

Cambridgeshire & Peterborough All Age Dementia Strategic Plan 2018- 2023

Dementia: Everybody's Business: better outcomes
for people living with dementia and their carers

*Cambridgeshire and Peterborough
Older People's Mental Health Delivery Board
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*Cambridgeshire and Peterborough CCG, Cambridgeshire County Council and Peterborough City Council,
Cambridgeshire and Peterborough NHS Foundation Trust, Cambridgeshire University Hospitals NHS
Foundation Trust, North West Anglia NHS Foundation Trust, The Alzheimer's Organization, The Carers' Trust,
Care Network*

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¹ <https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf> , online, accessed: 05.07.17

² PHE Dementia Profile

Glossary

Admiral Nurse		Nurses who provide specialist dementia support to families, working alongside people living with dementia and their families, helping them to live more positively with dementia by providing one-to-one support, expert guidance and practical solutions to the challenges they face
AIMS	Acute Inpatient Mental Health Services	A set of standards for Acute Inpatient Mental Health Services developed by the Royal College of Psychiatrists.
AWSB	The Ageing Well Strategy Board	A Clinical Community of the STP CAG which aims review, and make recommendations to improve the quality and outcomes of health and care services for older people across the Cambridgeshire and Peterborough STP footprint
CAG	Care Advisory Group	A sub-committee of the STP Board whose main purpose is to contribute to the overall delivery of STP objectives arising from the Fit for the Future programme, by reviewing care model design. See also HCE and STP below.
CAMTED-OP	Cambridge Training Education and Development- Older People	A countywide specialist multi-disciplinary training team offering training to a range of providers e.g. care homes, home care providers and acute hospitals in the areas of dementia care and functional mental health.
CCC	Cambridgeshire County Council	The countywide part of the two tier authority structure in providing local government services including adult social care services.
CCG	Clinical Commissioning Group	Clinically-led statutory NHS organisations created following the Health and Social Care Act in 2012 replacing Primary Care Trusts on 1 April 2013 responsible for the planning and commissioning of health care services to a particular area e.g. Cambridgeshire and Peterborough.
CQC	Care Quality Commission	The independent regulator of health and social care in England that aims to ensure that health and social care services are safe, effective, compassionate, high-quality care and that encourages providers to develop and improve quality.
Community Services Delivery Board		The multi-agency/-disciplinary group of people involved in improvement of outcomes and experience for adults aged 18 – 65 years.
CPFT	Cambridgeshire and Peterborough NHS Foundation Trust	The NHS provider of integrated physical and mental health services for adults and older people; specialist mental health and learning disability services; children and young people's mental health services; children's community services (Peterborough); social care.
CRHT	Crisis Resolution and Home Treatment Team	Specialist mental health teams commissioned to help people through short-term mental health crises by providing intensive treatment and support outside hospital, ideally in their own homes.
CUH	Cambridge University Hospital	Cambridge University Hospital NHS Foundation Trust: NHS Provider of local acute/general hospital services and a range of national specialist services.

DAA	Dementia Action Alliance	A group of businesses who meet together on a regular basis and encourage action at a local level
DCa	Dementia Café	A service provided by Alzheimer's Society for people with dementia, their carers and families providing a safe, comfortable and social environment for people to share experiences and ideas, get advice from trained members of staff and form friendships.
DCh	Dementia Champions	Individuals who are trained to deliver dementia awareness sessions as well as working with local employers to become more dementia friendly.
Dementia		A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. ³
DFC	Dementia Friendly Community	A group/network that already exists and seeks to make itself more dementia friendly internally – can be a geographical location e.g. a village, or a network e.g. a chain of supermarkets or faith community
DiADeM	Diagnosis of Advanced Dementia Assessment Tool	A tool developed by the Yorkshire and Humber Dementia Strategic Clinical Network, and supported by Alzheimer's Society to support GPs to diagnose dementia in people living with advanced dementia in care homes.
DIST	Dementia Intensive Support Team	Specialist dementia workforce within the Cambridgeshire and Peterborough Crisis Resolution and Home Treatment service.
DTOCs	Delayed Transfers of Care	A discharge from hospital of an individual who is fit for discharge that is delayed – often due to lack of availability of appropriate health or social care services/support.
DRC	Dementia Resource Centre	Alzheimer's Society provided service providing information, advice and support to people living with dementia and their carers.
Fit for the Future		A set of priorities agreed by health and care leaders/organizations across Cambridgeshire and Peterborough, aimed at improving the population's health and wellbeing within a defined financial envelope.
GPwSI	General Practitioner with a Special Interest	A GP who has a special interest in a specific condition/disease etc and who takes the lead in this area and advises on behalf of colleagues.
HCE	Health and Care Executive	Organisations from across the system have agreed to work together, taking joint responsibility for improving the population's health and wellbeing within a defined financial envelope. The purpose of the HCE is to provide strong, collective leadership to this process. The HCE's main purpose is to commission and oversee a programme of work that will deliver the Fit for the Future priorities.
Herbert Protocol		A scheme being introduced by West Yorkshire Police and other agencies which encourages carers

³ The ICD-10 Classification of Mental and behavioural Disorders, clinical descriptions and diagnostic guidelines' World health organisation 1992 ISBN 92 4 154422

		to compile useful information which could be used in the event of a vulnerable person going missing.
HH	Hinchingbrooke Hospital	A small district general hospital run by North West Anglia NHS Foundation Trust in Hinchingbrooke near Huntingdon, Cambridgeshire serving the Huntingdonshire area.
KLOE	Key Lines of Enquiry	A set of prompts and indicators developed by the Care Quality Commission to assess the performance of health and social care organisations
LA	Local Authority	An organization that is officially responsible and has specific statutory responsibilities for the public services and facilities in a particular area.
MCI	Mild Cognitive Impairment	A condition where an individual has cognitive deficits beyond those expected for their age and education, but which are not significant enough to interfere with their daily activities ⁴ .
MSNAP	Memory Service National Accreditation Programme⁵	A set of standards and criteria associated with Memory Services for dementia developed by the Royal College of Psychiatrists, drawn from key national policy and guidance documents related to dementia assessment, diagnosis including pre- and post- diagnostic support.
Neighbourhood Team		The physical and mental health care hub of the local community for over 65-year olds and adults requiring community services. Provided by CPFT, They work closely with GPs, primary care, social care and the third and independent sector to provide joined-up responsive, expert care and treatment.
PCC	Peterborough City Council	A unitary authority providing all local government services to the people of Peterborough and its surrounding areas.
PCH	Peterborough City Hospital	The acute general district hospital run by North West Anglia NHS Foundation Trust serving the Peterborough city, north Cambridgeshire, areas of east Northamptonshire and Rutland.
PCSP	Personalised Care and Support Planning	An approach that aims to transform the experience of care and support from largely reactive, i.e. responding when something goes wrong, to a more helpful proactive service, centred on the needs of each individual patient. It recognise the assets and value that patients, carers and communities can bring to help deliver more effective, person-centred and sustainable care for people with long-term conditions
NHS	National Health Service	Public provider of health care paid for from taxation and free at the point of care
NICE	National Institute for Clinical Excellence	Provides guidance, advice, quality standards and information services for health, public health and social care. Also contains resources to help maximise use of evidence and guidance.
No.	Number	Standard abbreviation for 'number'.
OPMH	Older People's Mental Health services	Mental health services commissioned/provided for adults aged over 65 years.

⁴ Petersen RC, Smith GE, Waring SC, Ivnik RJ, Tangalos EG, Kokmen E (1999). "Mild cognitive impairment: clinical characterization and outcome". Arch. Neurol. 56 (3): 303–8.

⁵ Memory Services National Accreditation Programme (MSNAP) – Standards for Memory Services, CCQI221, Royal College of Psychiatrists, 5th edn, 2016

SCIE	Social Care Institute for Excellence	An independent charity and improvement agency for the care and health sectors.
SDU	Service Delivery Unit	An overarching team established by system partners to oversee and support the delivery of the STP.
STP	Sustainability and Transformation Partnership	A partnership of senior leaders across the health and social care system in Cambridgeshire and Peterborough health and social care leaders working together to return the area to financial, clinical and operational sustainability through the Fit for the Future programme.

EXECUTIVE SUMMARY

Improving experience and outcomes for people living with dementia and their carers is a national priority. The Cambridgeshire and Peterborough Sustainability and Transformation Partnership (STP) which brings together leaders of health and social care organisations across the health and social care system to ensure that services are effective and efficient, has identified improving outcomes and experience for people living with dementia and their carers as a key priority for 2018/19 and beyond.

This Strategic Plan has been developed by the Older People's Mental Health (OPMH) Delivery Board to deliver that improvement. The Plan aims to address the needs of people of all ages living with dementia⁶ and mild cognitive impairment⁷ and their carers living in Cambridgeshire and Peterborough. It also aims to prevent or delay the onset of dementia and to identify ways that individuals and communities can be supported to improve the quality of life of people living with dementia as they go about their lives.

The Plan relates specifically to dementia. A definition of dementia has been agreed by those involved in dementia across the Cambridgeshire and Peterborough health and social care system:

Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement.⁸

It can be caused by a number of progressive neurodegenerative diseases, including Alzheimer's disease, frontotemporal dementia, vascular disease, Parkinson's disease and Huntington's disease. Not all cognitive impairment is due to dementia.

Mild cognitive impairment (MCI) is also included within the scope of the Strategic Plan because, whilst people with MCI are at higher risk of developing dementia, it is not possible or appropriate to make a positive diagnosis of dementia at the point when MCI is identified. It is important that people with MCI are identified, in particular to distinguish them so that they are not misdiagnosed with dementia. To do so would give a large number of people a diagnosis of a progressive terminal neurodegenerative disease which they do not have, and which may never develop. This would be inappropriate and unhelpful, causing unnecessary distress for individuals and their families. MCI can be defined as:

⁶ A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement.⁶

⁷ A condition where an individual has cognitive deficits beyond those expected for their age and education, but which are not significant enough to interfere with their daily activities⁷.

⁸ The ICD-10 Classification of Mental and behavioural Disorders, clinical descriptions and diagnostic guidelines' World health organisation 1992 ISBN 92 4 154422

A condition where an individual has cognitive deficits beyond those expected for their age and education, but which are not significant enough to interfere with their daily activities⁹.

Services for people with cognitive impairment that results from brain damage of a non-progressive nature are not included within the scope of the Strategic Plan because responsibility for commissioning and provision lies with a variety of organizations, groups and individuals beyond the boundaries of dementia commissioning and provision. However, it is essential that it is noted that there are gaps in services for people with non-progressive cognitive impairment. This issue has been drawn to the attention of STP leaders and commissioners by the Older People's Mental Health (OPMH) Delivery Board as part of its work to develop the Strategic Plan. Members of the Delivery Board are happy to provide assistance to those addressing these needs.

The case for prioritising the care and support of people living with dementia and their carers in Cambridgeshire and Peterborough is strong:

- Dementia affects the older population in significant numbers – an estimated 670,000 people in England¹⁰ and 8,600¹¹ in Cambridgeshire and Peterborough.
- There is a considerable economic cost associated with the disease estimated at £23 billion a year, which is predicted to triple by 2040. This is more than the cost of cancer, heart disease and stroke¹².
- An estimated 25% of hospital beds are occupied by people with dementia.
- Hospital stays of people with dementia are approximately 1 week longer than average¹³.
- 75% of people living in care homes have dementia¹⁴.
- Dementia is the leading cause of death for women¹⁵.
- It is estimated that the number of people living with dementia in Cambridgeshire and Peterborough will increase from 8,600 to 16,110 (7,510/86%) between 2016 and 2031. Action therefore needs to be taken to:
 - i) Do everything possible to prevent and delay the onset of dementia to slow the growth in numbers of people living with dementia.
 - ii) Ensure that the best use of the resources available is in order to manage the resulting increase in demand.
- Improving awareness and understanding of dementia will enable people living with dementia and their carers to live more comfortably with their families and communities.

⁹ Petersen RC, Smith GE, Waring SC, Ivnik RJ, Tangalos EG, Kokmen E (1999). "Mild cognitive impairment: clinical characterization and outcome". Arch. Neurol. 56 (3): 303–8.

¹⁰ The Prime Minister's Challenge on Dementia, DH, 2020

¹¹ Public Health England, 2016

¹² Commissioning for Value: Mental health and dementia pack, Public Health England, January 2017

¹³ The Prime Minister's Challenge on Dementia, DH, 2020/5 Year Forward View, DH, 2015

¹⁴ The Prime Minister's Challenge on Dementia, DH, 2020/5 Year Forward View, DH, 2015

¹⁵ The Prime Minister's Challenge on Dementia, DH, 2020/5 Year Forward View, DH, 2015

- If dementia is diagnosed early in its course, appropriate support can be provided in the present, and as the disease progresses, reducing the incidence of avoidable crises and interventions, improving experience and outcomes whilst also releasing resources for investment in other health and social care interventions.
- Across Cambridgeshire and Peterborough there is a desire to improve experience and outcomes for people who access any health and social care services.

The main thrust of national strategy is to ensure that people living with dementia are supported to live at home with their families for as long as possible. Early diagnosis and intervention including access to information, advice and guidance, advance care planning that is personalised, timely access to specialist assessment and treatment, and effective support for carers are key components of the strategy. Promoting better awareness and understanding of dementia amongst communities and businesses is essential if people living with dementia and their carers are to live and participate comfortably in their communities. Based on the work of the Alzheimer's Society, national strategy includes programmes to increase awareness through the development of dementia friendly communities and environments. There is much that can be done to prevent dementia by tackling key risk factors such as smoking, excess weight and physical inactivity. Overall, the aim is:

To enable people living with dementia to live independently for longer and to enjoy being part of their community¹⁶ and to keep them healthier for longer and out of hospital¹⁷.

A vision for people living with dementia and their carers in Cambridgeshire and Peterborough has been agreed:

We will work hard to prevent people in Cambridgeshire and Peterborough from acquiring dementia and ensure that those living with and affected by dementia receive compassionate, expert care and support, that is right for them to live positive and fulfilling lives we will support and empower them to take part in, and contribute to, the families and communities in which they live and work¹⁸.

Gaps and improvements that can be made to all of the above in Cambridgeshire and Peterborough have been identified through the work to develop the Strategic Plan. However, the biggest gaps identified are in:

- Early intervention and support including information, advice and guidance and advance care planning – primarily provided by the voluntary sector.

¹⁶ Dementia Implementation Guide, DH, 2017






¹⁷ The Five Year Forward View Implementation Guide, 2017-19, DH 2017

¹⁸ Adapted from Dementia UK's Strategy

- The infrastructure required to support the development of dementia friendly communities and environments – primarily provided by the voluntary sector..
- Support to maximise quality of life whilst living with dementia - for individuals living with dementia and their carers.
- Capacity to support people intensively to remain at home at times of crisis and/or enhanced need (service provided by Dementia Intensive Support Team (DIST)).
- Psychological treatment for people following diagnosis and in specialist dementia inpatient care.
- The seamlessness and co-ordination of care across both mental and physical health clinicians, teams and organizations.
- Personalised care planning and support.
- Specialist assessment, treatment and support for people diagnosed with early onset dementia¹⁹.

Addressing these gaps has been prioritised within the Strategic Plan. The Plan describes how the OPMH Delivery Board plans to work with its partners to achieve the vision for dementia using the pillars and cross-cutting themes of the Well Pathway for Dementia which provides a framework for delivery of the national dementia strategy as its basis. (See Figure i below).

Figure i: The Well Pathway for Dementia²⁰

NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA				
PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
 <p>Risk of people developing dementia is minimised</p> <p>"I was given information about reducing my personal risk of getting dementia"</p> <p>STANDARDS:</p> <p>Prevention⁽¹⁾ Risk Reduction⁽⁵⁾ Health Information⁽⁴⁾ Supporting research⁽⁵⁾</p>	 <p>Timely accurate diagnosis, care plan, and review within first year</p> <p>"I was diagnosed in a timely way"</p> <p>"I am able to make decisions and know what to do to help myself and who else can help"</p> <p>STANDARDS:</p> <p>Diagnosis⁽¹⁾⁽⁵⁾ Memory Assessment⁽¹⁾⁽²⁾ Concerns Discussed⁽³⁾ Investigation⁽⁴⁾ Provide Information⁽⁴⁾ Integrated & Advanced Care Planning⁽¹⁾⁽²⁾⁽³⁾⁽⁵⁾</p>	 <p>Access to safe high quality health & social care for people with dementia and carers</p> <p>"I am treated with dignity & respect"</p> <p>"I get treatment and support, which are best for my dementia and my life"</p> <p>STANDARDS:</p> <p>Choice⁽²⁾⁽³⁾⁽⁴⁾ BPSD⁽⁶⁾⁽²⁾ Liaison⁽²⁾ Advocates⁽³⁾ Housing⁽³⁾ Hospital Treatments⁽⁴⁾ Technology⁽⁵⁾ Health & Social Services⁽⁵⁾ Hard to Reach Groups⁽³⁾⁽⁵⁾</p>	 <p>People with dementia can live normally in safe and accepting communities</p> <p>"I know that those around me and looking after me are supported"</p> <p>"I feel included as part of society"</p> <p>STANDARDS:</p> <p>Integrated Services⁽¹⁾⁽³⁾⁽⁵⁾ Supporting Carers⁽²⁾⁽⁴⁾⁽⁵⁾ Carers Respite⁽²⁾ Co-ordinated Care⁽¹⁾⁽⁵⁾ Promote independence⁽¹⁾⁽⁴⁾ Relationships⁽³⁾ Leisure⁽³⁾ Safe Communities⁽³⁾⁽⁵⁾</p>	 <p>People living with dementia die with dignity in the place of their choosing</p> <p>"I am confident my end of life wishes will be respected"</p> <p>"I can expect a good death"</p> <p>STANDARDS:</p> <p>Palliative care and pain⁽¹⁾⁽²⁾ End of Life⁽⁴⁾ Preferred Place of Death⁽⁵⁾</p>
<p>References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.</p>				
<p>RESEARCHING WELL</p> <ul style="list-style-type: none"> • Research and innovation through patient and carer involvement, monitoring best-practice and using new technologies to influence change. • Building a co-ordinated research strategy, utilising Academic & Health Science Networks, the research and pharmaceutical industries. 				
<p>INTEGRATING WELL</p> <ul style="list-style-type: none"> • Work with Association of Directors of Adult Social Services, Local Government Association, Alzheimer's Society, Department of Health and Public Health England on co-commissioning strategies to provide an integrated service ensuring a seamless and integrated approach to the provision of care. 				
<p>COMMISSIONING WELL</p> <ul style="list-style-type: none"> • Develop person-centred commissioning guidance based on NICE guidelines, standards, and outcomes based evidence and best-practice. • Agree minimum standard service specifications for agreed interventions, set business plans, mandate and map and allocate resources. 				
<p>TRAINING WELL</p> <ul style="list-style-type: none"> • Develop a training programme for all staff that work with people with dementia, whether in hospital, General Practice, care home or in the community. • Develop training and awareness across communities and the wider public using Dementia Friends, Dementia Friendly Hospitals/Communities/Homes. 				
<p>MONITORING WELL</p> <ul style="list-style-type: none"> • Develop metrics to set & achieve a national standard for Dementia services, identifying data sources and set 'profiled' ambitions for each. • Use the Intensive Support Team to provide 'deep-dive' support and assistance for Commissioners to reduce variance and improve transformation. 				

¹⁹ This document contains key issues identified within the needs assessment undertaken to inform the Strategic Plan. The detail is contained in 'Early Onset Dementia, Needs Assessment', October 2017.

²⁰ <https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf> , online, accessed: 05.07.17

The aim is to ensure that delivery of the services under each pillar of the Well Pathway are effective and efficient and developed in line with national and local good practice. To achieve this, action plans to improve outcomes from the services under each of the Pillars and Cross Cutting Themes has been developed. (See Section 3.2). These are summarised in Table 1 below. The Strategic Plan aims to deliver the following outcomes:

- Prevention of the onset of dementia where this is possible.
- People living with dementia are supported to live safely for longer within the community and with their carers.
- Improved accessibility to, and consistency of, assessment, treatment and support for people living with dementia and their carers across Cambridgeshire and Peterborough.
- Increased choice and control for people living with dementia and their carers - at all stages of the disease.
- Improved outcomes and experience of services for people living with dementia and their carers at all stages of the disease and wherever they live i.e. at home, in care homes and when admitted to hospital..
- Well co-ordinated care that addresses physical and mental health and social care needs in a seamless way.
- Crises and avoidable admission to inpatient dementia services and acute hospitals are reduced.
- Better understanding and awareness of dementia within communities
- Better use of resources/value for money.

A key objective of the Strategic Plan is to reduce costs where possible, releasing resources for investment in new/improved services and/or for investment in other key areas of need.

Investment, capacity, activity and performance across the health and social care system in dementia diagnosis, assessment, treatment and support is not fully understood. The Plan aims to develop this understanding in order to identify opportunities for improved performance, outcomes and reduced cost in order to enable investment to address gaps in services and support. Improvement will be achieved primarily by ensuring early diagnosing, intervention and effective community based, reducing expenditure on more expensive specialist interventions in line with national guidance for CCGs²¹ and Local Authorities on cost effectiveness. Finally, the gap between current investment, improvements required and the increase in capacity necessary to match the likely increase in the numbers of people living with dementia will be identified. All of this will be brought together in a business case to the STP and to Peterborough City Council (PCC) and Cambridgeshire County Council (CCC).

²¹ Next Steps on the NHS Five Year Forward View, DH, 2017

A core data set to monitor quality, outcomes and activity based on the Memory Service National Accreditation Programme (MSNAP) quality standards, the reporting requirements of NHS and social care organisations has been developed and will be refined as part of the work to implement the Strategic Plan. Notwithstanding the need to report on core national and local activity, performance and outcomes, the key driver for the development of these outcomes will be to monitor the things that are of the greatest importance to people living with dementia and their carers.

Delivery of the Strategic Plan constitutes a major programme of work. A high level timeline for delivery of the actions/milestones required 2017 – 2019 has been developed to support delivery (See Figure ii below). An assessment of the risks to delivery of the Strategic Plan has been made with the following risks being identified:

- **Risk 1:** Insufficient capacity within OPMH commissioning and provider organisations to deliver a complex programme of work with the detailed level of analysis necessary to achieve the outcomes required.
- **Risk 2:** The need for system wide participation to successfully deliver the Strategic Plan.
- **Risk 3:** Lack of resources to support external facilitation for the development of the dementia care pathway.

At the time of completion of the Strategic Plan (January 2018), these are rated amber with mitigating actions in place to address them.

Table i: Summary of the Cambridgeshire and Peterborough Dementia Well Pathway Action Plans

Strategic Plan: Section	Pillar/Cross Cutting Theme and Standard	Key Objective 1	Key Objective 2	Key Objective 3	Key Objective 4
3.2.1	Preventing Well The risk of people developing dementia is minimised: "I was given information about my personal risk of getting dementia"	To build strategy to include evidence-based and equitable primary, secondary and tertiary prevention efforts across the life course.	To incorporate dementia risk reduction into current long-term disease approaches and unique messaging.		
3.2.2	Diagnosing Well Timely accurate diagnosis, care plan, and review within first year. "I am diagnosed in a timely way. I am able to make decisions and know what to do to help myself and who else can help".	To increase the dementia diagnosis rate.	To develop a robust pathway that meets the standards within NICE guidelines and MSNAP with protocols agreed between the Memory Assessment Service, GPs, older people's services and the voluntary sector, including protocols that ensure that advance planning is established consistently across Cambridgeshire and Peterborough (includes assessing the feasibility of commissioning a Memory Assessment Service that meets the standards required to achieve MSNAP accreditation).		
3.2.3	Supporting Well Access to safe high quality health and social care for people with dementia and	To develop a robust dementia pathway within which there is an action plan that supports improvement/achievement of the standards within NICE	To work with Acute providers to develop a plan for ongoing improvement in the quality of care for people with dementia when in hospital.	To improve awareness of and access to dementia care for hard to reach groups	To ensure that the quality of care of people living with dementia in care homes meets the Care Quality Commission

	their carers. "I am treated with dignity and respect. I get treatment and support which are best for my dementia and my life."	guidelines and MSNAP consistently across Cambridgeshire and Peterborough that relate to Living Well (includes assessing the feasibility of commissioning a Memory Assessment Service that meets the standards contained within NICE guidelines and MSNAP; as a minimum, standards relating to advance planning must be achieved).			requirements and best practice.
3.2.4	Living Well People with dementia can live normally in safe and accepting communities. "I know that those around me and looking after me are supported. I feel included as part of society."	To ensure geographical consistency in relation to Dementia Friendly Communities and Dementia Friendly Environments across Cambridgeshire and Peterborough	To ensure that people living with dementia have access to community based support that is robust and consistent across Cambridgeshire and Peterborough	To establish a robust infrastructure of support for carers that is consistent across Cambridgeshire and Peterborough	
3.2.5	Dying Well People living with dementia die with dignity in the place of their choosing. "I am confident my end of life wishes will be respected. I can expect a good death."	To improve the quality of care and support and outcomes at end of life for people living with dementia and their carers			
3.2.6	Early Onset Dementia	To ensure that people living with early onset dementia and their carers have access to			

		robust assessment, treatment and support.			
3.2.7	Researching Well	To ensure that every patient with a diagnosis of dementia is given the opportunity to participate in dementia research.	To evaluate the impact of the Dementia Strategic Plan		
3.2.8	Integrating Well	To ensure that care is seamless, addressing physical and mental health and social care needs in an holistic and cost effective way			
3.2.9	Commissioning Well	To improve the commissioning and leadership for health and social care commissioning.	To ensure that best use of resources is made.	To ensure that services are effectively commissioned.	
3.2.10	Training Well	To ensure that staff across the Cambridgeshire and Peterborough health and social care system are involved in and inform the development of and are trained in the operation of the integrated dementia pathway.			
3.2.11	Monitoring Well	To improve understanding of activity, performance and outcomes for people living with dementia and their carers in Cambridgeshire and Peterborough.	To develop a set of indicators of quality that include experience of services and support and outcomes for people living with dementia and their carers related to dementia across the Cambridgeshire and Peterborough health and social care system		

1 Introduction

In this Section, the scope, including the definition of dementia adopted by the Cambridgeshire and Peterborough health and social care community, rationale for the development of a Strategic Plan for dementia, the vision and aims are described.

1.1 Rationale

Improving experience and outcomes for people living with dementia and their carers is a national priority. The Sustainability and Transformation Partnership (STP) brings together leaders of health and social care organisations across the Cambridgeshire and Peterborough health and social care system to ensure that services are effective and efficient. The STP has identified improving outcomes for people living with dementia and their carers as a key priority for 2018/19 and beyond. This means that dementia will be given significant focus by leaders of organisations responsible for the commissioning and delivery of health and social care.

There are numerous reasons for prioritising the care and support of people living with dementia and their carers in Cambridgeshire and Peterborough. The key reasons are:

- Dementia affects the older population in significant numbers – an estimated 670,000 people in England²² and 8,600²³ in Cambridgeshire and Peterborough.
- There is a considerable economic cost associated with the disease estimated at £23 billion a year, which is predicted to triple by 2040. This is more than the cost of cancer, heart disease and stroke²⁴.
- An estimated 25% of hospital beds are occupied by people with dementia.
- Hospital stays of people with dementia are approximately 1 week longer than average²⁵.
- 75% of people living in care homes have dementia²⁶.
- Dementia is the leading cause of death for women²⁷.
- It is estimated that the number of people living with dementia in Cambridgeshire and Peterborough will increase from 8,600 to 16,110 (7,510(86%)) between 2016 and 2031. Action therefore needs to be taken to:
 - iii) Do everything possible to prevent and delay the onset of dementia to slow the growth in numbers of people living with dementia.

²² The Prime Minister's Challenge on Dementia, DH, 2020

²³ Public Health England, 2016

²⁴ Commissioning for Value: Mental health and dementia pack, Public Health England, January 2017

²⁵ The Prime Minister's Challenge on Dementia, DH, 2020/5 Year Forward View, DH, 2015

²⁶ The Prime Minister's Challenge on Dementia, DH, 2020/5 Year Forward View, DH, 2015

²⁷ The Prime Minister's Challenge on Dementia, DH, 2020/5 Year Forward View, DH, 2015

- iv) Ensure that the best use of the resources available is in order to manage the resulting increase in demand.
- Improving awareness and understanding of dementia will enable people living with dementia and their carers to live more comfortably with their families and communities.
- If dementia is diagnosed early in its course, appropriate support can be provided in the present, and as the disease progresses, reducing the incidence of avoidable crises and interventions, improving experience and outcomes whilst also releasing resources for investment in other health and social care interventions.

Across Cambridgeshire and Peterborough there is a desire to improve experience and outcomes for people who access any health and social care services.

1.2 Scope of the Strategic Plan and Definition of Dementia

A definition of dementia that will underpin the Strategic Plan and work to improve delivery and outcomes has been agreed by those involved in dementia across the Cambridgeshire and Peterborough health and social care system:

Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement.²⁸

The syndrome of dementia can be caused by a number of progressive neurodegenerative diseases, including Alzheimer's disease, frontotemporal dementia, vascular disease, Parkinson's disease and Huntington's disease. Not all cognitive impairment is due to dementia. Mild cognitive impairment (MCI) can be defined as:

A condition where an individual has cognitive deficits beyond those expected for their age and education, but which are not significant enough to interfere with their daily activities²⁹.

It is important that those with MCI are identified, in particular to distinguish them so that they are not misdiagnosed with dementia. Whilst people with MCI are at higher risk of developing dementia, it is not possible or appropriate to make a positive diagnosis of dementia at the point when MCI is identified. To do so would give a large number of people a diagnosis of a progressive terminal neurodegenerative disease which they do not have, and which may never develop. This would be inappropriate and unhelpful, causing unnecessary distress for individuals and their families.

²⁸ The ICD-10 Classification of Mental and behavioural Disorders, clinical descriptions and diagnostic guidelines' World health organisation 1992 ISBN 92 4 154422

²⁹ Petersen RC, Smith GE, Waring SC, Ivnik RJ, Tangalos EG, Kokmen E (1999). "Mild cognitive impairment: clinical characterization and outcome". Arch. Neurol. 56 (3): 303–8.

Onset of dementia is around age 40 years. The incidence at this age is very low. However, it doubles with every 5 year increase in age and by age 65 – 69 years, the incidence in the general population is approximately 2%. By age 85 years the incidence rises to approximately 20%.

The agreed definition of dementia specifically excludes stable cognitive impairment that results from brain damage of a non-progressive nature, including head injury, single vascular events (e.g. stroke), learning disability or cognitive impairment arising from alcohol misuse. The Strategic Plan does not directly address the needs of this group of people. However, it is important to note that there are gaps in services for many of these groups across Cambridgeshire and Peterborough. The OPMH Delivery Board has drawn this issue to the attention of STP leaders and commissioners as part of the work to develop the Strategic Plan. Its members are keen to provide assistance and will do so to those addressing these needs on request.

In summary, the Strategic Plan includes people of all ages living with dementia, mild cognitive impairment who live and receive services in the Cambridgeshire and Peterborough area, and their informal carers. It is important to note that, although the delivery of most strands of the strategic plan will be overseen by the OPMH Delivery Board, some strands are, and will be best managed elsewhere e.g. the early onset dementia workstream will be managed by adult mental health services through the Community Services Delivery Board.

1.3 Vision

Working with people living with dementia and their carers and others involved in dementia care across Cambridgeshire and Peterborough, members of the OPMH Delivery Board have agreed a vision for people living with dementia and their carers:

We will work hard to prevent people in Cambridgeshire and Peterborough from acquiring dementia and ensure that those living with and affected by dementia receive compassionate, expert care and support, that is right for them to live positive and fulfilling lives we will support and empower them to take part in, and contribute to, the families and communities in which they live and work³⁰.

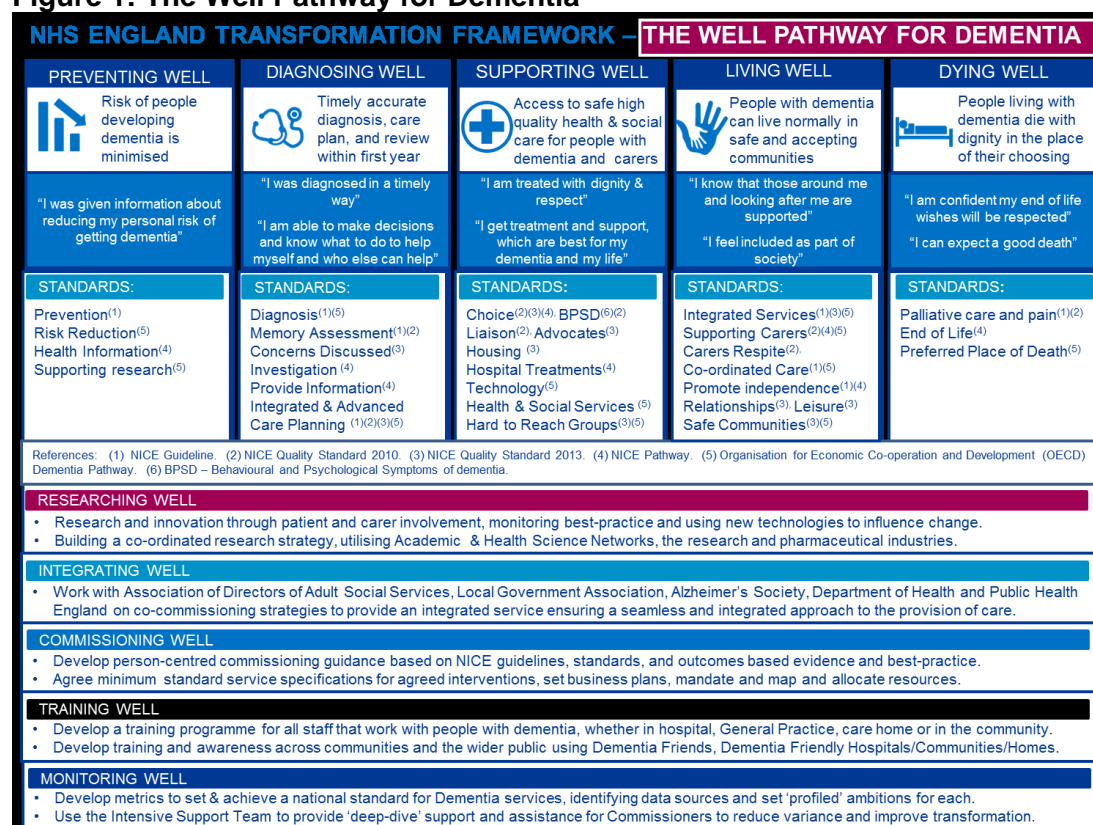
Dementia impacts on cognition, physical and mental health and wellbeing and has an increasing impact on the ability of the individual to function. Because it occurs more frequently in later life, people living with dementia may also be diagnosed with other physical conditions and/or be physically frail. Access to specialist assessment, treatment and support is essential. In order to be effective, assessment, treatment and support provided by a

³⁰ Adapted from Dementia UK's Strategy

variety of agencies working in both specialist mental and physical health services must be identified and met in a co-ordinated way.

The Well Pathway for Dementia provides a framework for delivery of the national dementia strategy and provides the basis of the Strategic Plan. (See Figure 1 below).

Figure 1: The Well Pathway for Dementia³¹



The objective is to ensure that delivery of the services under each pillar of the Well Pathway are effective and efficient and developed in line with national and local good practice. To achieve this, action plans to improve outcomes from the services under each of the Pillars and Cross Cutting Themes has been developed. The action plans are summarised in Table 1 below.

³¹ <https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf> , online, accessed: 05.07.17

Table 1: Summary of the Cambridgeshire and Peterborough Dementia Well Pathway Action Plans

Strategic Plan: Section	Pillar/Cross Cutting Theme and Standard	Key Objective 1	Key Objective 2	Key Objective 3	Key Objective 4
3.2.1	Preventing Well The risk of people developing dementia is minimised: "I was given information about my personal risk of getting dementia"	To build strategy to include evidence-based and equitable primary, secondary and tertiary prevention efforts across the life course.	To incorporate dementia risk reduction into current long-term disease approaches and unique messaging.		
3.2.2	Diagnosing Well Timely accurate diagnosis, care plan, and review within first year. "I am diagnosed in a timely way. I am able to make decisions and know what to do to help myself and who else can help".	To increase the dementia diagnosis rate.	To develop a robust pathway that meets the standards within NICE guidelines and MSNAP with protocols agreed between the Memory Assessment Service, GPs, older people's services and the voluntary sector, including protocols that ensure that advance planning is established consistently across Cambridgeshire and Peterborough (includes assessing the feasibility of commissioning a Memory Assessment Service that meets the standards required to achieve MSNAP accreditation).		
3.2.3	Supporting Well Access to safe high quality health and social care for people with dementia and their carers. "I am treated with	To develop a robust dementia pathway within which there is an action plan that supports improvement/achievement of the standards within NICE guidelines and MSNAP	To work with Acute providers to develop a plan for ongoing improvement in the quality of care for people with dementia when in hospital.	To improve awareness of and access to dementia care for hard to reach groups	To ensure that the quality of care of people living with dementia in care homes meets the Care Quality Commission

	dignity and respect. I get treatment and support which are best for my dementia and my life."	consistently across Cambridgeshire and Peterborough that relate to Living Well (includes assessing the feasibility of commissioning a Memory Assessment Service that meets the standards contained within NICE guidelines and MSNAP; as a minimum, standards relating to advance planning must be achieved).			requirements and best practice.
3.2.4	Living Well People with dementia can live normally in safe and accepting communities. "I know that those around me and looking after me are supported. I feel included as part of society."	To ensure geographical consistency in relation to Dementia Friendly Communities and Dementia Friendly Environments across Cambridgeshire and Peterborough	To ensure that people living with dementia have access to community based support that is robust and consistent across Cambridgeshire and Peterborough	To establish a robust infrastructure of support for carers that is consistent across Cambridgeshire and Peterborough	
3.2.5	Dying Well People living with dementia die with dignity in the place of their choosing. "I am confident my end of life wishes will be respected. I can expect a good death."	To improve the quality of care and support and outcomes at end of life for people living with dementia and their carers			
3.2.6	Early Onset Dementia	To ensure that people living with early onset dementia and their carers have access to robust assessment, treatment and support.			

3.2.7	Researching Well	To ensure that every patient with a diagnosis of dementia is given the opportunity to participate in dementia research.	To evaluate the impact of the Dementia Strategic Plan		
3.2.8	Integrating Well	To ensure that care is seamless, addressing physical and mental health and social care needs in an holistic and cost effective way			
3.2.9	Commissioning Well	To improve the commissioning and leadership for health and social care commissioning.	To ensure that best use of resources is made.	To ensure that services are effectively commissioned.	
3.2.10	Training Well	To ensure that staff across the Cambridgeshire and Peterborough health and social care system are involved in and inform the development of and are trained in the operation of the integrated dementia pathway.			
3.2.11	Monitoring Well	To improve understanding of activity, performance and outcomes for people living with dementia and their carers in Cambridgeshire and Peterborough.	To develop a set of indicators of quality that include experience of services and support and outcomes for people living with dementia and their carers related to dementia across the Cambridgeshire and Peterborough health and social care system		

As part of the work relating to each pillar and cross cutting theme will be to identify the strengths and the potential for improvement across the dementia pathway in greater detail. Through the development of the care pathway under Integrating Well, these findings will be drawn together. In its turn, development of the care pathway will inform the work on each area. It will also offer the opportunity for immediate and ongoing improvement.

Dementia has been identified by the STP as the pilot area for Personalised Care and Support Planning (PCSP). Review. In order to ensure that dementia care and support is driven by the individual living with dementia and their carers, the work on the dementia care pathway has been aligned to the PCSP project.

The Strategic Plan aims to deliver the following improvements to experience and outcomes for people living with dementia and their carers in line with national and local strategies:

- Prevention of the onset of dementia where this is possible.
- People living with dementia are supported to live safely for longer within the community and with their carers.
- Improved accessibility to, and consistency of, assessment, treatment and support for people living with dementia and their carers across Cambridgeshire and Peterborough.
- Increased choice and control for people living with dementia and their carers - at all stages of the disease.
- Improved outcomes and experience of services for people living with dementia and their carers at all stages of the disease and wherever they live i.e. at home, in care homes and when admitted to hospital..
- Well co-ordinated care that addresses physical and mental health and social care needs in a seamless way.
- Crises and avoidable admission to inpatient dementia services and acute hospitals are reduced.
- Better understanding and awareness of dementia within communities
- Better use of resources/value for money.

1.4 Delivering the Plan

The Strategic Plan has been developed and will be delivered by the Older People's Mental Health Delivery Board (OPMH Delivery Board). This Board is made up of commissioners and statutory and non-statutory providers and representatives of people who access dementia care and their carers and families across the area. It is accountable to the Clinical Advisory Group (CAG) and the Health Care Executive (HCE) of the STP. Those responsible for delivering the action plans developed under the Well Pathway are accountable to the organisations that employ them for delivery of the specific actions and workstreams agreed.

Delivery of the Strategic Plan constitutes a major programme of work. A high level timeline for delivery of the actions/milestones required 2017 – 2019 is included in Figure 2 below.

Figure 2: Dementia Strategic Plan: Timeline 2017- 2019

	2017			2018												2019		
	Oct	Nov	Dec	Jan	Feb	March	April	May	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	March
STP Sign Off: Strategic Plan		i) Primary Care Innovation Network	i) Clinical Advisory Group ii) Clinical Executive Committee	i) Health Care Executive														
OPMH Delivery Board: Well Pathway and Cross Cutting Themes: Action Plans	i) Strategic Plan: Engagement	i) Complete Strategic Plan ii) Review OPMH Delivery Board membership	i) Establish Task and Finish Groups and initiate actions ii) Review OPMH Delivery Board membership	i) All Task and Finish Groups established.	i) Task and Finish Group delivery against the agreed actions and timelines	i) Task and Finish Group delivery against Action Plans										i) Review of Action plans and planning: 2019/20		i) Action Plans finalised and implementation 2019/20 initiated
				Memory Assessment Service Self-Assessment against MSNAP standards		i) Memory Assessment Service identification of gaps and input to business case ii) Memory Assessment Service development of an Improvement Plan against items that relate to internal operation						i) STP Decision to work towards MSNAP accreditation						
OPMH Delivery Board: Development of Care Pathway and Business Case		i) Define project scope and agree outcomes ii) Agree timeline and initiate work	i) Plan and set up workshops	i) Hold workshops to review and develop pathway ii) Agree action plans and Implement required changes in a planned way where possible iii) Develop business case iv) Secure sign off													i) Secure final sign off	
				i) Identify and quantify opportunities for improvement			i) Develop business case											
STP Sign Off: Pathway and Business Case				Updates to Primary Care Innovation Network, Clinical Advisory Group Clinical Executive Committee as required										i) Primary Care Innovation Network	i) Clinical Advisory Group ii) Clinical Executive Committee		i) Health Care Executive	

2 Context and Drivers for Change

In this Section, the strengths and potential for improved outcomes and experience for people living with dementia and their carers are identified, along with areas where more information is needed to understand current performance and the overall effectiveness and efficiency of the dementia pathway. The epidemiology of dementia and the current and likely future demand for dementia care are described, along with a summary of national and local strategy that relates to dementia. Benchmarked data published by NHS England and by Public Health England (PHE) is combined with local data about performance, activity and investment in acute and community physical and mental health services and the views of managers, practitioners and commissioners involved in dementia care as well as of people living with dementia and their families and carers. This provides the basis for the gap analysis through which the current strengths and opportunities for improved outcomes for people living with dementia and their carers is identified.

Diagnosis, assessment, treatment and support for people aged 18 to 65 years has been identified as a significant gap in local provision. As part of the work to develop the Strategic Plan, a needs assessment was undertaken by the Cambridgeshire and Peterborough Public Health Department. The report provides a robust overview of the likely numbers of people living with early onset dementia and the current status of services. In order to provide a clear picture of the needs of this group and the action required to address them, the needs assessment is included at Appendix 1 and is referenced at appropriate places in this document.

2.1 National Context and Drivers for Change ³²

2.1.1 The Prevalence of Dementia

Dementia in People Aged 18 - 65 Years: Early Onset Dementia

It is estimated that there are approximately 42,325 people with early-onset dementia in the UK. They represent around 5% of the 850,000 people with dementia⁵. Early onset dementia is seen in slightly more men than women (21,519 men and 20,806 women), a male: female gender ratio of 1.03 to 1.00³³.

³² This section is supported by an appendix which shows the tables and charts referred to in this section.

³³ This document contains key issues identified within the needs assessment undertaken to inform the Strategic Plan. The detail is contained in 'Early Onset Dementia, Needs Assessment', October 2017.

Dementia in People Aged Over 65 Years

Globally, there are 47.5 million with dementia, which is predicted to rise to 150 million by 2050ⁱ. Global costs are estimated to be £356 billion (equivalent to 1% of global GDP).ⁱⁱ In the UK, it is estimated there are 850,000 people living with dementia. This will rise to 1 million by 2025 and 2 million by 2050. 62% of people with dementia are female and 38% are male. Dementia is the leading cause of death among women in the UK with 31,850 deaths a yearⁱⁱⁱ. There are around 21 million people in England with a close friend or family member with dementia. It is estimated that 1 in 3 people will care for a person with dementia in their lifetime. Half of these people will be employed when they are required to care and it is thought that some 66,000 people have already cut their working hours to care for a family member, whilst 50,000 people have left work altogether. There is a considerable economic cost associated with the disease estimated at £26.3 billion a year, with an average cost of £32,250 per person^{iv}. This is more than the cost of cancer, heart disease and stroke. Costs are predicted to triple by 2040.

2.1.2 The National Dementia Strategy

The key elements of the national strategy for dementia can be summarised under the 5 pillars and 5 cross cutting themes of the Well Pathway for Dementia developed from the National Dementia Strategy³⁴, publications such as The Prime Minister's Challenge on Dementia 2020 and the 2015 NICE Dementia Guidelines³⁵. These provide the overarching structure and aims are the backbone of this Strategic Plan. (See Figure 1 above).

The main thrust of national strategy is to ensure that people living with dementia are supported to live at home with their families for as long as possible. Early diagnosis and intervention, advance care planning, timely access to specialist assessment and treatment and effective support for carers are key components of the strategy. Promoting better awareness and understanding of dementia amongst communities and businesses is essential if people living with dementia and their carers are to live and participate comfortably in their communities. Based on the work of the Alzheimer's Society, national strategy includes programmes to increase awareness through the development of dementia friendly communities and environments. There is much that can be done to prevent dementia by tackling key risk factors such as smoking, excess weight and physical inactivity.

2.1.3 Guidelines and Best Practice in Dementia

In 2006, the National Institute for Clinical Excellence (NICE) and Social Care Institute for Excellence (SCIE) published joint guidelines on dementia³⁶. These address prevention,

³⁴ Living Well With Dementia: a national dementia, DH, 2009

³⁵ Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset, NICE, 2015

³⁶ Dementia: supporting people with dementia and their carers in health and social care, CG42, November 2006, last updated: September 2016, NICE, <https://www.nice.org.uk/guidance/cg42>

diagnosis, assessment and management of dementia in health and social care and include recommendations relating to Alzheimer's disease. The guidelines have informed the Strategic Plan and will be accessed as required during implementation. They can be accessed at: <https://www.nice.org.uk/guidance/cg42>. There are additional guidelines relating to dementia e.g. Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset³⁷.

The Memory Service National Accreditation Programme (MSNAP)³⁸ provides a quality framework for Memory Services. The standards aim to enable Memory Services to evaluate themselves against a set of agreed standards based on best practice and guidance defined by the Royal College of Psychiatrist (RCP) and including the NICE/SCIE guidelines³⁹. Although the primary focus is Memory Services, the standards address the treatment and support that should be available following diagnosis:

- Management
- Resources available to support assessment and diagnosis
- Assessment and diagnosis
- Ongoing care management and follow up
- Pharmacological interventions
- Psychosocial interventions

This means that the standards and quality indicators that relate to both the Memory Service and parts of the dementia pathway that are beyond it. They therefore provides a framework across the assessment, treatment and support parts of the care pathway.

A key outcome from the work to develop the Strategic Plan is agreement that the MSNAP standards provide a useful framework to support the improvement of outcomes for people living with dementia and their carers, and therefore that CPFT should work with partners across Cambridgeshire and Peterborough to achieve MSNAP accreditation. In order to achieve this, co-ordination across the Diagnosing Well, Supporting Well and Living Well pathways will be required. Undertaking this self-assessment will be one of the first steps in the implementation of the Strategic Plan.

2.1.4 Cost Effectiveness in Dementia Care

Both the 2015 5 Year Forward View⁴⁰ and The Prime Minister's Challenge on Dementia, 2020⁴¹ make the case for improving dementia assessment, treatment and support. The case made is as follows:

³⁷ Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset, NG16, October 2015, <https://www.nice.org.uk/guidance/ng16>

³⁸ Memory Assessment Service National Accreditation Programme (MSNAP): Standards for Memory Services, 5th edn., Pub.No. CCQ1221 Royal College of Psychiatrists, 2016

³⁹ Dementia: supporting people with dementia and their carers in health and social care, CG42, November 2006, last updated: September 2016, NICE, <https://www.nice.org.uk/guidance/cg42>

⁴⁰ The Five Year Forward View, DH, 2015

⁴¹ The Prime Minister's Challenge on Dementia 2020, DH, 2015

- Dementia affects the older population in significant numbers (670,000 people in England)
- There is a considerable economic cost associated with the disease estimated at £23 billion a year, which is predicted to triple by 2040. This is more than the cost of cancer, heart disease and stroke⁴².
- An estimated 25% of hospital beds are occupied by people with dementia
- Hospital stays of people with dementia are approximately 1 week longer than average
- 75 percent of people living in care homes have dementia
- Dementia is the leading cause of death for women

Whilst it is possible to demonstrate a direct return on investment or the impact of a change in service delivery clearly, there are many improvements to services that are made for which the direct impact cannot easily be quantified. This is particularly the case in relation to preventative measure and ensuring that there is early identification and support for people experiencing a specific disorder or condition. However, on occasion, this can be addressed e.g. by applying the experience of an individual to others with the same condition and/or the impact of an intervention for one condition to another.

There is specific evidence that effective community based care reduces cost and improves outcomes e.g. the health and care economy in the West Midlands has estimated that significant reduction in the need for more specialist, expensive health and social care resources, intervention and home-based care is estimated as having the potential to save £38 million through the reduction in acute hospital admissions (700 per annum), shorter lengths of hospital stay (25% reduction) and less use of high cost intensive interventions⁴³. This finding can be applied to Cambridgeshire and Peterborough in general and to dementia in particular.

In the section on mental health in the Five Year Forward View, the benefit of early intervention in mental health, including dementia, is made:

There is now good evidence that tackling some major mental health problems early reduces subsequent problems, improves people's life chances, and also saves money for the wider economy⁴⁴.

An evaluation of the Alzheimer's Society Dementia Advisor Services indicated a significant return on investment, with every £1 invested in such post-diagnosis support resulting in nearly £41 worth of benefits⁴⁵.

⁴² Commissioning for Value: Mental health and dementia pack, Public Health England, January 2017

⁴³ NHS West Midlands, 2010

⁴⁴ Next Steps on the NHS Five Year Forward View, DH, 2017.

⁴⁵ Dementia advisers: A cost-effective approach to delivering integrated dementia care, Alzheimer's Society, 2016

As a result of the above findings, one of the priorities for the NHS in England for 2017-19 is to free up 2000 – 3000 hospital beds with responsibility for this lying with NHS Improvement/NHS England and Local Authorities. The required action includes reducing delays caused by delays in accessing health commissioned community services and social care services.

The need and opportunity to improve the cost effectiveness of care informs Government guidance for CCGs relating to dementia and the delivery of care in general⁴⁶. The guidance requires improvement in the dementia diagnosis rate so that intervention can be made early in the course of an individual's illness. The main thrust of the guidance for all conditions, including dementia, is to seek improved outcomes and cost effectiveness by making improvements in the following areas:

1. Integrated care:
 - b. Integrated care around the patient with primary, community and hospital services working effectively together (vertical integration)
 - c. Long term partnerships with patients as opposed to episodic care
 - d. Management of systems/networks of care – not just organisations – networked care (horizontal integration)
 - e. Partnership with Local Authorities with collective responsibility for resources, population health and keeping people healthier for longer
 - f. Partnership with other partners sharing responsibility for resources and keeping people healthier for longer
 - a. Improved assessment, treatment and support for people with long term conditions, of which dementia is one.
 - b. Improved out of hospital care with much greater priority being given to this within the NHS
2. Increasing the value out of medicines and pharmacy
3. Improving support for carers
4. Population health management: and prevention
 - a. Improved prevention
 - b. Enhanced patient activation and supported self-management for long term conditions
 - c. Manage avoidable demand
 - d. Reduce unwarranted variation in line with the Right Care Programme

Overall, the main outcomes sought for people with dementia and their carers is improvement in quality of life for both with the key objective being:

To enable people living with dementia to live independently for longer and to enjoy being part of their community⁴⁷ and to keep them healthier for longer and out of hospital⁴⁸.

⁴⁶ Next Steps on the NHS Five Year Forward View, DH, 2017

⁴⁷ Dementia Implementation Guide, DH, 2017

⁴⁸ The Five Year Forward View Implementation Guide, 2017-19, DH 2017

If this outcome is not achieved with dementia being poorly managed, expensive health and social care resources will be needed to manage avoidable deterioration or crises and the experience and quality of life of people living with dementia and their carers will be poor.

2.2 Local Context

2.2.1 The Number of People Living with Dementia in Cambridgeshire and Peterborough

The Number of People Aged Under 65 Years Living with Dementia in Cambridgeshire and Peterborough

It is estimated that, in 2016, 123 men and 87 women (210 individuals) across Cambridgeshire and Peterborough had early onset dementia and that this would increase to 123 men and 87 women (246 individuals) by 2036. It is important to note that the definition used by the Alzheimer's Society report included Alcohol excess on their definition, so this is likely to have increased estimates. However, it still gives an indication of the current and increasing need for services to serve these people and their families. A recent local study indicated that the incidence of dementia in a population is slightly higher than national estimates. This means that the real number of people living with early onset dementia may be slightly higher. See Appendix 1 for more detail. .

The Number of People Aged Over 65 Years Living with Dementia in Cambridgeshire and Peterborough

Prevalence is a measure of the proportion of a population that has a condition at a specific point in time. We do not know the true number of people with dementia in Cambridgeshire and Peterborough due to people living with the condition who have not been diagnosed as having dementia. This means that we have to use ways to estimate the number of people with dementia in Cambridgeshire and Peterborough. Using estimates of the prevalence of dementia in a population, it is possible to estimate the number of people living with dementia.

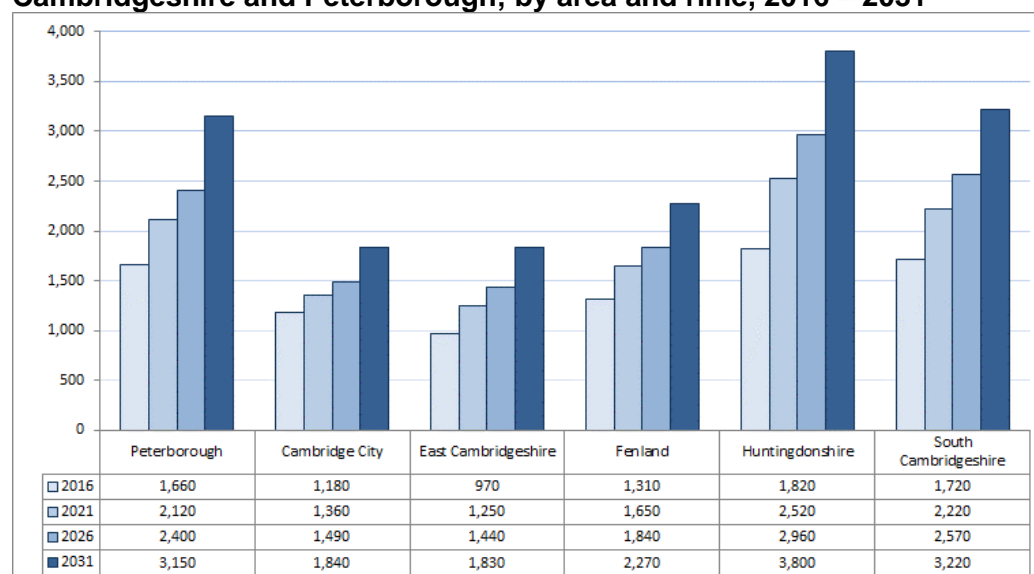
The Cognitive Function and Ageing Study (CFAS) (I and II) provides contemporary estimates of dementia prevalence based on a study of dementia in six geographical areas of England (including Cambridgeshire) over the past two decades⁹. The authors found a 'cohort' effect whereby later-born populations seem to have a lower risk of prevalence dementia than those born earlier in the past century. It was thought that this might be partly due to work on modifiable risk factors for dementia. This study therefore suggests that previous estimates of dementia have slightly over-estimated future prevalence of dementia. However, we know that the population in Cambridgeshire and Peterborough is getting older. The latest population forecasts estimate that there will be 220,000 people over the age of 65

by the year 2031, with a higher proportion of these older people being over 85 (18%). This will inevitably impact the number of people living with dementia in the area because the incidence of dementia doubles with every 5 year increase in age. The increase in age profile of the local population will significantly outweigh any benefit from a cohort effect as described in CFAS II where the incidence of dementia in the population was shown to have decreased, with the likely net result that the number of people living with dementia will increase. Dementia in the older population is also more likely to be comorbid with other conditions. Where there is co-morbidity, dementia is a single, though powerful, contributor towards greater frailty and its attendant increase in complex health and social care usage.

Applying the CFAS prevalence estimates to the Cambridgeshire and Peterborough population, it is estimated that in 2016, there were 7,000 people living with dementia in Cambridgeshire and 1,660 in Peterborough in 2016, a total of 8,660 aged over 65 years across the area. These figures do not include those with early onset dementia.

Figure 3 below shows how prevalence varies across Cambridgeshire and Peterborough and how it is expected to change over time. This shows that the number of people living with dementia is expected to increase by 86% over the next 15 years, from 8,660 to 16,110. It also shows that Huntingdonshire and South Cambridgeshire have the highest number of people living with dementia, and East Cambridgeshire and Cambridge City have the lowest number.

Figure 3: Estimates of the Number of people (aged 65+) living with Dementia in Cambridgeshire and Peterborough; by area and time, 2016 – 2031⁴⁹

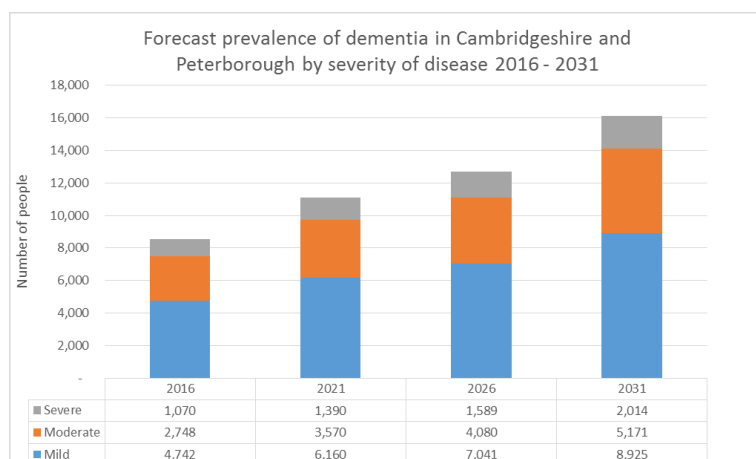


Dementia is a progressive illness from which there is no currently recovery. At different stages in this progression, the needs of people with dementia and their carers change. The changes that people experience have led to 3 groupings – mild, moderate and severe. In order to plan to assess, treat and support people effectively, it is necessary to understand

⁴⁹ Calculated using CFAS II prevalence estimates applied to local population forecasts (2015 based)

the numbers of people likely to be in each group. The Alzheimer's Society expert Delphi consensus statement estimates that 55.4% of people with late onset-dementia have mild dementia, 32.1% have moderate dementia and 12.5% have severe dementia. Applying these proportions to the dementia prevalence estimates in Cambridgeshire and Peterborough for 2016 to 2031 gives us an idea about the number of people living with mild, moderate and severe dementia (See Figure 4 below). It shows that, in 2016, there were an estimated 4,742 people (aged 65+) with mild dementia, 2,748 with moderate dementia and 1,070 with severe dementia in Cambridgeshire and Peterborough.

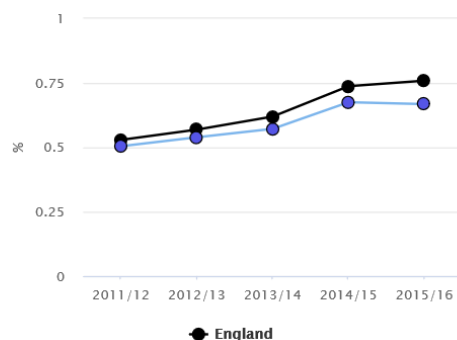
Figure 4: Forecast Prevalence of Dementia by Severity of Disease (Aged 65+), Cambridgeshire and Peterborough, 2016 – 2031



The recorded dementia prevalence provides an indication of the concentration, within a population, of the number of people who have been diagnosed and who are now living with the condition. The following data has been extracted from the Public Health England (PHE) Fingertips Dementia Profiles^{vi} and are based on the number of people with dementia recorded on their practice register within a CCG, as a proportion of people (all ages) registered at each GP practice within a CCG.

The data for Cambridgeshire and Peterborough is presented in Figures 3 and 4 above. The data show that there were 4,593 people recorded as having dementia in Cambridgeshire in 2015/16 (a prevalence of 0.7%) and 1,254 people recorded as having dementia in Peterborough (a prevalence of 0.6%). The difference between these numbers and the estimated numbers of people living with dementia indicate that there are a significant number of people in Cambridgeshire and Peterborough who have dementia but remain undiagnosed. Diagnosis of dementia will be explored further in Section 3. Figures 5 and 6 below also show that the recorded prevalence of dementia has increased between 2011/12 and 2015/16 in both Cambridgeshire and Peterborough.

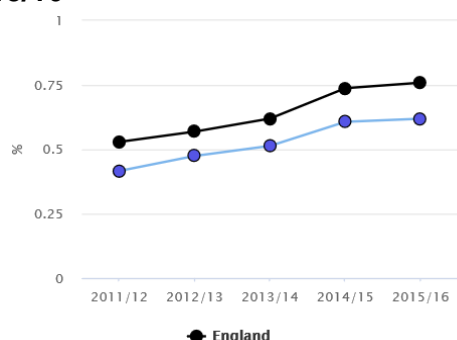
Figure 5: Recorded Prevalence of Dementia (All Ages), Cambridgeshire, 2011/12 – 2015/16⁵⁰



Period	Count	Value	Lower CI	Upper CI	East of England	England
2011/12	3,213	0.5	0.5	0.5	0.5	0.5
2012/13	3,486	0.5	0.5	0.6	0.6	0.6
2013/14	3,762	0.6	0.6	0.6	0.6	0.6
2014/15	4,538	0.7	0.7	0.7	0.7	0.7
2015/16	4,593	0.7	0.6	0.7	0.8	0.8

Source: Quality Outcomes Framework (QOF), NHS Digital

Figure 6: Recorded Prevalence of Dementia (All Ages), Peterborough, 2011/12 – 2015/16⁵¹



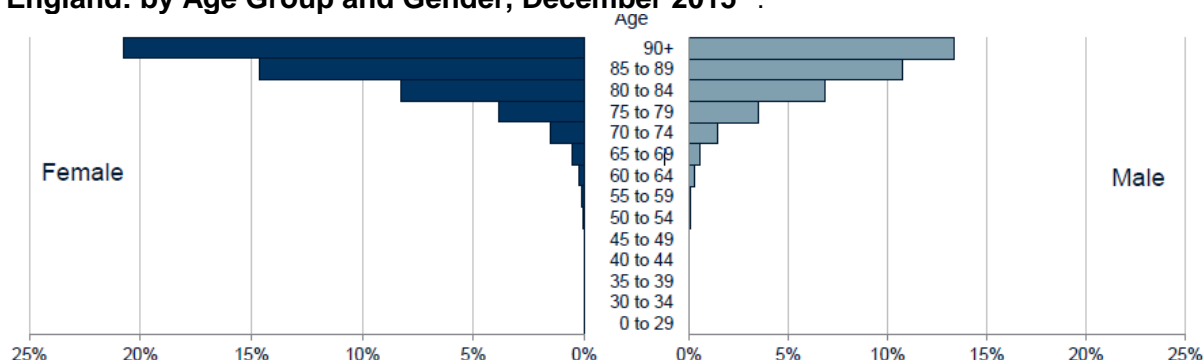
Period	Count	Value	Lower CI	Upper CI	East of England	England
2011/12	764	0.4	0.4	0.4	0.5	0.5
2012/13	890	0.5	0.4	0.5	0.6	0.6
2013/14	983	0.5	0.5	0.5	0.6	0.6
2014/15	1,189	0.6	0.6	0.6	0.7	0.7
2015/16	1,254	0.6	0.6	0.7	0.8	0.8

Source: Quality Outcomes Framework (QOF), NHS Digital

:

It is also possible to use data to see how recorded dementia prevalence varies with age and gender; this is shown in Figure 7 below, which presents national data from GP records (the Quality Outcomes Framework). It shows that dementia is more common in women than men, and prevalence increases with age.

Figure 7: Recorded Dementia Prevalence, Percentage of Registered GP Patients: England: by Age Group and Gender, December 2015⁵².



People with learning disabilities are at increased risk of developing dementia as they age; an estimated 1 in 5 people with a learning disability who are over the age of 65 will develop

⁵⁰ PHE Dementia Profile

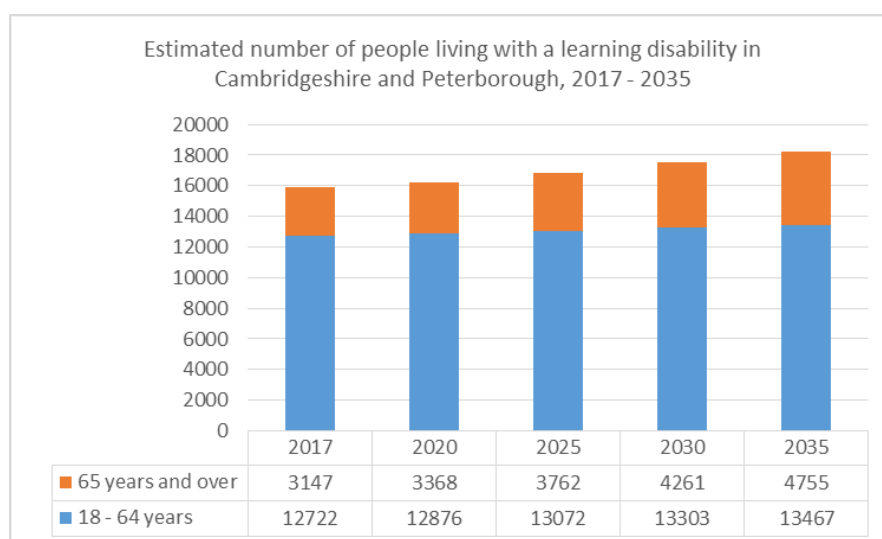
⁵¹ PHE Dementia Profile

⁵² Quality and Outcomes Framework Data, HSCIC, www.hscic.gov.uk/pubs/qofdemdec15

dementia. People with learning disabilities who develop dementia are more likely to do so at an earlier age. This is particularly true for people with Down's Syndrome. It is estimated that a third of people with Down's Syndrome develop dementia in their 50s.^{vii}

Figure 8 below shows that the number of older people in Cambridgeshire and Peterborough living with a learning disability is expected to increase by 51% over the next 18 years, from 3,147 in 2017 to 4,755 in 2035.

Figure 8: The Estimated Number of People Living with a Learning Disability in Cambridgeshire and Peterborough, 2017 – 2035⁵³



The most common cause of dementia is Alzheimer's disease. Other possible causes include vascular dementia, Lewy Body disease and other Parkinsonian syndromes and various forms of frontotemporal lobar degeneration. A large number of rarer conditions can cause dementia including infectious causes such as HIV or CJD and hereditary conditions such as Huntington's disease. The most common cause of dementia in younger people remains Alzheimer's disease, though other rare causes cause proportionately more cases compared to late onset disease. In Cambridgeshire there are 11.5 cases of dementia per 100,000 person years for those aged 45-64 of which 4.2 are Alzheimer's, 3.5 frontotemporal dementia and 0.8 Huntington's disease⁵⁴.

Evidence is increasing suggesting that the majority of cases in very late life are secondary to mixed disease, hence a rise in diagnosis of cases of 'mixed dementia'. Commissioning of disease specific pathways, for example for Parkinson's disease needs explicit consideration of how dementia in these patients is identified and managed to avoid clinical gaps appearing. Mild Cognitive Impairment (MCI) describes a condition where cognition is impaired but function is intact. People with MCI are an important group as they are at increased risk of developing dementia (at a rate of c10% per year). However it is important to differentiate them from those with dementia, as not all will deteriorate and develop full

⁵³ www.pansi.org.uk

⁵⁴ <http://www.neurology.org/content/71/19/1496.short>

blown disease. Whilst they are at high risk, they are not simply those with ‘early’ dementia and represent a large mixed bag of cases where accurate identification is important, estimates of the prevalence of this condition range from 3-19% in the over 65s.. A further important group, often neglected in commissioning, are those who have significantly impaired cognition and function secondary to a specific insult and whose condition may not be progressively declining. These include those with chronic impairment secondary to stroke or alcohol use.

2.2.2 Local Strategic Context

The local strategic context for this strategy is provided by the priorities of the Cambridgeshire and Peterborough Sustainability and Transformation Partnership⁵⁵ (STP). The strategic objectives of partner organisations – commissioners and providers - within the STP are increasingly aligned to the STP strategic priorities and therefore the STP priorities provide a summary of the strategic direction and objectives of local statutory and non-statutory health and care organisations. These priorities are summarised in Figure 9 below.

Figure 9: Cambridgeshire and Peterborough Sustainability and Transformation Plan Priorities for Change: 10 Point Plan

Priorities for Change	10 Point Plan
At home is best	1. People powered health and wellbeing 2. Neighbourhood care hubs
Safe and effective hospital care, when needed	3. Responsive urgent and expert emergency care 4. Systematic and standardised care 5. Continued world-famous research and services
We're only sustainable together	6. Partnership working
4Supported delivery	7. A culture of learning as a system 8. Workforce: growing our own 9. Using our land and buildings better 10. Using technology to modernise health

2.3. Dementia Services in Cambridgeshire and Peterborough

2.3.1 Overview

Dementia services are made up of community and acute physical and mental health and social care services. Although there are areas of average to good performance,

⁵⁵ Cambridgeshire and Peterborough CCG, Cambridgeshire County Council, Peterborough City Council, Cambridgeshire Community Services NHS Trust, Peterborough and Stamford Hospitals NHS Foundation Trust, Hinchingbrooke Healthcare NHS Trust, Cambridge University Hospitals NHS Foundation Trust, Cambridgeshire and Peterborough NHS Foundation Trust, Papworth Hospital NHS Foundation Trust

improvement is needed in a number of key areas. The improvements required include both changes to and development of specific services under each of the Well Pathway Pillars. In addition, there is a need for a much more clearly defined care pathway. This would improve both the accessibility of services and co-ordination of care across organisations and between professional groups. In addition, much closer working with people living with dementia and their carers is needed both to identify the changes that will make the biggest impact on both experience of, and outcomes from care.

2.3.2 Specialist Dementia Services

Across Cambridgeshire and Peterborough there are well established dementia services. These are commissioned by the CCG, CCC and PCC and provided by CPFT which provides:

- Assessment, diagnosis, post-diagnostic support, care and treatment of people newly diagnosed with dementia: Memory Services.
- Care and treatment of people with moderate and severe dementia.
- Acute hospital liaison dementia services in Cambridge University Hospital (CUH), Hinchingsbroke Hospital Care Trust (HH) and Peterborough City Hospital (PCH).
- Dementia Intensive Support Teams (DIST) for people with dementia in crisis as part of a Crisis Resolution and Home Treatment (CRHT) service.
- In-patient assessment and treatment for people with severe, complex and challenging dementias.
- Dementia training and education in acute hospitals and care homes: CAMTED-OP
- Admiral Nurses
- Dementia carers support

As well as providing access to diagnosis, assessment and support following diagnosis, the Memory Services offer access to Dementia Advisors who provide support around the time of diagnosis and a Dementia Support Service which provide ongoing support and advice. Both services are integrated within the Memory Service but are provided by the Alzheimer's Society.

Most CPFT clinical staff are based in locality teams where they are part of the multidisciplinary team and many staff work across a wider patient group than just those with a diagnosis of dementia. People who are assessed by the Memory Services as being sub-diagnosis i.e. with mild cognitive impairment will be referred back to their GP who will monitor and refer back to CPFT for further assessment as necessary e.g. if there is a deterioration in the individual's health. . Referral may also be to Adult Social Care for assessment of social care needs. The four Memory Services across Cambridgeshire and Peterborough are described in Table 2 below.

Table 2: Memory Services in Cambridgeshire and Peterborough

Peterborough and Borders	Provided in the Dementia Resource Centre (DRC) by clinical staff who outreach from the locality mental health team as well as from the locality base. The DRC is in purpose build dementia friendly building separate from the Integrated Care Team (Locality Team) and has space for groups and activities and has a café and drop in centre.
Cambridge	Located in Brookfields with the Integrated Care Team.
Huntingdon	Located in Hinchingsbrooke Hospital with the Integrated Care Team.
East Cambridgeshire and Fenlands	Located in Doddington with the Integrated Care Team with clinics in Wisbech and Ely.

There has been additional investment in Crisis Resolution and Home Treatment services (CRHT) for older people with mental health problems with the establishment and expansion of the Dementia Intensive Support Team (DIST) within the CRHT. The CRHT provides rapid and intensive community input, including treatment of behavioural and psychiatric symptoms of dementia and delirium, prevention of avoidable admissions and support to carers and for those in crisis in their own home and in residential and nursing homes. Expanded hours and increased staffing resources have enabled the DIST service to support 429 people with dementia in 2015/16.

2.3.3 Acute Hospitals and the Community and Primary Care

Health and Social Care Services

Primary care, community and acute hospital services have a critical role to play in the diagnosis, assessment and treatment of people living with dementia and their carers. This is particularly the case for older people living with dementia who are most likely to either be physically frail or to have more than one physical health condition. The services provided are described in detail elsewhere. However, of particular relevance to this Strategic Plan are GPs, the Community Neighbourhood Teams provided by CPFT, Adult Social Care Teams and the range of health and social care and voluntary sector services designed to prevent admission to Acute Hospital and/or to facilitate discharge when treatment is complete.

The CCG provides the Care Home Support Team, a team of nurses who act as care home facilitators. The team prioritises which care homes to work with based on areas that homes may need assistance with. This includes the areas of end of life planning and end of life care planning after death. The facilitators use quality improvement training, advice and signposting to empower care home staff to implement the change ideas. They also use external agencies to help identify where practice is sub optimal. In End of Life this is identified by the Hospice at Home Teams, the Community Palliative Nurses and the Acute Palliative Nurses as well as the End of Life facilitators within CPFT. The facilitators work with the Care Homes to improve their practice and identify the support available to them.

2.3.4 The Voluntary Sector

Voluntary sector organisations are commissioned to provide information, guidance and care and support for people diagnosed with dementia, their carers, families and the communities in which they live. The key voluntary sector organisations that are involved with dementia are:

- **The Carers' Trust:** provides support for carers across all client groups, including dementia.
- **Making Space:** provides specialised support for carers with mental health problems.
- **The Alzheimer's Society:** provides a wide range of information, advice and support available for people living with dementia and their carers, including advocacy, dementia advisers, dementia cafés, activities, information and peer support. In Peterborough, support is provided through the DRC. In Cambridgeshire the services are provided alongside the Memory Services provided by CPFT. The Alzheimer's Society also supports the development of Dementia Friendly Communities and Environments.

Although these services are seen overall to be appropriate and of good quality services are not commissioned consistently across Cambridgeshire and Peterborough.

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2.3.5 The Independent Sector

The independent sector are commissioned to provide home care, residential and nursing home and home/domiciliary care to meet the needs of people who are eligible for support by the Councils and/or CCG.

2.3.6 Investment in Dementia Care

Further work is needed to understand the total health and social care investment in dementia care across Cambridgeshire and Peterborough. This work will be completed as part of the work to develop and review the dementia care pathway to 30.09.18.

2.4 Gap Analysis

Benchmarked data published by NHS England and by Public Health England along with local activity data relating to the performance of acute and community services and specialist mental health services was analysed included in Sections 2.4.1 and .2.4.2 below. The data published by Public Health England was chosen over the Right Care data for the final analysis because it enabled differentiation in performance in Cambridgeshire and Peterborough because this assisted with identifying plans and prioritising areas for improvement. The data provided is from Public Health England unless otherwise indicated.

This information was supplemented by local performance data from monitoring undertaken by health and social care services.

This analysis was combined with a summary of the views of stakeholders - managers, practitioners and commissioners in statutory, voluntary and independent sector organisations, and people living with dementia and their families and carers. The summary was developed using the outcomes of engagement events undertaken over the previous 2 years, information collected routinely during service delivery and commissioning processes and engagement events arranged specifically to allow a wide range of stakeholders to review and input to the Strategic Plan. The findings provide the basis for identification of the priorities for improvement and are therefore summarised under the headings for each of the Well Pathway pillars and cross cutting themes in Sections 3.2. The full gap analysis is included at Appendix 1.

3 Our Vision, Priorities and Actions

In this section, the findings from Section 2 are drawn together and prioritised action plans for improvement against each of the Well Pathway pillars and cross cutting themes are identified. The structure for each section is the same. However, as each section has been written by the lead for that specific aspect of dementia, there is some inconsistency in styles of writing within this part of the Strategic Plan.

3.1 Our Vision

Members of the OPMH Delivery Board worked with stakeholders to agree a vision for dementia in Cambridgeshire and Peterborough:

We will work hard to prevent people in Cambridgeshire and Peterborough from acquiring dementia and ensure that those living with and affected by dementia receive compassionate, expert care and support, that is right for them to live positive and fulfilling lives we will support and empower them to take part in, and contribute to, the families and communities in which they live and work.

Adapted from Dementia UK's Strategy

3.2 Our Priorities

3.2.1 Preventing Well

The Standard

The risk of people developing dementia is minimised: "I was given information about my personal risk of getting dementia"

The standard includes the following parts of the Well Pathway:

- Prevention
- Risk reduction
- Health information
- Supporting research

Overview

There is clear evidence that a number of modifiable risk factors, including smoking, physical inactivity and obesity, increase an individual's risk of developing dementia. The prevalence of these risk factors varies across Cambridgeshire and Peterborough, with a general pattern

of higher rates of harmful health behaviours seen in Peterborough and Fenland. There is an opportunity to use recent guidance published by NICE and Public Health England (PHE) to take public health action to reduce these risk factors and incorporate messages of dementia risk reduction into existing programmes of work.

Best Practice and Guidelines

The Blackfriars Consensus⁵⁶: The Blackfriars Consensus (2014) makes the case for concerted action to reduce people's risk of dementia by supporting them to live healthier lives and manage pre-existing conditions that increase their risk of dementia.

NICE Guidance (NG16) 'Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset'⁵⁷: Guided by evidence reviews conducted by The Cambridge Institute of Public Health, NICE recently published guidance on mid-life approaches to delay or prevent the onset of dementia, disability and frailty in later life. It sets out the case for promoting a healthy lifestyle to reduce the risk of or delay the onset of dementia. The guidelines also highlight that there is emerging evidence on the importance of psychosocial risk factors throughout life such as loneliness, isolation and depression. The recommendations within the guidelines make it clear that risk reduction is complex and requires multiagency action.

Public Health England Guidance: The most recent guidance on the effect of midlife risk factors on dementia from Public Health England⁵⁸ is based on a review conducted by the Personal Social Services Research Unit which found evidence that the following risk factors in mid-life are associated with an increased risk of dementia later in life:

- Physical inactivity in mid-life is highly prevalent and increases the risk of all-cause dementia: people inactive in midlife have more than double the risk of dementia in old age than those who are physically active.
- Current smoking increases the risk of all-cause dementia: the risk of dementia in old age is slightly higher for smokers in midlife than for non-smokers, but past smoking is not associated with an increased all-cause dementia risk.
- Diabetes increases the risk of all-cause dementia; while the samples in several reviews include older people, there are some original studies specifically from midlife which suggest that people with diabetes have around 2.5 times the risk of onset of dementia in old age.

⁵⁶ Blackfriars Consensus on promoting brain health: reducing risks for dementia in the population (2014). Public Health England & the UK Health Forum and Public Health England. Available from:

http://nhfshare.heartforum.org.uk/RMAssets/Reports/Blackfriars%20consensus%20%20_V18.pdf

⁵⁷ National Institute for Health and Care Excellence (2015) Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset. NICE guideline (NG16)

⁵⁸ Read S, Wittenberg R, Karagiannidou M, Anderson R & Knapp M at the Personal Social Services Research Unit, London School of Economics and Political Science on behalf of Public Health England (2017). The Effect of Midlife Risk Factors on Dementia in Older Age. Available from:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/633096/effect_of_midlife_risk_factors_on_dementia_in_older_age.pdf.

- Hypertension in mid-life increases the risk of all-cause dementia: people with hypertension in midlife are at slightly greater risk of dementia in old age
- Obesity in mid-life increases the risk of all-cause dementia: people who are obese have around 1.6 times the risk of onset of dementia in old age
- Depression increases the risk of all-cause dementia; while the samples in several reviews include older people, there are studies specifically for midlife depression which suggest that people with depression in midlife are at slightly greater risk of dementia in old age.
- Mental activities in mid-life are associated with a lower risk of dementia in later life: for example, higher complexity of working with data among lower educated people in midlife can roughly halve the risk of dementia in old age.

In addition to the above guidance which focuses on mid-life risk factors, Public Health England have published an evidence-based resource for local authorities and commissioners on changing risk behaviours and promoting cognitive health in older adults⁵⁹. The report uses the findings of three systematic reviews which examine the evidence on the effectiveness of interventions aimed at reducing unhealthy behaviours in older people, whether these result in the prevention or delay of cognitive decline or dementia, and any barriers or facilitators to success. The guidance concludes that:

There is evidence that changes in health behaviour in older age can have beneficial effects on cognitive function in the short term although no intervention studies to date have reported longer term impact on the prevention or delay of dementia onset.'

It summarises the available evidence for a number of risk factors (including diet, physical activity, cognitive stimulation and social isolation) and recommends that efforts should focus on developing and implementing guidance, policies and interventions to reduce smoking and alcohol consumption across the population, including in older adults.

Modelling of the potential of primary prevention by Norton et al⁶⁰: In 2015, Norton et al reported that a third of Alzheimer's cases worldwide might be attributable to potentially modifiable risk factors. Alzheimer's disease incidence might be reduced through reduction in seven risk factors: diabetes mellitus, midlife hypertension, midlife obesity, physical inactivity, depression, smoking and low educational attainment. It was estimated that by 2050, if these seven risk factors were reduced by 10%, 170,000 (8.8%) of UK cases of Alzheimer's disease could be prevented. If these seven risk factors were reduced by 20%, 314,000 (16.2%) of predicted cases could be averted. We have applied these potential reductions in prevalence through primary prevention to the Cambridgeshire and Peterborough population. Table 3 below shows the estimated number of cases of Alzheimer's disease that could be prevented through effective reductions in these seven risk factors. A 20% reduction across

⁵⁹ Lafortune L, Kelly S, Olanrewaju O, Cowan A & Brayne C at the Cambridge Institute of Public Health on behalf of Public Health England (2016). Changing risk behaviours and promoting cognitive health in older adults – an evidence-based resource for local authorities and commissioners. Available from:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/571471/changing_risk_cognitive_health_report.pdf

⁶⁰ Norton S, Matthews FE, Barnes DE, Yaffe K, & Brayne C (2014). Potential for primary prevention of Alzheimer's disease: an analysis of population-based data. *The Lancet Neurology*. 13:788-94.

these seven risk factors could prevent 3,067 (9.2%) of Alzheimer's disease across Cambridgeshire and Peterborough by 2036.

Table 3: Impact of a 10% and 20% Reduction in the Risk Factors for Dementia Per Decade on the Estimated Number of Cases of Dementia in Cambridgeshire and Peterborough

Indicator	2016 %	2021 %	2026 %	2031 %	2036 %
% reduction in prevalence of dementia resulting from a 10% reduction per decade in the relative prevalence of the 7 risk factors	0.0	2.4	4.6	6.8	8.8
% reduction in prevalence of dementia resulting from a 20% reduction per decade in the relative prevalence of the 7 risk factors	0.0	4.8	9.2	12.9	16.2
Indicator	2016 No.	2021 No.	2026 No.	2031 No.	2036 No.
Reduction in number of cases of dementia with 10% reduction in risk factors	0	-267	-585	-1,095	-1,666
Reduction in number of cases of dementia with 20% reduction in risk factors	0	-534	-1169	-2,078	-3,067
Number of people with dementia if a 10% reduction in risk factors is achieved	8,560	10,850	12,130	15,010	17,260
Number of people with dementia if a 20% reduction in risk factors is achieved	8,560	10,590	11,540	14,030	15,860

Specific NICE guidance includes NG 16 Dementia, disability and frailty in later-life – mid-life approaches to delay or prevent onset².

Local Data

The following data is taken from the Public Health England Dementia Profiles (see Section 2.2.1 for further detail about the indicators and data source).

- Smoking prevalence in adults is below the national average in Cambridgeshire 15.2% but just above in Peterborough at 17.6%.
- In Cambridgeshire, 25.3% of adults are physically inactive which is lower than the national average. In Peterborough, 34.3% of adults are physically inactive which is higher than the national average.
- In Cambridgeshire 63.2% of adults are overweight or obese – this is less than the national average. In Peterborough, 70.8% of adults are overweight or obese which is greater than the national average.
- In Cambridgeshire 9.6% and in Peterborough 10.4% of the eligible population had received their NHS health check.

Key Objectives

Key Objective 1: Build strategy to include evidence-based and equitable primary, secondary and tertiary prevention efforts across the life course.

Key Objective 2: Incorporate dementia risk reduction into current long-term disease approaches and unique messaging.

Measuring Success:

The ultimate aim of this strand of work is to reduce the prevalence of dementia through efforts to tackle modifiable risk factors across the life course, with a focus on mid-life. However, the latest PHE report on dementia prevention states that a reduction in some risk factors, for example smoking, affects mortality as well as dementia incidence. People who change behaviours in middle age may experience considerably improved life expectancy. It is, therefore, possible that while they may gain a reduced risk of onset of dementia at a given age, for example in their seventies, their lifetime risk of onset of dementia may rise and be higher than if they had not changed their behaviours. In addition, there are challenges to measuring the true prevalence of dementia in a given area (see Section 3.2.2. below Diagnosing Well for more information). It will therefore be appropriate to measure success of this pillar of work using process measures (e.g. inclusion of dementia prevention messages in behaviour change training) and measures of health behaviours in the population. In addition, the evidence base for dementia prevention, especially on targeting unhealthy behaviours in older people, should continue to be monitored to inform the development of this area of work.

Action Plan

Action	Further information	Measures of success	Lead	Timescales
1.1 Continue delivery of public health strategy and interventions that aim to support people to lead healthy lifestyles throughout their life course, including: <ul style="list-style-type: none"> - Stopping smoking; - Being more physically active; - Reducing their alcohol consumption; - Adopting a healthy diet; - Achieving and/or maintaining a healthy weight. 	<ul style="list-style-type: none"> • This work is coordinated by the Health Improvement Team within public health with services being commissioned by the public health Joint Commissioning Unit. • Integrated lifestyle services (including weight management and smoking cessation) are provided by Everyone Health in Cambridgeshire and Solutions for Health in Peterborough. • This links with implementation of the older people's primary prevention JSNAs. 	KPIs of integrated lifestyle services and prevalence of health behaviours (e.g. smoking, physical inactivity, excess weight)	Public health (Core public health business overseen by health improvement lead Consultant)	Ongoing
1.2 Work with public health commissioners and local providers to ensure that these	<ul style="list-style-type: none"> • NHS Health Checks already include messages around preventing dementia. • Work with colleagues in the Health Improvement Team and Joint Commissioning Unit in public health and the healthy lifestyle 	Effective inclusion of dementia risk reduction messages in healthy lifestyle interventions and the	Public health (Senior Public Health Manager –	Jan to June 2018

healthy lifestyle interventions include messages around dementia risk reduction.	<p>providers (Everyone Health in Cambridgeshire and Solutions for Health in Peterborough) to understand current practice and implement inclusion of messages about dementia risk reduction in healthy lifestyle interventions.</p> <ul style="list-style-type: none"> • Link with the Cambridgeshire and Peterborough Diabetes Prevention Programme to ensure messages of dementia prevention are included within the programme. 	diabetes prevention programme.	Older People)	
1.3 Raise awareness about how the risk of dementia can be reduced by keeping physically and mentally healthy using public health campaigns.	<ul style="list-style-type: none"> • Ensure messages about dementia risk reduction are included in local public health campaigns that act to promote healthy lifestyles. • This will include local campaigns in Cambridgeshire, the Healthy Peterborough campaigns and pharmacy public health campaigns. • Dementia prevention will be included as a quality standard in the public health communications strategy. 	Effective inclusion of dementia risk reduction messages in all relevant public health campaigns.	Public health (Communications Lead)	Ongoing
1.5 Work with commissioners and providers to ensure Healthy Conversation Skills and Behaviour Change training includes messages around dementia risk reduction.	<ul style="list-style-type: none"> • Public health are currently working with the CCG to develop a programme of healthy conversation skills training. • Behaviour change training is delivered by Everyone Health. • Target training to appropriate frontline staff e.g. social care, voluntary sector organisations. 	Effective inclusion of dementia risk reduction messages in behaviour change training and healthy conversation skills training.	Public health (Lead for health coaching)	Jan to June 2018
1.6 Continue delivery of work place health programme with employers across Cambridgeshire and Peterborough which aims to support employees to lead healthy lifestyles.	<ul style="list-style-type: none"> • The Workplace Health Programme is currently delivered by Living Sport. • Provision includes Mental Health First Aid Lite Training and Health Champion Training alongside tailored advice and support networks for employers. • Messages about dementia risk reduction and supporting those with dementia in the workplace can be included as part of support network content. 	Effective inclusion of dementia risk reduction messages in the workplace health.	Public health (Work place health lead)	Ongoing
1.7 Work with colleagues through the Older People's	<ul style="list-style-type: none"> • Review the evidence base for secondary and tertiary prevention of dementia. 	Evidence base is used to design and deliver messages on diagnosis to enable	Public health (Senior Public Health	April to September 2018

Mental Health Board to identify the current provision of secondary and tertiary prevention (including healthy lifestyle advice and signposting to lifestyle services) and address any identified gaps.	<ul style="list-style-type: none"> Link with the strategy lead for diagnosing well pathway to understand current practice. 	effective secondary prevention where appropriate.	Manager – Older People)	
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3.2.2 Diagnosing Well

The Standard

Timely accurate diagnosis, care plan, and review within first year. “I am diagnosed in a timely way. I am able to make decisions and know what to do to help myself and who else can help”.

This standard includes the following parts of the Well Pathway:

- Diagnosis
- Memory assessment
- Concerns discussed
- Investigation
- Provide information
- Integrated and advance care planning

Best Practice and Guidelines

MSNAP⁶¹ provides a quality framework for Memory Assessment Services. The standards aim to enable Memory Assessment Services to evaluate themselves against a set of agreed standards based on best practice and guidance defined by the Royal College of Psychiatrist and including the National Institute for Clinical Excellence (NICE) guideline, Dementia: supporting people with dementia and their carers in health and social care⁶². Although the primary focus is Memory Assessment Services, the standards address the treatment and support that should be available following diagnosis:

- Management
- Resources Available to Support Assessment and Diagnosis
- Assessment and diagnosis
- Ongoing care management and follow up
- Pharmacological interventions
- Psychosocial interventions

This means that the Standards include items that feature under the Supporting Well and Living Well Pillars of the Well Pathway. MSNAP includes a set of quality indicators relating to key aspects of the Pathway. (Appendix xx). They will therefore be used to underpin the development of the pathway that are defined under Diagnosing Well, Living Well and Supporting Well.

⁶¹ Memory Assessment Service National Accreditation Programme (MSNAP): Standards for Memory Assessment Services, 5th edn., Pub.No. CCQI221 Royal College of Psychiatrists, 2016

⁶² Dementia: supporting people with dementia and their carers in health and social care, CG42, November 2006, last updated: September 2016, NICE, <https://www.nice.org.uk/guidance/cg42>

Local Data

National guidelines relating to Diagnosing Well, are contained within Dementia: Supporting people with dementia and their carers in health and social care⁶³. MSNAP⁶⁴ incorporates these guidelines into a set of standards that give more detailed guidance relating to diagnosing dementia and supporting individuals and their carers pre- and post diagnosis. It also includes standards that aim to enable people living with dementia and their carers to participate and live independently in their communities, as well as standards relating to ongoing care management and follow up, pharmacological and psychosocial interventions. MSNAP⁶⁵ includes a set of quality indicators and therefore provides a basic quality framework for both Memory Assessment Services and the wider dementia care pathway.

The overall aim of the national dementia guideline and MSNAP is to enable people to live independently and safely at home for as long as possible, avoiding crises and hospital admission wherever possible. The aim of these guidelines is therefore to ensure diagnosis as early in the course of the illness as possible in order to ensure that there is access to the information, advice, guidance that people need to make choices and take control of their care. It also aims to ensure that treatment and support needs are identified and addressed early, and that advance care planning takes place so that individuals' needs and wishes are addressed in a way that is in accordance with their wishes as the disease progresses.

The gap analysis showed that the diagnosis rate for Cambridgeshire is slightly below average - 62.7% against the national target (67%). However, Peterborough performs well when compared with the rest of the county with a diagnosis rate of 78.4%. However, there is significant variation in diagnosis rates between GP practices. Stakeholders identified access to and speed of diagnosis as a strength in local provision. The following gaps/opportunities for improvement were identified:

- Advance care planning so that crises, avoidable admission to hospital is minimised, particularly in the event of a carer being unable to care temporarily and plans are made for end of life
- Case finding in care homes.

These gaps will be addressed through the Key Objectives identified below. In addition, the Memory Assessment Service will work towards MSNAP accreditation.

Key Objectives:

Key Objective 1: To increase the rate of diagnosis of dementia

⁶³ Dementia: supporting people with dementia and their carers in health and social care, CG42, November 2006, last updated: September 2016, NICE, <https://www.nice.org.uk/guidance/cg42>

⁶⁴ Memory Assessment Service National Accreditation Programme (MSNAP): Standards for Memory Assessment Services, 5th edn., Pub.No. CCQI221 Royal College of Psychiatrists, 2016

⁶⁵ Memory Assessment Service National Accreditation Programme (MSNAP): Standards for Memory Assessment Services, 5th edn., Pub.No. CCQI221 Royal College of Psychiatrists, 2016

Key Objective 2: To develop a robust dementia pathway within which there is an action plan that is supporting improvement/achievement of the standards within NICE guidelines and MSNAP with protocols, agreed between the Memory Assessment Service, GPs, older people's services and the voluntary sector consistently across Cambridgeshire and Peterborough, (includes assessing the feasibility of commissioning a Memory Assessment Service that meets the standards required to achieve MSNAP accreditation; as a minimum, standards relating to advance planning must be achieved).

Action Plan

Key Objective 1: To increase the dementia diagnosis rate.				
Objective	How Improvement will be Measured	Timescale	Action Required	Lead
1.1 To ensure that the waiting time for and rate of diagnosis in Cambridgeshire so that it at least exceed the national targets (6 weeks and 67%)	Diagnosis rate across Cambridgeshire: Target: exceed national target: 67% Peterborough: Target: at least maintain current rate: 79% Waiting time for diagnosis: achieve 18 weeks referral to assessment (KLOE)	31.03.19	i) Engagement/work with GP practices: Cambridgeshire ii) Ensure that all GPs have received recent training on dementia diagnosis (in hand through CAMTED-OP) (KLOE) iii) Ensure that all GPs and primary care staff have received training in dementia within minority ethnic communities (KLOE)	CPFT Clinical Lead (OPMH) with CCG Clinical Lead (OPMH)
1.2 Ensure consistency in diagnosis rates within Cambridgeshire and Peterborough, reducing variation.	Diagnosis rate across Cambridgeshire: Target: exceed national target: 67% Peterborough: Target: at least maintain current rate: 79% Waiting time for diagnosis: achieve 18 weeks referral to assessment (KLOE)	31.03.20	i) Engagement/work with GP practices: Cambridgeshire and Peterborough ii) Ensure that every practice is using the Data Quality Toolkit to cleanse data re:patients with dementia (http://www.necsu.nhs.uk) (KLOE) iii) Ensure that every practice is using the DiADeM tool in care homes (KLOE)	CPFT Clinical Lead (OPMH) with CCG Clinical Lead (OPMH)
1.3 Increase the rate of diagnosis of dementia in care homes	Rate of diagnosis of dementia in residential and nursing homes	31.03.20	i) Roll out use of the Dementia Case Finding Tool for Care Homes ii) Develop a system for measuring the rate of dementia diagnosis in care homes	CPFT Clinical Lead (OPMH) with CCG Commissioner (OPMH)
Key Objective 2: To develop a robust pathway that meets the standards within NICE guidelines and MSNAP with protocols agreed between the Memory Assessment Service, GPs, older people's services and the voluntary sector, including protocols that ensure that advance planning is established consistently across Cambridgeshire and Peterborough (includes assessing the feasibility of commissioning a Memory Assessment Service that meets the standards required to achieve MSNAP accreditation).				
Objective	How Improvement will be Measured	Timescale	Action Required	Lead
2.1 Ensure that the Memory Assessment Service achieves the closest fit possible with NICE dementia guidelines as reflected in the MSNAP	Aspirational: Memory Assessment Service achieves MSNAP accreditation meeting 100% Of MSNAP Type 1 standards Memory Assessment Service meets 80% of MSNAP Type 2 standards	30.09.21	i) Undertake a gap analysis, including Memory Assessment Service self-assessment against the MSNAP standards, prioritising advance care planning as part of the work to revise the dementia care pathway: e.g. everyone diagnosed with dementia is referred to a	CCG Clinical Lead (OPMH) with CPFT Clinical Lead (OPMH)

<p>standards within the resources available as part of the work to develop a robust dementia pathway; at a minimum the standards relating to advance planning must be achieved.</p>	<p>Memory Assessment Service meets 60% of MSNAP Type 3 standards</p> <p>Alternative to the above: there is clarity about the standards that can/can't be met by the Memory Assessment Service and an action plan with SMART objectives that will support improved outcomes for people living with dementia and their carers</p> <p>% of people who have an advance care plan within 8 weeks of diagnosis</p> <p>% of people who receive a diagnosis following assessment and start treatment within 6 weeks (KLOE)</p> <p>% referrals for assessment at a Memory Service that receive a diagnosis of dementia (KLOE)</p>		<p>voluntary sector organization for information, advice, guidance and support following diagnosis: 30.06.18</p> <p>ii) Assess resources required to achieve accreditation and undertake a cost/benefit analysis: 30.09.18</p> <p>iii) Develop a business case for improvement of the dementia pathway: 30.09.18</p> <p>iv) Seek approval for the proposed improvements and investment required from each organization and the STP: 31.12.18</p> <p>v) Implement the agreed improvements to the dementia pathway: 01.04.19</p>	
<p>2.2 Assess the gap between current dementia services and the MSNAP standards and determine the improvement and investment that may be required to achieve MSNAP accreditation</p>		<p>31.03.19</p> <p>31.03.20</p> <p>30.09.20</p>	<p>i) Secure STP agreement to consider working towards the commissioning of Memory Assessment Service MSNAP accreditation : 31.01.18</p> <p>ii) Assessment/self-assessment of performance of current Memory Assessment Service and related pathway against MSNAP standards as part of the development of the multi-agency/multi-disciplinary care pathway with key stakeholders: 30.09.18</p> <p>iii) STP decision re: investment/actions required to achieve the MSNAP standards included in the business case for the STP Dementia business case based on ii) above: 31.03.19</p>	<p>CPFT Clinical Lead (OPMH) with CCG Commissioner (OPMH)</p>

			iv) Decision re: attainment of MSNAP accreditation: 31.01.20 v) CPFT/Commissioner Agreement of standards to be attained and monitored from 01.04.20: 31.03.20	
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3.2.3 Supporting Well

The Standard

Access to safe high quality health and social care for people with dementia and their carers. “I am treated with dignity and respect. I get treatment and support which are best for my dementia and my life.”

The standard includes the following parts of the Well Pathway:

- Choice
- Behavioural and Psychological Symptoms of Dementia
- Liaison
- Advocates
- Housing and accommodation
- Hospital treatments
- Technology
- Health and social services
- Hard to reach groups

Best Practice and Guidelines

The guidelines relating to Living Well, are contained within Dementia: Supporting people with dementia and their carers in health and social care⁶⁶. Standards relating to ongoing care management and follow up, pharmacological and psychosocial interventions included in the MSNAP standards apply to assessment, treatment and support in Cambridgeshire and Peterborough because the Memory Assessment Service undertakes diagnosis and initial care planning, but then discharges cases to primary care where no further assessment and treatment is required at the time, or to the Community Mental Health Teams where further assessment, treatment and care planning is required to meet identified needs for treatment and support. (See Section 3.2.2, Diagnosing Well: Best Practice and Guidelines above.).

The national guideline also includes a standard relating to inpatient dementia services, stating that as far as possible, dementia care should be community-based, but that psychiatric inpatient admission may be considered in certain circumstances, including if an individual is severely disturbed and needs to be contained for his or her own health and/or the safety of others or if assessment in a community setting is not possible e.g. if the individual has complex physical and psychiatric problems. It states that as far as possible dementia care services should be community-based, but psychiatric inpatient admission may be considered in certain circumstances, including if an individual is severely disturbed and

⁶⁶ Dementia: supporting people with dementia and their carers in health and social care, CG42, November 2006, last updated: September 2016, NICE, <https://www.nice.org.uk/guidance/cg42>

needs to be contained for his or her own health and/or the safety of others or if assessment in a community setting is not possible e.g. if the individual has complex physical and psychiatric problems.

Local Data

Through the gap analysis, the following strengths were identified:

- Management of dementia in acute hospital (Right Care).
- Early work undertaken in relation to meeting the needs of people from minority groups with dementia.
- Percentage of patients whose care was reviewed at least annually by GPs (Right Care).
- The mortality rate for people with dementia in Cambridgeshire and Peterborough is slightly lower than the England average at 845 per 100,000 people.

Gaps:

- Sufficient capacity in voluntary sector services to enable access.
- The availability of transport to access services.
- Advance care planning so that crises, avoidable admission to hospital is minimised, particularly in the event of a carer being unable to care temporarily and plans are made for end of life.
- The availability of care at home, particularly in more rural areas.
- Pressure on the cost of nursing home care in Cambridgeshire as an affluent area.
- Access to nursing home care for those with the most complex needs, particularly on discharge from hospital.
- Dementia care in residential care and nursing homes.
- Assessment, treatment and support for people with early onset dementia.

Key Objectives

Key Objective 1: To develop a robust dementia pathway within which there is an action plan that supports improvement/achievement of the standards within NICE guidelines and MSNAP consistently across Cambridgeshire and Peterborough that relate to Living Well (includes assessing the feasibility of commissioning a Memory Assessment Service that meets the standards contained within NICE guidelines and MSNAP ; as a minimum, standards relating to advance planning must be achieved).

Key Objective 2: To ensure geographical consistency in relation to Dementia Friendly Communities and Dementia Friendly Environments across Cambridgeshire and Peterborough.

Key Objective 3: To improve awareness of and access to dementia care for hard to reach groups.

Key Objective 4: To ensure that the quality of care of people living with dementia in care homes meets the Care Quality Commission requirements and best practice.

Action Plan

Key Objective 1: To develop a robust dementia pathway within which there is an action plan that supports improvement/achievement of the standards within NICE guidelines and MSNAP consistently across Cambridgeshire and Peterborough that relate to Living Well (includes assessing the feasibility of commissioning a Memory Assessment Service that meets the standards contained within NICE guidelines and MSNAP; as a minimum, standards relating to advance planning must be achieved).				
Objective	How Improvement will be Measured	Timescale	Action Required	Lead
1.1 Ensure that the Memory Assessment Service achieves the closest fit possible with NICE dementia guidelines as reflected in the MSNAP standards within the resources available as part of the work to develop a robust dementia pathway; at a minimum the standards relating to advance planning must be achieved.	<p>Aspirational: Dementia Pathway meets the MSNAP accreditation meeting 100% Of MSNAP Type 1 standards Memory Assessment Service meets 80% of MSNAP Type 2 standards Memory Assessment Service meets 60% of MSNAP Type 3 standards.</p> <p>Aspirational: Dementia Pathway fully meets the standards contained within the Nice Guidelines.</p> <p>A care pathway between organisations with a key role in dementia across the health and social care system in place.</p> <p>Protocols in place between services across the care pathway e.g. the Memory Assessment Service, GPs, older people's services and the voluntary sector consistently across Cambridgeshire and Peterborough. Alternative to the above: there is clarity about the standards that can/can't be met by the Memory Assessment Service and an action plan with SMART objectives that will support improved outcomes for people living with dementia and their carers.</p> <p>% of people who have an advance care plan within 8 weeks of diagnosis.</p>	30.09.21	<p>i) Identify and seek agreement to the core standards within the NICE dementia guidelines that relate to Living Well and Supporting Well that should be met as a minimum across Cambridgeshire and Peterborough: 31.03.18</p> <p>ii) Link the outcome of i) above with the requirements for MSNAP accreditation.</p> <p>iii) Undertake a gap analysis between services currently commissioned and the minimum and full standards identified in ii) above, including Memory Assessment Service self-assessment: 31.03.18</p> <p>iv) Identify opportunities for improved outcomes and efficiency, quantify and develop an implementation plan, including the potential offered by community pharmacy: 30.09.18</p> <p>v) Assess the additional investment required to achieve the key as part of the review of the dementia pathway and undertake a cost/benefit analysis: 30.09.18</p> <p>vi) Develop a business case for improvement of the dementia pathway if/as appropriate: 30.09.18</p> <p>vii) Seek approval for the proposed improvements and investment required from each organization and the STP: 31.12.18</p> <p>viii) Implement the agreed improvements to the dementia pathway: 01.04.19</p>	CCG Clinical Lead (OPMH) with CPFT Clinical Lead (OPMH), CCG Commissioner (OPMH), CCC/PCC Commissioner, (MH)

	<p>Determine cost/benefit of moving to a functional/organic rather age based (under/over 65 yrs) approach to mental health services.</p> <p>Services are commissioned to provide effective pre-and post diagnostic support</p> <p>The Alzheimer's Society is commissioned to provide pre- and post diagnostic support (KLOE)</p>			
1.2 To determine the impact of the likely increase in the number of people living with dementia in Cambridgeshire and Peterborough and the action needed to meet likely additional demand	Over time: capacity meets demand so that KPIs continue to be met	31.03.22/ 31.03.27/ 31.03. 32		CCG Clinical Lead (OPMH) with CPFT Clinical Lead (OPMH), CCG Commissioner (OPMH), CCC/PCC Commissioner, (MH)
Key Objective 2: To work with Acute providers to develop a plan for ongoing improvement in the quality of care for people with dementia when in hospital.				
Objective	How Improvement will be Measured	Timescale	Action Required	Lead
2.1 To improve patient and carer experience and outcomes of Acute Hospital care	All acute hospitals meet the standards for a dementia friendly environment	31.03.22	<p>i) Establish a Task and Finish Group/s to identify, prioritise and deliver the improvements required in Acute Hospital care, including ensuring meeting the requirements of providing a Dementia Friendly Environment and carer/ patient experience and timely discharge to an appropriate setting (See Key Objective 2, 3.2.4 below): 31.03.18</p> <p>ii) Identify the gaps in investment required: 30.09.18</p> <p>iii) Undertake a cost benefit analysis and include in the dementia business case: 31.12.18</p> <p>iv) Develop an action plan/s to include improving understanding of the experience and outcomes of people diagnosed with dementia through</p>	CCG Commissioner (OPMH)/CCG Clinical Lead (OPMH)/ Acute Hospital Clinical and Managerial Leads

			improved coding of dementia (See 3.2. below): 31.09.18	
2.2 To ensure that admission to Acute Hospital occurs only when medically necessary	i) Reduction in no. of avoidable admissions to Acute hospital care ii) Reduction in no. of avoidable admissions to specialist dementia Inpatient Care	31.03.22	i) Establish a Task and Finish Group/s ?? include in the workstream for Key Objective 1,1.1 above: 31.03.18 ii) Include as a key objective within 1.1 i. (above) and include within the dementia business case: 31.12.18 iii) Include as a key objective under Integrating Well: 31.03.22	CCG Commissioner (OPMH)/CCG Clinical Lead (OPMH)/ Acute Hospital Clinical and Managerial Leads
2.3 To improve understanding of the experience and outcomes of people diagnosed with dementia in Acute Hospital care	i) Robust coding of dementia as primary and secondary reason for admission	31.03.19	i) Include in the work of the Acute Hospitals Task and Finish Groups. Also see Monitoring Well (Section 3.2.12 below).	CCG Commissioner (OPMH)/CCG Clinical Lead (OPMH)/ Acute Hospital Clinical and Managerial Leads
Key Objective 3: To improve awareness of and access to dementia care for hard to reach groups				
Objective	How Improvement will be Measured	Timescale	Action Required	Lead
3.1 Develop an action plan that addresses priorities building on recent work on cultural variation in understanding of, and approach to dementia to improve engagement with hard to reach groups.	i) An increase in the no. and % of people from hard to reach groups diagnosed with dementia ii) An increase in the no. and % of people from hard to reach groups dementia care	31.03.20	i) Set up a task and finish group to improve access to, and outcomes from dementia care, building on the research undertaken 2016/17: 31.01.18 ii) Work with key stakeholders to identify priority groups for improved access to dementia care: 30.09.18 iii) Review the findings of the work on cultural variance in approach to dementia services by ethnic minorities and develop an action plan to address the priorities identified under ii) above: 30.09.18 iv) Identify the investment required and undertake a cost/benefit analysis for inclusion in the dementia business case: 30.09.18 v) Deliver the improvements that can be achieved with minimal/no investment: 31.3.20	CCC/PCC Commissioner (MH) and CPFT Clinical Lead

			vi) Implement the action plan according to the outcome of the business case: 31.3.20	
Key Objective Four: To ensure that the quality of care of people living with dementia in care homes meets the Care Quality Commission requirements and best practice.				
Objective	How Improvement will be Measured	Timescale	Action Required	Lead
4.1 To ensure that standards of care for people living with dementia in care homes across Cambridgeshire and Peterborough improve, at least achieving the minimum standards in Care Homes⁶⁷	<ul style="list-style-type: none"> i) An increase in the % of care homes that are rated outstanding and good ii) A reduction in the % of care homes that are rated inadequate or requires improvement iii) All homes will achieve the minimum required to achieve the dementia care standards including: <ul style="list-style-type: none"> i) Appropriate prescribing. ii) Effective advance planning. iii) An increase in the percentage of people living with dementia in care homes who have the same access to NHS assessment, treatment and support as people in the general population; ultimately 100% achievement of this objective. To include: <ul style="list-style-type: none"> a) A reduction from 22% in the percentage of people living in care homes who have difficulty accessing mental health services.. b) An increase in the rate of referral into psychological therapies for people over 65 years. c) A reduction in the % of avoidable admissions to acute hospitals. d) Determine whether an increase in the rate of contact with secondary MH services ?? 	30.09.17 and 31.03.20	<ul style="list-style-type: none"> i) Establish a task and finish group to develop an action plan and oversee improvement. ii) Review and secure agreement to the targets proposed under 'How improvement will be measured'. iii) Agree a set of standards for dementia in care homes in Cambridgeshire and Peterborough. iv) Work with The Care Homes Support Team and care homes to support care homes to follow a programme of continuous improvement using evidence based guidance prioritising: <ul style="list-style-type: none"> a) Improvement of recruitment, retention and training of care home staff. b) Leadership. c) Defining the care pathway within the home, including working with NHS services – Primary Care and CPFT inc. Admiral Nurses to improve access to assessment, treatment and support, reduce avoidable use of acute hospital services, develop information sharing agreements/protocols and ensuring regular review of care plans within care homes (KLOE) d) Identify gaps in services/resources and develop business case to be part of the wider dementia business case. 	CCG commissioner (OPMH) and CCC/PCC Commissioner (MH) and CPFT lead

⁶⁷ The Fundamental Standards in Care Homes, Care Quality Commission, accessed 21.12.17, <https://www.cqc.org.uk/what-we-do/how-we-do-our-job/fundamental-standards>

	<p>including inpatient stays would improve outcomes/experience for people living with dementia and their carers or whether the current low rate of admission reflects a well developed community based dementia assessment and treatment service.</p> <p>iv) Improvement in performance against standards for end of life (see Dying Well section 3.2.5).</p> <p>Decrease in the use of bank and agency staff in care homes</p>	30.09.17		
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3.2.4 Living Well

The Standard

People with dementia can live normally in safe and accepting communities. “I know that those around me and looking after me are supported. I feel included as part of society.”

The standard includes the following parts of the Well Pathway:

- Integrated services
- Supporting carers
- Carers’ respite
- Co-ordinated care
- Promote independence
- Relationships
- Leisure
- Safe communities

Best Practice and Guidelines

The guidelines relating to Living Well, are contained within Dementia: Supporting people with dementia and their carers in health and social care. Standards relating to the provision of information, advice and guidance ongoing care management, pre- and post-diagnostic counselling and support and advance care planning that relate to Supporting Well are included in the MSNAP standards because following diagnosis the Memory Assessment Service discharges those people who have no need for further assessment and treatment is required at the time, back to their GPs with advice about the support available in the community. The national guideline also includes a standard relating to inpatient dementia services. Additional good practice includes support based on the work of the Alzheimer's Society which recommends approaches to promoting awareness of dementia and building individual and community resilience to help communities and organisations become dementia friendly. Initiatives include Dementia Cafes, Dementia Friendly Communities, Dementia Champions, Dementia Environments and the development of Dementia Action Alliances to support this across communities and wider networks e.g. regional/national organisations and communities of interest. (See Figure 10 below).

Figure 10: Becoming Dementia Friendly⁶⁸



⁶⁸ Alzheimer's Society

Local Data

Strengths:

- Dementia friendly communities
- The Dementia Resource Centre in Peterborough which provides a focus for dementia support

Gaps:

- Geographical consistency and capacity in relation to the Dementia Resource Centres (commissioned in Peterborough but not in Cambridgeshire and insufficient capacity and potential for development in Peterborough)
- Geographical consistency in relation to Dementia Friendly Communities
- Geographical consistency in relation to Dementia Friendly Environments
- Information, advice, guidance and support for carers so that they can continue caring when they wish to do so.
- Carer-reported quality of life score for people caring for someone with dementia: Cambridgeshire is slightly higher than the England average (7.7) at 7.9 and the Peterborough average score is significantly lower than the England at 6.7
- The proportion of adult carers who feel that they have as much social contact as they would like: Cambridgeshire is approximately in line with the national average of 38.6%, whilst Peterborough is significantly lower at 29.7%.
- Carer assessment and support

Key Objectives

Key Objective 1: To ensure geographical consistency in relation to Dementia Friendly Communities and Dementia Friendly Environments across Cambridgeshire and Peterborough.

Key Objective 2: To ensure that people living with dementia have access to community based support that is robust and consistent across Cambridgeshire and Peterborough

Key Objective 3: To ensure that support for carers is robust and consistent across Cambridgeshire and Peterborough

Action Plan

Key Objective 1: To ensure geographical consistency in relation to Dementia Friendly Communities and Dementia Friendly Environments across Cambridgeshire and Peterborough				
Objective	How Improvement will be Measured	Timescale	Action Required	Lead
1.1 To support the Dementia Action Alliances, Dementia Friends, Dementia Champions, Dementia Friendly Communities and those currently signed up to working towards providing Dementia Friendly Environments	<p>Increase in no. of Dementia Friendly Communities increases across Cambridgeshire and Peterborough</p> <p>Increase in no. of Dementia Action Alliances across Cambridgeshire and Peterborough</p>		i) Commissioners and the Alzheimer's Society to work with District Councils to find ways of supporting the current Dementia Friendly Communities and Dementia Action Alliances while the work to develop the care pathway is undertaken: 31.03.19: Strengthen the network of Dementia Action Alliance and Dementia Friendly Communities working with the District Councils to formalise the existing networks (this is an enabling objective that appears in the Living Well part of the Strategy; Undertake an option appraisal in order to determine the best way to provide a resource for the provision of information, advice and guidance assessing the cost/benefits of the Cambridgeshire and Peterborough Dementia Resource Centre and Wellbeing Network models.	CCC/PCC Commissioner (MH)/CCG Commissioner (OPMH)
1.2 Within the work to develop the dementia care pathway, to determine the potential and cost/benefit of supporting an increase in the number of Dementia Friends, Dementia Champions, Dementia Friendly Communities and	<p>There is an increase in the no/% the adult population who are Dementia Friends across Cambridgeshire and Peterborough year on year</p> <p>There is an increase in the no./% people/the adult population Dementia Champions across Cambridgeshire and Peterborough year on year</p> <p>There is an increase in the no. of Dementia Friendly Communities across Cambridgeshire and Peterborough year on year</p>		<p>i) See Section 3.2. 3 Key Objective 1, (1.i) above</p> <p>ii) MH Commissioners support the 4 key statutory organisations across Cambridgeshire and Peterborough – CPFT, CCC, PCC, CCG – to work towards becoming Dementia Friendly: 31.03.19</p>	CCC/PCC Commissioner (MH)/CCG Commissioner (OPMH)

organisations currently signed up to and working towards providing dementia friendly environments	There is an increase in the no./% organisations that are signed up to becoming and working towards Dementia Friendly Environments across Cambridgeshire and Peterborough year on year			
1.3 To work with Primary Care at scale and the emerging GP Federations to meet the basic requirements in relation to Dementia Friendly Practices Environments as outlined in the Forward View for Primary Care to include exploring how the GP with a Special Interest (GPwSI) can enhance outcomes for people living with dementia and their carers	<p>No./% dementia friendly GP practices (KLOE)</p> <p>An increase in no./% dementia friendly GP practices</p> <p>All GP practices have achieved more than the minimum standard (locally agreed standard) for a Dementia Friendly Practice</p>	31.03.20	<p>i) Establish a task and finish group: 31.01.18</p> <p>ii) Review national best practice to determine the minimum local requirement to qualify as a Dementia Friendly Practice: 30.04.18</p> <p>iii) Undertake a gap analysis in relation to achievement of the minimum local requirement to qualify as a Dementia Friendly Practice: 30.09.18</p> <p>iv) Identify the investment required and the cost/benefit of achieving the minimum local requirement to qualify as a Dementia Friendly Practice: 30.09.18</p> <p>v) Build the findings of i) – iv) above into the business case for improvement in dementia outcomes: 31.10.18</p>	CCG Commissioner (OPMH)/CCG Clinical Lead (OPMH)
1.4 To work with Primary Care at scale and the emerging GP Federations to build on 2.3 above to achieve more than the minimum requirement for Dementia Friendly Environments as outlined in the	All GP practices have an action plan which supports improvement in the attainment the standards required of a Dementia Friendly Practice	31.03.21	i) According to the outcome of 1.3 above, follow the same process	CCG Commissioner (OPMH)/CCG Clinical Lead (OPMH)

Forward View for Primary Care				
1.5 To ensure that Acute Trusts exceed the basic requirements for Dementia Friendly Environments	<p>(KLOE)</p> <p>No./% of Acute Trusts that meet the standards for Dementia Friendly Environments (KLOE)</p> <p>All Acute Trusts have achieved more than the minimum standard for a Dementia Friendly environment</p>			
Key Objective 2 To ensure that people living with dementia have access to community based support that is robust and consistent across Cambridgeshire and Peterborough				
Key Objective 3: To establish a robust infrastructure of support for carers that is consistent across Cambridgeshire and Peterborough				
Objective	How Improvement will be Measured	Timescale	Action Required	Lead
3.1 To ensure that people living with dementia have access to community based support that is robust and consistent across Cambridgeshire and Peterborough	<p>Reduction in no./% admissions to residential and nursing home care</p> <p>Reduction in average LOS in residential and nursing home care</p> <p>Reduction in no./% avoidable admission to Acute Hospital care</p> <p>Reduction in average LOS in acute hospital</p> <p>Reduction in no./% presentations at Accident and Emergency Departments that do not lead to admission</p> <p>An increase in community resources - voluntary sector and communities – for people living with dementia and their carers</p>	31.03.21	<p>i) Establish a task and finish group to assess the extent to which the needs of people living with dementia are being met and to address any gaps 31.01.18</p> <p>ii) Identify and determine the action needed to address the key gaps in support for, identifying any gaps, including considering developing a hub and spoke model of support e.g. extending the Dementia Resource Centre or building on the Carers' hub and spoke model.</p> <p>iii) Determine whether there is a need to improve housing options for people living with dementia including for people who are self-funders e.g. extra care housing, sheltered housing; initiate a review and implement recommendations as appropriate and progress/implement the findings. .</p> <p>iv) Determine whether there is a need to improve housing options for people living with dementia including for people who are self-funders e.g. extra care housing,</p>	CCG Commissioner (OPMH)/CCC/PCC Commissioner (MH)/ Director of Integration (CPFT)

	<p>An increase in the no. and % of carers of people with dementia receiving services advice or information</p> <p>An increase in awareness and use of community/voluntary sector resources by people living with dementia who self-fund support</p> <p>An increase in capacity and use of independent living and supported accommodation for people living with dementia e.g. sheltered housing, extra care housing</p> <p>An increase in the use of assistive technology</p>		<p>sheltered housing; initiate a review and implement recommendations as appropriate and progress/implement the findings. .</p> <p>v) Initiate an action plan arising from ii) above as necessary.</p> <p>vi) Determine the investment needed and the cost/benefit of addressing the identified gaps.</p> <p>vii) Include unmet needs in the business case for dementia (See 3.2.3 (1.i) above: 31.12.18.</p>	
<p>3.2 To ensure that the gaps in support for carers are being addressed: Carers and family members have access to the following:</p> <p>i) Individual/group psychoeducation</p> <p>ii) Peer support groups tailored to the needs of the person they are caring for i.e. stage of dementia</p> <p>iii) Support, information, advice and guidance by telephone and through the internet</p> <p>iv) Support, information advice</p>	<p>Reduction in length of stay of people with dementia in residential and nursing home care</p> <p>Reduction in no./% avoidable admissions* and length of stay of people with dementia to Acute Hospital care</p> <p>Reduction in no./% presentations* and length of stay of people with dementia at Accident and Emergency Departments that do not lead to admission</p> <p>An increase in the no. and % of carers of people with dementia receiving services advice or information</p> <p>An increase in the no. and % of carers or people with dementia accessing and receiving psychological therapies</p>	31.03.21	<p>i) Establish a task and finish group 31.01.18</p> <p>ii) Through the task and finish group, develop and begin to deliver a prioritised work plan that will improve outcomes for carers of people living with dementia are being met including identification of key gaps and the actions and develop a business case (see 3.2.3 (1.i)) above if necessary to address any gaps (aimed at delivering improvement in 3.2.i – vii: 30.09.18 (Training for carers will be one of the priorities). To include learning from work to improve outcomes for carers of people with other needs e.g. cancer and developing more effective processes for gathering and responding to feedback of care from local carers.</p> <p>iii) Agree how carer experience and outcomes will be monitored/measured e.g. as part of the care pathway/personalised</p>	<p>CCG Commissioner (OPMH)/CCC/PCC Commissioner (MH)/ Director of Integration (CPFT)</p>

<p>and guidance pre- and post diagnosis</p> <p>v) Training about dementia, services and benefits, communications and problem solving in the care of people with dementia</p> <p>vi) Psychological therapy including cognitive behavioural therapy to address psychological distress</p> <p>vii) Carers have access to support and activities:</p> <p>i) With the person they care for</p> <p>ii) Without the person they care for</p> <p>viii) Improve processes for receiving and addressing feedback (positive and negative) from carers.</p>	<p>Any carer who is suddenly no longer able to care is offered an 72 hours support</p> <p>Friends and Families Tests: NHS Trusts</p> <p>Carer surveys/feedback: PCC and CCC</p> <p>% CCG funding used to support carers (KLOE)</p> <p>An increase in % CCG funding used to support carers</p>		<p>care planning and support development</p> <p>build seeking and recording carer feedback into the pathway.</p>	
<p>3.3 To improve access to appropriate options for respite care, including transport, short breaks accompanied by access to meaningful activity</p>	<p>An increase in the no. and % of carers of people with dementia being supported to continue caring with an appropriate offer of respite care</p> <p>Eligible carers are able to access respite care that responds to their individual needs/wishes in respect of breaks from caring:</p>		<p>i) Establish a task and finish group: 31.01.18</p> <p>ii) Review current provision against carers' needs: 30.06.17</p> <p>iii) Include proposals for improved access to respite care in the business case developed under 3.2.3 (1.i) above.</p>	<p>CCG Commissioner (OPMH)/CCC/PCC Commissioner (MH)/ Director of Integration (CPFT)</p>

for the individual living with dementia	i) Transport ii) Short breaks People living with dementia have access to meaningful activities during a short break			
3.4 To support carers following the death of the individual they cared for	Following the death of the person they cared for carers have access to: i) Peer support groups ii) Support from voluntary sector ii) Psychological therapy iii) Bereavement services		i) Establish a task and finish group: 31.01.18 ii) Review current provision against carers' needs: 30.06.17 iii) Include proposals for improved access to respite care in the business case developed under 3.2.3 (1.i) above.	CCG Commissioner (OPMH)/CCC/PCC Commissioner (MH)/ Director of Integration (CPFT)

3.2.5 Dying Well

The Standard

People living with dementia die with dignity in the place of their choosing. “I am confident my end of life wishes will be respected. I can expect a good death.”

Overview

NICE guidance includes advice on adopting a palliative approach to dementia care and ensuring that people with dementia have equal access to palliative care services.

Palliative care is for people living with a terminal illness where a cure is no longer possible. It is for people diagnosed with any terminal condition or for people who have a complex illness and need their symptoms controlled. Palliative care aims to treat or manage pain and other physical symptoms. It will also help with any psychological, social or spiritual needs. Treatment will involve medicines, therapies, and any other support that specialist teams believe will help their patients. It includes caring for people who are nearing the end of life.

End of life care is an important part of palliative care for people who are nearing the end of life. End of life care is for people who are considered to be in the last year of life and aims to help people live as well as possible and to die with dignity. It also refers to treatment during this time and can include additional support, such as help with legal matters. The aim is to help everyone affected by the diagnosis achieve the best quality of life. A person with dementia might receive palliative care alongside particular treatments, therapies and medicines, such as chemotherapy or radiotherapy.

Providing optimal palliative care to patients with dementia requires excellent co-ordination and communication across the whole system: between primary and secondary care; between secondary care organisations; between health and social care; and, between these and the voluntary care and third sectors. It is key to have systems in place to facilitate communication and a cultural environment whereby all professionals involved in the care of people with dementia and their families have the knowledge appropriate to their role to promote and provide good quality palliative care (including end of life care).

Provision of best care in the last months, weeks and days of life can be guided by knowledge of individuals' wishes and preferences. Opportunities to explore and communicate wishes and support future care plans should be taken at all stages from diagnosis forward. More formal processes such as advance decisions/refusals and Powers of Attorney for health, welfare and finances should be flagged up early, with advice given where necessary on how to produce and register these, so that they can be successfully enacted at the appropriate time. Closer links between specialist and non-specialists in end of

life and dementia care across disciplines should be fostered to promote and share best practice.

Stakeholders identified the following strengths:

- The percentage of people over 65 with dementia dying in hospital is comparatively low compared to the England average (25% v 30% England average (Figures 10 & 21))
- The percentage of people over 65 with dementia dying in their usual place of residence is higher than the England average (74% v 69% England average (Figures 10 & 21))
- The percentage of people over 65 with dementia dying in a care home is higher than the England average (63% v 59% England average (Figures 10 & 21))
- A local audit found that the standard of end of life care was very high in Addenbrookes Hospital (evidence was not collated for other local hospitals)

The following gaps were identified:

- Advanced care planning for those dying with dementia is minimal. (A local audit demonstrated that only 11% of those dying with dementia had any form of advanced care planning)
- Preferred place of death is not recorded frequently for end of life. However, dying in preferred place was found not to be a top priority (in a population based study only 34% ranked 'dying in preferred place' as their top care-related priority and this can often change as end of life is approached)
- End of life care training relevant to people with dementia is not consistent across the patch

Improving end of life care has been identified as a key priority by Cambridgeshire and Peterborough STP. The National End of Life Intelligence network (NEnd of lifeIN) profiles indicate that in Cambridgeshire and Peterborough approximately 6,700 die each year. The total number of deaths has remained fairly constant from 2014/15 until present day with a small decrease in 2015/16.

In Cambridgeshire and Peterborough in 2015/16 26.7% of people died in ⁶⁹their own homes. This percentage is the highest compared to other most similar CCGs and is significantly higher than the national average. However, 41.9% of people die in hospital, 5.9% in a hospice and 23% in a care home⁷⁰.

In comparison, in Cambridgeshire and Peterborough in 2015, of over 65s with Dementia dying, 10.8% died in ⁷¹their own homes, higher than the national average (8.9%). However, 24.8% of people died in hospital and 62.9% in a care home (Figures 10 & 21).

⁷⁰ British Social Attitudes Survey: http://bsa-30.natcen.ac.uk/media/36320/bsa_30_dying.pdf

The percentage dying in hospital is lower than the England wide percentage (30%) but shows that there are a large number of admissions at the end of life for people with dementia. A number of these admissions may have been avoidable with high quality future care planning and provision of support and expertise in end of life care in the community.

Population-based studies of preferences for place of death indicate that over 60% of people in general (including those who were not facing life-threatening illness at the time) would prefer to die at home. Whilst this has been an important driver for improving end of life care at home, the 'place of death' is not necessarily the highest priority for everybody. In a population-based study involving just under 10,000 adults across England, only 34% ranked 'dying in preferred place' as their top care-related priority: the rest were split fairly evenly between the other two options of 'having as much information' as they wanted and 'choosing who makes decisions' about their care.

In the 2012 British Social Attitudes survey, 60% of those who stated that they would prefer to die at home would change their mind if sufficient support from family, friends or social and medical professionals were not available. The need to be pain free (24%) came a close second to the presence of family and friends (28%), in terms of the most important aspects of their end of life care. The general conclusion, is that we do not know the proportion of UK patients that would prefer to die at home. What we do know is that, from surveys of the general public, given the opportunity and the right support, most people would prefer to die at home (Hoare et al, 2015). We also know that preferences can often change as a person approaches end of life.

Best Practice and Guidelines

The needs of people with dementia at the end of life are comparable to those of people with cancer with physical, social, financial and spiritual support required: a major difference is that the palliative phase of dementia may go on for several years. Many people with dementia however do not get the end of life care that they need, with pain, in particular, undertreated near the end of life.

In 2009, the Department of Health set out a national dementia strategy. The end of life objective in the strategy was simply "Improve end of life care for people with dementia". This should result in two outcomes:

- People with dementia and their carers will be involved in planning end of life care
- Services will consider people with dementia when planning local end of life services.

NICE guidelines on supporting people with dementia and their carers explicitly recommend that:

'Dementia care should incorporate a palliative care approach from the time of diagnosis until death. The aim should be to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their choosing, while also supporting carers during their bereavement, which may both anticipate and follow death.

Specifically NICE guidance includes:

- Adopting a palliative approach to dementia care

- Ensuring that people with dementia have equal access to palliative care services
- Good communication between teams when a person with dementia is nearing the end of life
- Encouraging people with dementia to eat and drink by mouth for as long as possible
- Individual assessment of the need for antibiotics at the end of life for a person with dementia with a fever
- Care facility policies to reflect the unlikely success of CPR in patients with advanced dementia
- Resuscitation decisions to take place in accordance with the Mental Capacity Act taking into account an individual's stated wishes and preferences where available.

In 2014 a white paper, defining optimal palliative care for older people with dementia, identified 11 domains in which 57 recommendations were made. The eleven domains include:

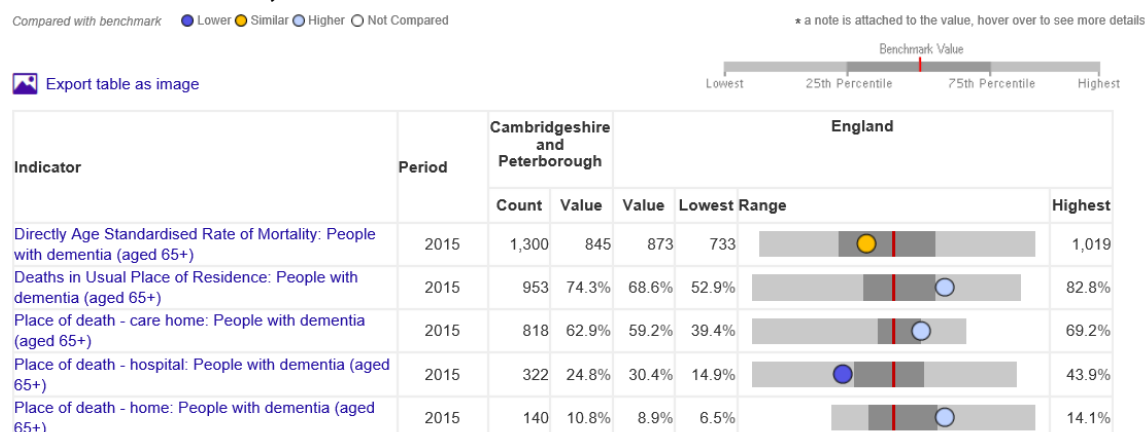
- Applicability of palliative care – dementia can be regarded as a terminal condition
- Person-centred care, communication and decision making – decision making should stem from the patient's perspectives
- Setting care goals and advance planning – makes planning proactive
- Continuity of care – there should be no interruptions even with transfer
- Prognostication and timely recognition of dying – advanced care planning principles
- Avoiding overly aggressive, burdensome or futile treatment – treatment should take into account care goals and the stage of dementia
- Optimal treatment of symptoms and providing comfort – a holistic approach to treatment of symptoms is paramount
- Psychosocial and spiritual support – includes emotional support, spiritual support and ensuring a comfortable environment
- Family care and involvement – families may need support throughout the trajectory
- Education of the healthcare team – education is required for the whole healthcare team in applying a palliative care approach
- Societal and ethical issues – patients and their carers should have equitable access to palliative care and support as for other terminal diseases

The two domains that received the highest endorsement during a Delphi process were 'person centred care, communication and shared decision making' and 'optimal treatment of symptoms and providing comfort'. Advance care planning, continuity of care, education of the healthcare team and continuity of care were also identified as priority areas.

Local Data

Cambridgeshire and Peterborough generally performs well in terms of the place of death for people with dementia. It has higher than average proportion of people dying in their usual place of residence, at home and in care homes, and a lower than average proportion of people dying in hospital. (See Figure 11 below).

Figure 11: Spine Chart Showing Performance of the Cambridgeshire and Peterborough STP Area against the England Average for a Range of ‘Dying Well’ dementia indicators, 2015⁷²



A recent local audit of end of life care for people with dementia dying at the local Cambridge acute hospital, Addenbrookes Hospital, based on the relevant white paper recommendations found that of the 40 patients dying between June and December 2015, the standard of end of life care was very high when approaching death had been recognised. However, for only 11% of the patients was there any documentation of advance care planning including preference for place of care. (Three patients had advance care planning, one had Lasting Power of Attorney arrangements in place.) Few patients had documentation in their community records regarding resuscitation discussions/decisions and none of the case notes evidenced discussion about alternative plans to hospital admission on presentation to A&E.

A further analysis was made of those patients known to the local Community Services and Mental Health Provider, Cambridgeshire & Peterborough Foundation Trust (CPFT) (24/40). Only 21% of these had any documented discussion about advance care planning, which was all related to lasting powers of attorney for finance. Another study analysed the clinical notes of a cohort of 20 patients admitted to Denbigh (specialist dementia) ward in CPFT in 2016. Of the 20 admissions, only seven had documented discussions related to future care planning. (One patient had discussed advance care planning, six had discussed Lasting Powers of Attorney.) This was despite 5 of the 20 patients being within one year of death and two dying within weeks of the admission. This suggests that the key issue is whether discussions take place at all on End of Life planning rather than if the plans are communicated. Having end of life conversations is difficult. Conversations need to be held early on in dementia before cognitive powers decline. However, those with early dementia may not wish to hold such conversations. Creating the opportunity to discuss advance care planning at the right time is key.

⁷² PHE Dementia Profile

Training

Training in end of life care for people with dementia is active in the region, but is neither co-ordinated nor consistent. Staff have varying degrees of awareness of approaching end of life. Currently, non-specialists in dementia care receive little training in end of life care. End of life dementia training is being delivered in the Community Trust by a team comprising liaison psychiatry and palliative care based in Cambridge. There are also pockets of training taking place across the system by different organisations. High quality dementia training is currently being delivered by CAMTED-OP and an end of life facilitator in the Peterborough area who deliver a one day course in end of life care in dementia available to CPFT staff; this is run on a small scale with very little funding. A review of education and training programmes across the system would identify any duplication and gaps. There may be areas of duplication but more likely there are large gaps in access to focused training.

The 2017 dementia business case, that is currently being implemented, aims to increase provision of training on dementia awareness, including training on end of life planning for people with dementia. Through the implementation of the business case, the aim is that more staff will be trained to provide improved care and support for people with dementia and their carers in preparation for end of life.

Key Objectives

Key Objective 1: To improve the quality of care and support and outcomes at end of life for people living with dementia and their carers

- To improve care of people with dementia and their families toward the end of life across care settings, thereby reducing futile interventions and avoiding non-essential hospital admissions
- To improve quality of life at the end of life stage for people with dementia and their carers by being more likely to die in their place of choice.
- To enhance links between palliative care and dementia care.
- To ensure that people with dementia have a personal care and support plan.
- To ensure that patients and their families have been fully involved in the development of the plan, the decisions and have their choices recorded.
- To ensure that all people in CPFT dementia units and/or their families have had a DNAR conversation and that the decision is recorded in their plan.
- To ensure that care plans for people with dementia contain end of life planning with preferred place of care, including alternative plans to hospital admission where appropriate.
- To ensure access by all relevant professionals to personal care and support plans.
- To avoid unnecessary admissions for people with dementia towards the end of life.
- To provide education, training and support for care and health professionals to increase their general skill base for supporting people with dementia in planning for end of life care.
- To strengthen the interface with voluntary sector organisations, primary care, acute trusts and social care organisations.
- To increase the end of life training given to care homes.

Action Plan

Key Objective 1: To improve the quality of care and support and outcomes at end of life for people living with dementia and their carers				
Improvement Required	How Improvement will be Measured	Action Required	Timescale	Lead
1.1 Improve care and quality of life of people with dementia and their families at end of life	<p>% with personal care and support plans</p> <p>% Care plans that include Advanced life (end of life) care plans</p> <p>% that have reviews of their care plans conducted on increasing frequency plan according to trigger points being reached</p>	<p>i) Ensure links with C&P END OF LIFE Strategy work Embed future care planning including end of life care planning in routine practice in all settings</p> <p>ii) Train and empower professionals/ carers/ individuals to have conversations about end of life and dying well: Conversations about dying should be able to happen at any stage, in particular, at the early stages by all sector professionals and encourage people to think about advance care plans (consider specifically END OF LIFE dementia support worker) Health care professionals will offer discussion about future care preferences (including end of life care wishes) as a routine part of dementia post diagnostic support</p> <p>iii) Proactive review of future care plans throughout the care pathway both routinely and at trigger points e.g. re referral into services, hospital admission, at times of crisis or when deteriorating functional status is recognised.</p> <p>iv) Trigger points for review need to be identified</p> <p>v) Promotion of advance care planning and legal processes e.g. Power of Attorney across the system; deliver a local awareness and promotion campaign on planning for the future, working alongside local charities e.g. Age UK, Alzheimer's society, Dying Matters</p>	31.03.20	CCG Commissioner (OPMH)/CPFT Lead

Key Objective 1: To improve the quality of care and support and outcomes at end of life for people living with dementia and their carers				
Improvement Required	How Improvement will be Measured	Action Required	Timescale	Lead
1.2 Improve care planning for end of life	Care plans contain preferred place of dying Treatment options and future care decisions plan to include CPR status, culturally sensitive information, spiritual information Powers of Attorney in place Carer what-if plans in place and carer information included	i) Develop core contents of personal care and support plan to include: Preferred place of dying DNAR information Culturally sensitive information Spiritual information and/or requests powers of attorney Carer information	31.03.19	CCG Commissioner (OPMH)/CPFT Lead
1.3 Ensure that end of life care plans are accessible to those who need to understand them	Health and care professionals' access to treatment options and future care decisions plan	i) Electronic and paper systems to capture future care preferences and plans so they can be shared widely across the system and acted on when appropriate (END OF LIFE Dashboard already in existence). This will be especially important when patients are acutely deteriorating and acute hospital admission may be considered ii) Consider how the plans can be integrated so that they follow patients through the system	31.03.19	CCG Commissioner (OPMH)/CPFT Lead
1.4 Ensure that those involved in caring for people with dementia and their carers at end of life are appropriately educated and trained.	% of care professionals trained to provide improved care and support for people with dementia and their carers towards the end of life Estimate of avoided admissions at end of life through various measures % of people with dementia dying in their usual place of residence compared to national statistics	i) Upskill care professionals across the disciplines to support and provide end of life care to patients and their families, working alongside specialist colleagues where needed (part of dementia business case being implemented in 2017/18) ii) Care home staff are being trained in END OF LIFE as part of the Care Home Support Team's remit Potential extension or consolidation of the DIST team to support care of advanced dementia including end of life care. iii) Train staff to support these developments, working closely with colleagues in elderly care	31.03.19	CCG Commissioner (OPMH)/CPFT Lead

Key Objective 1: To improve the quality of care and support and outcomes at end of life for people living with dementia and their carers				
Improvement Required	How Improvement will be Measured	Action Required	Timescale	Lead
		and palliative care and local promotion of future care planning.		
1.5 Deliver additional improvements in end of life care and quality of life of people with dementia and their families	Carer/service user feedback % of deaths who are on END OF LIFE register % offered to go on GP palliative care register % that have reviews of medication conducted on increasing frequency plan according to trigger points being reached	i) Review feedback and use to improve end of life care ii) Ensure patients are placed on END OF LIFE register iii) Ensure patients are placed on Palliative care register where appropriate iv) Encourage pharmacists to be pro-active in discussing medication changes that could be needed with prescribers	31.03.20	CCG Commissioner (OPMH)/CPFT Lead

3.2.6 Early Onset Dementia⁷³

The Standard

Diagnosis, access, assessment, treatment and support should be consistent for people of all ages living with dementia and their carers. (Locally agreed standard)

Local Context

Specialist assessment, treatment and support for people with early onset dementia was identified as the biggest single gap in dementia care across Cambridgeshire and Peterborough.

Key Objectives

Key Objective 1: To ensure that people living with early onset dementia and their carers have access to robust assessment, treatment and support. Also See Appendix 1

⁷³ Early Onset Dementia Needs Assessment: Cambridgeshire and Peterborough, October 2017

Action Plan

Key Objective 1: To ensure that people living with early onset dementia and their carers have access to robust assessment, treatment and support.				
Improvement Required	How Improvement will be Measured	Action Required	Timescale	Lead
1.1 Establish a Task and Finish group to deliver the recommendations made in the Early Onset Dementia Needs Assessment.	<p>A Task and Finish Group established.</p> <p>Recommendations that can be achieved within existing resources delivered.</p> <p>A service specification developed.</p> <p>A business case produced.</p> <p>Improved experience and outcomes for people living with early onset dementia and their carers.</p>	<p>i) Confirm that leadership should come from adult mental health services.</p> <p>ii) Finalise and implement the action plan including:</p> <p>a) Update CPFT's webpage with an accurate description of support currently available.</p> <p>b) Establish consistent recording within health and social care services to ensure accurate estimates of service burden are obtained.</p> <p>iii) Develop a service specification and business case.</p>	<p>31.03.18</p> <p>31.03.19</p> <p>30.09.18</p>	<p>CPFT Clinical Lead/ CCG Commissioner MH/CCC/PCC Commissioner (MH)</p>

3.2.7 Researching Well

Local Context

The following strengths in relation to Researching Well were identified:

- CPFT has a very active programme of clinical trials which allows patients to access the latest potential treatments for dementia if they wish.
- There is a strong research base across the health and social care community in Cambridgeshire and Peterborough. This includes a strong research base for dementia.

Key Objectives

Key Objective 1: To ensure that every patient with a diagnosis of dementia is given the opportunity to participate in dementia research⁷⁴.

Key Objective 2: To evaluate the impact of the Dementia Strategic Plan.

⁷⁴ This is an objective of the National Institute for Health Research Join Dementia Research programme of which CPFT is a member organisation <https://www.joindementiaresearch.nihr.ac.uk/>

Action Plan

Objective 1: To ensure that every patient with a diagnosis of dementia is given the opportunity to participate in dementia research.				
Objective	How Improvement will be Measured	Action Required	Timescale	Lead
1.1 Include the opportunity to participate in dementia research for all those given a diagnosis of dementia in the care planning process.	<p>No./% patients signed up to 'Join Dementia Research</p> <p>No./% patients taking part in CRN funded research projects</p> <p>No. active CRN funded projects</p> <p>Improved experience and outcomes for people living with dementia and their carers (see Section 5 below)</p>	i) Incorporate in the dementia pathway/Memory Service operational policy.	31.03.19	CPFT Clinical Lead (OPMH)/CCG Commissioner (OPMH)/CCC/PCC Commissioner (MH)
Objective 2: To evaluate the impact of the Dementia Strategic Plan				
2.1 Identify options for evaluation of the impact of the Strategic Plan.	The impact of the Strategic Plan is evaluated/quantified.	<p>i) Consider options for evaluating the impact of the Strategic Plan including the possibility of undertaking a longitudinal study of dementia in Cambridgeshire and Peterborough.</p> <p>ii) Progress the preferred option/s.</p>	31.03.19	CPFT Clinical Lead (OPMH)/CCG Commissioner (OPMH)/CCC/PCC Commissioner (MH)

3.2.8 Integrating Well

Local Context

Ensuring that care is co-ordinated with physical and mental health and social care needs assessed and addressed in a seamless way and that statutory and voluntary sector services across community, primary and secondary health and social care staff work together within a clearly defined care pathway was identified as the biggest opportunity for improvement arising from the gap analysis. The objective is to ensure that people living with dementia are supported to live at home for as long as possible. Delivery requires that a detailed multi-agency pathway (process map) from pre-diagnosis to end of life is agreed for adults of all ages for each of Cambridgeshire and Peterborough with the core processes the same but reflecting local differences in infrastructure.

The opportunity afforded by the development of the integrated care pathway includes improvement to both outcomes and cost effectiveness. A gap analysis will be completed and plans to address the gaps will be developed. The gap analysis will include an assessment of the need/potential to shift investment to the front end of the pathway i.e. to community based services. The estimated changes in numbers of people living with dementia will be included, with a 3 to 10 year projection of the impact of any likely changes in demand being factored in. Proposals to achieve this objective will be developed and agreed jointly by commissioners and providers through the process of developing care pathways. It is therefore essential that representatives from specialist mental health services and community services are involved – across health and social care. This includes involving frontline staff.

Key Objectives

Key Objective 1: To ensure that care is seamless, addressing physical and mental health and social care needs in an holistic and cost effective way.

Action Plan

Key Objective 1: To ensure that care is seamless, addressing physical and mental health and social care needs in an holistic and cost effective way				
Objective	How Improvement will be Measured	Timescale	Action Required	Lead
1. To ensure that health and social care staff work effectively together and with the voluntary sector and community to identify and meet the physical and mental health and social care needs of people living with dementia and their carers.	<p>Dementia care pathways/services are informed by/compliant with the evidence base for dementia</p> <p>Improved system-wide performance in dementia care, experience and outcomes (see Section 5 below)</p> <p>Improved experience and outcomes for people living with dementia and their carers (see Section 5 below)</p> <p>Clearly defined multi-agency care pathways agreed and in place</p> <p>.</p>	31.03.19	<p>i) Define project scope and agree desired outcomes</p> <p>ii) Agree timeline and initiate work programme</p> <p>iii) Plan and set up workshops to include people living with dementia and their carers</p> <p>iv) Hold workshops to review and develop pathway</p> <p>v) Agree action plans and implement required changes in a planned way where possible</p> <p>vi) Develop business case</p> <p>vii) Secure STP sign off</p> <p>viii) Ensure that the local dementia network is linked to and supported by the regional/national clinical network (KLOE)</p> <p>See also Section 3.2.5 above.</p>	CCG Commissioner (OPMH)/CCC/PCC Commissioner (MH)/OPMH Clinical Lead (OPMH)
2. Deliver the agreed improvements to multi-professional/agency working	<p>Improved system-wide performance in dementia care, experience and outcomes (see Section 5 below)</p> <p>Improved experience and outcomes for people living with dementia and their carers (see Section 5 below)</p>	01.04.19 – 31.03.22	<p>i) Initiate implementation of work programme</p> <p>ii) Embed the roles of community pharmacists and opticians in the pathway</p> <p>iii) Monitor and review progress</p>	CCG Commissioner (OPMH)/CCC/PCC Commissioner (MH)/OPMH Clinical Lead (OPMH)
3. Develop standard information sharing practices between primary and secondary care, particularly around diagnosis (KLOE)	<p>Data can be shared to the extent that effective multi-disciplinary/agency working is not severely impacted</p> <p>Information sharing protocols between primary and secondary care are in place (particularly around diagnosis) KLOE</p>	31.03.20	<p>i) Develop multi-agency information sharing agreements/protocols for dementia based on system-wide agreements</p> <p>ii) Embed the information sharing agreement/protocol for dementia in the newly developed care pathways</p>	

	<p>Information sharing protocols between statutory and non-statutory organisations are in place (particularly around diagnosis)</p> <p>Information sharing protocols with carers are in place</p>		<p>iii) Ensure that practices review their registers using other measures as specified within KLOE.</p>	
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3.2.9 Commissioning Well

Local Context

Effective health and social care commissioning and leadership in dementia care was identified as a gap in dementia care.

Key Objectives

Key Objective 1: To improve the commissioning and leadership for health and social care commissioning.

Action Plan

Key Objective 1: To improve the commissioning and leadership for health and social care commissioning.				
Objective	How Improvement will be Measured	Timescale	Action Required	Lead
1.1 To establish effective arrangements established for aligned (joint) health and social care commissioning of dementia care	<p>Leads for commissioning of dementia care identified in CCG and CCC and PCC.</p> <p>CCG, CCC and PCC dementia leads involved in and attending the OPMH Delivery Board regularly.</p> <p>CCG, CCC and PCC dementia leads appropriately leading/involved in decision making within the OPMH Delivery Board.</p> <p>Clear leadership re: distribution of resources across the pathway and improvements made.</p> <p>Improved system-wide performance in dementia care, experience and outcomes (see Section 4 below)</p> <p>Improved experience and outcomes for people living with dementia and their carers (see Section 4 below)</p>	31.03.18	<p>i) Confirm lead for OPMH commissioning in CCG and PCC/CCC</p> <p>ii) Establish Joint Commissioning Group (OPMH) agreeing Terms of Reference, including aims, objectives for joint/aligned commissioning, governance arrangements, membership etc.</p> <p>iii) Embed the commissioning activities arising from the Strategic Plan within the work plan for the Group</p>	CCG Director for Integration/ PCC/CCC Assistant Director (Commissioning)
1.2 Build on the current strong partnerships to ensure a collaborative approach with stakeholders through the OPMH Delivery Board and the Ageing Well Strategy Group in the delivery of the Strategic Plan.	<p>Agencies – statutory and voluntary and independent sector - across the dementia pathway – physical and mental health and social care are and/or have been actively involved in the delivery of the Strategic Plan.</p> <p>People living with dementia, their carers and members of communities are and/or have been actively involved in the delivery of the Strategic Plan.</p>	31.03.19	i) Ensure commissioning leadership for delivery of the Strategic Plan and OPMH Delivery Board.	CCG Director for Integration/ PCC/CCC Assistant Director (Commissioning)

	Improved system-wide performance in dementia care, experience and outcomes (see Section 4 below)			
	Improved experience and outcomes for people living with dementia and their carers (see Section 4 below)			
Key Objective 2: To ensure that best use of resources is made.				
2.1 Identify and review health and social care investment in dementia care.	<p>Improved system-wide performance in dementia care, experience and outcomes (see Section 4 below)</p> <p>Improved experience and outcomes for people living with dementia and their carers (see Section 4 below).</p> <p>Improved cost effectiveness/use of resources</p>	31.03.19	<p>i) Refine current understanding of health and social care investment in dementia care including investment in:</p> <p>a) Voluntary sector.</p> <p>b) Specialist mental health services (CPFT).</p> <p>c) Acute hospitals.</p> <p>d) Residential and nursing home care. (31.05.18)</p> <p>ii) Support, monitor and pull together the findings from the dementia workstreams to support recommendations for overall improvement in outcomes, experience and cost effectiveness. (30.09.18)</p> <p>iii) Develop a business case based on ii) above. (31.12.18)</p>	CCG Commissioner (OPMH)/CCC/PCC Commissioner (MH)/OPMH Clinical Lead (OPMH)
Key Objective 3: To ensure that services are effectively commissioned.				
3.1	<p>Improved system-wide performance in dementia care, experience and outcomes (see Section 4 below)</p> <p>Improved experience and outcomes for people living with dementia and their carers (see Section 4 below).</p> <p>Improved cost effectiveness/use of resources</p>	31.03.19	<p>i) In partnership with providers, undertake a joint (health and social care) review of current service specifications:</p> <p>a) Voluntary sector.</p> <p>b) Specialist mental health services (CPFT).</p> <p>c) Acute hospitals.</p> <p>d) Residential and nursing home care. Taking into account the findings from the dementia workstreams. (31.12.18)</p> <p>ii) Respecify the above services. (31.12.18)</p>	CCG Commissioner (OPMH)/CCC/PCC Commissioner (MH)/OPMH Clinical Lead (OPMH)

3.2.10 Training Well

Local Context

A gap in training in cross-agency/pathway working was identified. This is primarily because of the lack of an integrated care pathway in the first place.

Key Objectives

Key Objective 1: To ensure that staff across the Cambridgeshire and Peterborough health and social care system inform the development of and are trained in the operation of the integrated dementia pathway.

When the integrated care pathway has been agreed, implementation must include training of staff in working across agencies to ensure that people living with dementia and their carers are diagnose early and provided with assessment and treatment early in the course of their illness and on an ongoing basis as the disease progresses. This requirement will be included in the business case. A first step is to ensure that staff at the frontline are involved in the development of the integrated care pathway.

Action Plan

Key Objective 1: To ensure that staff across the Cambridgeshire and Peterborough health and social care system inform the development of and are trained in the operation of the integrated dementia pathway.				
Objective	How Improvement will be Measured	Timescale	Action Required	Lead
1. To provide training for staff to support implementation of the integrated care pathway.	<p>Frontline staff across the health and social care system have been involved in the development of the integrated dementia pathway.</p> <p>Frontline staff across the health and social care system have been involved in the ongoing development and review of the integrated dementia pathway</p> <p>Improved system-wide performance in dementia care, experience and outcomes (see Section 5 below)</p> <p>Improved experience and outcomes for people living with dementia and their carers (see Section 5 below)</p>	<p>31.03.19 and 31.03.122</p>	<p>i) Involve frontline staff in the development of the integrated care pathway.</p> <p>ii) Involve frontline staff in the identification of training needs to support implementation of the integrated care pathway</p> <p>iii) Involve frontline staff in the ongoing development of the integrated care pathway.</p>	<p>CCG Commissioner (OPMH)/CCC/PCC Commissioner (MH)/OPMH</p>

Further develop the knowledge and expertise of staff in both the physical and mental health aspects of dementia care, delivery of a fully integrated multi-agency/multi-disciplinary approach and the range of services and support available for people diagnosed with dementia and their carers. This will be underpinned by the improvements identified through the work on Local Priority 1.

3.2.11 Monitoring Well

Local Context

Gaps were identified in the following areas:

- Detailed understanding of activity relating to dementia in acute hospitals e.g. where dementia is not the main reason (primary diagnosis) for admission.
- Detailed monitoring of activity, finance and outcomes relating to dementia within and across statutory services – health and social care
- Agreement to work towards the MSNAP and to adoption of the related quality indicators (Appendix xx).

Key Objectives

Key Objective 1: To improve understanding of the activity, performance and outcomes for people living with dementia and their carers.

Key Objective 2: To develop a set of indicators of quality that include experience of services and support and outcomes for people living with dementia and their carers related to dementia across the Cambridgeshire and Peterborough health and social care system.

Action Plan

Key Objective 1: To improve understanding of the activity, performance and outcomes for people living with dementia and their carers.				
Objective	How Improvement will be Measured	Action Required	Timescale	Lead Organization/ Individual
1.1 Agree and monitor a set of indicators/outcomes that monitor what is important to people living with dementia and their carers and integrate these with 1.2 below.	A set of indicators identified by people living with dementia and their carers. Improved experience and outcomes for people living with dementia and their carers	i) Specify this as an outcome from the process of development of the a dementia care pathway	31.12.18	CCG Commissioner (OPMH)/CCG Clinical Lead (OPMH)/CCC/PCC Commissioner (MH),
1.2 Develop a system wide set of performance indicators for dementia base on the MSNAP standards and that meet the requirements for reporting of the NHS and Councils.	A system-wide data set that supports monitoring of achievement of the MSNAP standards and meets the national for dementia is in place and being monitored Improved system-wide performance in dementia care, experience and outcomes Improved experience and outcomes for people living with dementia and their carers (see Section 1.1. above)	i) Set up a task and finish group to develop and implement a set of high level performance indicators with the SDU ii) Monitor and report on performance against the agreed indicators to key Boards and organisations iii) Refine/develop the data set	31.12.18	CPFT Clinical Lead/ CCG Commissioner (OPMH)/CCC/PCC Commissioner (MH),
1.3 Work with the acute hospital trusts in Cambridgeshire and Peterborough to increase understanding of acute hospital utilisation by people with dementia including improve identification and recording of people with a primary and secondary diagnosis of dementia.	Validity of reporting of primary and secondary diagnoses of dementia reflects activity More appropriate use of Acute Hospital care by people with dementia More appropriate use of Specialist Mental Health/Dementia care by people with dementia	i) Assess the validity of current reporting of primary/secondary diagnoses in Acute Hospital settings ii) Address the gaps/make the necessary improvements iii) Monitor and report on performance against the agreed indicators to key Boards and organisations iv) Refine/develop the data set	31.12.18	CCG Commissioner (OPMH)/Acute Hospital Dementia Lead/s

Key Objective 2: To develop a set of indicators of quality that include experience of services and support and outcomes for people living with dementia and their carers related to dementia across the Cambridgeshire and Peterborough health and social care system.				
2.1 Review the core health and social care data set identified within the Strategic Plan to develop a prioritised set of indicators that supports effective monitoring of the delivery and outcomes of dementia care.	<p>A set of indicators agreed by commissioners, practitioners, people living with dementia and their carers that monitor what is important to service users and carers as well as what is required for local and national monitoring.</p> <p>Routine monitoring of the agreed data set in place with processes to address exceptions in place</p>	<p>i) Set up a task and finish group (will also include monitoring financial performance).</p> <p>ii) Review the proposed data set and agree data collection/monitoring processes.</p> <p>iii) Monitor performance and outcomes and address exceptions.</p> <p>iv) Identify key issues to inform the business case.</p> <p>v) Support the other Task and Finish Groups as they progress their plans and develop business cases.</p>	31.12.18	CCG Commissioner (OPMH)/CCG Clinical Lead (OPMH)/CCC/PCC Commissioner (MH),

4 Performance and Outcomes and Impact of the Strategic Plan and Risk Assessment

In this section, the intended impact and benefits arising from implementation of the action plans and the outcome of the Council and CCG Equality Impact Assessments are summarised. The risks to delivery of the Strategic Plan are also summarised.

4.1 Outcomes and Performance

The Strategic Plan aims to deliver the following improvements to experience and outcomes for people living with dementia and their carers in line with national and local strategies:

- Prevention of the onset of dementia where this is possible.
- People living with dementia are supported to live safely for longer within the community and with their carers.
- Improved accessibility to, and consistency of, assessment, treatment and support for people living with dementia and their carers across Cambridgeshire and Peterborough.
- Increased choice and control for people living with dementia and their carers - at all stages of the disease.
- Improved outcomes and experience of services for people living with dementia and their carers at all stages of the disease and wherever they live i.e. at home, in care homes and when admitted to hospital..
- Well co-ordinated care that addresses physical and mental health and social care needs in a seamless way.
- Crises and avoidable admission to inpatient dementia services and acute hospitals are reduced.
- Better understanding and awareness of dementia within communities
- Better use of resources/value for money.

Overall, the outcome sought for people with dementia and their carers is improvement in outcomes and experience for both with the key objective being:

To enable people living with dementia to live independently for longer and to enjoy being part of their community⁷⁵ and to keep them healthier for longer and out of hospital⁷⁶.

⁷⁵ Dementia Implementation Guide, DH, 2017

⁷⁶ The Five Year Forward View Implementation Guide, 2017-19, DH 2017

A core data set to monitor quality, outcomes and activity based on the MSNAP quality standards, the reporting requirements of NHS, including KLOE, and social care organisations has been developed as part of the process of developing this Strategic Plan. This will be developed and refined as part of the work to implement the Plan. Notwithstanding the need to report on core national and local activity, performance and outcomes, the key driver for the development of these outcomes will be to monitor the things that are of the greatest importance to people living with dementia and their carers. Monitoring of these indicators, and identification of the additional indicators and measures needed to monitor performance and outcomes will be initiated during the first year of implementation of the Strategic Plan.

4.2 Financial Impact

The actions and plans outlined in the Strategic Plan aim to both improve the experience and outcomes for people living with dementia and their carers. Most of these are based on strategies and interventions that have been shown to improve the cost effectiveness of dementia care. The aim during the first year of the plan is to apply national and local evidence and experience of service improvement to identify and quantify the potential to improve cost effectiveness across the physical and mental health and social care pathway in order to develop a business case to the STP to support improved outcomes and cost effectiveness. The potential for such improvement lies within the following:

- Reduction in no./% of crises.
- Reduction in avoidable admission to inpatient dementia services and acute hospitals.
- Reduction in no./% presentations to Accident and Emergency Departments that do not lead to an admission.
- Reduction in no./% of people living with dementia who die in hospital.
- Reduction in the average length of stay in care homes.

The aim is to reduce costs, where possible by diagnosing and intervening early in order to reduce expenditure on more expensive specialist interventions releasing resources for investment in community based services and support.

4.3 Equality Impact Assessment

Equality impact assessments were completed for the CCG, CCC and PCC⁷⁷. These showed that the impact of the Plan is either positive or neutral on all groups. See Table 5 below:

⁷⁷ Available on request from jo.pugh1@nhs.net

Table 5: Summary of Equality Impact Assessment, CCG, CCC and PCC

Positive Impact
<p>Age: Currently there are inequalities in assessment, treatment and support for dementia related to age with greater attention being given to dementia in people aged over 65 years. The Strategic Plan addresses, this, identifying improvement of outcomes for people 65 years and under as a key priority. However, there is also an opportunity to improve outcomes and experience for people aged over 65 years. For people living with dementia aged 65 years or under, there are real and significant gaps in services that address needs effectively. Dementia affects a much wider circle of people than the individual who is diagnosed with dementia. It therefore has an impact on people of all ages.</p> <p>Disability: Dementia can affect anyone. Therefore the statement relating to particular age groups above can be applied to this group.</p> <p>Pregnancy and Maternity: The onset of dementia is extremely unusual in people aged under 40 years, except where the individual has a learning disability. Therefore, people in this group are unlikely to be diagnosed with dementia and therefore are not likely to be affected directly. However, they may have friends or a family member who is living with dementia and therefore be indirectly affected. They may also be in a caring role.</p> <p>Race: Predictions suggest that there will be seven fold increase in dementia amongst people from minority ethnic communities. At present, some cultural groups are under-represented in services and are more likely to be diagnosed at a later stage in the illness due to a lack of awareness, stigma and availability of appropriate services. The needs of this group are addressed in the Dementia Strategic Plan.</p> <p>Religion or Belief: Dementia can affect anyone. Therefore the statement relating to particular age groups above can be applied to this group. Where the difference relates to a difference in race, action will be taken under the actions related to race above.</p> <p>Rural: One of the objectives within the Strategic Plan is to ensure equality of/consistent access to, treatment and support across Cambridgeshire and Peterborough. To achieve this, issues related to rurality will be addressed.</p> <p>Deprivation: One of the objectives within the Strategic Plan is to ensure equality of/consistent access, treatment and support across Cambridgeshire and Peterborough. To achieve this, issues related to deprivation will be addressed.</p>
Negative Impact
None
Neutral Impact
<p>Gender Reassignment: The Strategic Plan does not directly address the needs of this group. However, dementia can affect anyone. Therefore the statement relating to particular age groups above can be applied to this group.</p> <p>Marriage and Civil Partnership: The Strategic Plan does not directly address the needs of this group. However, dementia can affect anyone. Therefore the statement relating to particular age groups above can be applied to this group.</p> <p>Sex: The Strategic Plan does not directly address the needs of this group. However, dementia can affect anyone. Therefore the statement relating to particular age groups above can be applied to this group.</p> <p>Sexual orientation: The Strategic Plan does not directly address the needs of this group. However, dementia can affect anyone. Therefore the statement relating to particular age groups above can be applied to this group.</p>

4.4 Risk Assessment

There are a number of risks to delivery of the Strategic Plan. The key risks and actions to mitigate these are summarised in Table 6 below.

Table 6: The Dementia Strategic Plan: Risks and Mitigating Actions

	Risk	Impact	Mitigating Actions	Current Status
1	Insufficient capacity within OPMH commissioning and provider organisations to deliver a complex programme of work with the detailed level of analysis necessary to achieve the outcomes required	1. Inability to deliver the required improvement to outcomes and experience for people living with dementia and their carers. 2. Lack of a proper understanding of where there are opportunities for improved effectiveness and efficiency and/or a need for investment. 3. Inability to develop the business case: Autumn 2018.	1. Prioritisation of actions following the gap analysis 2. Secured programme support: CCG and CCC/PCC 3. Seeking SDU support for analysis of activity and performance across the health and social care system.	
2	The need for system wide participation in delivery of the strategy.	1. Inability to deliver the required improvement to outcomes and experience for people living with dementia and their carers. 2. Lack of a proper understanding of where there are opportunities for improved effectiveness and efficiency and/or a need for investment. 3. Inability to develop the business case: Autumn 2018.	1. Identification of the risk and securing commitment to address the issue as part of the process of sign off of the Strategic Plan. 2. Liaison with key managers within each organization. 3. Advance planning of workshops etc.	
3	Lack of resources to support external facilitation for the development of the care pathway	1. Inability to deliver the required improvement to outcomes and experience for people living with dementia and their carers. 2. Lack of a proper understanding of where there are opportunities for improved effectiveness and efficiency and/or a need for investment. 3. Inability to develop the business case: Autumn 2018.	1. Seeking resources to support delivery of the PCSP programme from NHS source and CCC/PCC transformation funds.	

5 Next Steps

5.1 Next Steps

A high level plan for delivery of the actions/milestones required from 2017/18 – 2018/19 is included at Figure 2 above. This aims to confirm support for the Strategic Plan from all relevant commissioning and provider organisations across the health and social care system, to deliver the action plans for each of the Pillars and Cross Cutting themes of the Well Pathway for Dementia and early onset dementia. From all of these, a business case for dementia is produced for consideration by the STP. CCC and PCC during the Autumn of 2018 with implementation from 2019/20.

Following this process, the action plans for each Pillar and Cross Cutting Theme of the Well Pathway will be reviewed according to the outcome of the business case and progress with implementation of each action plan with revised action plans being agreed for implementation during 2019/20 and 2020/21.

Implementation of the Strategic Plan will be overseen by the OPMH Delivery Board. Regular progress reports will be made within the lead organisations and to the relevant Boards across Cambridgeshire and Peterborough.

Appendix 1: The Cambridgeshire and Peterborough Well Pathway for Dementia: Gap Analysis

1. Preventing Well

Gap Analysis

In considering prevention of dementia, it is important to consider health throughout the life course. Risk factors for dementia have been identified from preconception to early, mid and later life. This section presents the epidemiology of these risk factors in Cambridgeshire and Peterborough.

Figure 11 below is taken from the PHE Dementia Profile and shows how Cambridgeshire and Peterborough compare against England and East of England region for a number of these risk factors. Yellow indicates that there is no significant difference between the local area and the England average, dark blue indicates that the local area is lower than the England average and light blue indicates it is higher than the England average.

Figure 11: Summary dashboard for key dementia prevention indicators, East of England

Indicator	Period	England	East of England region	Bedford	Cambridgeshire	Central Bedfordshire	Essex	Hertfordshire	Luton	Norfolk	Peterborough	Southend-on-Sea	Suffolk	Thurrock
Smoking Prevalence in adults - current smokers (APS)	2016	15.5	14.4	15.1	15.2	10.3	14.0	13.5	16.3	13.5	17.6	17.2	14.7	20.8
Percentage of physically active and inactive adults - inactive adults	2015	28.7	27.6	27.2	25.3	22.7	28.0	25.9	30.9	29.0	34.3	29.5	28.3	29.6
Excess Weight in Adults	2013 - 15	64.8	65.6	66.0	63.2	67.1	66.3	62.8	64.6	67.0	70.8	67.0	66.1	70.3
Admission episodes for alcohol-related conditions (Narrow) - 40-64 yrs	2015/16	904	820	729	874	732	799	665	1131	1003	1037	778	788	788
People receiving an NHS Health Check per year	2016/17	8.5	9.7*	6.6	9.6	9.2	10.7	7.5	9.0	8.9	10.4	9.5	12.7	11.3
Hypertension: Recorded prevalence (all ages)	2015/16	13.8	14.1	13.7	12.7	14.0	15.0	12.8	12.0	15.8	11.8	15.2	15.2	14.0
Stroke: Recorded prevalence (all ages)	2015/16	1.7	1.7	1.5	1.5	1.5	1.7	1.6	1.2	2.2	1.3	1.7	2.0	1.5
Diabetes: Recorded prevalence (aged 17+)	2015/16	6.5	6.2	7.0	5.5	6.0	6.4	5.5	7.6	6.7	6.5	6.5	6.3	6.4
CHD: Recorded prevalence (all ages)	2015/16	3.2	3.1	3.0	2.9	3.0	3.2	2.7	2.5	3.8	2.6	3.3	3.7	2.6
Depression: Recorded prevalence (aged 18+)	2015/16	8.3	8.0	9.3	7.7	8.6	7.7	7.9	6.5	7.9	7.4	8.5	8.9	8.5

Source: PHE Dementia Profile

In summary this shows that:

- Smoking prevalence in adults is below the national average in Cambridgeshire 15.2% but just above in Peterborough at 17.6%.
- In Cambridgeshire, 25.3% of adults are physically inactive which is lower than the national average. This is classified as doing less than 30 “equivalent” minutes of at least moderate intensity physical activity per week in bouts of 10 minutes or more in the previous 28 days. It is important to note that this definition falls below accepted national recommendations.

- In Peterborough, 34.3% of adults are physically inactive which is higher than the national average.
- In Cambridgeshire 63.2% of adults are overweight or obese – this is less than the national average. In Peterborough, 70.8% of adults are overweight or obese which is greater than the national average.
- In Cambridgeshire 9.6% and in Peterborough 10.4% of the eligible population had received their NHS health check.

2. Diagnosing Well

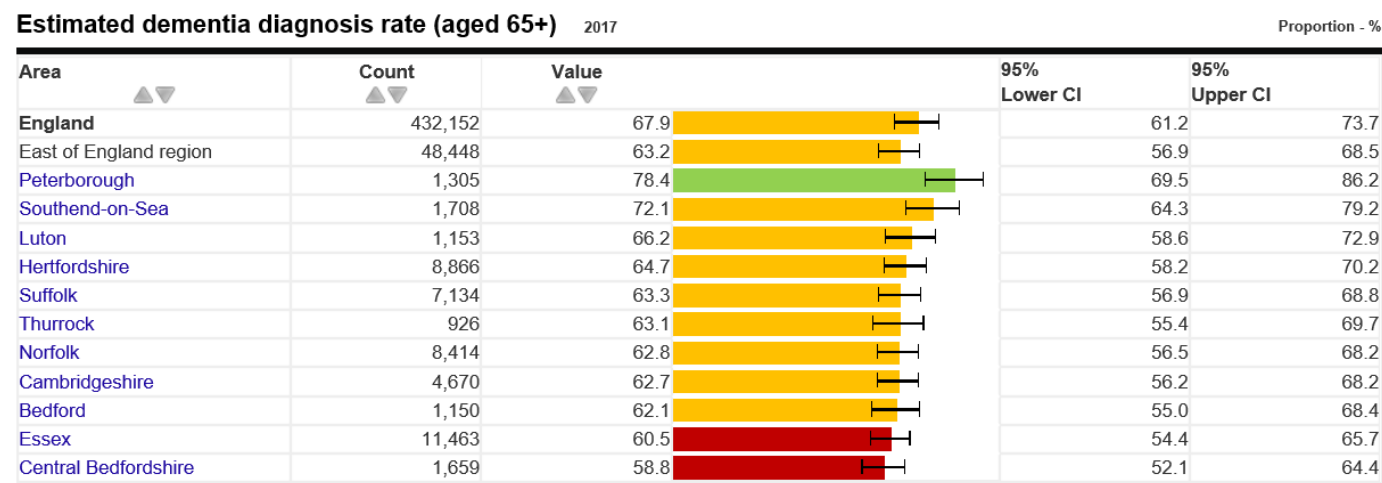
The 'Prime Minister's 2020 Challenge on Dementia' included a commitment to increase the number of people living with dementia who have a formal diagnosis. The rationale being that a timely diagnosis enables people living with dementia, their carers and healthcare staff to plan accordingly and work together to improve health and care outcomes. This commitment was further supported by the NHS 2014-15 mandate which set a target of increasing the Estimated Dementia Diagnosis Rate by two-thirds by March 2015 and to sustain this throughout 2015/16.

The diagnosis rate is defined as the rate of persons aged 65 and over with a recorded diagnosis of dementia per person estimated to have dementia given the characteristics of the population and the age and sex specific prevalence rates of the Cognitive Function and Ageing Study II, expressed as a percentage with 95% confidence intervals.

Diagnosis rates for each local authority in the East of England are presented in figure 8 below. Yellow indicates that the area is in line with the national average, green indicates that the area has a statistically significantly higher than national average diagnosis rate, and red indicates that it is statistically significantly lower.

Figure 12 below shows that Peterborough performs well when compared with the rest of the county with a current diagnosis rate of 78.4%, whilst Cambridgeshire is slightly below average with a diagnosis rate of 62.7%.

Figure 12: Estimated dementia diagnosis rate (aged 65+), East of England and England, by local authority area, 2017 (Source: PHE Dementia Profile)



Current waiting times for Memory Services are well within the current national target of 18 weeks averaging between 8 and 12 weeks. The very small number of people who wait longer than 18 weeks are for very specific reasons that are not related to the service. On average the service sees 2,000 people a year out of which some 18 people had waited longer than 18 weeks.

Stakeholders identified the following strengths:

- Access to and speed of diagnosis

The following gaps/opportunities for improvement were identified:

- Variation in diagnosis rates between GP practices.

- Advance care planning so that crises and avoidable admission to hospital can be prevented, particularly in the event of a carer being unable to care temporarily
- Case finding in care homes (being addressed through STP investment in a case finding tool)

3. Supporting Well

The 'NHS England Well Pathway for Dementia' states that people with dementia and their carers should have access to safe and high quality health and social care.

Figures 13 and 14 below show data on the number of people with dementia using inpatient hospital services as a percentage of recorded diagnosis of dementia. This ratio gives a useful indication of the use of inpatient general hospital services for people diagnosed with dementia. Both Cambridgeshire and Peterborough currently have a higher than average proportion of people diagnosed with dementia using inpatient hospital services. This requires further investigation to understand the possible causes and implications of this figure.

Figure 13: Ratio of inpatient service user to recorded dementia diagnoses, Cambridgeshire, 2012/13 – 2015/16

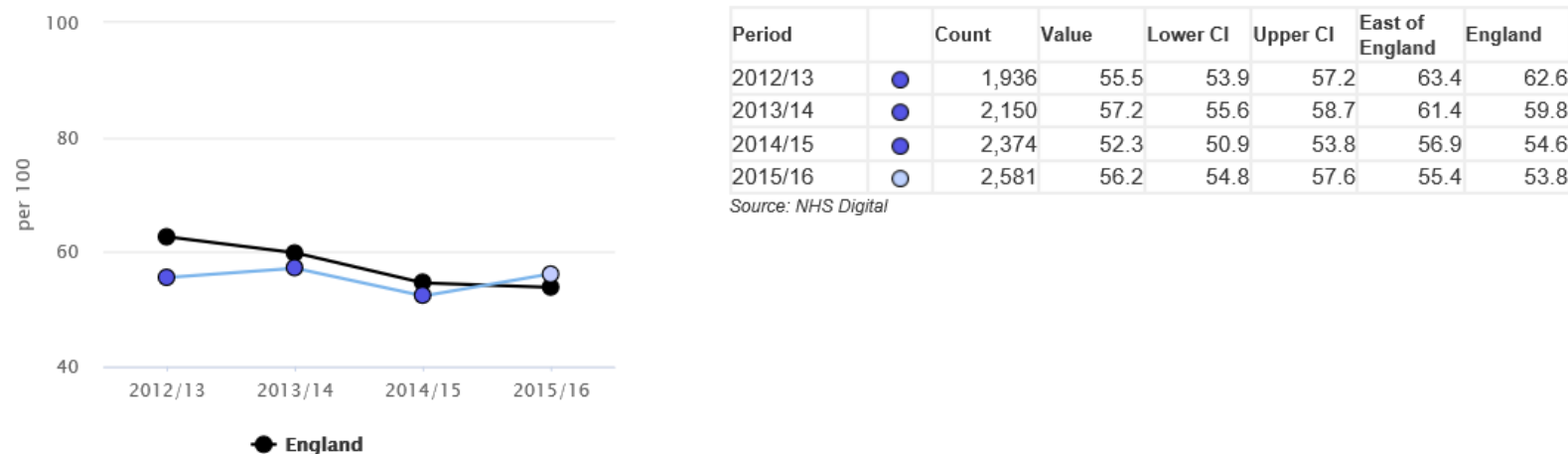
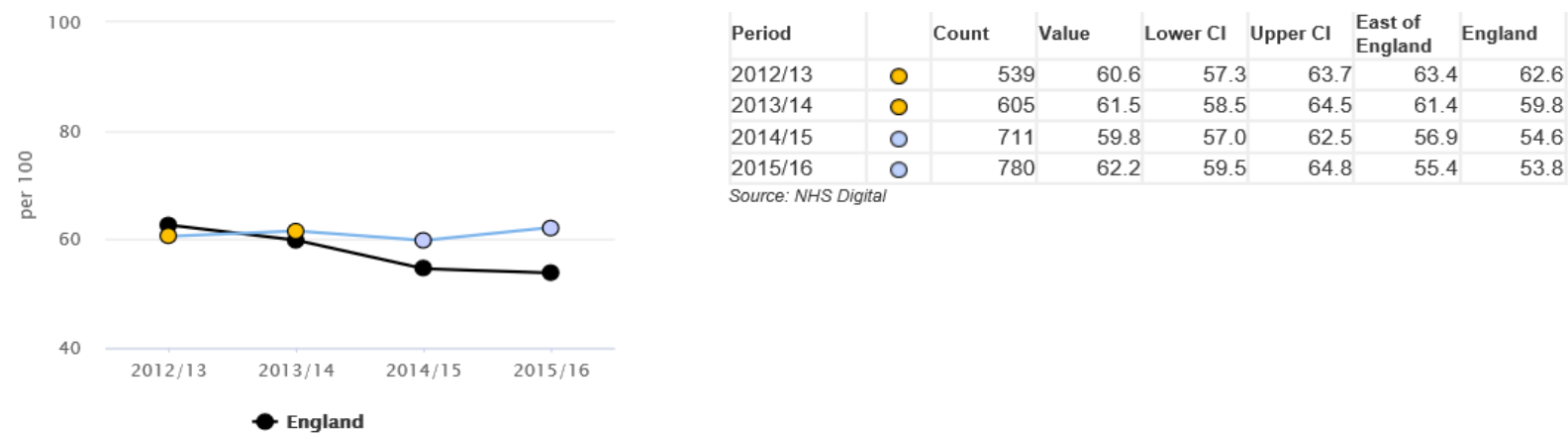


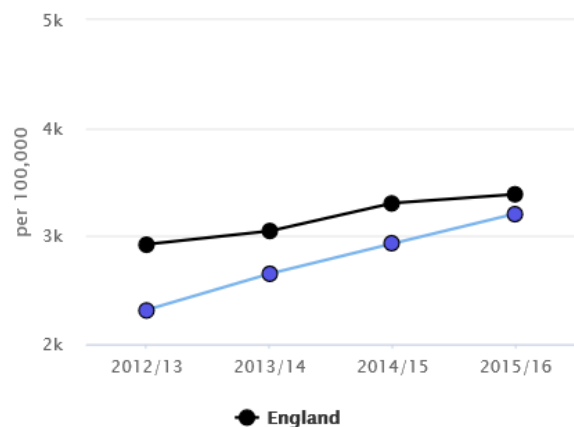
Figure 14: Ratio of inpatient service user to recorded dementia diagnoses, Peterborough, 2012/13 – 2015/16



Source: PHE Dementia Profile

Figures 15 and 16 show data on the rate of emergency admissions for people with dementia aged 65 years and over. It is important to note that these admissions may not be *due* to person’s dementia and will include a range of different reasons for admission. They show that there is an upward trend in this indicator in both Cambridgeshire and Peterborough. The rate in Cambridgeshire is lower than the national average, whilst the Peterborough rate is significantly higher than the national average. This requires further investigation to understand the possible causes and implications of this figure.

Figure 15: Directly age standardised rate of emergency inpatient hospital admissions for people with dementia (aged 65+) per 100,000, Cambridge, 2012/13 – 2015/16

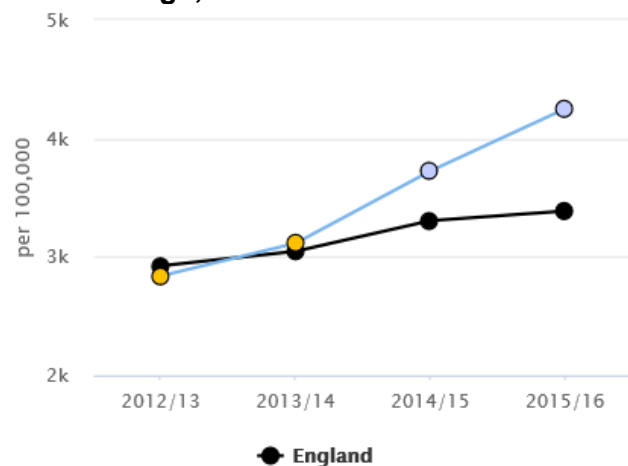


Period		Count	Value	Lower CI	Upper CI	East of England	England
2012/13		2,540	2,318	2,228	2,410	2,643	2,924
2013/14		2,975	2,652	2,558	2,750	2,795	3,047
2014/15		3,407	2,931	2,833	3,032	3,103	3,306
2015/16		3,771	3,208	3,106	3,313	3,108	3,387

Source: NHS Digital

(Source: PHE Dementia Profile)

Figure 16: Directly age standardised rate of emergency inpatient hospital admissions for people with dementia (aged 65+) per 100,000, Peterborough, 2012/13 – 2015/16



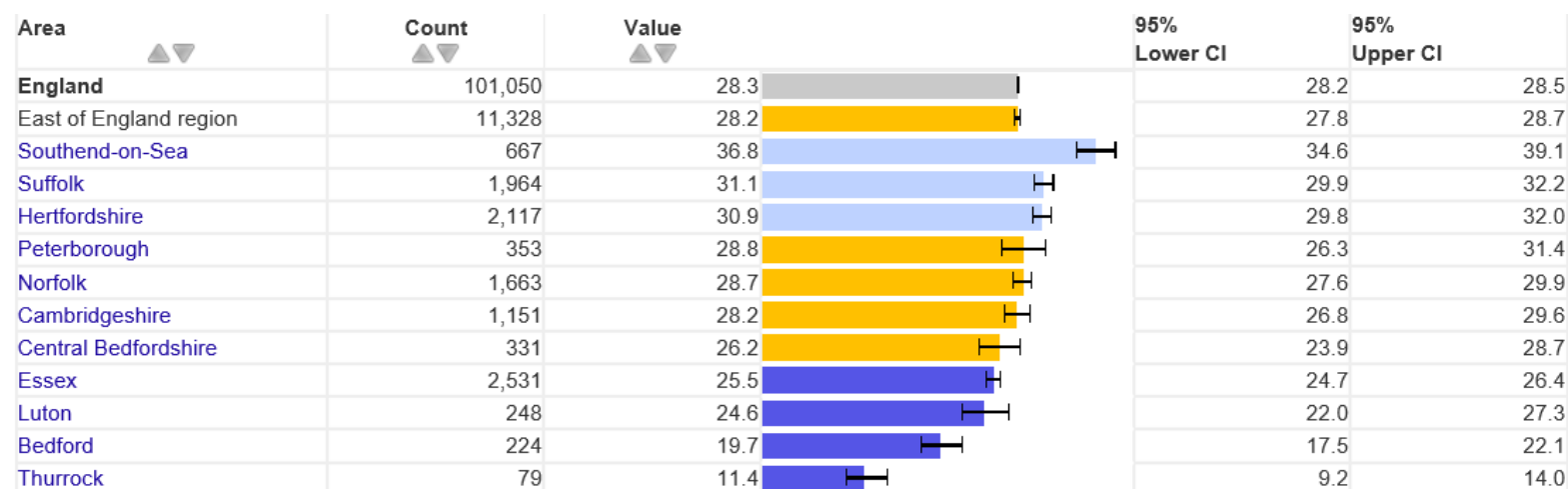
Period		Count	Value	Lower CI	Upper CI	East of England	England
2012/13		758	2,839	2,638	3,050	2,643	2,924
2013/14		850	3,115	2,907	3,333	2,795	3,047
2014/15		1,050	3,725	3,501	3,959	3,103	3,306
2015/16		1,213	4,251	4,013	4,499	3,108	3,387

Source: NHS Digital

Source: PHE Dementia Profile

Figure 17 below shows how Cambridgeshire and Peterborough compare to the rest of the region and England in terms of the proportion of emergency inpatient admissions for people (aged 65+) with dementia which are short stays, i.e. 1 night or less. This indicator is important as changes in the surrounding environment can increase the levels of anxiety and stress for an individual. People with dementia can be more susceptible to these changes, which can cause additional distress. Admissions to hospital, particularly ones of short duration should be avoided if at all possible for this population. It shows that Cambridgeshire and Peterborough have similar rates of short stay admissions as the national and regional average of 28%. This rate has remained broadly stable over the last four years.

Figure 17: Percentage of emergency inpatient admissions for people (aged 65+) with dementia that are short stays, East of England and England, by local authority area, 2015/16



Source: Health and Social Care Information Centre (HSCIC)

Source: PHE Dementia Profile

The mortality rate for people with dementia in Cambridgeshire and Peterborough is slightly lower than the England average at 845 per 100,000 people.

The average number of admissions from care homes within the Cambridgeshire and Peterborough region per month for the months April 16 to March 17 was 323. For each admission to the hospital there is an average cost of £1,337.29 and for every emergency department attendance there is an average cost of £97.39 excluding the cost of calling an ambulance which is £247. In 2016/2017 49% of all non-elective admissions from care homes in

Cambridgeshire and Peterborough had a code of dementia recorded as part of their admission, taking into account the admission costs of £1,337.29 the total cost to the NHS was 2.5 million pounds. RightCare data indicates that Cambridgeshire and Peterborough CCG spending on dementia non-elective admissions is higher than the average of the 10 most demographically similar CCGs. The data from RightCare indicates that Cambridgeshire and Peterborough CCG are better performing on average for short stay admissions for residents with dementia, however the dementia sufferers are more likely to die in a place that is not their usual residence indicating that End of Life Care for dementia sufferers can be improved to ensure that residents die within their preferred place of care with advanced care planning in care homes.

Care Homes

Currently Cambridgeshire and Peterborough region has 141 Residential and Nursing Care Homes and a further 15 Residential and Nursing Care Homes that can utilise the Cambridgeshire and Peterborough secondary care services due to their geographical location. There is variation in the standards within the care homes across the county, there are currently no CQC rated outstanding care homes. There are 54 care homes with 845 beds within the Cambridgeshire and Peterborough region registered with the CQC specialising in learning disabilities. National studies indicate that it is likely that people with a learning disability aged under 65 years who develop dementia are likely to be moved inappropriately into care homes for older people. National studies show that, on average, 70% of people living in care homes are suffering with Dementia. The Care Homes within Cambridgeshire and Peterborough provide over 6000 beds for people unable to live independently. It is likely that 4200 residents within Cambridgeshire and Peterborough care homes are living with dementia.

The CQC report, Cracks in the Pathway (2014) stated that it is likely that someone living with dementia will experience poor care at some point while living in a care home or being treated in hospital, the reasons behind this are:

- Assessment of care needs
- Providers working together
- Involvement in care
- Planning and delivery of care
- Staffing

- Monitoring of the quality of care

The identification of dementia, depression and delirium is paramount to ensure a timely response to resident's needs. Currently there is no formal process in place for care homes to utilise a dementia case-finding tool for care workers to use with individuals living in care homes, with a view to identifying people with dementia, thereby increasing the rate of diagnosis. There is little evidence within the region to show that care home staff routinely follow evidenced based practice such as the NICE dementia quality standards when care planning with and for their residents. Key stakeholders want to develop a partnership with care homes to support care homes to deliver best practice to ensure that care is person centred and of a high quality and that care home staff are able to recognise and promote mental and emotional wellbeing. All care homes should be able to demonstrate the achievement of the Dementia Care standards.

The Care Home population are often disregarded when considering the needs of the local population and Care Home Managers feel that they are considered as very separate to the NHS and Social Care System and let down by this system when trying to access help for their residents. This has also been evidenced nationally by the Alzheimer's Society who states that "...the NHS is failing to provide adequate, timely access to vital services including continence advice, physiotherapy and dentistry....we have also found that some GP practices are wrongly charging care homes, and the people who pay care home fees, for NHS services that should be free. These practices contravene the NHS Constitution, which states that everyone, regardless of who they are or where they live, should have access to the NHS services they need and these should be free at the point of use."

Research has found that the prevalence of comorbid conditions in people with dementia is high. Studies have estimated that 61% of people with Alzheimer's disease have three or more comorbid diagnoses. As the severity of the dementia increases, so does the rate of comorbid conditions. (Dementia and comorbidities: Ensuring parity of care, 2016). People with dementia living in a care home are more likely to go into hospital with avoidable conditions (such as urinary infections, dehydration and pressure sores) than similar people without dementia. (Prime Minister's challenge on dementia 2020, 2015). Research has found that the prevalence of comorbid conditions in people with dementia is high. Studies have estimated that 61% of people with Alzheimer's disease have three or more comorbid diagnoses. As the severity of the dementia increases, so does the rate of comorbid conditions. (Dementia and comorbidities: Ensuring parity of care, 2016). The CQC and the British Geriatrics Society have shown that many the health needs of people with dementia living in care homes are not regularly assessed and met. One consequence is avoidable admissions to hospital. Nationally, poor access to NHS services has led to people with dementia being bedbound, incontinent and sedated.

The average number of admissions from care homes within the Cambridgeshire and Peterborough region per month for the months April 16 to March 17 was 323. For each admission to the hospital there is an average cost of £1,337.29 and for every emergency department attendance there is an average cost of £97.39 excluding the cost of calling an ambulance which is £247. In 2016/2017 49% of all non-elective admissions from care homes in Cambridgeshire and Peterborough had a code of dementia recorded as part of their admission, taking into account the admission costs of £1,337.29 the total cost to the NHS was 2.5 million pounds. RightCare data indicates that Cambridgeshire and Peterborough CCG spending on dementia non-elective admissions is higher than the average of the 10 most demographically similar CCGs. The data from RightCare indicates that Cambridgeshire and Peterborough CCG are better performing on average for short stay admissions for residents with dementia, however the dementia sufferers are more likely to die in a place that is not their usual residence indicating that End of Life Care for dementia sufferers can be improved to ensure that residents die within their preferred place of care with advanced care planning in care homes.

Advance care plans have also been found to reduce the number of inappropriate hospital admissions in patients with dementia. People with dementia and their carers need to be involved in planning end of life care which recognises the principles outlined in the Department of Health End of Life Care Strategy. There is a disjointed service within the region for end of life care. There are currently no agreed multi-agency protocols in place regarding end of life pathways and care home residents. The result of poor proactive management results in residents being admitted to hospital via A&E. One of the hospices within the region offers a Gold Standard Framework (GSF) for Care Homes training programme at a charge, however there has been little engagement. Regionally the Care Homes need to be included within the End of Life Care Strategy and include the requirement to consider dementia.

Previous research has found that poor pathways between care homes and hospitals are resulting in people with dementia receiving poor care. In 2014, the CQC found variable or poor care regarding arrangements for sharing information when people moved between services in 83% of hospitals (Care Quality Commission, 2014). When arriving at the emergency department, elderly frail people and people with dementia suffer from higher delays in diagnosis, unsuspected diagnoses such as Delirium, depression, drug and alcohol use, elder abuse, polypharmacy. They receive under treatment for certain conditions and management and overtreatment with higher rates of Foley catheters and overuse of sedation and restraints as examples and have poorer outcomes as a result of being in hospital. (Bannerjay & Conroy, 2017, CQC, 2014).

Many people with dementia who live in care homes have high levels of mental health needs as a result of the cognitive, psychological and behavioural symptoms of dementia and other mental health conditions such as depression. Nationally, 45% of care home managers surveyed by the Alzheimer's society said that the NHS isn't providing residents with dementia with adequate and timely access to mental health services, in a report commissioned

by Cambridgeshire and Peterborough CCG 22% of care home managers expressed difficulty in accessing mental health reviews and assessments. When accessing Mental Health services in a crisis there has been a lack of clarity for care home managers in Cambridgeshire and Peterborough, when ringing 111 and utilising the option 2 service. One care home manager recalled a distressing event when contacting 111 and choosing option 2 for mental health crisis and was informed that this service was for under 65 years of age only. The incident resulted in a compromise of staff and patient safety involving the police. Cambridgeshire and Peterborough CCG has one of the lowest rates of referrals into access into psychological therapies for residents over the age of 65 and the rate of contact with secondary MH services by people aged 65+ per 100,000 with no inpatient stay is one of the lowest nationally.

The issue of recruitment and retaining staff is a major concern; we do not see a significant change in the current issues of attracting staff changing in the coming years. Furthermore support is required for Care Homes in addressing the current challenges by excessive use of Agency Nurses. There is a requirement for improved quality of care for people with dementia in care homes through:

- The development of explicit leadership for dementia care within care homes
- Defining the care pathway within
- Commissioning of specialist in-reach services from community mental health teams
- Through inspection regimes
- Support from the county wide system through the Care Home Support Team to ensure care homes are allowed to follow continuous improvement processes using evidenced based guidance

Stakeholders identified the following strengths:

- Management of dementia in acute hospital (Right Care).
- Early work undertaken in relation to meeting the needs of people from minority groups with dementia.
- Percentage of patients whose care was reviewed at least annually by GPs (Right Care).
- Working to meet the needs of people with dementia from hard-to-reach groups.

and gaps:

- Sufficient capacity in services to enable access.

- Advance care planning so that crises, avoidable admission to hospital is minimised, particularly in the event of a carer being unable to care temporarily and plans are made for end of life.
- The availability of transport to access services.
- The availability of care at home, particularly in more rural areas.
- Pressure on the cost of nursing home care in Cambridgeshire as an affluent area.
- Access to nursing home care for those with the most complex needs, particularly on discharge from hospital.
- Dementia care in residential care and nursing homes; care that is at least of the minimum standard with a percentage of care homes achieving the 'outstanding' rating and equity of access to NHS assessment, treatment and support
- Support and treatment to remain at home for people living in residential care and nursing homes
- Assessment, treatment and support for people with early onset dementia.
- Detailed understanding of activity relating to dementia in acute hospitals e.g. where dementia is not the main reason (primary diagnosis) for admission.
- Need for stronger commissioning/leadership for dementia care within both CCG and the Local Authorities.
- Dedicated psychological treatment within the Memory Assessment Service
- Access to psychology in inpatient MH wards.

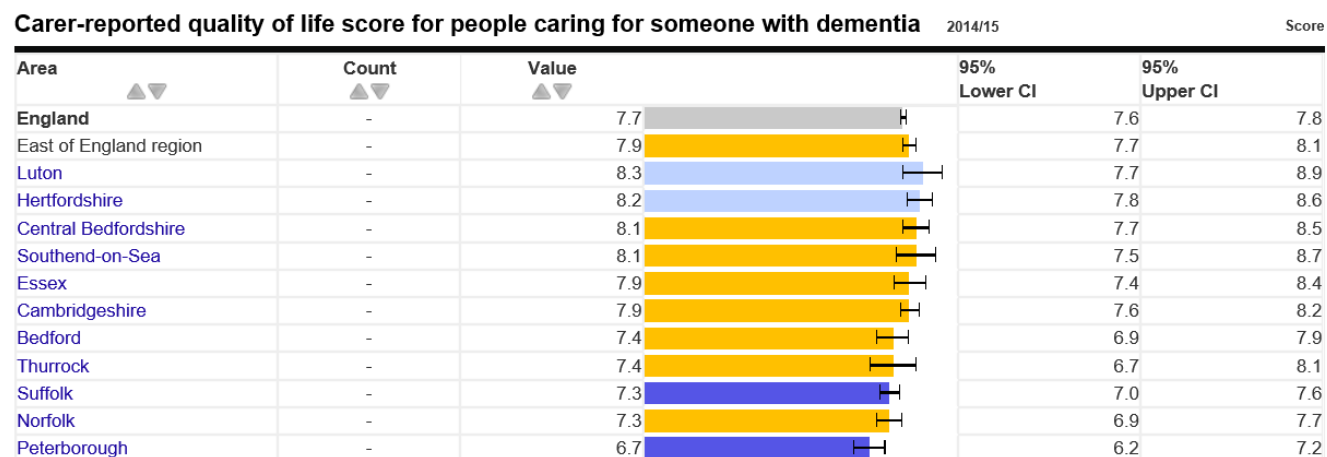
In December 2016, a review was conducted of care homes with the top ten A&E attendance rates (using ambulance data) plus a further 8 care homes added to the study. The most common reason for calling an ambulance from care homes was for falls (47%). The study identified particularly poor relationships between care homes and acute providers including poor handover from A&E to care homes, lack of involvement of care home in discharge planning, lack of information sharing with care home staff, and failure to return medications and/or DNAR paperwork. It also identified inappropriate use of 999, a disjointed approach to end of life care planning in care homes, and a common disregard for care planning by ambulance staff where it is in place. The review concludes that the issues identified in the report, including those highlighted above, results in residents being admitted to hospital via A&E, although hospital admission may be unnecessary and against the wishes of the resident or the agreement of the family. The Care home support team, working alongside Admiral UK, will promote End of Life care in Dementia in care homes, with the aim of improving some of the areas identified in this study.

4. Living Well

The 'Prime Minister's 2020 Challenge on Dementia' states that carers of people with dementia should be made aware of and offered the opportunity for respite, education, training, emotional and psychological support so that they feel able to cope with their caring responsibilities and to have a life alongside caring.

Figure 18 shows how the **carer-reported quality of life score for people caring for someone with dementia** varies across the East of England region. This measure gives an overarching view of the quality of life of carers based on outcomes identified through research by the Personal Social Services Research Unit. This is a current measure related to quality of life for carers looking after people with dementia and supports a number of the most important outcomes identified by carers themselves to which adult social care contributes. It shows that the average score in Cambridgeshire is slightly higher than the England average (7.7) at 7.9 and the Peterborough average score is significantly lower than the England at 6.7.

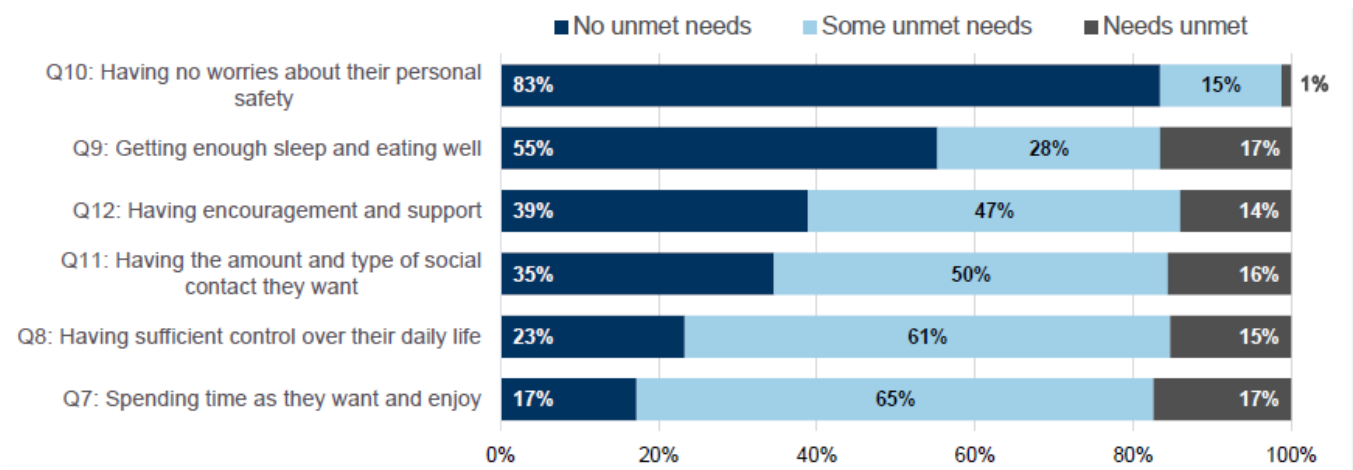
Figure 18: Carer-reported quality of life score for people caring for someone with dementia, East of England and England, by local authority area, 2014/15 (Source: PHE Dementia Profile)



Source: NHS Digital, ASCOF

A national survey of adult carers in 2014/15 (see figure 10) showed that the most commonly felt unmet need was being able to spend time as they want and enjoy, having sufficient control over their daily life and having the amount and type of social contact they want. The majority of carers (83%) felt that they had no unmet needs in terms of worrying about their personal safety.

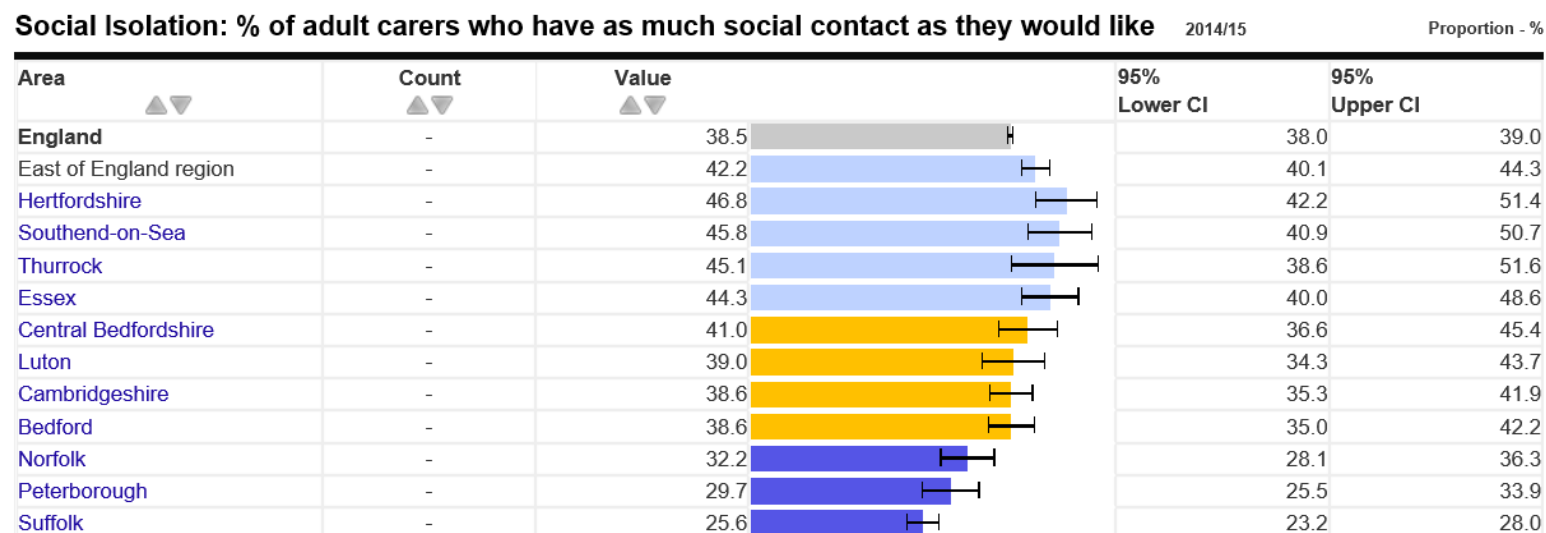
Figure 19: Carers’ agreement with survey statements in the Personal Social Services Survey of Adult Carers in England, 2014-15



Source: www.hscic.gov.uk/pubs/psscarersurvey1415

Figure 20 below shows how Cambridgeshire and Peterborough compare to England and local authorities in the East of England in terms of the proportion of adult carers who feel that they have as much social contact as they would like. It shows that Cambridgeshire is approximately in line with the national average of 38.6%, whilst Peterborough is significantly lower at 29.7%. Loneliness and social isolation can have a significant impact on individual’s health and wellbeing; evidence shows a link between loneliness and social isolation and increased risk of diseases such as cardiovascular disease and dementia.

Figure 20: Proportion of adult carers who have as much social contact as they would like, East of England and England, by local authority area, 2014/15



Source: Personal Social Services Survey of Adult Carers in England (HSCIC)

Source: PHE Dementia Profile

Stakeholders identified the following strengths:

- Dementia friendly communities
- The Dementia Resource Centre in Peterborough which provides a focus for dementia support

and gaps:

- Geographical consistency and capacity in relation to the Dementia Resource Centres (commissioned in Peterborough but not in Cambridgeshire and insufficient capacity and potential for development in Peterborough)
- Geographical consistency in relation to Dementia Friendly Communities

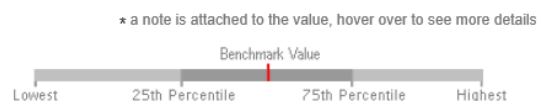
- Geographical consistency in relation to Dementia Friendly Environments
- Carer assessment and support
- Information, advice, guidance and support for carers so that they can continue caring when they wish to do so.

5. Dying Well

The 'NHS England Well Pathway for Dementia' states that people living with dementia should be able to die with dignity in the place of their choosing. Figure 21 is a spine chart comparing the Cambridgeshire and Peterborough STP area against the England average for a number of end of life care indicators. This shows that:

Figure 21: Spine chart showing performance of Cambridgeshire and Peterborough STP area against the England average for a range of 'Dying Well' dementia indicators, 2015

Compared with benchmark ● Lower ● Similar ● Higher ○ Not Compared



Export table as image

Indicator	Period	Cambridgeshire and Peterborough		England			
		Count	Value	Value	Lowest	Range	Highest
Directly Age Standardised Rate of Mortality: People with dementia (aged 65+)	2015	1,300	845	873	733	<div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div></div><div><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Source: PHE Dementia Profile

Cambridgeshire and Peterborough generally performs well in terms of the place of death for people with dementia. It has higher than average proportion of people dying in their usual place of residence, at home and in care homes, and a lower than average proportion of people dying in hospital.

6. Early Onset Dementia

Early onset dementia is defined as dementia occurring before the age of 65 years. The conditions that are the underlying causes of the dementia syndrome are different in early onset dementia compared to late onset. Though Alzheimers disease is the most common there is a greater contribution from frontotemporal dementias and Huntington's disease. It is an ongoing debate as to whether cases of early onset Alzheimer's disease differ from late onset disease and if they are best served by a separate service or being cared for in general dementia teams. The relative rarity of early onset dementia means that the teams are often small and therefore not robust if there is unexpected sickness or staff turnover for any other reason. Currently in Cambridgeshire early onset patients are cared for in all age dementia services. We have excellent diagnostic clinics for Parkinson's disease (and related Parkinsonian conditions such as progressive supranuclear palsy, corticobasal degeneration and multi-system atrophy), Huntington's disease and frontotemporal dementia. These clinics provide excellent diagnosis, access to research and neurological assessment. We have worked hard to build links between these diagnostic clinics and community services to make sure after care is coherent and excellent. We will further strengthen these relationships and work with colleagues in the University, neurology and the acute hospital to make sure the community offer for these patients is robust.

7. Researching Well

We are lucky in Cambridgeshire to be close to a world class university which has expert dementia clinicians and academics. We already have very strong local research and participation in international research in Alzheimer's, Parkinson's, Lewy body disease, Huntington's disease, mild cognitive impairment and frontotemporal dementia. We also have high levels of engagement with the Clinical Research Network who in 2017 exceeded their target for recruitment in to dementia studies. Our aim is to give every person diagnosed with dementia the chance to take part in high quality research. We recognise that not every patient will want to do this, and will work with CPFT to make sure robust measures are in place in the electronic patient

record which safeguards patient autonomy and choice. Any contacts for research will be within NHS guidance and frameworks. We also recognise that not every patient may wish to take part in research which involves experimental therapy. We will therefore offer a wide range of potential research projects so no person is excluded. We will continue to work with the Windsor clinical research unit at Fulbourn hospital. They currently offer 14 different studies and recruit approximately 300 patients per year. Our aim is to double this number. Studies offered include commercial and non-commercial drug trials, trials of assistive technology and cognitive stimulation, service evaluation, quality of life studies and bio-banking. With regards to the latter we aim to make Cambridgeshire a world leader in incorporating research opportunity in to 'business as usual'. We will work with CPFT and CUH to make sure that patients who have a scan have the opportunity for their scan to become part of an anonymised research library which will be available for future academic research. We will work with 'Join Dementia Research' (JDR) to give patients a continued offer of research participation and also work closely with research coming out of the University of Cambridge. Our services will make full use of JDR to make sure that patients only need to make a single expression of interest to open up the opportunity of all the research relevant to them.

Stakeholders identified the following strengths:

- A strong research base and access to the latest drugs through trials conducted there.

8. Integrating Well

Stakeholders identified the following strengths:

- Cohesion and partnership working across agencies – statutory and non-statutory.
- A bottom up approach to improvement.

and the following gaps:

- A clearly defined multi-agency dementia pathway, including:
 - Meeting physical and mental health needs in a seamless way ensuring that both health and social care and physical and mental health needs are considered in an holistic way.

- Fiona – this bit is what CPFT are all about. I could write another 120 pages but, in brief. CPFT are national leaders in bringing together physical and mental healthcare. We will continue to work with them to make sure that patients diagnosed with dementia have their needs assessed and dealt with holistically without requiring the individual to navigate care. The unification of community care under one organisation gives a great opportunity to develop this approach and we will work with CPFT to make sure that dementia patients are assessed holistically and can seamlessly access all community services they may require, including district nursing, occupational therapy, physiotherapy, SALT, podiatry, specialist nursing, emergency nursing, continence, tissue viability and if necessary physical inpatient rehabilitation as well as a full range of inpatient and outpatient dementia specific care.
- Knowledge and understanding of the wider care pathway of staff in community and specialist teams.

9. Commissioning Well

Gaps identified:

- Need for stronger commissioning/leadership for dementia care within both CCG and the Local Authorities.

10. Training Well

A gap in training in multi-agency working to ensure that care is seamless and use of all the resources available within the community and assessment, treatment and support is timely was identified.

11. Monitoring Well

The performance of specialist dementia services in Cambridgeshire is currently monitored by CCG and Council Commissioners as required through the national mental health integrated dashboard as follows:

- Memory Service clinic waiting times (CCG).

- Neighbourhood Teams (CCG).
- Inpatient ward performance (CCG).
- Carers of people with mental health problems receiving services advice or information (Councils).
- No. Care packages (Councils).
- Take up of self-directed support/direct payments.
- Use of nursing and care home services (CCG and Councils).
- Use of home care (Councils).

Gaps were identified in the following areas:

- Detailed understanding of activity relating to dementia in acute hospitals e.g. where dementia is not the main reason (primary diagnosis) for admission.
- Detailed monitoring of activity, finance and outcomes relating specifically to dementia within and across mental and physical health and social care services.
