure more cognitive stimulation is provided, including continuation groups afterwards.
e. Commissioners and providers should work together to ensure people with a dual diagnosis do not fall between services.
f. Norfolk County Council should commission more respite which is flexible, offers choice and includes expansion of domiciliary respite. Commissioners and providers should work together to make respite more affordable.
g. Norfolk County Council and Clinical Commissioning Groups should commission more activity-based groups for people with dementia.
h. Commissioners and providers should ensure that current and future services are accessible to service users and carers of different ethnic groups, religions and lesbian, gay, bisexual and transgender communities.
i. Commissioners and providers should collect information about users in accordance with the Equality Act 2010 to ensure services are equitable.

6. **Training**
a. Training provided should focus on the outcome of successfully delivering person-centred care, rather than numbers attending training.
b. Providers, especially acute hospitals, community healthcare, care homes and domiciliary care organisations, should include essential dementia skills and knowledge in their job specifications when recruiting staff.
c. Providers and commissioners should work with the Norfolk and Suffolk Dementia Alliance in order to develop their workforce in accordance with the “dementia dozen”.
d. Providers should use the Dementia Care Coaches model for workforce development.
e. Providers should ensure that staff are sufficiently knowledgeable about the Mental Capacity Act (2005) and Mental Health Act (1983 amended 2007).
f. Providers should ensure that frontline health and social care staff are trained in cultural competence.
g. Commissioners and providers should not consider Dementia Friends training as sufficient for health and social care staff.

7. Integration
   a. Commissioners and all providers throughout the dementia pathway should work together to develop joint referral pathways and where appropriate agree tools. This approach should be county-wide, but modifiable for local differences. This should include review of the shared care agreements.
   b. Acute trusts should share learning, examples of good practice and expertise in older people’s medicine across the county.
   c. Norfolk Constabulary, health services and adult social care should work together to identify people at risk of going missing and intervene early within integrated pathways.

8. Secondary care
   a. In 2015 an independent review should take place of the current provision of dementia assessment beds, including comparison with other comparable areas and localities, to assess if the current provision is adequate.
   b. Acute hospitals should adopt the King’s Fund principles for Enhancing the Healing Environment for wards looking after people with dementia and specific areas within A+E and acute assessment units.
   c. People with dementia admitted to an acute hospital as an emergency should receive a comprehensive multi-disciplinary team review including social work and consultant involvement within 24 hours and make every effort to ensure that the patient goes to the right ward first time.
   d. All patients with dementia should have their nutritional needs assessed and immediate action taken where appropriate.
   e. Acute hospitals should ensure that discharge letters of people with dementia accurately reflect medications on discharge and any reasons for medication changes.
   f. People diagnosed in neurology or older people’s medicine should be referred to mental health memory services for further support requirements.

9. Personal care and housing
   a. Norfolk County Council should commission a comprehensive Flexible Dementia Support Service for people with dementia who have a crisis which is free at the point of use and also provide more night sitters.
   b. Care First system should have a section to record dementia.
   c. Clinical Commissioning Groups and Norfolk County Council should support the pilot of the Dementia Adaptations Housing Scheme. If successful it should be rolled out throughout the county.
   d. Housing modification information should be given to all people with dementia and their carers as part of a holistic advice and information service.

10. Home carers
    a. The role of paid home carers should not be undervalued. Commissioners and providers should ensure they receive adequate dementia training and information, especially in relation to difficult behaviour.
    b. Providers of home carers should make every effort to ensure consistency of staff.
11. Care homes

a. Care homes should be encouraged to conduct outreach in the community to de-stigmatise dementia, improve the image of care homes and help make Norfolk a dementia friendly county.

b. Commissioners and supporting organisations should focus on improving the culture and leadership in care homes that have residents with dementia. Good examples of high quality dementia care and best practice in care homes should be shared.

c. Care homes should be encouraged to sign the Dementia Pledge.

d. All care homes with residents with dementia should agree to the Herbert Protocol.
Acknowledgements

We would like to specifically acknowledge a number of people who have contributed to this report.

- HealthWatch Norfolk for undertaking focus groups with people with dementia and their carers
- The Dementia Needs Assessment Group for contributing to the design of the report and each domain
- Those who contributed to focus groups
- Individuals who have provided data for the report or permission to use data or graphs
- People with dementia and carers who provided their expert views.
VII. Appendixes

Appendix 1: Mapping Exercise
Mr and Mrs Smith

How do I get financial and legal support?
- Life Story Book: Alzheimer's Society Advocates
- Advice Line: CAB
- Community Link: ECCHRI
- Other

What end of life support is available?
- Care Pix
- Other

What social care services are available?
- Social Care
- Care Home Providers: Specialist palliative care services
- Community Care
- Other

How do I get access to aids and adaptations?
- Community Alarms
- Other

What support is available when I go into hospital?
- Mental Health liaison workers
- Other

What support is available during a crisis?
- Social Services
- Other

How do I get access to drug and CST therapies and support?
- Pharmacy
- Other

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## Appendix 2: Sources of Data:

- **NHS Information Centre (IC)**
  
  http://nww.indicators.ic.nhs.uk/webview/

- **Eastern Region Public Health Observatory (ERPHO)**
  
  http://www.erpho.org.uk/

- **Department of Health (DH)**
  
  http://www.dh.gov.uk/

- **Norfolk Insight**
  
  http://www.norfolkinsight.org.uk/

- **Office for National Statistics (ONS)**
  
  http://www.statistics.gov.uk/

- **Quality and Outcomes Framework (QOF) data**
  
  http://www.qof.ic.nhs.uk/

- **Projecting Adult Needs and Service Information (PANSI)**
  
  http://www.pansi.org.uk/

- **Projecting Older People Population Information (POPPI)**
  
  http://www.poppi.org.uk/

- **NHS Norfolk and Waveney Business Intelligence (BI)**
  
  http://www.norfolk.nhs.uk/

- **Open Exeter**
  
  https://nww.openexeter.nhs.uk/nhsia/index.jsp

- **Mental Health Minimum Data Set (MHMDS)**
http://www.mhmdsonline.ic.nhs.uk/

- North East Public Health Observatory (NEPHO)
  http://www.nepho.org.uk/

- Yorkshire and Humber Public Health Observatory (YHPHO)

- Dementia Partnerships (Dementia Prevalence Calculator)
  http://www.dementiapartnerships.org.uk/diagnosis/dementia-prevalence-calculator/
## Appendix 3: QOF GP practice disease registries, 2012/13

Table 23: GP practice profile (including GP practice patient’s registration April 2013, mean age, deprivation score and local deprivation quintile IMD 2010), and GP practice disease registries for Dementia 2012/13

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<th>QOF Dementia Rate</th>
<th>Estimated number of people with dementia</th>
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**Note:** The number given in bracket beside each GP practice code represents the local deprivation quintile for that GP practice (1 being the most deprived quintile and 5 being the least deprived quintile).
Table 24: Estimated number of people with dementia by GP practice, severity and place of residents (Community versus care) for Norfolk and Waveney, 2012/13

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Table 25: Estimated incidence (new cases) of Dementia among men by CCG, and age band for Norfolk and Waveney, April 2013

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Table 26: Estimated incidence (new cases) of Dementia among men by CCG, and age band for Norfolk and Waveney (Lower level of 95% Confidence Interval), April 2013

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Table 27: Estimated incidence (new cases) of Dementia among men by CCG, and age band for Norfolk and Waveney (Upper level of 95% Confidence Interval), April 2013

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<tr>
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</table>

Table 28: Estimated incidence (new cases) of Dementia among women by CCG, and age band for Norfolk and Waveney, April 2013

<table>
<thead>
<tr>
<th></th>
<th>65-69</th>
<th>70-74</th>
<th>75-79</th>
<th>80-84</th>
<th>85+</th>
<th>Total 65+</th>
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<td>465</td>
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<td>33</td>
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<td>113</td>
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<td>30</td>
<td>59</td>
<td>100</td>
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<td>474</td>
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Table 29: Estimated incidence (new cases) of Dementia among women by CCG, and age band for Norfolk and Waveney (Lower level of 95% Confidence Interval), April 2013

<table>
<thead>
<tr>
<th></th>
<th>65-69</th>
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<th>80-84</th>
<th>85+</th>
<th>65+</th>
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<td>11</td>
<td>30</td>
<td>65</td>
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<td>310</td>
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<td>15</td>
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<td>77</td>
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<td>14</td>
<td>34</td>
<td>68</td>
<td>178</td>
<td>311</td>
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<td>Norfolk &amp; Waveney</td>
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<td>62</td>
<td>160</td>
<td>324</td>
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<td>7</td>
<td>17</td>
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Table 30: Estimated incidence (new cases) of Dementia among women by CCG, and age band for Norfolk and Waveney (Upper level of 95% Confidence Interval), April 2013

<table>
<thead>
<tr>
<th></th>
<th>65-69</th>
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<th>80-84</th>
<th>85+</th>
<th>65+</th>
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<td>90</td>
<td>105</td>
<td>349</td>
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<td>68</td>
<td>115</td>
<td>124</td>
<td>383</td>
<td>812</td>
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<td>62</td>
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<td>323</td>
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<td>3,968</td>
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<td>471</td>
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<td>3,392</td>
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<td>32</td>
<td>51</td>
<td>58</td>
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<td>371</td>
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Table 31: Estimated incidence (new cases) of Dementia among persons by CCG, and age band for Norfolk and Waveney (Lower level of 95% Confidence Interval), April 2013

<table>
<thead>
<tr>
<th></th>
<th>65-69</th>
<th>70-74</th>
<th>75-79</th>
<th>80-84</th>
<th>85+</th>
<th>65+</th>
</tr>
</thead>
<tbody>
<tr>
<td>GYW</td>
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<td>94</td>
<td>139</td>
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<td>84</td>
<td>122</td>
<td>341</td>
<td>668</td>
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<td>46</td>
<td>63</td>
<td>98</td>
<td>284</td>
<td>530</td>
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<td>67</td>
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<td>119</td>
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<td>31</td>
<td>37</td>
<td>55</td>
<td>146</td>
<td>296</td>
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Table 32: Estimated incidence (new cases) of Dementia among persons by CCG, and age band for Norfolk and Waveney (Upper level of 95% Confidence Interval), April 2013

<table>
<thead>
<tr>
<th></th>
<th>65-69</th>
<th>70-74</th>
<th>75-79</th>
<th>80-84</th>
<th>85+</th>
<th>65+</th>
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<tbody>
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<td>202</td>
<td>287</td>
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<td>182</td>
<td>252</td>
<td>573</td>
<td>1,394</td>
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<tr>
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<td>147</td>
<td>136</td>
<td>202</td>
<td>476</td>
<td>1,090</td>
</tr>
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<td>216</td>
<td>183</td>
<td>246</td>
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<td>187</td>
<td>158</td>
<td>219</td>
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<td>6,643</td>
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<td>100</td>
<td>80</td>
<td>113</td>
<td>244</td>
<td>627</td>
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Table 33: GP practice with high or low statistically significant dementia prevalence from the Funnel plot for of GP practice dementia prevalence Distribution in Norfolk and Waveney using QOF registers for the 2012/13

<table>
<thead>
<tr>
<th>GP practice</th>
<th>CCG</th>
<th>Population</th>
<th>IMD score</th>
<th>Mean age</th>
<th>Number</th>
<th>%</th>
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<td>229</td>
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<tr>
<td>D83011(3)</td>
<td>GYW - Waveney</td>
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<td>140</td>
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<tr>
<td>D83022(4)</td>
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<td>50.8</td>
<td>87</td>
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<td>D83035(4)</td>
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<td>49</td>
<td>154</td>
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<tr>
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<td>9.6</td>
<td>46.2</td>
<td>105</td>
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<tr>
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<td>15.8</td>
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<td>46</td>
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<td>GYW - GY</td>
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<td>0.23</td>
</tr>
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<td>Area</td>
<td>Population</td>
<td>Infant Mortality Rate</td>
<td>Maternal Mortality Rate</td>
<td>Births</td>
<td>Local Deprivation Quintile</td>
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<td>------------------------</td>
<td>--------</td>
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</tr>
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<td>0.43</td>
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<td>12.9</td>
<td>46.5</td>
<td>15</td>
<td>0.36</td>
</tr>
<tr>
<td>D82084(4)</td>
<td>South</td>
<td>8,573</td>
<td>13.2</td>
<td>46.6</td>
<td>37</td>
<td>0.42</td>
</tr>
<tr>
<td>D82085(5)</td>
<td>South</td>
<td>5,165</td>
<td>12.7</td>
<td>44.5</td>
<td>17</td>
<td>0.33</td>
</tr>
<tr>
<td>D82615(5)</td>
<td>South</td>
<td>1,727</td>
<td>9.5</td>
<td>43.9</td>
<td>4</td>
<td>0.22</td>
</tr>
<tr>
<td>D82023(4)</td>
<td>South</td>
<td>11,093</td>
<td>15.3</td>
<td>39.6</td>
<td>37</td>
<td>0.32</td>
</tr>
<tr>
<td>D82037(5)</td>
<td>South</td>
<td>9,358</td>
<td>10.0</td>
<td>41.9</td>
<td>24</td>
<td>0.26</td>
</tr>
<tr>
<td>D82099(1)</td>
<td>West</td>
<td>13,893</td>
<td>28.8</td>
<td>36.3</td>
<td>40</td>
<td>0.29</td>
</tr>
<tr>
<td>D82604(2)</td>
<td>West</td>
<td>3,108</td>
<td>20.1</td>
<td>47.4</td>
<td>6</td>
<td>0.19</td>
</tr>
<tr>
<td>D82105(2)</td>
<td>West</td>
<td>5,236</td>
<td>21.6</td>
<td>43.5</td>
<td>18</td>
<td>0.34</td>
</tr>
<tr>
<td>D82043(4)</td>
<td>West</td>
<td>6,395</td>
<td>16.4</td>
<td>43.8</td>
<td>18</td>
<td>0.28</td>
</tr>
<tr>
<td>D82035(2)</td>
<td>West</td>
<td>7,915</td>
<td>25.1</td>
<td>43.2</td>
<td>37</td>
<td>0.39</td>
</tr>
<tr>
<td>D82086(1)</td>
<td>West</td>
<td>5,974</td>
<td>34.8</td>
<td>34.7</td>
<td>20</td>
<td>0.34</td>
</tr>
<tr>
<td>D82051(1)</td>
<td>West</td>
<td>16,369</td>
<td>27.4</td>
<td>42.9</td>
<td>74</td>
<td>0.45</td>
</tr>
<tr>
<td>D82044(2)</td>
<td>West</td>
<td>21,570</td>
<td>21.4</td>
<td>44.9</td>
<td>104</td>
<td>0.48</td>
</tr>
</tbody>
</table>

**Note:** the number given in bracket beside each GP practice code represents the local deprivation quintile for that GP practice (1 being the most deprived quintile and 5 being the least deprived quintile).
## Appendix 3: International Classification of Diseases (ICD10) - Dementia coding

### Table 34: International Classification of Diseases for mental health conditions

<table>
<thead>
<tr>
<th>Disease or medical Condition</th>
<th>ICD 10 code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia</td>
<td>F00-F03</td>
</tr>
<tr>
<td>Other organic, including symptomatic, mental disorders</td>
<td>F04-F09</td>
</tr>
<tr>
<td>Psychoactive substance abuse</td>
<td>F10-F19</td>
</tr>
<tr>
<td>Schizophrenia, schizotypal &amp; delusional disorders</td>
<td>F20-F29</td>
</tr>
<tr>
<td>Mood disorders</td>
<td>F30-F39</td>
</tr>
<tr>
<td>Neurotic, stress-related &amp; somatoform disorders</td>
<td>F40-F48</td>
</tr>
<tr>
<td>Behavioural syndromes</td>
<td>F50-F59</td>
</tr>
<tr>
<td>Disorders of adult personality &amp; behaviour</td>
<td>F60-F69</td>
</tr>
<tr>
<td>Mental retardation</td>
<td>F70-F79</td>
</tr>
<tr>
<td>Disorders of psychological development</td>
<td>F80-F89</td>
</tr>
<tr>
<td>Behavioural/emotional disorders – usual child/teen onset</td>
<td>F90-F98</td>
</tr>
<tr>
<td>Suicide</td>
<td>X60-X84</td>
</tr>
</tbody>
</table>

| Undetermined injury (included within boarder definition of suicide)| Y10-Y34 excluding Y33.9 |

### International Classification of Diseases: classification used in Singleton's national adult survey

<table>
<thead>
<tr>
<th>Disease or medical Condition</th>
<th>ICD 10 code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any neurotic disorder</td>
<td>F40-F48</td>
</tr>
<tr>
<td>* Mixed anxiety/depression disorder</td>
<td>F41.2</td>
</tr>
<tr>
<td>* Generalised anxiety disorder</td>
<td>F41.1</td>
</tr>
<tr>
<td>* All phobias</td>
<td>F40</td>
</tr>
<tr>
<td>* Obsessive compulsive disorder</td>
<td>F42</td>
</tr>
<tr>
<td>* Panic disorder</td>
<td>F41.0</td>
</tr>
<tr>
<td>Depressive episode</td>
<td>F32-F33</td>
</tr>
<tr>
<td>Personality disorder</td>
<td>F60-F69</td>
</tr>
<tr>
<td>Probable psychotic disorder</td>
<td>F20-F29, F30-F31</td>
</tr>
</tbody>
</table>
Experiences of dementia services in Norfolk

A report on experiences of health and social care dementia-related services for Norfolk’s Dementia Health Needs Assessment
June 2014
About this report

This report sets out the findings and recommendations of a research project on local people’s experiences of using dementia-related health and social care services in Norfolk. It is intended to help inform the Dementia Health Needs Assessment (2014) undertaken by the Public Health Department of Norfolk County Council using intelligence drawn from a range of organisations and services.

Who this report is for

This report is intended for the Dementia Health Needs Assessment Steering Group and the Health and Wellbeing Board. It will be also be of interest to:

- Residents of Norfolk; people with dementia who use health and social care services
- Unpaid/family carers of people with dementia
- Commissioners of dementia services in Norfolk County Council and Norfolk’s five Clinical Commissioning Groups
- Voluntary and community organisations whose beneficiaries are people with dementia and carers of people with dementia
- Norfolk Insight Team (local data observatory and Joint Strategic Needs Assessment)

Acknowledgements

We gratefully acknowledge the contribution of the people who took part in this research.
Executive Summary
Since April 2013 Healthwatch Norfolk has been gathering public feedback on health and social care services which suggests that access to and experience of dementia-related services can be variable. There are at least 13,000 people in Norfolk with dementia and dementia is a priority area for Healthwatch Norfolk and Norfolk’s Health and Wellbeing Board. In January 2014 the Board of Healthwatch Norfolk agreed that a research project should be carried out to explore people’s experiences of dementia services and that the results be used to inform the Norfolk Dementia Health Needs Assessment.
The approach taken was a qualitative one and sensitive to the needs of people with dementia. The areas of investigation were chosen to fit with the Dementia Health Needs Assessment and included diagnosis, day to day support, urgent help and emergencies and the quality of services used. Detailed information about access to and experience of health and social care services for people with dementia and their carers was gathered through interviews which took the form of focus group discussions. In total, 63 people consented to participate in the focus groups of whom 13 had dementia and 50 were carers. The discussions were recorded, transcribed and the content coded and sorted. Emerging themes were validated and the model for analysis further refined.
The dominant themes arising from analysis of the discussions were:

- A delayed diagnosis can result in a decline in the health and wellbeing of the person with dementia, in stress for family members and friends and a missed opportunity for timely, effective prescription medication. Carers held the view that the relationship with the GP is key and that the point of diagnosis is the best time to be given information about what to expect.
- Access to services varied greatly among participants and a lack of timely and accurate knowledge is a barrier to accessing the right help and support from the right service at the right time. It was apparent that obtaining good quality information about services is not easy for many people and that not all dementia services are available on an equitable basis.
- Family (unpaid) carers were providing the bulk of daily care for the person with dementia. Information about the funding of personal care was not clear to most people and carer’s spoke of facing practical problems and financial hardship on a regular basis. Advice and assistance with giving personal care, administering medicines and dealing with incontinence were frequently raised. The amount of care offered or received appeared to vary considerably. Many carers said that the amount of care the person with dementia received was not adequate to meet their needs.
- Overall, there appeared to be uncertainty about the types of services that could be called upon in an emergency situation, particularly those happening out-of-hours. The findings suggest there insufficient volume of service provision for emergency care and support for people with dementia and their carers during the evening, weekends and at night time.
- Support services for carers are a lifeline but carers had felt the impact of funding cuts by a reduction or loss of organised and facilitated carers support groups with specialist advice.
- A minority of participants were able to describe experience of specialist dementia services that were largely positive. The majority did not know what was available and how to access it.
- The behaviours of a person with dementia can be challenging on a day to basis and more advice on how to cope with dementia-related behaviours would be valuable to carers.
The key findings and recommendations from this research project are intended to help inform the Dementia Health Needs Assessment and to influence the future commissioning of dementia services in the county. The findings will also inform Healthwatch Norfolk’s information and signposting service and our ongoing work on unpaid carers in Norfolk.
1. Introduction
1.1 About people with dementia in Norfolk
There are around 194,700 people in Norfolk\(^{90}\) aged 65 years or older. In 2010, the Norfolk Dementia Health Needs Assessment estimated that were over 13,000 people in the county with dementia and that this would rise significantly to over 24,000 by 2030\(^{91}\). Information from the Quality Outcome Framework registers of 2010-2011 showed that the percentage of patients on a dementia register at their GP surgery varied considerably from 0.6% to 20% across Norfolk and Waveney practices. There has been a gradual increase in the recording of dementia\(^{92}\) since 2009, with the Clinical Commissioning Groups in Great Yarmouth and Waveney, North Norfolk, and South Norfolk showing the biggest increases in the recording of dementia patients on a disease register. Some recent modelling of dementia diagnosis rates\(^{93}\), however, estimate that diagnosis rates vary from between 35% to 49% between the Clinical Commissioning Groups in Norfolk. This suggests that there are people in Norfolk who have dementia but are not yet diagnosed and therefore very likely unaware and unable to access appropriate services.

1.2 Our insight
Our insight into people’s experiences of dementia services has come from a number of sources. Starting in the summer of 2013, Healthwatch Norfolk conducted the Conversation with Norfolk to listen to the public’s concerns about health and social care services in the county. Since April 2013 we have logged every call, comment and enquiry from the public about local services, including dementia services. The Healthwatch Norfolk team have engaged with commissioning and provider organisations across the county and beyond, in order to better understand the local landscape of services. In addition, we have around 40 volunteers who act as our ‘eyes and ears’ on the ground and who attend many meetings and events on our behalf. All of this helps to build our insight into local services:

- From our public survey we heard that there is a lack of information given to patients and carers upon receiving a diagnosis of dementia about the services and people they might encounter along the patient journey, benefit entitlements, eligibility for services, self-help and support groups. In summer 2013, only 2 out of 3 wards the Hammerton Court Dementia Intensive Care Unit at the Julian Hospital were open and people were concerned about the number of acute and respite beds available.

- Our public survey July-October 2013 highlighted people’s concerns for older people in Norfolk and some of the gaps in health and social care services for people with dementia and their carers, for example, support for carers, home carers and access to GP appointments particularly for those in rural areas.

- Our volunteers told us that not everyone in Norfolk had access to the same services and that for some, access to services depended largely on where they lived and the quality of information provided by GPs and mental health professionals upon diagnosis.


\(^{91}\) Norfolk Dementia Health Needs Assessment (2010) [www.norfolkinsight.org.uk/resource/view/resourceId=399](http://www.norfolkinsight.org.uk/resource/view/resourceId=399)


\(^{93}\) Diagnosis rates are a model of expected numbers of people with dementia versus numbers with a diagnosis. Dementia Partnerships: Dementia Prevalence Calculator [http://dementiapartnerships.com/diagnosis/dementia-prevalence-calculator/](http://dementiapartnerships.com/diagnosis/dementia-prevalence-calculator/)
• Our earlier work on *Unpaid Carers in Norfolk* highlighted the difficulties facing the thousands of carers in our county, particularly in light of cuts to funding for carer’s support services.

• The Norfolk and Suffolk Foundation NHS Trust is the provider of mental health services in Norfolk and implemented a new service strategy\(^\text{94}\) in 2012. Volunteers attending public consultations about mental health service changes told us about a reduction in the number in-patient acute beds on Blickling Ward at the Julian Hospital in Norwich and a proposal to permanently close the 12 dementia assessments beds on Larkspur Ward at Carlton Court in Lowestoft and the likely impact upon people with dementia and their carers.

• Reports from volunteers and Healthwatch Norfolk officers on their attendance to Clinical Commissioning Group meetings suggests that whilst there is a will for integrated commissioning, each Clinical Commissioning Group has its own priorities around dementia and each is concerned with services for the population they serve. All of this means that no single organisation has its eye on the county perspective, thus services can be patchy for people. In addition, some Clinical Commissioning Groups have plans to ensure that dementia is diagnosed more quickly and if this is the case, is the range of services appropriate and is there sufficient volume within them?

From the patient, service user and carer comments and feedback, the strongest themes emerging about dementia and local dementia services were:

• Having the first few difficult conversations with a loved one or friend
• What to do when first diagnosed with dementia
• Difficulty in finding out what information, support and help is available to a person with dementia and to their family members and carers
• Caring for someone with dementia; dealing with challenging behaviour; feeling isolated; getting medication right; taking on legal and financial responsibilities; making difficult decisions
• Eligibility for help and support; access to services, financial pressures
• Getting help when it is needed, especially during the evenings, at night and weekends
• Choosing a care home for someone with dementia

1.3 Public voice in Norfolk’s Dementia Health Needs Assessment
Dementia is a priority in the Norfolk Health and Wellbeing Strategy. The Public Health Department of Norfolk County Council are producing the 2014 Norfolk Dementia Health Needs Assessment. The needs assessment is a process which looks at the number of people in Norfolk who have dementia, the number requiring treatment and care and the type and scale of services that are required to meet people’s needs. The process will end with a document that will be used by the people and organisations who plan, buy and provide dementia services on behalf of people in Norfolk.

1.4 Research objective

\(^{94}\) Norfolk & Suffolk NHS Foundation Trust Service Strategy 2012 -2016
Healthwatch Norfolk has a statutory seat on the Health and Wellbeing Board and is a partner in the Dementia Health Needs Assessment. This means there is an opportunity to inform the Dementia Health Needs Assessment through the contribution of public views and experiences of local dementia services. At the Healthwatch Norfolk board meeting in January 2014, a scoping paper on dementia services was presented. The Board endorsed a proposal for a qualitative research project to be conducted in order to gather the views and experiences of people with dementia and their carers, for the purpose of using the findings to contribute public voice to the Dementia Health Needs Assessment and thereby influence the future commissioning of dementia services.
2. Method

2.1 Research questions
The research questions were framed by the themes contained in the Dementia Health Needs Assessment (see Figure 1). The approach adopted was a qualitative one, adopting interviews in the form of focus group discussions, in order to generate a depth of insight and understanding of service experience.

Figure 1. The ten themes of Norfolk’s Dementia Health Needs Assessment (April 2014)

2.2 Approach: framework analysis of experience of dementia services in Norfolk
The sections of the Dementia Health Needs Assessment relating to patient’s views and experiences of local services were used as a basis for the research project and to determine the way in which the content of the focus group discussions would be analysed - a so-called ‘framework analysis’ (see Figure 2). In discussion with partners, Healthwatch Norfolk offered to explore people’s views and experiences of the quality of services in Norfolk, from the perspective of people with dementia and their carers, from early to advance stages of dementia, from diagnosis to living with dementia day to day and emergencies.

Figure 2 Framework analysis of people’s experience of dementia services in Norfolk

The next step was to shape the structure of the focus groups by first identifying a number of factors which resonated with some of the feedback to Healthwatch Norfolk.

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95 A framework analysis is where the objectives of the investigation are set in advance and shaped by the information requirements of a funding body or sponsor; the thematic framework for the content analysis is identified before the research commences.
from the public, patients and carers. This was taken from a variety of sources such as feedback at our engagement events, public surveys and through our volunteers’ meeting reports (Figure 3).

**Figure 3** Factors in dementia to guide participant selection and the development of focus groups

<table>
<thead>
<tr>
<th>Knowledge and awareness of dementia</th>
<th>Unaware</th>
<th>Knowing very little</th>
<th>Quite well informed</th>
<th>Very well informed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>Undiagnosed</td>
<td>Misdiagnosed</td>
<td>Diagnosed</td>
<td>Prognosis</td>
</tr>
<tr>
<td>Stage of illness/disease</td>
<td>Early</td>
<td>Mid stage</td>
<td>Advanced stage</td>
<td>End of life</td>
</tr>
<tr>
<td>Support and care</td>
<td>Primary healthcare</td>
<td>Community healthcare</td>
<td>Secondary healthcare</td>
<td>Specialised services</td>
</tr>
<tr>
<td></td>
<td>Mental healthcare</td>
<td>Social care</td>
<td>Domiciliary care</td>
<td>Respite care</td>
</tr>
<tr>
<td>Information &amp; advice service</td>
<td>Social clubs &amp; groups</td>
<td>Voluntary services</td>
<td>Carers support</td>
<td></td>
</tr>
<tr>
<td>Individual life-stage</td>
<td>Of working age</td>
<td>Approaching retirement</td>
<td>Retired</td>
<td>Long since retired</td>
</tr>
<tr>
<td></td>
<td>Partner/spouse</td>
<td>Parent or child or both</td>
<td>Widow, widower, bereaved</td>
<td>End of life</td>
</tr>
<tr>
<td>Age</td>
<td>60 - 64 years</td>
<td>65 - 69 years</td>
<td>70 - 74 years</td>
<td>75 - 79 years</td>
</tr>
<tr>
<td></td>
<td>80 - 84 years</td>
<td>85 - 89 years</td>
<td>90+ years</td>
<td></td>
</tr>
<tr>
<td>Geography</td>
<td>Wells</td>
<td>Cromer</td>
<td>Hunstanton</td>
<td>Mundesley</td>
</tr>
<tr>
<td></td>
<td>North Walsham</td>
<td>Ditchingham</td>
<td>Blofield</td>
<td>Caistor-on-Sea</td>
</tr>
<tr>
<td></td>
<td>Downham Market</td>
<td>Hingham</td>
<td>East Dereham</td>
<td>Sheringham</td>
</tr>
<tr>
<td></td>
<td>Eaton &amp; Coltishall</td>
<td>Holt</td>
<td>Fakenham</td>
<td>Ludham</td>
</tr>
<tr>
<td></td>
<td>The Terringtons</td>
<td>Worstead</td>
<td>Loddon</td>
<td>Old Buckenham</td>
</tr>
<tr>
<td></td>
<td>Hoveton &amp; Coltishall</td>
<td>Kings Lynn</td>
<td>Diss</td>
<td>Watton</td>
</tr>
<tr>
<td>Living with dementia: day to day activities</td>
<td>Eating &amp; drinking; food preparation &amp; cooking</td>
<td>Washing &amp; dressing</td>
<td>Physical activity</td>
<td>Resting and sleeping</td>
</tr>
<tr>
<td></td>
<td>Loved ones, family &amp; friends, relationships</td>
<td>Pet care</td>
<td>Driving, transport, mobility</td>
<td>Hobbies &amp; interests</td>
</tr>
<tr>
<td></td>
<td>Domestic chores (shopping, cleaning, gardening)</td>
<td>Healthcare, medication etc</td>
<td>Holidays and events (personal, spiritual)</td>
<td>Employment, volunteering</td>
</tr>
<tr>
<td>Quality of life, events</td>
<td>Amazing</td>
<td>Great</td>
<td>Good</td>
<td>OK</td>
</tr>
</tbody>
</table>

96 These market towns and villages were selected based on the demographic profiles at MSOA level, of the percentage of people aged 60 years and over observed in the maps of the interactive atlas on the Norfolk Insight website [http://www.norfolkinsight.org.uk/jsna](http://www.norfolkinsight.org.uk/jsna)
2.2 Participants

Participants in this research project were people with dementia - at any stage of dementia - and their carers. Having sought advice from health and social work professionals, in addition to referring to the evidence base for qualitative approaches in dementia research, we understood it would be challenging to engage people in the mid-stages and advanced stages of dementia meaningfully in a group discussion. For these individuals, family members and carers became the participant alongside the person with dementia they were caring for.

The aim was to recruit and interview between 30 - 80 people with dementia and/or their carers.

2.3 Sampling and recruitment

The sampling approach adopted was purposive sampling. Purposive sampling is the selection of participants who have knowledge or experience of the area being investigated. The nature of the feedback previously collated by Healthwatch Norfolk influenced the decision not to recruit service users through existing dementia-related services in Norfolk. Our feedback suggested that not everyone has clear and timely information about and access to dementia services and people with that range of experiences were purposely sought. Therefore, several alternative recruitment routes and channels were selected including:

- Attendance at Patient Participation Groups
- Written approaches to Parish Councils in rural communities, notices in Parish newsletters
- Approaches to, and offers of support from, community and voluntary groups, including carer’s support groups
- A notice in the Healthwatch Norfolk member’s newsletter
- Word-of-mouth through our staff, volunteers and members

A Dementia Research Project Information Sheet (see Figure 4) was created and distributed through the channels listed above.

Figure 4 Information Sheet
2.4 Focus groups
Interviews took the form of a semi-structured focus group discussions held for between 40 to 90 minutes. Focus groups were comprised of between 3 and 6 participants who were people with dementia or were a carer of someone with dementia. The groups were arranged in a variety of locations around the county.
Participants were given information about the research project and asked to give their consent to participate and for the discussion to be recorded for the purpose of note-taking and transcription.
The focus groups were facilitated by a researcher and the style was informal and flexible to encourage the free expression of views.

A discussion guide (see Figure 5) was used to pose four basic questions to participants and further questions used when helpful in soliciting more detailed responses. Participants were invited to add further comments or initiate further discussion on matters they felt had not yet been discussed or fully explored. The focus group discussions were recorded using a portable, digital voice recorder and the audio files transferred and stored within password-protected files on a secure system.

**Figure 5 Focus group discussion guide**

<table>
<thead>
<tr>
<th>Theme</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Diagnosis</td>
</tr>
<tr>
<td>1. Looking back, when did you begin to realise that something wasn’t right?</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td></td>
</tr>
<tr>
<td>2. When you hear the word dementia, what comes to mind?</td>
<td></td>
</tr>
<tr>
<td>3. Did someone else raise the topic of your mental health? If so, who? When they were talking to you, how did they seem?</td>
<td></td>
</tr>
<tr>
<td>4. What was the first time you heard the word ‘dementia’ used, to you or about you?</td>
<td></td>
</tr>
<tr>
<td>5. Did anyone give you any information about dementia services and support?</td>
<td></td>
</tr>
<tr>
<td>6. In the early days, do you think people in general want to know if they have dementia? If not, why not?</td>
<td></td>
</tr>
<tr>
<td>7. Who is the best person to tell you that you have dementia?</td>
<td></td>
</tr>
</tbody>
</table>

**2. Day to day support**

| 1. Do you want any help or support on a day to day basis? |
| 2. Do you get any help or support? If so, help with what? |
| 3. Do you have a carer in the family who helps you? If yes, who is your carer? Does your carer work outside the home? |
| 4. Do you feel you got enough help at the start? |
| 5. Are you happy with the amount of support that you currently receive? |
| 6. Who you get help from? |
| 7. When do you most need help? Is help there when you most need it? |
| 8. Does your carer want support? If yes, what sort, when and from whom? |
| 9. Do you feel you need help from a specialist? At what point? |
| 10. Does it matter who gives you help and support? |

**3. Urgency**

| 1. Are there times when you need help or support urgently? |
| 2. What do you do in an emergency? |
| 3. Have you needed to go into hospital? If so, how long for? Were you able to keep in touch with family and friends? |

**4. Quality**

| 1. Do [health/social care workers]/people listen to you? |
| 2. Are you able to talk about your needs? |
| 3. Have you been involved in decisions about your treatment or care? |
| 4. Have you been treated with respect? |
| 5. What have you found to be most helpful? |
| 6. What do you think has been done well? |
| 7. What needs improving? |

### 2.5 Data processing and preparation

Following each focus group, the recordings of the focus group discussion was manually transcribed from an audio to text file format. The conversations were transcribed word for word (verbatim).

### 2.6 Analysis

#### 2.6.1 Developing a way to organise the data

The transcriptions of the focus group conversations were briefly reviewed and an initial ‘coding’ model developed so that the content of the transcriptions could be deconstructed and assigned (coded) to a number of categories that would be meaningful for the Dementia Health Needs Assessment. These categories were initially set according

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98 Verbatim Transcripts are a type of transcript where means that every single word or line mumbled or spoken is written as it was spoken by the speaker in the audio file, including half sentences and phrases, pauses and gestures. Verbatim transcript involves a great deal of time and attention hence these are the most detailed type of transcript.
to the framework for the analysis developed in the early stages of the research project (Figure 2). The main categories were:

- People with dementia; people with the early signs of dementia, early, mid- and advanced stage dementia
- Carers of people with dementia; unpaid or family carers, paid carers
- Quality of services; health services, social care services, voluntary and community sector organisation services
- Quality of services; upon diagnosis, day to day living, emergencies

2.6.2 Peer review of content
When the series of focus groups had almost been completed, Healthwatch Norfolk team members helped to review some of the focus group discussion content. This enabled the model of what had been found to be tested and then refined for use in analysis (see Figure 6). The main addition at this point was the inclusion of a category for ‘behaviours’ reflecting the emphasis placed on the behaviours in dementia by focus group participants which became an emerging theme in the transcription texts.

![Figure 6 Coding model for data analysis](image)

2.7 Participant validation of emerging themes
Before further work to code the data took place, one final focus group was held with previous participants as a ‘participant validation’ exercise. The purpose was to present some of the thinking around the emerging themes from the focus group discussions and get feedback on whether these themes resonated with participants in terms of their experiences of services. Participants were satisfied with the main components of the coding model but requested a few further refinements, including the addition of a major category on access to service and information. This was suggested in order to capture
the very early stages of the dementia pathway (patient journey) from both the patient and carer perspective. Figure 7 shows the detail of the coding model section relating to quality of services experienced. The participants were also invited to reflect on the quality of their engagement in the Healthwatch Norfolk dementia research project and how this might be improved or changed for future research projects.

**Figure 7** Detail of coding of experiences of the quality of dementia services

The transcripts were imported into analysis software[99] and the content coded and grouped into the categories displayed in Figures 2, 6 and 7.

3. **Findings**

Forty eight (48) people in total were interviewed in-depth through 12 focus groups held in a variety of locations around Norfolk. Two individuals were interviewed separately as a focus group was not appropriate for the person with dementia (for a number of reasons). The researcher also took up the offer to attend a dementia-carers support group comprised of 13 carers of people with dementia and used the opportunity to record carers concerns and experiences. In total, 63 people contributed their views and experiences, of whom thirteen had dementia (11 people in the early or mid-stages of dementia, 2 people with advanced dementia) and 50 were carers. The focus groups took place in venues such as community hospitals, village halls and the homes of participants.

[99] QSR International NVIVO v.10 - this a software package that enables a researcher to collect, organize and analyse content from interviews, focus group discussions, surveys, audio, social media, videos and webpages etc.
The focus groups lasted between 40 minutes and 1 hour 45 minutes and on average lasted for one hour.

3.1 Diagnosis
Participants were asked to recall the point in time when they begin to feel that something was wrong. All carers were able to identify a time or place when they begin to suspect something was not right and after a while had begun to suspect dementia.

**Researcher:** Looking back to the beginning, was there a point when you thought to yourself something’s not quite right?

**Participant (carer, female):** “I can pinpoint it very precisely. [My husband] used to do my accounts, I was treasurer and I can’t count so he used to do my accounts for [a charitable organisation] and he kept saying ‘there’s something wrong with the calculator’ and he took a week and he couldn’t finish it. And then I discovered we hadn’t got any car insurance and we hadn’t had any for two years. So I realised there was something wrong.”

Carers were keen to stress that often the signs of dementia are noticeable for some time before an ‘official’ diagnosis of dementia is made by a health or social care professional.

**Participant (carer, female):** “It easier to deal with when you’ve got a diagnosis. You’ve got a label you can put on it and it’s easier to cope with because people with dementia do all sorts of funny things and if you’ve got a label it’s easier to deal with.”

Many spoke about months or even years, for example, nine months to two and a half years of noticing a change in a person, in recognising the signs of memory loss and in seeing dementia-related behaviour being displayed, prior to a formal diagnosis of dementia. For around half of participants, obtaining a diagnosis was relatively straightforward experience and for the other half it was a challenging and drawn-out experience.

For some people with dementia, their condition can go unrecognised and untreated for a long period of time; months or even years.

**Participant (carer, female):** “...things had been difficult for some time. [My husband] had started to miss things like his GP appointments. He would telephone the surgery and make the appointment, then forget he had done it. This happened several times and there were about five or so missed appointments but no-one from the surgery had called to ask why or to check up and see if he was OK. If [my husband] did make his appointment, he would occasionally be ten minutes late as he would forget something or get distracted along the way. When he arrived at the surgery he would be told that he was late and the GP could no longer fit him in. This happened about five or six times. In all that time - about a year I think it was - not a single NHS person called to check up on him or ask why it was happening. It was about that time when I was diagnosed with severe depression and was admitted into [a local hospital]. I actually was kept in for a couple of months. [My husband] lived at home, completely alone, with no help for his dementia at all. No-one checked up, or called in. He got into quite a bad state. It was only on my insistence as I began to get a bit better myself in hospital...that a social worker was asked to call in on him and check all was well. All was not well. He hadn’t been eating, hadn’t cleaned the house, not washed himself or his clothes, had not tended the garden or put the rubbish out for two months.”

Most participants appeared willing to accept the diagnosis of dementia and many carers in particular expressed relief. A minority said they found the diagnosis of dementia unpalatable and attempted to deny that anything was wrong with their memory or
health. The diagnosis was often the confirmation of something that the close family member or carer had suspected for some time - it rarely seemed to come as surprise and sometimes it came almost too late for treatment, help and support to be really beneficial.

Participant (carer, female): “The test, oh yes…I mean I was sure long before his actual diagnosis, I had no doubts it was Alzheimer’s and um, what happened in the end was, we were referred to Addenbrooks because I said to the GP ‘Look, this is absolute nonsense, I know he has Alzheimer’s but I just want to know if we should be doing anything, or if he should be on any medication’. So when we were referred to Addenbrooks they were terrific there, absolutely terrific and they said ‘Of course he has Alzheimer’s, no doubt about it’ you know and ‘We’re sorry you’ve had all this carry on to get it diagnosed’.”

The diagnosis is the key to the door leading to referrals and access to services and support. A delayed diagnosis can result in a decline in the health and wellbeing of the person with dementia, a great deal of stress for family members and loved ones, can cause tension and arguments between the person with dementia and close relatives and creates the potential for a missed opportunity for prescription medication to be effective at the right stage of treatment.

Researcher: “Can I ask when you first heard the word dementia mentioned?”
Participant (carer, male): “Oh yes, I remember that clearly. I took her to the GP. I made the appointment for myself under the pretence of talking about some rubbish or other maybe my prostate or something because I thought how can the GP refuse me or you know that’s a fascinating subject for GPs and people always going on about cancer and cancer in your bowels and all that. So I took her with me and I said ‘Oh doctor, while I’m here can I just talk to you about [my wife]? She’s been acting oddly’ and he said ‘Oh right’ and then talked to [my wife]…well he tried to talk to [my wife] but of course she didn’t say much, just a few things, nodding and being polite but she had a bit of a far-away expression on her face. The GP asked her these questions about oh I don’t know things like who is the prime minister and so on. The GP then said he would set up an assessment for us, some sort of assessment, for [my wife] sorry, and that it might take a while, maybe up to eight weeks. I think he might have said dementia assessment or assessment for dementia or something like that. That was the first time anyone said it to me, directly to me and in front of my wife. She didn’t pay any attention. That’s how it is, nowadays.”

People with dementia and their carers had some different experiences of a formal diagnosis of dementia but the most common ways in which a diagnosis was made was:
- Making an appointment with a GP, suspecting that dementia or something similar would be the cause of a change in health, wellbeing or particular in behaviours
- Following an assessment done by the GP in the surgery

Participant (carer, female): “I remember that the GP did a mini mental health assessment and asked [my husband] about ten questions which he recalled as general knowledge questions but couldn’t remember exactly what the questions had been when he came back from the surgery. The GP made a referral to the mental health trust and a nurse called to say that [my husband] needn’t go to the [hospital in Norfolk] but she
would come out to see him at home and do an assessment there. She said it was better that she came out to see [my husband] at home because he would be in familiar surroundings and would feel more at ease with the assessment.”

- Following an assessment undertaken at a hospital specialist clinic
- Following an assessment undertaken by a specialist at home

Participant (carer, male): “I did leave it ‘till the next day. In the morning I said ‘Shall we phone the surgery and make an appointment about your headaches’ and straight away she said ‘Yes’ and she didn’t mention what had happened, and neither did I. She duly called and the receptionist or whoever it was obviously mentioned her missed appointment and she apologised for that and made another one and I said ‘Do you want me to come with you?’ and she said ‘Yes you can if you like’ so I did I drove her there and I came into the surgery with her and I knew it might upset her but I thought I’m going to have to mention this to her and I said ‘you might want to think about mentioning that you’ve been forgetting things’ and she said ‘Alright’. Well she did, she was in there a long time, a good fifteen minutes or even longer I should think and then the doctor came out and he called me in and he told me he’d been talking to [my wife] about her headaches, her high blood pressure and about forgetting things and he said ‘[Your wife] has asked me if I can speak to you while you are here and it is simply to say that I am going to refer her to the Julian Hospital, to the memory clinic, to have some tests.’ He said that he thought somebody might come out and see us at home or rather to see [my wife] at home and that the test was not a scientific...er...no I mean it wasn’t a laboratory type test I suppose more of an assessment was how he described to us and the test would help us to find out if [my wife] was having some problems with her memory.”

Participant (carer, female): “The doctor did some kind of test with questions. He wanted [my husband] to go for some special kind of test with the psychiatrist or something. We went up to the hospital to get that done. We went back to the doctor to get the results. [My husband] asked me not to come in that time. Although the doctor came out and called me in. I think [my husband] really wanted it all to be some kind of big mistake or misunderstanding. But the doctor said that [my husband] had dementia. And that was that”.

- During an admission to hospital, either for a routine procedure or as an emergency

Participant (carer, female): “...she had a collapse... they don’t know what it was, but I thought it was some form of mini-stroke, she was admitted to hospital...and they said she should have scan but they couldn’t do it because it was a weekend and at that point I thought ‘What!’ and her doctor did come and visit her the hospital and because she was with nurses all the time, without any sort of...suddenly it was all...everybody knew my mum had dementia. You know what I mean? I spent - having spent a year going ‘please somebody diagnose this’ and I knew...nobody actually said to us ‘Oh your mum’s got dementia’ but the people - the Sister - was saying ‘Well of course your mum has dementia’ you know what I mean? She didn’t mean it to be unkind because she thought everyone knew my mum had dementia...”
3.2 Access to services
The experiences of accessing services varied greatly, in both participants with dementia and in carers. People gave many and varied reasons for this. The most frequently cited were the following list:

1. “You don’t know what you don’t know”: if a person does not know what kind of information, services and support exists, they do not know what to ask for.

   Participant (male, carer): “I have found it difficult to get information on the types of help and support and services that are available. There is just nothing out there. Telephoning the doctors surgery, or the district nurse, or social services can be a nightmare. All the systems are automated and this is extremely upsetting for someone with dementia who cannot manage to keep track of the questions they are being asked, there are no steps ‘to go back’ if you think you’ve made a mistake. Health and social care services should have help lines and appointment booking systems that are ‘speaking to people the old-fashioned way’. It is all very impersonal, very technical and there is no human or social interaction.”

2. The positive influence of the GP: having a productive relationship with the GP; a GP who is willing to listen; a GP who is supportive of both the person with dementia and the main carer; a GP who is perceived to be willing to assist in the diagnosis of the dementia.

   Person with dementia (female): “He was…compared to one I’ve got he was marvellous…he was concerned”. Participant (carer, female): “And he saw her as a whole person didn’t he? He sat and talked to you and [my husband] for a long, long time and [my husband] came home and said he was fantastic and he was the first one who really said ‘Yeah, let’s see if we can get you referred’ and that took us a long while and but I think also, but I’m not sure because at the time we didn’t quite know how these things were joined up, I know [a member of the family] had been getting in touch with the team at [a GP surgery in Norfolk] and the mental health team and had tried to get some help from there but we couldn’t get the two thing synced and it was hugely frustrating for the family and we were all worried because [my mother-in-law] was keen – if there was medication - to take it, [my mother-in-law] was prepared to take it…”

   This can be particularly important when the GP has knowledge of specialist services that would be an appropriate part of a person’s treatment or care and will make a referral to that service.

   Participant (carer, female): “The GP suggested an Admiral Nurse and she is just amazing. There are days when [my husband] drives me absolutely bonkers. The nurse can give us a bit of respite and really helpful practical advice. The main thing was that [the Admiral Nurse] understands what it’s like to live with someone with dementia and
when you have feelings like you are really at the end of your tether, they tell you that they are normal.”

3. The less positive influence of the GP: a GP who is perceived as wanting to focus on managing the physical symptoms of disease; a GP who is perceived as unwilling to listen to the concerns of close family members; a GP who is perceived as excluding close family members from a diagnosis of dementia on the grounds of patient confidentiality.

Most participants said they appreciated why it would not be possible to be part of every conversation and recognised that GP’s have a duty to the patient which must come first.

Participants were able to describe a number of different experiences with a GP where the real and pressing problems faced by the person with dementia and their carers could not be helped or progressed.

**Participant (carer, female):** We had real problems with mum’s GP, lady GP in [town in Norfolk] we got absolutely no-where for a very long time, I’m talking a couple of years, nowhere at all and um mum’s son and daughter...both went and saw the GP and she refused to speak to them about mum and [her son] is actually at that surgery and they wouldn’t engage with us at all in any way shape or form. And because we were backwards and forwards with the other bits and pieces, with the medical problems, and I had been there and seen the GP and seen how she handled mum, it got to the point where you (turning to the person with dementia) asked if I would go with you because mum was coming and wasn’t sure what had been said or we’d come out with pieces of paper and not know what they were so I’ve witnessed very poor handling of the situation…”

**Participants (carer, female):** “…to absolutely honest we didn’t have help from the GP, because the GP just focused on the medical things like getting the diabetes sorted…”

Carers shared stories of repeatedly trying to help for a person with dementia when they felt the person with dementia may not have received the best attention or appropriate care because they were not able to articulate specific symptoms or pain and they were also elderly.

**Participant (carer, female):** “She then had another interesting experience with the GP. She was in a lot of pain. She kept going like this (makes action of guarding her hip with her hands) we knew she had a bit of rheumatism and so I took her to the doctor and he was absolutely horrible. He has apparently got a bit of a name for it because I used to work at the school and a lot of people there went to him and he had such a bad name I later found out. And he just got her up on the table, examined her and she had a - apparently - a mass or what he described as a mass and he just said, in front of my mum which is fair enough I suppose but he didn’t say it very nicely he went ‘Well, she’s got cancer’ and er and I said ‘Oh’ and because of my ruthless streak I wasn’t as upset as some people would have been I thought ‘Well, she’s an old lady, people do - I just don’t want her to be pain, and she was’. And um, he said ‘Well she’s got cancer and I’ll refer her to the hospital’. I said ‘She is in a lot of discomfort’ and he said ‘Keep taking paracetamol’ and I said - I sort of was a bit baffled and my mum was fairly lucid for a
moment and said ‘Cancer? I’ve got cancer?’ and she was getting dressed, and I was helping her get dressed but she was literally within five minutes ‘Well, at least there’s nothing wrong with me’. It was like that sick joke; you’ve dementia and you’ve got cancer and ‘Oh, at least I haven’t got cancer’. It was exactly like that. She was a bit distressed, she didn’t like his tone, my mum is no fool but you don’t have to be. I took her home, by the next two days my mum was in absolute agony so I went back to the doctor’s surgery and stood in front of the Receptionist and I told her exactly what had happened with this horrible doctor...and said that my mum is in so much pain that I don’t know what to do... I went through, told [another doctor at the same GP surgery] exactly what had happened and he said ‘You can’t diagnose cancer, you can suspect cancer, but you can’t diagnose cancer like that’. And I said ‘No, I thought it was well you can pretty much know what it is but you can be surprised’. He said ‘If she’s in that much pain I’ll come straight after evening surgery’. He was round there really quickly and my mum didn’t have cancer, he said ‘She’s got a hernia’ and she must have been in so much pain and it should have been operated on. The earlier it’s operated on, the better and it should have been operated on immediately. He said ‘I will call an ambulance, but I think it will be quicker if you can cope with it to drive your mum to hospital and while you’re doing that, I’ll phone ahead’. She was operated on that night. And I think that’s all to do with being old. There’s this sort of, there’s some – the way my mum’s been treated for medical things has been less good as she’s got older. It’s very dismissive.”

4. Provision of information by the GP to the patient or carer: having access to good quality and accurate information about the range of services on offer to people with dementia and to carers was described as highly important.

**Person with dementia (male):** “People with dementia need to have one person to rely on and to call when things get too much. This should be a GP or a Social Worker. It could be either. Not everyone will have a social worker, or be put in touch with social services...not sure why this is but it does mean that some people seem to get great care whilst others don’t. The GP is especially important when you get the diagnosis. People will be turning to their GP in the expectation of getting some information, where you can go to get help and so on.”

**Person with dementia (female):** “Say even if he had said there may be a problem and we’d better look into it, I think everyone needs a leaflet ‘These are the services available. This is what’s available. This is what you’re entitled to and this is a phone number’.”

The majority of participants identified the GP as having a powerful role around the time of diagnosis in providing some basic but accurate information about what to expect and where to go for help and support along with other professionals such as social workers although this didn’t always happen.

**Researcher:** “Did you get any help from your GP or the social worker with finding a carer for your wife?”

**Participant (carer, male):** (laughing) “We didn’t get any help with that whatsoever. The social worker did mention to me that I could arrange help this way, I mean, to just
do it myself so I did. I looked on the internet and I ordered brochures and I called Age UK and...Dementia UK and the Alzheimer’s Society I think, to get advice.”

5. Information about support groups: support groups, however run or funded, appear to provide people with dementia and their carers a great deal of information and practical advice and help on a very wide range of topics. Support groups and their membership are an extremely rich and valuable source of information to both the person with dementia, their carers, friends and family members as well as being an enjoyable and beneficial social activity.

6. Accurate information on funded and self-funded services: there is confusion around the services that can be accessed free on the NHS or through assessment by social care services and those that will need to be self-funded; some carers had been given the message that because they or their loved ones had ‘assets’ that meant they were entitled to no help whatsoever which meant they were allowed to no access to support groups or a GP referral to another service and so on.

Participant (paid carer, female): “Whilst dementia and Alzheimer’s affects people in different ways, people have some common needs in information and knowing what services are available, what they can access for free and what might need to be paid for...”

7. Wasted time: carers and close family members in particular reported spending a large amount of time trying to find out information on what help and support is available for the person with dementia and for carers. Around a quarter of carers had created a special book, file or scrapbook where they could store all the information they discovered on dementia, coping with dementia and the sorts of health, social care and support and social activities available in the district borough council areas and the county in general. Carers were only too keen to share their hard won knowledge with others to save them wasting time and experiencing the isolation and helplessness they had themselves experienced.

Participant, (carer, female): “I had by strange coincidence, over the course of the last five years, three elderly neighbours where one of the partners has actually had Alzheimer’s and they all went through it in a different way and progressed at a different time, had different results etcetera etcetera and people my parents had known for decades so you see the behaviours change and everything. So it was remembering things you’ve been told so that was a little bit insightful. And then again doing little bits of research and just things that you stumble across and then people like [my friend] and I who have got relatives in a similar situation and we swap information. And we found out about the Home Instead and the wonderful workshop they do which is incredible. And then as a result of that we went to the SCAM awareness thing where other people were talking about vulnerability of old people and other little bits and pieces come up...”

The composition and location of the focus groups meant that people with dementia and carers could compare their experiences with one another, about accessing services. The analysis of the discussions reveal that obtaining good quality information about services
is not straightforward for many people and a proportion find it very difficult indeed. It became apparent in some of the discussions that not all dementia services are available on an equitable basis across the county. Norfolk has five Clinical Commissioning Groups and this sort of patient experience may suggest that services are commissioned differently in the five different localities. Healthwatch Norfolk volunteers have been telling us that access to dementia services across Norfolk is not equitable and the findings of this research based on the experiences of the participants would validate that view.

When asked the question “how could the quality of services be improved?” many people responded that making information about the kinds of services available to people - both funded and self-funded - would be the single most helpful thing services could do.
3.3 Day to day living
3.3.1 Personal care
Some of the carers involved in the discussions held a positive attitude and outlook to
dementia and to their caring responsibilities. They were keen to stress that for some
people, caring for a person with dementia can be manageable and is always done with
love and care. Some felt that negative reporting of dementia in the national and local
media can give people the wrong impression of being a carer for someone with
dementia.

Participant (carer, female): “There is something about personal circumstance that
plays into it, if I’d still been [working] I couldn’t have done it. And then I would have to
be on, and say I need some arrangements, I need stuff, I need help here because I
couldn’t have done it. So I suspect there’s a lot of people exactly in my position who
kind of...you don’t even really get counted in a sense, which is absolutely fine, but if
you’re trying to compile, umr, the story of what goes on and a broad sense of what goes
on I thought it was worth saying ‘Well, you know, there are lot of us people here, and
it’s actually OK, it’s alright’.”

Many carers spoke about practical help with the personal care required by someone with
dementia. The analysis shows that this is the area that carers would like the most
support and help with and that they would like more than they are already getting.

Participant (female, carer): “[My husband] still manages to dress himself OK but I find
I have to wait until he’s finished to do it...partly because of the shower system here but
partly because I like to keep an eye on what’s happening, dirty things go back in the
cupboard, clean things go in the wash, hair isn’t washed and things like that so it’s just
keeping an eye on it, so I wait usually until after he’s dressed and then I dress myself
and if we’re going to do something or something happening on that day sometimes
that’s a bit of a pressure to get ready in time myself.”

Participant (female, carer): “He went through a phase about eighteen months, or a bit
longer than that, maybe about two years ago, if you left him on his own something
would be taken to pieces, the grandfather clock got take to pieces and we couldn’t put
it back it together. Apparently I’m very lucky because men do things like take the gas
cooker to pieces or things like that when they’re on their own and even now you have
to be careful because if he decides he wants to change a plug or something like that...I
mean he couldn’t do it...it might get so far as unscrewing something, you just have to
very careful and watch them all the time, you can’t leave them on their own and as
well as that, because he’s got Lewy Bodies he’s likely to fall and hurt himself...he’s very
wobbly, you’ve got to watch out.”

A small number of carers described a social worker performing an assessment, to assess
the need for functional care (home care) for the person with dementia.

Researcher: “[Participant], did you arrange for the carers for your wife?”
Participant (carer, male): “No dear the social worker did the assessment for us. Very
much like this gentleman here said [the social worker] came out to see [my wife] at
home and there were forms to fill in but it seemed quite straight forward although we
didn’t get the full allocation or whatever it is no, wait a minute, I’m confusing it with
the attendance allowance...I did get the full whack for the attendance allowance
because I have to get up with [my wife] in the night or rather I tend to wake [my wife]
up several times a night because otherwise you know she might be incontinent and she’ll wet the bed because often I can’t get her to the toilet on time and it all happens so quickly. So I get the Attendance Allowance for her and then the carers come twice a day for helping with washing and bathing. They only come for 15 minutes at a time though so it’s barely long enough to get a lick and a promise as my mother used to call it but they do help [my wife] and she seems to like them. I’m happy to take care of [my wife] myself most of the time, we’ve been together a long time and I know her and she knows me and she’s happy with me there. She usually only frets and gets upset if I’m not there. Up until recently I was able to leave her on her own for a while and she’d be OK for twenty minutes if I just popped round to see a neighbour or if I had to drive quickly to the post office or the shops for some milk or something like. But it got recently, in these last few months, quite difficult to leave her alone, I’m worried she’s going to fall and hurt herself again like she did before, you know, she might break something or burn herself. She moves so slowly and she’s lost some of her coordination and that. I think the more she sits about, and she does seem to sit about quite a bit these days but I think that’s not good for her because when she is on her feet she gets wobbly which is why it’s so useful to have some help to dress her because I can’t always manager her...well, er, physically, on my own.”

A recurring theme of the conversations was the confusion over who to contact with a specific request for help.

Participant (carer, male): “People need help with many different things. For example, there is the medical side of it and the financial side of it. These are not the same thing and you wouldn’t expect financial advice from your GP and you wouldn’t ask your bank manager about your health. Both these aspects are important in dementia. There is also the practical, day to day side of it which people do recognise as the ‘care’ side, though not everyone would think to call social services if some of the day to day stuff was going wrong”.

Most people spoke about wanting useful information and practical help. The thing about ‘living well with dementia’ or being a ‘dementia friend’ is not enough. The messages about getting an assessment and the thresholds for receiving state-funded care services are mixed and confusing.

Participant (carer, male): “We don’t qualify for any help. The doctor did arrange for a social worker to come and visit myself and [my partner] at home - she came out to our house, a very nice girl - she asked us lots of questions and so on but at the end of all that and filling in an incredibly long and tedious application form, it turned out we weren’t eligible for any support because I had my Navy pension plus a private pension and we have a house and so on. It was something to do with having assets over and above a certain threshold, I seem to recall something about twenty five thousand pounds being the upper threshold, and we just didn’t qualify. So, I do get help for [my partner], she has a personal assistant come in and help her with bathing and dressing and the personal things like that. But I pay for it.”

Participant (carer, female): “But what about the needs of self -funders? Often it feels as if these people are ‘left to get on with it’.”

3.3.2 Financial help
The cost of paying for help with personal care, domestic help and house cleaning and for championship were all raised during the conversations. Guidance on making an
application for financial support or funding would be especially welcome, as this could be confusing. Paying for help with personal care can incur considerable expense for some families.

**Participant (carer, male):** “So, I do get help for [my wife], she has a personal assistant come in and help her with bathing and dressing and the personal things like that.”

**Researcher:** “May I ask if you cover the cost of that yourself?”

**Participant (carer, male):** “Yes, we do. I pay for it. I pay for everything, every aspect of care, well every external or outside bit of care that [my wife] gets, I pay for it. We pay for it, rather.”

**Person with dementia (female):** “These things get jolly expensive.”

People also told stories of having to face some very difficult financial situations and make significant decisions based on the need to provide care for a person with dementia.

**Participant (carer, female):** “I needed to sell our home in order to be able to pay for care for [my husband] through getting somewhere a lot smaller. I was absolutely horrified to find out what it would cost for care. I was too afraid to pay that sort of money. Very quickly I worked out I would be left with very little indeed. At least at that point, with nothing, I would be entitled to get some help from the NHS and social services. Why should we be penalised for having worked all our lives, for having saved and gone without, and brought up our children, to then learn we were not entitled to any help at all? We did go through this...er... financial assessment...to see what help we were entitled to. Because we had sold the house we were told we had the money to pay for [my husband’s] care. I argued that the money was there to enable us to buy a smaller house. We are now having to rent a house. I am trying to keep the money from the sale of the house to one side and not use it. I cannot really work these days because [my husband] requires so much care from me”.

The combination of providing round-the-clock personal care, running a household and managing on a limited or fixed income can be tiring and extremely stressful. Carers spoke of looking for opportunities to secure funded support and the difficulty of finding time to fill in application forms to apply for various benefits. The ways and means to obtain financial support for the level of care they were providing proved to be a mystery for some carers.

**Participant (carer, female):** I can’t get the...whoever it is that gives it...I can’t get a full Attendance Allowance, I only get half an Attendance Allowance I’m struggling to find enough money... I would like to say that I think that the forms you have to fill in this Attendance Allowance just don’t cover Alzheimer’s. They’re more for people who’ve got physical defects. I have to be here twenty four hours a day. I mean I couldn’t leave him for a night. But because he doesn’t take medication, because I don’t always have to get up for him when he wants to go to the loo, and all sorts of things, I can’t get the Attendance Allowance. I can only get half and the first time I applied for the half that was turned down, the Doctor said it wasn’t necessary because there was nothing wrong with him and you know, this was after an Alzheimer’s diagnosis so it was outrageous! It just doesn’t make sense!

3.3.3 Coping with incontinence
Carers raised the problems of managing incontinence in a person with dementia. This subject was raised only by carers of people with moderate or advanced-stage dementia. They felt it was an important subject to raise because the consequences of incontinence
had a significant impact on their day to day lives and that of the person with dementia they were caring for. Also, people said that incontinence wasn’t a topic that had come up in their earlier conversations with health and social care professionals. In particular, some information on how to care for a person who is incontinent and where to get continence aids would be useful.

Participant (carer, female): “It was really that usually when he stirred at night I woke up and took him through the loo but when he was becoming more of a problem through the day and continence becoming more of a problem, he was in an absolute mess there and I thought ‘What am I going to do’?”

In the early stages, carers said that they had not given much thought to this topic as there were already other issues to cope with. Carers described the need for a better understanding of incontinence and of keeping a person with dementia hydrated, encouraging them to drink regularly and wanted clarity on the quantities of fluids they should be encouraging incontinent people to drink. A small number of carers could describe experiences of outings that had to be systematically and rigorously planned to include access to toilets or changing areas or outings and visits been curtailed as a result of incontinence.

Participant (carer, male): “I have to get up with [my wife] in the night or rather I tend to wake [my wife] up several times a night because otherwise you know she might be incontinent and she’ll wet the bed because often I can’t get her to the toilet on time and it all happens so quickly.”

Two carers made reference to a referral made to a specialist continence nurse, one to a clinic at their GP surgery and the other had a home visit made to the person with dementia. Both reported the experience to be highly productive and led to both obtaining a secure supply of incontinence aids that they had previously not known about, as well as useful advice.

3.3.4 Prescription medication

When asked about day to day living with dementia, many participants also made many references to having access to prescription medication for dementia and articulated the expectation that prescribed medicines would be beneficial to the person with dementia.

Participant (carer, female):” It didn’t occur to me to ask about what the future might hold, if they thought that [my husband] might be able to be prescribed some sort of medication that could help or delay the dementia. He had to wait another 7 weeks before he went to the hospital to discuss medication. I can’t remember the name of the drug he was prescribed. He didn’t take it for very long because he had complained of quite severe headaches, which is something that he had never had before, and about feeling dizzy as well. I thought, well noticed anyway, quite a big difference in [my husband] when he was taking the medication, he seemed worse as he seemed ...‘fuzzy’...when trying to think or answer questions and appeared to be stumbling around a lot more.”

Some carers expressed regret in that the diagnosis of dementia had come too late for medication to be prescribed or have any noticeable effect. Helping someone to take their medicines and to what out for side effects is an important aspect of being a carer for someone with dementia.

Participant (person with dementia, male): “She got me a machine that bleeped when my tablets were ready...when I had to take my tablets...the machine would bleep and flash and I take my tablets”.

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Participant (carer, female): “Yes I did but what did you do Dad? You didn’t like the bleeping, so you shut the lid down again and wandered off. He didn’t take his tablets. He didn’t like things bleeping at him he said. It seemed to make him more cross than anything”.

Carers also made reference to the difficulty of encouraging a person with dementia to take their medicine.

Participant (carer, male): “Some days it’s a bit of a fight to get her to take her medicine.”

One or two carers spoke about an increased level of anxiety, general distrust and suspicion of tablets in the person with dementia that they were caring for.

Participant (carer, female): “Helping someone to take their medicines and what to look out for side effects is an important aspect of being a carer for someone with dementia. [My husband] has difficulty sleeping, he is a very active man and takes medication to help him sleep as well as to help keep him calm. He takes Diazepam. Getting him to take his medication is particularly difficult when he is in an aggressive mood. Also swallowing medication is becoming increasingly difficult for him.”

Overall, people were confused about the type and amount of help available to help a person with dementia look after themselves on a day to day basis. The key needs identified were: help with buying and preparing meals, ensuring the person with dementia drinks and eats regularly, ensuring any prescription medication is taken in the correct quantity at the right times of day, ensuring the person has a daily wash or bath and puts on clean clothing appropriate to the temperature/weather, help with going to the toilet and managing incontinence ensuring that electrical and gas appliances are off or on safely, ensuring the building is safe and secure, protecting people from rogue traders and postal/telephone scams, ensuring the person with dementia has access to the money that they need but also that their finances are protected.

Most people seem to want useful information and practical help. The thing about ‘living well with dementia’ or being a ‘dementia friend’ is not enough.

3.3.5 Long term care

Carers raised the topic of facing a number of difficult decisions with regards to ensuring a person with dementia gets the amount of care they need at the more advanced stages of dementia. These decisions related to practical things such as daily, personal care for the person with dementia, the suitability and safety of their living environment, correct use of prescribed medicines and the availability of staff around-the-clock.

Participant (carer, female): “But I thought, oh dear, is this going to happen on a more regular basis, one’s not going to be able to cope and everyone sparked very quickly from ringing social services at Norfolk County Council and the Social Worker came out two days later and she said - our son came - and she spent two hours and took quite a lot of trouble in listening to [my husband] in what he could say and what he could understand and what he couldn’t and she said ‘Well I suggest you and your son decide on two care home that you think are the best’, meanwhile we tried one or two including [a care home] for short period, ‘Choose the two you think are the best and let me know which one you think would be good and I’ll try and arrange respite care that will then probably need to go into permanent care and so we chose the one he’s actually in and um, he was in there for two weeks and then they said ‘Well look, we are having a room coming empty, just after [my husband] was due to come home and we have people wanting to come in there but do you want [your husband] to stay? Because if so you’d better stake a claim now otherwise we don’t know when they’ll be another
one’. So I think we decided it was better to continue because he seemed fairly happy and settled and that’s what happened in fact.”

The majority of carers were busy and fully engaged with everyday life, with few having time to think much about the future. Attending support groups for people with dementia and their carers makes a big contribution to the week’s plans and activities.

**Researcher:** “Do you think about your future together?”

**Participant (carer, male):** “Now not really, take it as it comes, just let it flow along. I realised that to go out and have lunch together, there’s a lot of people at the group who are much more far advanced than we are with dementia and they can’t go out together. You know, like [my wife]...she wouldn’t eat and she wouldn’t sit still, she kept wandering off. So I think we’ve got to live for today because you might not be able to do it tomorrow. I might be out shopping, we go out to Norwich and we do a bit of shopping or I think we’ll go and have some lunch out so we have our lunch out.”

**Person with dementia (female):** “We have our lunch out.”

**Participant:** “And you don’t know when that’s going to stop. I don’t look that far ahead.”

**Person with dementia:** “No.”

**Participant:** “And she always looks forward to next month’s meeting of the Alzheimer’s Society Support Group. We had one Monday and now she can’t wait until the next one comes around.”

**Person with dementia:** “I like it to look forward to, as well. When [my husband] said we were coming here today I was really looking forward to coming. I like coming out. We like doing things together.”

Our research project did not set out to specifically capture information on choosing long term care for people with dementia but it was a topic frequently raised by those taking part in the focus group discussions and warrants further investigation.

**Participant (carer, male):** “I do believe there will come a point when I shall have to get some help at night for [my wife]. I won’t always be able to cope. I like to think I could go on for some years yet. I have no idea how long this dementia thing will last or what the future holds for us. Probably something not very nice I should imagine.”
3.4 Behaviours

A large proportion of the focus group discussions between participants centred around the behaviours of people with dementia and the difficulties faced by carers in recognising and coping with challenging behaviour in their family member with dementia. Changes in the behaviour were very often described as the early signs of dementia. Participants with dementia were less likely to raise or get involved in discussions about their behaviours but the majority verbalised their regret at causing trouble or upset to their loved ones as result of the behaviours they displayed.

Participant (carer, female): “When you know someone really well, like I know [my sister], you know how they are on a day to day basis. You see them a lot and you know what’s normal for them - their little ways and things. Things they might annoyed about, people being rude and forgetting to bring things on time the postman or delivery man not coming at the right time. That sort of stuff. This was different to that. Different to those small everyday things you might get annoyed at. I saw her getting more and more irritated, more and more angry and I did worry about her. I thought she would give herself a heart attack or something. Or a stroke or whatever it is people get when they get mad and their face is purple you know.”

Participant (carer, female): “He was always so precise in everything he did. He was a technician all his life, working on planes - aeroplanes - engines, engineering work. He did all the technical stuff. He’d retired by then of course but he started forgetting things, misplacing things, quite normal at first so I ‘spose I didn’t catch on straightaway. Things started appearing in the wrong place. Like when he put the dog’s collar and lead in the washing machine...he put the dog’s lead in the washing machine. I found some paracetamol tables in the kitchen cupboard next to the Weetabix, you know the breakfast cereals. He put his gardening shoes in the fridge one afternoon!” (Laughing).

The behaviour changes observed in the person with dementia sometimes went unnoticed by other family members for some time. Often the main carer of the person with dementia felt quite alone or even guilty for drawing attention to challenging behaviours or appearing to be critical of the person with dementia. Many expressed a sense of great relief when unusual behaviours were also picked up on by other family members.

Participant (carer, female): “Well my son was like ‘Oh you’re making a fuss about nothing Mum. There’s nothing really wrong’. Until he took his Dad out for the day and they went to look at cars and he got a load of gobbled-gook from his father and he came back and it was like ‘What’s the matter with Dad and what are you doing about it? There’s something terribly wrong here. Why aren’t you sorting it out?’ And when you say ‘I have, I’ve told you its dementia’. ‘Well, what are you going to do, what’s the action to take?’ And they don’t understand that you can’t do anything. You’ve just got to live with it. People don’t understand, you’ve just got to get on with it.”

For some, the presence of other mental illness made the situation more confusing.

Participant (carer, female): “Totally confused. She would ask the same questions over and over about when she was going home and where [her husband] was and what was happening. She started talking more and more about us both when we were children
and growing up and she started talking more about our mum and dad...people in the family we hadn’t seen for years. Or who’d been dead a long time. She was going backwards in her mind. She wasn’t taking care of herself - couldn’t take care of herself. At first me and [my husband] had helped her find a little bungalow to rent but after about - oohh - not even a year, she was getting in a terrible state. She didn’t wash. She wasn’t always eating properly. She didn’t clean the house. [My husband] helped her with the garden and all that and I started doing her shopping for her, we did together - me and [a friend] I mean and then I started taking her washing home once a week because she wasn’t doing it. The house and garden got so untidy. She didn’t empty the bins. There was all sorts of food rotting in the fridge and stuff in the freezer and she would turn the freezer off, in fact she’d turn everything off because she said she was worried about electrical items. She didn’t seem to notice the smell. I took her to see her GP and the GP said she was probably depressed and I asked how would you know if she was depressed when she had dementia? Or if somebody had dementia first how would he know the depression was separate, was an extra thing not just part of the dementia? So she came to live us. That lasted about six - no, eight months.”

Those carers that attended carer support groups or dementia seminars or workshops expressed a higher degree of confidence in coping with dementia-related behaviours. They also spoke of a degree of comfort they achieved through attending support groups and hearing the stories of others in a similar situation to themselves. The memory loss in people with dementia resulted in a range of behaviours and carers described different patterns of behaviours. Memory loss and associated behaviours which led to increased risk and potentially dangerous situations were frequently raised by carers and caused a great deal of concern regarding the welfare and safety of the person with dementia. Some examples of these types of behaviours were described as:

- Hazards in the home environment: switching on electrical or gas appliances, leaving them on unattended which led to a safety or fire hazard
- Driving and transport: changes in driving behaviour, being unable to recall familiar routes, displaying more aggressive driving behaviours, driving erratically or unsafely, loss of confidence in using public transport, finding public transport overwhelming, getting lost
- Walking: Leaving the house, not being able to remember the purpose of the journey, not being able to get home again, crossing roads with heavy traffic
- Vulnerability: Speaking to members of the public or ‘strangers’: accepting offers of help from strangers - some of whom carers felt could not be trusted to put the welfare and safety of the person with dementia first, giving money to strangers for an unknown reason (sometimes several hundred pounds in cash), being the victim of postal, telephone or door-to-door scams and fraudulent traders often resulting in the loss of considerable sums of money

Participant (paid carer, female): “He would answer the phone whenever it was ringing, as he’s a friendly sort of chap and happy to chat to whoever was calling. He purchased a holiday in Florida for £750, giving his bank card details over the phone. He forgot about the holiday completely. A man called pretending to be from the company undertaking the 2011 Census, saying the [my client] had not completed his questionnaire and would need to pay a fine of £1,000 or face going to prison. [My
[client] was very scared and thankfully he didn’t not pay, although he considered the threat to be real. After that time, many other people called and [my client] began to find this quite frightening. He did not know why so many people were calling and why so many of them were asking for payments. [My client] had had a mobile phone contract with TalkTalk mobile phones. He had stop using it when he became uncomfortable using it, he got a bit scared of it really, and had, or so he thought, cancelled the contract. He was still being billed after 2 years, although in all that time he had not used the phone.”

- Personal care: dressing in clothing inappropriate to the temperature and weather conditions, forgetting to wash or bathe, wearing dirty clothing, getting clean and dirty laundry muddled up, becoming incontinent, forgetting to cook, eat and drink, not taking the correct quantity of prescribed medicines at the right time

Participant (carer, male): “…she’s always looked after herself. A very smart lady. And she does still like to choose what’s she’s going to wear but I have to help her because she doesn’t always pay attention to the temperature or the weather and we can end up with some very strange combinations indeed. But always with style!”

- Lifestyle choices: a change in alcohol consumption (both gradual change and dramatic change were described), lighting a cigarette and putting it down in an unsuitable place, setting fire to clothing and soft furnishings, taking up smoking after having quit many years ago, buying large amounts of lottery tickets

There were several discussions about the vulnerability of people with dementia as a result of the predatory nature of some individuals and organisations. Two carers in different focus groups raised the helpfulness of Norfolk County Council’s Trading Standards team when they had made enquiries about scams in the county and how to reduce the likelihood of being a victim of a rogue trader or postal or telephone scam. This appeared to be a different concern to the views expressed generally about public awareness and acceptance of dementia. Both people with dementia and their carers, however, did speak about the behaviour of members of the public for example shop assistants, bank workers, taxi drivers, restaurant waiting staff etc as making a contribution to the wellbeing and safety of the person with dementia and to the peace of mind of the carer.

Carers spoke about the anguish they experienced as a result of the loss of some important or cherished shared memories in the person with dementia. This was spoken of as perhaps one the most upsetting aspect of observing the impact dementia in a loved one. Carers said that they were able to recognise and accept that a person was losing a lot of their memories but it caused them grief and sadness nonetheless. There were other behaviours described by carers which did not in themselves pose a specific risk to the person with dementia but which nonetheless were deemed to be very upsetting for carers. Some examples of these types of behaviours were:

- Irritation and aggression: becoming more irritable with ordinary things which had not caused irritation before, becoming increasingly irritated by questions, being irritated by a family carer attempting to give personal care, being quick to start an argument, expressing anger and occasionally physical anger such as pushing, slapping or hitting another person (usually a carer)
- Denial: the person with dementia not being aware that they are acting differently or that their behaviour is upsetting to the person who is caring for them, not wishing to see a health professional about the problems they are having, a person with dementia telling family members or friends that another family member -
often the main carer - was fabricating stories about them (which often led to family confrontations and arguments, although the carers were ultimately vindicated when a diagnosis of dementia was made).

- Sexual behaviours: displaying ‘untypical’ sexual behaviours, saying untypically ‘sexy’ things, flirting with other people, approaching people in the street to start a conversation

This research project did not set out to explore the behaviours of people with dementia however, it was a subject which comprised a dominant component of the focus group discussion. The key behavioural themes were expressed in terms of safeguarding the welfare and safety of the individual with dementia, the impact of behaviours upon a carer’s mental wellbeing and the ability to care for the person with dementia to their satisfaction, particularly over a long term period.

Carers said they would like more guidance, support and practical help in anticipating, recognising and dealing with behavioural changes in a person with dementia.

3.5 Emergencies

3.5.1 Out of hours services

A section of the focus group discussions was dedicated to exploring what people do when they need help urgently, in an emergency situation.

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<tr>
<th>Participant (male, carer): “God knows what would happen. If something happened to me, well I suppose I’d call my neighbour. She’s a nice lady and she would come straight round. If I needed the doctor or an ambulance she’d do all that for me.”</th>
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Carers in particular had a lot to say about what goes on outside of the hours between 9am and 5pm. Many said that services operate predominantly between these hours and they understood why, however, they had many examples of requiring care or treatment outside of ‘normal working hours’. One person mentioned being able to contact the District Nurses in the evening and two others made reference to Norfolk County Councils out-of-hours services (‘Swifts’ and ‘Night Owls’).

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<th>Participant (carer, male): “There are...say [my wife] fell out of bed and I can’t pick her up on me own, there’s two groups called Swallows and Swifts or something and one works during the day and one works during the night but I’ve been told there’s only about eight persons covering the whole of Norfolk and Suffolk. So you might have to wait twenty, twenty five minutes depending on where they are but then again if it’s so bad you can call out a medic. I found that out through these committees that we go to.”</th>
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The majority made the point that a person with dementia will, at some point, become unaware of the time and that time can lose it’s meaning for them. This can mean the person with dementia desires to get up and get dressed after dark or in the early hours of the morning and to be active. People with dementia may be very restless at night and may not sleep well - as a result neither will the carer. Both become very tired and the combination of a lack of awareness of time and restlessness, confusion and discomfort were cited as the risk factors behind an accident or a fall in the evening or at night.

During these sorts of instances carers said that they were most likely to call upon other members of the family or a friend to help them with the person with dementia. Friends and family appeared to be the first port of call.

3.5.2 Emergencies

<table>
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<th>Researcher: “Do you have anyone who would look after [your wife] at short notice, say, if you were ill?”</th>
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Participant 1 (carer, male): “No, not really, not really. As I say, my neighbour would come over and help us in an emergency but she couldn’t really look after [my wife], not for any length of time because she’s getting on herself and she’s not up to it. I suppose, I don’t know, I haven’t really thought about it much because I’m always busy thinking about this afternoon or today so...I suppose [my wife] would have to go into a home.”

Participant 2 (carer, male): “Who would arrange that though, if you were ill? If it wasn’t you, who would do that?”

Participant 1 (carer, male): “Well I guess if I was ill I’d have to wait until perhaps the carers showed up morning or evening. [My wife] wouldn’t be able to help me. [My wife] probably wouldn’t notice anything was up not that she’s not that she would do it deliberately but she just wouldn’t notice. Probably wonder when her tea will be coming or something like that.”

Carers were generally unclear – and even confused – about the types of services available to someone with dementia who needs help urgently. A small mentioned that personal or community alarm services had alerted them to the emergency and that this service was very helpful. The types of services that carers were clear about or had called upon during unexpected or emergency situations included:

- Dialling 999 for an ambulance for a person who has fallen and injured themselves e.g. suspected broken bones, bleeding cuts to the head
- Calling Norfolk County Council’s ‘Swifts’ or ‘Night Owl’ service for assistance with a person who has fallen out of bed or fallen over, help with managing incontinence
- Taking the person with dementia to an Accident and Emergency Department

People spoke about the length of time they had spent waiting for an ambulance which was often longer than they would wish but none said unacceptably delayed or a delay resulting in a bad outcome for the person with dementia. Those that had called an ambulance spoke highly of the paramedics and the reassurance they had offered to both the person with dementia and the carer (and other family members now present at the scene). A very small number of carers living in rural areas spoke about First Responders arriving at the home of the person with dementia prior to the ambulance crew arriving. This support was received very well and provided some comfort and reassurance whilst waiting for a paramedic to arrive.

A small numbers of carers had taken a person with dementia to an Accident and Emergency Department at the nearest hospital. They described this action as something they considered to be in the best interest of the person with dementia and the desire to seek help and treatment. All spoke of their experience of the Accident and Emergency Department with some misgivings; these came from; the busy atmosphere of the department, the level of noise and disturbance, “the brusqueness of the staff...at two in the morning”, the effect of the surroundings on the person with dementia in that they become very confused and frightened. One carer said “A&E is no place for someone with dementia”.

Notably, no-one mentioned telephoning the person’s GP or telephoning their GP surgery out of hours.

Around a quarter of the carers made a reference to holding a carer’s emergency card, whereby their details were held on database managed by Norfolk County Council and the pertinent details about the person with dementia. In the event of an emergency, such as the carer falling ill or being involved in an accident, a telephone number could be called.
and some emergency arrangements for the cared-for person would be organised on a temporary basis.

**Participant (carer, female):** Yes it’s a yellow card...and you have one of those and you have one on your car keys, so if anything ever happens to me...apparently they ring the number and Cross Roads have also got that number so if anything happens to me or if there’s an emergency they will come and sort you out and it’s anything from two to seventy-two hours and they’ll come and look after them.

Overall, there appeared to be uncertainty about the types of services that someone with dementia or their carer could call upon in an emergency situation, particularly those happening ‘out-of-hours’. When the subject of the carer’s emergency card was raised, not all those present had hear of it.

**Researcher:** So, how did you find out about the Yellow Card? By accident, or did somebody...

**Participant (carer, female):** Yes, how did I find out? I think the Social Worker said ‘Have you got a scheme in place?’ and I hadn’t heard about it and she, it took an awful long time...it took something like nine months to get that and I’m a double carer because I look after [a member of the family] as well, it was pretty urgent, but it took nine months. But now I’ve got the peace of mind so if I’m out and about — if I trip over and bang my head on the pavement that somebody will soon find the card and they would send out somebody immediately. Or if I didn’t get back the lady would try to ring my mobile...”

Most people appeared to rely on family and friends to give immediate support or telephoned 999 for an ambulance if a fall or injury had occurred. Experiences of the ambulance crew were largely satisfactory and offered reassurance. Experiences of Accident and Emergency Departments were largely unsatisfactory and deemed frightening to the person with dementia.

There were few references to telephone helplines but there were specific references made by people with dementia and carers having made ‘urgent’ telephone calls to:

- The Samaritans
- Alzheimer’s UK
- District nursing teams
- West Norfolk Carers
- Care Agencies (when carers had not arrived at the expected time)

Participants did not mention the Out of Hours service or NHS 111. Telephone helpline for information and advice and for assistance with urgent needs or problems were discussed in terms of being highly valuable if they were open outside of normal working hours and maintained in the long term.
3.6 Support services for carers

Participant (carer, female): “It’s just not possible for people to think that you can neatly separate the carer and the person with dementia that they are caring for into different compartments or services...or help or whatever - what happens to one affects the quality of life of the other - our lives are completely and constantly woven together”.

Participant (carer, female): “As a carer you bear a heavy burden not knowing if you are making the right decisions for the person you care for because gradually they lose the ability to tell you”

Participant (carer, female): “I realised the other day that I am now the only person who can still understand what my husband is trying to say when he is struggling with the few words he has left ... No one else can do this now, not even [our daughter]. Only me. I am quite, quite alone in this. It makes me feel unique but it is also the most incredible burden. A blessing and a burden”.

A minority of carers were looking to the future and making reference to media reporting about the ageing population and the anticipation of rising numbers of people with dementia. With this in view, some carers suggested that online forums would be the most useful thing to develop in the near future.

Participant (carer, female): “Something has occurred to me...I don’t know if there are forums for us, or forums or whatever you call it, on the website, on the web, that people would know about, where people can have a dementia chat with somebody else. Do you know what I mean? Where they can, if they want to go on and chat to somebody and go ‘I’ve had a really rotten day’. But of course there’s all sorts of security issues and worries about doing things like that. I do wonder whether something like that might be, particularly, particularly, as this isn’t going to go away. Erm, it’s going to affect people, people like me, later on, hopefully not me but why not me, in a sense, people who actually, their families will be totally digital, totally online so their first thought will probably be what I find on there to tell me about it, what can I find for help so I think getting as much as possible online and setting up networks and things, particularly where people for various reasons can’t get people to day centres and different things. The information is there, people can use it or not, and people can do a kind of chat thing, where they just kind of vent their frustrations and then carry on with their lives.”

All carers said there was a very real need fo places to go where they could be with others in the same situation, get information and relax a little. This was viewed as separate to designated support for carers, on a more individual basis. Some carers said that they were quite alone in caring for the person with dementia and just knowing that someone was looking out for them would give them peace of mind. This was viewed as important especially for those living in rural areas where there might be fewer amenities available close by.

Participant (carer, female): The other thing would be and I don’t know if this is doable, but obviously people with dementia have a GP practice and I’m thinking if there could be somebody who works a bit like the district or community nurses, but not a community nurse, not necessarily medically trained, someone who supported a group of practices, who knows and who could get a picture of all the people, you know, just how
many families were affected erm in the area, could monitor them and could act as a liaison and could make occasional phone contact or email contact to say ‘How you doing? I know you’re there, you haven’t dropped off the end of the world. We’re having a so-and-so day in your area would you like to bring mum along it’s just an informal coffee morning type thing’. The occasional thing rather than a commitment thing that might actually be quite helpful. Someone who was in contact, could feed back, could be an intermediary, could contact families and just do a little bit of support like that, maybe just an email or phone call occasionally. But at the same time, could feed data back up through the chain, so they could see groupings for example ‘there’s quite a few families in just this little area of villages here, I wonder if they’d like to put in touch with other, so they can arrange, you know how people arrange their own toddler mornings because they know each other they could arrange their own stuff. That is, if there was some money to fund it, that would I think, could be very valuable.”

Some carers said that they particularly enjoyed getting out of the house to a specific location or ‘hub’ where they could get information.

Participant (care, male): “Well you can go to carer’s meetings, they’ve got leaflets, they sit there and talk and you can learn things. Like I say I picked up a leaflet about respite care.”
Researcher: “So going to groups is a good way to get information?”
Participant: “Definitely. It stops you feeling like you’re…”
Person with dementia (female): “You’re alone…”
Participant: “Like you’re the only person in the world who’s experiencing this…”
Person with dementia: “You feel like that all the time.”

The sorts of information that carers needed was not just about services but also about where to go to get practical and financial help.

Participant (carer, male): “There is a real need for carers to have a place or space for information sharing, learning about what’s on for people with dementia and their carers, to get information about important issues such as financial help, finding and securing good respite care or domiciliary care or companionship care.”

A small number of carer’s talked about the utility of telephone helplines, saying that they had had some previous experience of them and that they could be very useful particularly when facing an emergency that didn’t require a 999 call or ambulance. There was some discussion about a local telephone helpline provided by a charity but that this helpline was not available outside the hours of 9am-5pm and that they thought it had been effected (i.e. shut down) by funding cuts.

3.6.1. Respite care

Participant (carer, female): “So day to day, a hard thing is finding time for yourselves…does there come a point where day to day things start to get too difficult and you’d like more help just to be able to go to the shops or take your husband shopping and more personal care like washing…you bet there does.”

Carers voiced a very strong need for respite care. A break from caring responsibilities for even an hour or half day was something that was highly prized by carers. There was a general agreement that respite care was very expensive - for many prohibitively expensive.
Respite care was discussed mostly in terms of carers needing to have a rest from intensive caring responsibilities and for reasons ranging from; improving the general
health and wellbeing of the person with dementia; improving and maintaining the carer’s general health and wellbeing; recovering from periods of illness or stress; following a family bereavement or taking a holiday away with family or friends. Carers said that they did not know how to access respite care or who to approach to request it.

Participant (carer, female): “The only time I’ve ever heard it mentioned was a couple of weeks ago when I’d had two weeks on the trot where I’d arranged to go out and to have somebody sit with my husband and he threw a wobble and he said he wasn’t having anybody in the house and so I didn’t get out and I did ring the Alzheimer’s people and they said ‘Well in perhaps three to six months you ought to think about it’. But otherwise, nobody’s mentioned it.”

Some had experiences of arranging respite care privately which they funded themselves. Some reported that even a short stay of two weeks can cost as much as £1,500 which most carers felt was outrageously expensive and completely unaffordable. People described a real need for respite care, the type that is delivered in the person’s own home, rather than residential respite care. People with dementia are too disorientated by leaving their home, even for a short period, to go away for respite care. Carers desperately need these types of breaks and home based respite care would help considerably. Carers can usually obtain short term domiciliary help from social services but this is usually restricted to visiting no more than 4 times a day which, for some people with dementia, is just not enough.

Participant (carer, female): “You know if you need to go out or even if you don’t need to but you want, you actually want to go out for a few minutes on your own for a bit, but it’s very expensive”
Participant (carer, female): “It’s very expensive”
Participant (carer, female): “It’s fourteen pounds an hour to go out”

Support services were described by participants as integral to the ability to provide consistent and good care for loved ones with dementia. Support services provide timely and accurate information, enable carers to meet and discuss problems with others in a similar situation and provide an enjoyable and social activity along with an opportunity to have a short break from caring. Carers described a number of recent changes to support services and that the funding for local carers support groups had been reduced or stopped completely. This had had an impact on the number of local carers support groups and the frequency of the groups meetings.
3.7 Quality of services
3.7.1 Social care services
For the majority of carers and people with dementia, the length of time they had to wait for a social worker’s assessment was felt to be too long. The minimum wait was reported to be 6 weeks and some reported having waited three months. Some people spoke about waiting for a social worker to visit and carry out an assessment after a person with dementia has been discharged from hospital, again with a minimum waiting time of 6 weeks.

For those that had experienced a social worker’s assessment at home, the quality of the assessment was reported to be very thorough and carer’s in particular were pleased with the home assessment, some saying it was “excellent”, “very patient and thorough” and “very good indeed”.

A small number of people with dementia and their carers had been assigned a named social worker which they said they gave them peace of mind and made problem-solving a lot easier.

Participant (person with dementia, male): “My social workers is special because she has so many contacts with all the other...local services and will work hard to put things in order as fast as possible”.

A small number of people with dementia and some of their carers, were receiving domiciliary care (or home care). Approximately half were funding this service themselves using independent or commercial care agencies and the other half receiving domiciliary care funded by Norfolk County Council’s Adult Social Services through care agencies, several mentioned Care UK. The amount of care offered or received appear to vary considerably. Many carers said that the amount of care the person with dementia received was not adequate to meet their needs. Some received up to four visits a day whilst others were visited twice or three times a week.

Participant (carer, male): “Well as I said I’m really lucky in that [my wife] does have help although we don’t have carers four times like [other participants]. The carer comes in to help [my wife] twice a day with getting up and getting dressed and getting undressed and getting in bed, sometimes having a wash that sort of thing. I sort out all her medicines and I do the cooking though I am awful I have to say, I try but you know I never really learnt because [my wife] loved to cook, well she still does and she will help me in the kitchen but I have to be in charge and tell her what to do.”

The majority of people with experience of domiciliary care services were very complimentary about the attitude and personalities of the carers themselves, with many commenting on their kindness and caring attitude. Less were convinced of the carer’s ability to deal with challenging behaviours and reported occasions where the carer would leave only a few minutes after having arrived as the person with dementia would refuse to let them into the house, had forgotten the carer was coming or indeed that they received home care at all.

It was not unusual for people using domiciliary care services to find that the carers sent by the agency would frequently change and be replaced by another carer who would either appear to be inadequately trained for the role in caring for someone with dementia or be unknown to the person with dementia who would be anxious as a result.

Participant (paid carer, female): “I was disgusted...in the beginning [the family carer] got no help at all. Social care arranged for a carer to come in twice a day at first, which was OK I suppose but the carer was so young, well, she seemed very young to me...”
anyway and she wasn’t sure what to do about the tablets. The carer gave [my client’s] tablets to [his wife]!

Inconsistency of carers was a key area of concern for family carers and for people with dementia. Carers reported that they would need to explain the preferences of the person with dementia many times over which they found stressful. This also meant that carers’ felt that they often needed to be present when an agency carer arrived to ensure that they stayed and that the person with dementia was happy to receive care. For some, this meant that the precious opportunity for a 15 minute interval or rest did not actually take place.

Some carers had personal experience of care services or had worked in care services themselves, these individuals had a sophisticated understanding of the impact of good quality home care and also the effects of poor quality home care, particularly in terms of training for home care staff.

Participant (carer, female): “I didn’t always feel satisfied with the calibre of the home carers. I know that home carers do not get paid very well, have long distances to travel in between client visits and receive very little training. I felt that home carers need more training about dementia awareness. It wasn’t really their fault. You can’t blame them. But the standard of home care could be very much improved. For example, the carers really needed to look in my father’s fridge every day to keep an eye on the best before dates and eat-by dates on the food items. I would often visit to find spoiled and rotting food items in his fridge and occasionally find he had eaten spoiled or rotten food items because they had not been removed and he could no longer realise that these could be at best unpleasant and at worst, harmful. I was absolutely heart broken. I then decided to buy ready meals for him as a means for him to have a hot meal easily twice a day. Sadly though, and I wasn’t around, his friends and neighbours did not like the concept of ready meals and encouraged my father not to eat them. This meant he would not eat, become hungry, thirsty, confused and subsequently become under the weather or even fall as a result of dizziness.”

A minority of participants spoke about personal budgets and said that it was difficult to obtain information about how to get a personal budget and they had not known who to ask. All said that a social worker had initiated a conversation about a personal budget during either a visit or a review meeting with the person with dementia and the carer. One carer reported that their loved one received a personal budget but did not have a named social worker. If there are issues with the personal budget there isn’t a named individual for that person to get in touch with and it can be very confusing if a person is passed around between departments and teams when they are looking for a simple answer.

3.7.2 Health care services
When talking about health services, participants made frequent references to the GP, to hospitals including the Julian Hospital, to out-patient departments, accident and emergency departments and fewer references to practice nurses, district nurses, occupational therapists and specialist dementia practitioners.

One of the participants had encountered a specialist practitioner in dementia, discovered that this professional had undergone specialist training in dementia and was very knowledgeable and helpful.
Participant (carer, female): “I think that every surgery should have a dementia nurse that is really specialised and knows what to look for at least. I mean we seem to be quite fortunate at [our GP surgery] in that we do have a nurse...that we can go and talk to if need be but this is a new thing...very new...so I think it’s important - yes - that wants chasing up”.

People with dementia and their carers discussed the dilemma of not always knowing which service to contact. In some conversations it was apparent that people do not always understand the different areas of responsibility and service provision or understand what is classified as a health service or a social care service. Some services for people with dementia are offered by the district or borough councils but again, not everyone knows about this or understands why it should be different.

Participant (carer, female) “If you are living alone with dementia it is a different story. Mum still lives alone. She has just got a personal alarm system. It took an extraordinary amount of hassle just to get the alarm. First of all I called NHS 111 asking for help with this particular problem. The NHS 111 person got quite cross and asked why I was ringing the helpline. Eventually I called adult social services and spoke to someone who advised on the best place to go to get the right forms to fill in. I was told to contact her local district council, as mum lived in a council property, well it’s. Once I spoke to the right person, it did not take long at all to get the alarm fitted, a few days”.

Carers in particular made reference to other medical conditions that a person with dementia may have and that having dementia will have an impact upon how that person can manage and cope with existing or newly diagnosed conditions. Diabetes, depression, heart failure, chronic obstructive airways disease and asthma were specifically mentioned. People with dementia will likely need additional help with managing these conditions and especially with taking prescribed medicines in the correct dose and so on.

Participant (carer, male): “…my wife needs insulin injections four times a day but the District Nurse can only come once a day to give her the insulin. How is that meant to help? What is meant to happen on the other three occasions? Not all carers can administer insulin and administering insulin to someone with dementia can be hugely difficult if the person does not want the injection...or has lost a lot of weight, has very little muscle on them, even on their stomach area.”

3.7.3 Hospital stays and discharge home

People talked about hospital admissions mostly in terms of an emergency or unplanned admission to hospital and in terms of mental health assessment and out-patients appointments. Many carers described a hospital stay for someone with dementia happening as a result of a prolonged deterioration in that person’s health and wellbeing - something they may have observed over a period of several months.

Participant (carer, male): “...[my wife] had had a fall and cut herself quite badly. She had needed an ambulance to take her to hospital as it was suspected that she had also had a head injury of some nature. She found the hospital stay terribly distressing from beginning to end. She constantly asked where she was, when she was going home and so on. She could not keep still in the bed or even sit still and was constantly getting up and moving around. She had a fall in hospital again which was upsetting because I’d thought ‘at least in hospital, she’ll be safe, she’ll get the right care...someone will be around twenty-four seven to keep an eye on her’. She had quite a deep laceration on her thigh from falling at home and whilst in hospital, this developed an infection which needed to treated with antibiotics. The hospital staff found it difficult to encourage
her to swallow her antibiotics and I found it near on impossible to get her to take her antibiotics. She needed to go back to her surgery but as a carer it is very difficult to get to speak to any health professionals on her behalf.”

Some carers spoke about an admission to hospital following an accident or injury to the person with dementia which they attributed to dementia and that person no longer being able to look after themselves independently, or safely. Some specific examples of hospital admissions were given following a fall at home; a fall outside; an untreated hernia; noticeable dehydration and malnutrition and a mini-stroke. Not all carers experienced a sense of relief when the person with dementia was admitted to hospital. They gave various reasons for this unease. The main reason was knowing that their loved one would be upset and confused for the duration of their hospital stay. Another was that they were very concerned about the quality of care and attention that their loved one would receive from nursing staff; some talked about concerns about the person with dementia being offered drinks regularly, not being helped with their meals and not being helped to use the bathroom or toilets. Three carers gave specific examples of visiting their loved one on a hospital ward to find them either wearing soiled clothes or lying in soiled, unchanged bed linen. Carers had not spoken out at the time of the hospital stay as they had feared that by doing so they would compromise the care given to the person with dementia.

There appeared to be a strong association between a person with dementia spending a period of time in hospital and the carer noticing in their loved ones what they described as a ‘step down’ in health, wellbeing or functioning.

Often the hospital stay signalled a deterioration for the person with dementia and triggered a subsequent stepping up of care or intervention upon discharge from hospital. A small number of carers recognised that discharge from hospital was a period when additional support and help from services was very important. Other carers spoke of very little contact from hospital staff prior to the person with dementia being discharged and this led to misunderstandings and further problems.

Participant (carer, female): “And we walked in and mum was sat there with her bag on her lap and they were discharging her. And we were like ‘Oh right’ and in the middle of that she’d been told off because she hadn’t got out of bed and the nurse said to me that my mum had been - there was no reason for my mum to have stayed in bed all that time and it wasn’t good for her and I was like ‘Well, nobody told us and she hasn’t got any clothes with her’ and my mum probably thought ‘I’m in hospital I’m supposed to stay in bed’ and so my mum was quite upset um and she was wearing awful...she was wearing the clothes she’d been admitted in which were wrong and she had her bag on her lap so we were like ‘Well how could she go home?’ because it was obvious she was physically ill and we were like ‘What do we do?’. And they said ‘Well she’s obviously alright isn’t she because you’re living with her’ and we were like ‘Well why do you think that?’...because of course we weren’t. I was working here and my brother lives [in another country]!”

3.7.4 Specialist dementia services
Around a third of participants could describe an assessment or service provided by the Norfolk & Suffolk Mental Health Trust, such as attending a memory clinic or having a memory assessment undertaken in their own homes. A minority of participants described
experiences of specialist dementia services, two carers spoke about Admiral Nurses and two spoke about the Dementia Intensive Support Team.

**Participant (carer, female):** “My Dad had some structured rehabilitation at the community hospital, a few weeks I think. When discharged home, my Dad’s home support package was increased. Home carers called to see him four times a day, only for about fifteen minutes or so, not a great deal and he was also discharged into the care of the Dementia Intensive Support Team. Between them, there was responsibility for his functional care and for his dementia care. I continued to visit my Dad regularly. Luckily, some friends and neighbours rallied around him when he came out, so he had someone close by looking out for him.”

Experiences were reported to be largely positive and participants described a great deal of faith and trust in the professionals themselves. However, experience of these specialist service did not in any way appear to be the norm, however, we recognise the number of participants in our focus groups constitutes a small sample size. Many of the participants we spoke to had very limited experience of specialist services, did not know what was available or how to request it.

### 3.7.5 Voluntary and community services

A number of specific examples of the services provided by voluntary and community organisations which are highly valued by people with dementia and their carers were:

- Support groups for people with dementia and their family members and carers e.g. Pabulum Cafes, Age UK Dementia Cafes, Alzheimer’s UK Carer’s Support Groups
- Carers’ Support Groups associated with West Norfolk Carers
- Age UK home assistance service e.g. a home visit by a Support Worker in the winter months to do a home energy efficiency, clearing a loft so that insulation could be installed to improve the energy efficiency of the home of a person with dementia
- Age UK information, advice and advocacy services e.g. on personal alarms
- Information and practical help from Crossroads Care
- Home visit following a hospital discharge by the British Red Cross, to an elderly person living alone (at the time when a diagnosis of dementia had not yet been made)

### 3.7.6 Independent care providers

Five focus group participants with dementia were living at home alone with regular support from family members and additional care provided through agency carers. It seemed to be the case that they had been involved in the discussions and choosing of home care, a close family member or carer had arranged the care on their behalf.

Home Instead was reported by carers to be a good provider of paid-for care. Some carers had attended a free dementia workshop hosted by Home Instead which explains a lot about dementia and the sorts of care on offer. Carers said that they considered the care more appropriate for people with dementia who have companionship needs as opposed to functional care needs (although they recognised many people will need both). The companionship might include visiting as a ‘friend’, taking someone to the library, cooking a meal with someone or helping them to choose clothing appropriate to the temperature and weather conditions.
Carers spoke about the kinds of support services they had arranged for the person with dementia and voiced concerns about the quality of care and the value for money provided by agency’s supplying home carers.

**Participant (carer, male):** “It can be expensive and it’s very difficult to get good quality help. We have had one or two awful experiences with a couple of agencies, sending people at the wrong time or, just simply sending the wrong sort of person because not everybody is predisposed to caring or nursing others. I do sometimes worry about the level of training some of these people have because so many of them seem so very young and I don’t quite see how they can have gained all the right experience”.

Without an understanding of how people with dementia might behave when faced with a stranger, carers felt that home carers were at a disadvantage and at times unable to deliver the care they were meant to.

**Participant (carer, female):** “...these pop-in carers, I’ve heard of so many people having this experience - I phoned them up and I set it up several times, not all the time, but several times people knocked on the door and she said - they would say ‘I’ve come to help you with your lunch’ instead of saying ‘Hello..., your daughter has sent me, can I just pop in for a minute’ and being tactful about it. My mum’s reaction was ‘I don’t need any help with my lunch’ and she’d send them away again. And then we would see it in a log, somewhere, written ‘Patient said they did not need help’ and you’re thinking? And then several times in the log it said ‘Came to give [the client] her lunch and she said she’d already eaten so we just had a cup of tea’ and I was sitting there thinking ‘I don’t believe it’.”
4. Summary

4.1 Appraisal of methods

The scope of the discussions were guided by some the gaps to be filled in the Dementia Health Needs Assessment. There were subjects raised by participants which were not included in the framework, for example, dealing with behaviours in people with dementia or information and access to services. These two subjects are strong themes present in the focus group discussions arising from the analysis. They were important to participants, they cannot be ignored.

Exploratory questions on end of life care were not included in the discussion guide, neither was there and exploration of experiences of seeking longer term care for the person with dementia.

This project was undertaken by an in-house team as this was deemed the most appropriate approach according to the resources allocated to the project. Expenditure of funds (£500 in total out of a £5,000 allocated by the Healthwatch Norfolk Board) was limited to the cost of booking venues for focus groups and for reimbursing the travelling expenses of participants. Staff time in undertaking this project end-to-end is estimated to be 35 full working days between late January and the end of June 2014.

4.2 Limitations

Healthwatch Norfolk recognises that these findings have some limitations:

- Participants in the focus groups were self-selecting - however, we expected this as a consequence of our purposive sampling approach (so we are confident in saying our sampling approach was successful) and we did indeed recruit and interview people who had experienced challenges and barriers in accessing dementia services, information, help and support.

- The content of the discussions are not an objective exploration of dementia services, however, this was not the intention of the research project. We suggest that any exploration of experiences of health and social care services will always be subjective from the perspective of the person using the service (or their family members and carers).

There are challenges in engaging people with dementia meaningfully in semi-structured, conversations. These challenges are well documented in the literature and we attempted to incorporate the learning from the literature in: understanding that dementia affects different people in different ways and that some people with dementia would be able to contribute more to a group discussion than others; keeping the number of questions to a minimum (people with dementia are sometimes very uncomfortable with lots of questions and happier with statements); being flexible about the location and venue of the focus group so that the person with dementia could be in familiar surroundings and be with familiar people; keeping the number of focus group participants fairly small e.g. 3 to a maximum of 6 people; and being very flexible about the structure of the focus group allowing frequent pauses or breaks in the proceedings.

The participant validation process employed in our methodology was extremely useful and we have learnt that this exercise needs to be repeated in our future work. Participants also gave useful feedback on how they viewed their engagement in this research project and how this could be improved in future. On aspect raised was the emotive nature of the focus groups. Whilst carers expressed their willingness to be involved in projects such as this, they also recognised that for some people, speaking about poor service experiences could be upsetting. It was suggested that Healthwatch Norfolk could ensure that helpline telephone numbers were made available to
participants who wished to speak to someone on a personal basis or to find out more information about counselling.

4.3 Dominant themes arising from analysis of the discussions

4.3.1 Diagnosis

The diagnosis is the key to the door leading to referrals and access to services and support. Most participants said that they wanted to know about a diagnosis of dementia in order to be fully prepared and aware. A delayed diagnosis can result in a decline in the health and wellbeing of the person with dementia, a great deal of stress for family members and loved ones, can cause tension and arguments between the person with dementia and close relatives and creates the potential for a missed opportunity for prescription medication to be effective at the right stage of treatment. Carers in particular expressed the view that a person’s relationship with their GP is key to getting a timely diagnosis.

4.3.2 Access to services

The experiences of accessing services varied greatly among participants, in both participants with dementia and in carers. Participants gave many and various reasons for this and were able to compare experiences in their different localities. It became apparent in some of the discussions that obtaining good quality information about services is not easy for many people and that not all dementia services are available on equitable basis across the county. Norfolk has five Clinical Commissioning Groups and this sort of patient experience may suggest that services are commissioned differently in the five different localities. Healthwatch Norfolk volunteers have been telling us that access to dementia services across Norfolk is not equitable and the findings of this research based on the experiences of the participants would validate that view.

When asked the question “how could the quality of service improved” many people responded that by making information about the kinds of services available to people - both funded and self-funded - would be the single most helpful thing services could do.

4.3.3 Day to day care

Amongst those interviewed, it was predominantly family (unpaid) carers who were providing the bulk of daily care to people with dementia. Personal care was provided by paid carers, including domiciliary (home) carers funded by social services as well as that which was funded privately by individuals. Carers expressed the real need for more practical help with personal care and with activities such as shopping, cooking, washing and dressing as well gardening, housework and social activities. For those receiving home care, all were complimentary on the attitudes of home carers and recognised the challenges facing them regarding low pay and a lot of travel in rural areas. Some carers expressed reservations as to the quality of dementia training provided to home carers. Information about the funding of personal care was not clear to most people. Carers spoke of facing financial hardship as a result of their caring responsibilities and the difficulties in getting financial help. Access to financial help was successful for a minority who had received some support from a social worker or charity worker in making an application. Ensuring that the person with dementia was taking prescription medicines correctly was also a challenge. A number of carers also raised the problem of incontinence and the need for practical help; those that had received specialist input had benefited greatly from it.

Around a third of people with dementia and some of their carers, were receiving domiciliary care (or home care). Approximately half were funding this service themselves using independent or commercial care agencies and the other half receiving domiciliary care funded by Norfolk County Council’s Adult Social Services through care
agencies, several mentioned Care UK. The amount of care offered or received appear to vary considerably. Many carers said that the amount of care the person with dementia received was not adequate to meet their needs. Some received up to four visits a day whilst others were visited twice or three times a week. Overall, people were confused about the type and amount of help available to help a person with dementia look after themselves on a day to day basis. Most people wanted useful information and practical help. The thing about ‘living well with dementia’ or being a ‘dementia friend’ is not enough.

Healthwatch Norfolk will be taking a keen interest in the implementation of the Care Act by Norfolk County Council from April 2014. The Care Act will mean that entitlement to assessment changes to any adult with care and support needs and any carers caring for any adult with care and support needs. There will then be a new national eligibility criteria applied to determine eligibility for care and support. It is not known at this stage how this may look or what positive impact this may have on people with dementia and carers of people with dementia in Norfolk but the implementation of the Care Act gives people a new entitlement to assessment and widens the criteria for carers to receive an assessment.

4.3.4 Behaviours
This research project did not set out to explore the behaviours of people with dementia however, it was a subject which comprised a dominant component of the focus group discussion. The key behavioural themes were expressed in terms of safeguarding the welfare and safety of the individual with dementia and in terms of the impact of behaviours upon carer’s mental wellbeing and ability to care for the person with dementia to their satisfaction, particularly over a long term period.

Carers would like more guidance, support and practical help in anticipating, recognising and dealing with behavioural changes in a person with dementia. The behaviour of members of the public is also key to ensuring the safety and wellbeing of people with dementia. Many carers said how important it was for members of the public to at least be aware of dementia and the way in which it may affect a person. Only three people made a specific reference to ‘Dementia Friends’ initiative but the objectives of that initiative were echoed in the conversations that took place and appeared to be well understood and valued by people with dementia and their carers.

4.3.5 Emergencies
Overall, there appeared to be uncertainty about the types of services that someone with dementia or their carer could call upon in an emergency situation, particularly those happening ‘out-of-hours’. Most people appeared to rely on family and friends to give immediate support or telephoned 999 for an ambulance if a fall or injury had occurred. Notably, no-one mentioned telephoning the person’s GP or telephoning the GP surgery out of hours. Experiences of the ambulance crew were largely satisfactory and offered reassurance. Experiences of Accident and Emergency Departments were largely unsatisfactory and deemed frightening to the person with dementia.

These discussions suggest there is a gap in service provision for emergency care and support for people with dementia and their carers during the evenings, weekends and at night time. We would like the Dementia Health Needs Assessment to fully consider the scale and level of out of hours support available to people with dementia and their carers.

4.3.6 Support services for carers
The majority of carers spoke of the real need for carers to have a place or space to go to for information, advice and support. This was best provided by those with expert
knowledge but also influenced by other carers of people with dementia. Healthwatch Norfolk notes that Norfolk County Council has reduced the funding for carer’s support services and the impact of this reduction in service provision urgently needs a review. We will be ensuring the needs of carers of people with dementia are included in our ongoing work on services for unpaid carers in Norfolk. We would like the Dementia Health Needs Assessment to fully consider the scale and level of support for carers of people with dementia in Norfolk: there are thousands of them and they are providing a vital source of care for people with dementia in Norfolk.

4.3.7 Quality of services

The health service most frequently used by both the person with dementia and their carer was the GP surgery. The experience of GP services varied greatly between the project’s participants. For those that had a good relationship with the GP, the process of getting a diagnosis of dementia ran relatively smoothly. Having a good GP was also discussed in terms of having good access to appropriate treatment and care as well as the carer receiving support. A person’s GP was seen as being particularly influential around the time of diagnosis, providing a key opportunity for information sharing on what to expect in the future.

A minority of participants described experiences of specialist dementia services, two carers spoke about Admiral Nurses and two spoke about the Dementia Intensive Support Team. Experiences were reported to be largely positive and participants described a great deal of faith and trust in the professionals themselves. Experience of these specialist service did not in any way appear to be the norm, however, we recognise the number of participants in our focus groups constitutes a small sample size. Many of the participants we spoke to had very limited experience of specialist services, did not know what was available or how to request it.

The majority of people with experience of domiciliary care services were very complimentary about the attitude and personalities of the carers themselves, with many commenting on their kindness and caring attitude. Less were convinced of the carer’s ability to deal with challenging behaviours.

Around a third of participants had had contact with social services and several had experienced a social workers assessment. Some people expressed dissatisfaction with the time spent waiting for the assessment, from six weeks to almost four months, however all were satisfied with the quality of assessment and the service they received.

Some of the most positive reports of service quality were for carer support services offered by community and voluntary sector organisations. Carer’s support services were seen as an absolute lifeline for carers, a source of information about services and a means to spend time with others.

4.4 Dementia related care in Norfolk’s care homes

Our research project did not set out to specifically capture information on choosing long term - residential - care for people with dementia but it was a topic frequently raised by those taking part in the focus group discussion. Since April 2013 we have received number of comments from the public on the quality of dementia care in some care homes in Norfolk. Our statutory powers extend to beds and care provided in care homes (including private care establishments) which are funded by social services (Norfolk County Council) and the NHS (for example, NHS Continuing Health Care). In light of these
comments and the findings of this research, this topic warrants further investigation through use of our ability to Enter and View in-patient settings.

\section*{4.5 Next steps}
Our findings suggest the quality of specialist dementia services is largely good but experiences of dementia-related health and social care services are mixed. It is information, accessibility and the volume and scale (equity) of provision across all localities in Norfolk where there are big gaps and that is key, as is the relationship with the GP. The relationship with the GP can mean the difference between getting a diagnosis of dementia or not, and accessing appropriate services or not. Many people also viewed the GP as being highly influential in providing good quality and accurate information at the point of diagnosis, which would empower both the person with dementia and their carer and reduce the time wasted in searching for information about services and support. The messages to the public generally about what kinds of care is funded and what is not funded appears to be mixed and confusing.

The Dementia Friends initiative was viewed positively and many participants spoke about the need for raising awareness of dementia in the public in general. Nonetheless, people with dementia and their carers want real practical help, not just Dementia Friends.

The findings of this research project have enabled us to arrive at a number of recommendations and we will be reporting on the progress with these over the coming year.
### 5. Recommendations

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<tr>
<th>Evidence</th>
<th>Recommendation</th>
<th>For</th>
<th>Follow-up action</th>
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<tr>
<td>1. Access to information and advice When asked the question “how could the quality of service improved” many people responded that making information about the kinds of services available to people, both funded and self-funded, would be the single most helpful thing services could do.</td>
<td>Work with partners and service users to scope existing information on dementia services, review and collate as appropriate for our Information &amp; Signposting Service (re-allocating the £4,500 project underspend)</td>
<td>Healthwatch Norfolk Team</td>
<td>Information produced in an appropriate format, reviewed and endorsed by end September 2014</td>
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<td>2. Awareness of specialist services Disparity in awareness of and experiences of specialist dementia services by participants between the five NHS commissioning localities in the county.</td>
<td>Fully consider the scale and type of out of hours support available to people with dementia and their carers</td>
<td>The Dementia Health Needs Assessment Steering Group and the Health and Wellbeing Board</td>
<td>Healthwatch Norfolk to assess inclusion of the dementia project recommendations in the county’s Dementia Health Needs Assessment August 2014, reporting on progress through our Board Meetings in public and our communication channels</td>
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<td>3. Gap in provision of out of hours support There is a gap in service provision for emergency care and support for people with dementia and their carers outside of 9-5 hours.</td>
<td>Fully consider the scale and type of out of hours support available to people with dementia and their carers</td>
<td>Healthwatch Norfolk Team</td>
<td>Reporting on progress through our Board Meetings in public and our communication channels, project completed by end March 2015</td>
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<td>4. Impact of funding cuts to carers support services Funding for carer support services have been reduced and/or stopped with a subsequent impact on carer’s practical support networks.</td>
<td>Fully consider the scale and level of support for carers of people with dementia</td>
<td>Healthwatch Norfolk Board</td>
<td>Reporting on progress through our Board Meetings in public and our communication channels, project completed by end March 2015</td>
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<td>5. Entitlement to funded domiciliary care People with dementia and their carers are not able to self-fund the amount of home care they need</td>
<td>Consider inclusion within 2015-2016 Work Programme, a review of the implementation of the Care Act 2014 on entitlement to assessment and receipt of funded domiciliary care (home care)</td>
<td>Healthwatch Norfolk Board</td>
<td>Reporting on changes through our Board Meetings in public and our communication channels, project completed by end March 2016</td>
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<tr>
<td>6. Residential care for people with dementia Research findings and public comments combined suggest that the quality of care for people with dementia in some care homes in Norfolk requires exploration.</td>
<td>Proposal to Healthwatch Norfolk Quality Control Panel in August 2014 to undertake an Enter &amp; View project on care homes* in Norfolk for residents who have dementia</td>
<td>Healthwatch Norfolk Board</td>
<td>Reporting on progress and outcomes through our Board Meetings in public and our communication channels, project completed by end March 2015</td>
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