

# **Dementia**

## **Joint Strategic Needs Assessment**

### **November 2016**

Public health department ESCC

# Dementia Joint Strategic Needs Assessment

## November 2016

### About this document:

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# Executive Summary

## Section 1. Context /setting the scene

### 1.1 Purpose of the JSNAA:

The purpose of this Joint Strategic Needs and Assets Assessment (JSNAA) on dementia is to summarise the available evidence and information about the local population to inform commissioning intentions for East Sussex County Council and CCGs.

This takes account of national and local policy on dementia, in the context of East Sussex Better Together,<sup>i</sup> and Connecting 4 You<sup>ii</sup> which are transformational programmes improving the co-ordination of health and social care in East Sussex.

In 2015, dementia was estimated to affect 850,000 people in the UK, and it is expected to rise to 1 million by 2025. Two thirds of people with dementia are women. According to the Alzheimer's Society one in six people aged 80 and over have dementia.<sup>1</sup>

Approximately eighty percent of people living in residential and nursing homes are estimated to have dementia or significant cognitive impairment.<sup>2</sup>

Dementia is more common in care homes than the number of recorded diagnoses would suggest. A recent study showed a high prevalence of depression and behavioural symptoms in care homes as well.<sup>3</sup>

There are 40,000 younger people with early onset dementia and 25,000 people with dementia from black and minority ethnic groups in the UK. It costs the UK society an estimated £26 billion per year. However, the statistics miss the unique life stories of individuals, carers, family and friends. Each person with dementia and their family have their own journey and challenges, with good times and bad.

Over the past five years in East Sussex, dementia has come a long way but there is still much to be done since the East Sussex Dementia Delivery Plan for Dementia Care<sup>4</sup> was introduced in 2012. The momentum that has been built from the many achievements to-date needs to be sustained and progress continued, as East Sussex strives to become a Dementia Friendly county.

This report describes the needs of people with dementia and their carers in East Sussex and makes recommendations to support Commissioners in future planning of services. The aim is to review the health issues facing individuals with dementia and their wider social network, leading to actions that will support early diagnosis and care for individuals with dementia and their carers.

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<sup>i</sup> This has been adopted by **Hastings and Rother CCG, and Eastbourne, Hailsham and Seaford CCG.**

<sup>ii</sup> This has been adopted by **High Weald, Lewes and Havens CCG.**

## 1.2 The report aims to:

### **Draw together the strategic drivers from central and local government.**

- Describe the local picture of need and model future trajectories to enable forward planning.
- Set out the current pathways and services for people with dementia and their carers including diagnosis, treatment and post-diagnostic support.
- Identify and understand the gaps in service provision for local residents and their carers.
- Review guidance and evidence to inform best practice locally.
- Make recommendations to inform future planning by the Council and across the three CCGs to meet likely future needs.

Information has been collected from a variety of sources including audit, relevant policy and research as well as local data provided by stakeholders, service providers, service users and carers.

This Executive Summary is also available as a separate report on the JSNA website at <http://www.eastsussexjsna.org.uk/comprehensive>

Throughout this document people with dementia have been referred to as patients, service users, clients or customers. These terms have been employed in different sections depending on the context and relationships.

## 1.3 Key Facts

### **Local epidemiology**

An estimated 10,172 people in East Sussex currently have dementia (either diagnosed or undiagnosed). This is equivalent to 1.88% of the population, or 1 in every 53 people, *in East Sussex*. To give a relative idea of size: 10,170 people is around the same as the populations of Buxted, Rotherfield and Mayfield villages combined.

Eastbourne, Hailsham and Seaford [EHS] CCG has the highest *number* of people with dementia reflecting its larger elderly population and also has the highest estimated *proportion* of people with dementia. The expected number of people living with dementia in East Sussex will have risen to 15,900 by 2030, slightly more than the current population of Uckfield.

The greatest growth of dementia cases will be in people over 85 years old.

There are about 2 500 new cases of dementia, per year (diagnosed or undiagnosed) in East Sussex. This is 17 *new* cases per 1,000 persons in the population aged over 65. This would amount to about 60 people newly developing dementia *each year* in Peacehaven, though not all would present to their doctor in the early stages.

Most GPs in the UK can expect to have between 12 and 20 people with dementia to care for at any one time.

The incidence of dementia [the number of new cases per year in a population] increases with age, but is not a natural part of ageing.

Between one in seven and one in five of the population over the age of 70 are estimated to have Mild Cognitive Impairment, most commonly affecting their memory.

Just over half of people with dementia have mild dementia and those remaining have moderate or severe disease. About two thirds of people with dementia live in the community, the rest live in long term care.

### **Risk factors for dementia<sup>5</sup>**

A recent epidemiological study in the USA has shown the benefits of optimising cardiovascular risk in the prevention of dementia.

Preventive efforts to reduce the risks of cardiovascular disease in middle age are ongoing in East Sussex. It is hoped these will reduce the number of cases which are attributed to vascular dementia. To what extent these efforts will counteract the predicted rise in the number of cases of people who will be living with dementia is unknown.

Other risk and protective factors are summarised under the headings of genetic, metabolic, lifestyle, psychosocial and other categories including environmental toxins and infections.

## **Section 2. The Local Picture**

### **2.1 Epidemiology:**

East Sussex has an ageing population. The total number of people aged 65 and over will increase substantially from 135,500 in 2015 to 185,100 by 2030.

The number and proportion of elderly and very elderly people living with dementia will increase more than elsewhere in the Region. The situation will be complicated by the forecast increase in number of people living alone over the next 15 years.

An estimated 10,172 people in East Sussex currently have dementia (either diagnosed or undiagnosed). This is equivalent to 1.88% of the population, or 1 in every 53 people, in East Sussex.

The expected number living with dementia in East Sussex will have risen to 15,900 by 2030. The greatest growth of dementia cases will be in people over 85 years old.

More intensive case finding will identify people in the community with early cognitive [memory] problems before they present with more advanced symptoms. Different epidemiological studies give different estimates of the extent of undiagnosed cases in the population, depending on where and in what way cases of dementia are looked for.

People with dementia have reduced survival, compared to those of the same age group who do not have dementia, in all age groups.

### **2.2 People with protected characteristics**

The proportion of the total population from ethnic minority groups is relatively small in East Sussex, eight per cent, with only one per cent in those aged 65 and over.

There is some evidence that people from BME groups are at greater risk of developing dementia and may present differently to services.

It is difficult to be clear about how many people there are in the LGBT group in the elderly population. Evidence suggests that the number of older LGBT people is likely to increase in future.

There are a small number of people with a learning disability who are at a greater risk of developing dementia. Many of these people at the higher end of the care needs spectrum are already known to the adult social care department in ESCC. There is a care pathway to meet their needs.

## Section 3. Best Practice:

### 3.1 Timely diagnosis

Studies have shown that people want to know their diagnosis. A diagnosis of dementia is a gateway to allow people with dementia and their carers to make informed decisions about the future.

Barriers to early diagnosis are found among health care professionals as well as factors within the patient and their families. Patient barriers include thinking that the changes occurring are a part of natural ageing, while professional barriers include insufficient time to diagnose accurately and with little perceived benefit.

The local health and care community in East Sussex has a coherent plan of work to improve dementia care and to improve early diagnosis.

*There is variation in the rate of diagnosis of dementia between CCGs in East Sussex from **64.9% in Eastbourne, Hailsham and Seaford [EHS] CCG to 57.6% in High Weald, Lewes, Havens [HWLH] CCG.*** This variation is also reflected at individual practice level within CCGs.

All three CCGs in East Sussex (High Weald Lewes Havens [HWLH], Eastbourne Hailsham and Seaford [EHS], and Hastings & Rother [H&R]) have shown an increase in the numbers of dementia cases on GP practice QoF registers.

There is variation between practices in their numbers of referrals to the Memory Assessment Service [MAS]. There is variation in the 'conversion' rates: the number of diagnosed cases of dementia resulting from the referrals to the MAS made by practices. This could be explained by differences in the population on GP practice lists and challenges in the early identification of dementia. Exercises to improve the quality of coding in GP practices have been undertaken and achieved increases in the recording/reporting of diagnosed cases of dementia.

Working relationships are generally positive, and it appears that values and ambitions are shared.

The rate at which newly diagnosed persons with dementia die and how this affects achieving the NHS targets for diagnosing 2/3 of the expected number of cases in the population at any given time is not yet clearly understood. The attrition rate of people diagnosed with dementia is estimated at 13% of people with dementia dying per year in HWLH CCG.

### 3.2 What interventions can improve managing dementia at a CCG level?

The National Screening Committee does not currently support a screening programme for dementia.<sup>6</sup>

Interventions that have been shown to improve the management of dementia include:

- ➔ Encouraging high levels of providing the Enhanced Service for Dementia (DES) amongst GPs.
- ➔ Undertaking coding reconciliation exercises and monitoring of QOF performance.
- ➔ Commissioning dementia advisor services to support timely diagnosis and post-diagnostic support.
- ➔ Encouraging training of health care professionals.
- ➔ Providing training for carers.
- ➔ Encouraging advance care planning.
- ➔ Facilitating access to respite care.

### **3.3 Carers in the population**

Interventions to support carers can reduce the burden on the care giver and delay the time when the person being cared for is put into an institution.

East Sussex has a total of 59,500 unpaid carers, representing 11% of the total population of East Sussex. Ten percent of all carers in England are estimated to be caring for someone with dementia.

The number of carers in East Sussex has been increasing and will be expected to continue to increase substantially in future as dementia prevalence increases.

### **3.4 Dementia Friendly Community Development:**

Dementia friendly communities are recognised as important in improving the everyday lives of people with dementia and raising awareness of the condition.

Apart from geographical communities, communities also include support groups [day care, dementia cafés], community groups, ethnic, cultural and faith communities.

Dementia friendly communities can now choose to work towards and be recognised by the British Standards Institution [BSI] specification. There are examples of best practice in England and Europe which are being implemented locally.

One of the first towns to start the development of a dementia friendly community in East Sussex was Bexhill-on-Sea; another is Rotherfield. Dementia Action Alliances are developing further dementia friendly communities in East Sussex.

Innovative programmes with local museums and arts based therapies have been implemented in some areas.

### **3.5 Assistive Technology**

The published evidence about the use of telecare is equivocal.

Information from Sussex Police identifies the scale of the problem of missing persons aged over 65, some of whom have dementia.

A case history of the local use of a GPS system shows how the appropriate use of assistive technology can enable a person with dementia and their family to maintain their quality of life and delay their transfer to a care home.



A small successful local pilot study of the use of assistive technology suggests its use is likely to increase. It showed a reduction in carer stress, while three cases demonstrated the potential for significant savings to be accrued over time as a result of delaying transfers to higher levels of care.

Technical solutions need to be tailored to the individual and to their carers.

### **3.6 Evidence based models of dementia care** <sup>7</sup>

Recently published examples of the different service models of best practice nationally have been put forward for local consideration. Models of dementia care best practice differ in their estimated cost per case, ranging from £396 to £877 per case.

It is unclear which service model would offer best value for money in the long run, locally. Some care pathway models will require additional commitments to resourcing including staffing, diagnostic imaging and ongoing clinician training.

There is a primary care-led memory assessment service in the Hastings and Rother and Eastbourne, Hailsham and Seaford CCGs, which is well-established. A different service model is being piloted on a small scale in Buxted, part of HWLH CCG, with the intention of improving the co-ordination of patient care.

There are pros and cons for either adopting a primary care led or a secondary care led model of dementia care. The majority of the management of people with dementia can take place in primary care.

## **Section 4. Service Provision**

### **4.1 Introduction**

The hierarchy of care needs of people with differing degrees of severity of dementia is presented as a pyramid, ranging from people who self-care at the bottom to people having the most complex needs at the top. How these needs are currently being met by health and social care services is shown at each level of the pyramid.

The main focus of this section is on primary care. Routine performance indicators for the annual GP dementia patient review and whether baseline investigations have been undertaken for managing dementia are described, together with an overview of two primary care pilot projects in East Sussex. One is a model for providing a more integrated service while the other provides increased carer support.

The challenges for the SEC ambulance service [SECAMB] which is at the interface between primary and secondary care show that progress is being made in identifying vulnerable people at risk in the community and raising operational staff awareness of complex mental health issues.

This is followed by a description of developments in acute hospital in-patient care for people with dementia in terms of staff training and improving the care environment.

Social care provision, both at home and in care homes, follows. Gaps in the social care system are identified, including the closure of nursing home beds and limited respite bed availability. End of life care is briefly summarised in terms of improving the communication

between professionals and the importance of preferred care planning to meet the person's wishes as far as practicable.

A summary of the ways in which medicines management initiatives are helping to improve the safety and efficacy of prescribing are included.

Opportunities for developing the health and social care workforce conclude the section.

## **4.2 to 4.7 Primary and Community healthcare services**

There is a well-established primary care-led memory assessment service [MAS] scheme in H&R and EHS CCGs which is also shifting much of the responsibility for dementia care into primary care. As part of the primary care led memory Assessment Service [MAS], a second research project is looking at the benefits of community support workers in Bexhill GP practices.

A separate local research project in Buxted, on a smaller scale, is evaluating a more co-ordinated, integrated, multi-disciplinary care model of dementia management in primary care [The Golden Ticket], to respond to a person's changing clinical needs. From the HWLH stakeholder consultation, staff had identified a lack of a clear care pathway; the need for more GP training about dementia; and the lack of a single point of contact for service users or their carers.

All GP practices in East Sussex CCGs participate in the Quality and Outcomes Framework [QoF] and have a dementia register, as with other long term conditions. The performance of practices in East Sussex in doing an annual care review of patients with dementia shows good achievement for most practices.

A new Locally Commissioned Service [LCS] specifically for managing dementia has been introduced in H&R and EHS CCGs. By reducing duplication this will simplify care plans and improve co-ordination for individual patients, as well as encouraging timely diagnosis.

A range of community support services are already in place, or planned for implementation, across East Sussex. These are summarised in Appendix 3.

A number of services have been commissioned from the Alzheimer's Society to support people with dementia and their carers. East Sussex has currently opted for the dementia advisor model after diagnosis. There are no Admiral Nurses currently employed by the NHS in East Sussex, although HWLH CCG are going through a procurement exercise for a new post-diagnosis support service.

The Sussex Partnership Foundation trust [SPFT] Specialist Older Adults Mental Health Service is community based, providing assessment and treatment for older adults with both functional mental health problems and dementia. A dementia specialist care home in-reach service is commissioned from SPFT. Care homes work with this team on a voluntary basis.

There is no specialist Sussex Community Trust dementia service in High Weald, Lewes and Haven CCG, although community teams do accept referrals about people with dementia.

NICE guidelines recommend Cognitive Stimulation Therapy for all people with dementia. This was trialled in East Sussex with limited benefit and the resource re-allocated. There is further commissioning of this from April 2016 in H&R and EHS CCGs, and in a different format in HWLH CCG.

## **4.8 Secondary healthcare services**

Approximately 1 in 3 to 1 in 5 people in hospital have dementia. In the two years 2013/14 and 2014/15, the number of *recorded* hospital admissions with dementia represented 7.0% of all emergency admissions of East Sussex residents, however.

Most of the admissions for people with dementia are as an emergency. The main reasons for admission of people with dementia are for the management of their other medical problems.

There are higher rates of admission in Hastings and Eastbourne local authorities compared with the other East Sussex Districts and Boroughs. This could reflect either different service provision, or patterns of service utilisation. The age-specific rates of admission are broadly comparable between East Sussex local authorities. Some electoral wards have higher rates than others.

In East Sussex Healthcare Trust [ESHT], which deals with the majority of admissions of people with dementia in East Sussex, there are more admissions to Eastbourne Hospital than to the Conquest Hospital.

In ESHT there is a pathway of care for the person with dementia. One ward at the Conquest Hospital is for complex care and one ward at Eastbourne District General Hospital is working towards becoming a complex care ward.

The Royal Sussex County Hospital [RSCH] and Princess Royal Hospital [PRH], part of Brighton & Sussex University Hospitals Trust [BSUH], deal with the majority of admissions from HWLH CCG in the West of East Sussex. There are specialist dementia wards in the RSCH [Emerald Ward] and in the PRH [Poynings Ward].

In Sussex Partnership Foundation Trust [SPFT], admissions to the Elderly Mentally Infirm [EMI] wards have relatively prolonged lengths of stay. It is expected that these will reduce when the bed reconfiguration is completed and redesigned community services are introduced.

In SPFT: mental health liaison services are in place across both Eastbourne DGH and the Conquest Hospital sites. Mental health liaison is also provided to both hospitals in BSUH. The number of in-patient beds was reviewed in the Business Case for Reconfiguration of Acute Dementia Services. NHS dementia beds were provided on two sites by Sussex Partnership Foundation Trust [SPFT] and were under-occupied. A single site consolidation is now taking place in Hastings with the bed numbers at an equivalent occupancy level. As part of the business case, investment has been agreed in community-based services including step-up/step-down beds and a community-based crisis team.

Admissions with prolonged lengths of stay in hospital can occur because adult social care services need to arrange long-term care involving patient and family choices and agreeing financial contributions.

## **4.9 to 4.11 Social Care**

The Care Act 2014 includes the new responsibility to promote wellbeing, and to undertake an assessment of needs of both client and carers, with appropriate review as these needs change. There is a requirement to assess need at the initial assessment and an expectation of a review at least annually. There are substantial resourcing implications to ESCC of implementing the Care Act 2014 in future years on account of the ageing population, more community provided care, more people living alone, and more complex cases with multiple

co-morbidities. Types of social support potentially available for people with dementia and their carers are summarised in this section.<sup>8</sup>

Support to carers can reduce the adverse impact of caring on the carers' health and wellbeing, as well as preventing carer breakdown. Carer support and counselling at diagnosis has been demonstrated to reduce care home placement.<sup>9</sup>

The published evidence on the benefit of respite care is conflicting. It may be that only the most severe cases have been studied in depth and that the research evidence may not have been of sufficient quality to measure carer burden adequately.

Carers may not be aware of all support that is available. There may be financial barriers. Carers may be putting off obtaining respite care long after when it is needed. There are also negative outcomes for seeking respite care (guilt, stigma, concerns over quality of care and difficulty in readjustment when the period of respite is over), as well as potential positive outcomes (maintaining relationships, catching up on sleep and rest.) Respite may be moderating the negative effects of the caring role in a deteriorating scenario.

A range of services should be available to allow carers to have a choice over the timing, flexibility and length of respite break. There is a lack of accessible respite care in East Sussex which, although bookable, in practice has to be arranged at short notice and may not be available.

Extra care housing schemes, which are defined as specialised housing with additional care provision, and the location of these schemes in East Sussex, are summarised at CCG level.

In the H&R CCG area there is relatively more care home provision, a lower proportion of self-funders (57%) of their own nursing and residential home care, and a higher proportion of clients who are funded by Adult Social Care.

In HWLH CCG there is a relatively higher proportion of clients managed in the community and a much higher proportion of people (74%) funding their own nursing or residential home care.

There have been ten care home closures in East Sussex since May 2015. In the homes which have closed in the past year there were 270 nursing home beds, of which 117 were designated as intended for dementia residential care. The closure of a further two homes is subject to appeal to the Care Quality Commission. This represents a loss of 3% of the sector's capacity in the past year. A further ten homes are currently non-operational [closed to admissions]. This will have caused problems with hospital discharge and also for people with escalating needs in the community.

The extent to which dementia friendly environment recommendations have been implemented in the care home sector across East Sussex is not clear. To clarify this would require specific local audits.

## **4.12 End of Life Care**

Early discussions with people with dementia are important so that people can plan ahead for their future care, including palliative and end of life care, while they still can.

Other published needs assessments have identified a lack of information and knowledge amongst patients and carers about writing wills and lasting power of attorney.

The emotional wellbeing of carers is key during end of life care. Carers need to be supported throughout the end of life phase and in their bereavement.

The locally commissioned service [LCS] for palliative care in East Sussex should improve communication between professionals both in-hours and out-of-hours.

A pilot study of methods for reviewing the pathway for End of Life Care was undertaken by the Care Quality Commission in the autumn of 2015 in HWLH CCG. The pilot study report for HWLH CCG, part of a national CQC report, is awaited. The CQC findings for ESHT have been published showing a need for improvement in terms of safety, responsiveness and leadership, whilst being recognised as caring and effective.

CCGs and ESCC continue to implement the Sussex, Integrated End of Life and Dementia pathway. This includes training for professionals and promotion of Advance Care Planning [ACP] at all phases of the pathway as appropriate.

HWLH CCG is procuring a post-diagnosis support service specifically to assist with Advanced Care Planning for all people with dementia.

There is limited evidence available to demonstrate how effectively the policy of Advanced Care Planning is being implemented.

The proportion of East Sussex residents with dementia dying in their usual place of residence is higher than the regional and England average.

#### **4.13 Medicines Management and prescribing**

Community pharmacists often come into contact with a range of vulnerable people and may be the first health professional to suspect memory loss.

The Healthy Living Pharmacy concept may enable greater signposting to community services for dementia in future. Locally commissioned services include the offer of 'flu immunisation as part of improving access, as well as broadening the pharmacist's role. Community pharmacies also support people with difficulties accessing the pharmacy with their medicine delivery services, although these are not currently commissioned.

Pharmacists have an important role to play in ensuring that appropriate Medication Use Reviews [MURs] are undertaken both at home and in care homes and in informing the GP of non-adherence to prescribed treatment. MURs can be further encouraged along with the continuation of the New Medicines Service.

Pharmacies can potentially reduce the risk of avoidable medication errors with new prescription checking decision support software and help to reduce avoidable admissions because of drug toxicity.

The quality of communication about medications on discharge between hospital and primary care has been identified in other JSNAs. This issue has been raised with the community pharmacists in the course of the East Sussex JSNA process.

There was more total spending on the more expensive dementia drugs in HWLW CCG than in either of the other two CCGs in the last financial year. This refers only to primary care prescribing and these differences are marginal when prescribing of dementia drugs for patients still under the management of SPFT is taken into account.

New initiatives in East Sussex will improve the quality of prescribing in care homes and are specifically aiming to improve the use of anti-psychotic drugs.

Pharmacies have a prevention role in reducing CVD risk in the general population through their participation in smoking cessation campaigns. They are also well placed to be a dementia friendly and carer friendly environment.

#### **4.14 to 4.17 Workforce education and development**

There is a wide range of dementia training available across East Sussex. This training is provided by several organisations and targeted at different staff roles and groups.

There are many different levels of dementia specialist staff including dementia specialist nurses, dementia advisors, dementia support workers and Admiral Nurses Health Education England and the Skills for Care educational programme have identified nationally recommended levels of tiered dementia training.

Every worker involved with people living with dementia should have had basic dementia awareness training to identify early symptoms and have an understanding of support available. Dementia leads, champions and specialist nurses can train others within their organisations and within their sphere of influence.

Adult Social Care [ASC], Sussex Community Trust [SCT] & East Sussex Healthcare Trust [ESHT] and Sussex Partnership Foundation Trust [SPFT] each have a detailed programme of staff training.

CCGs and ASC are continuing to raise the profile of dementia training. There is the opportunity to improve the uptake of dementia training among all relevant staff.

A hospital staff survey reported from another JSNA in Norfolk found that most staff felt they have had insufficient training about dementia including: communication skills, assessing cognition, dealing with aggressive behaviours and recognising pain. Knowledge of the Mental Capacity Act was also identified as a gap in a Government Select Committee report.

### **Section 5. What people say about services/local provision**

A short survey asking the opinions of key stakeholders about provision for dementia care was carried out in the autumn of 2015. Key findings include:

There are differences of approach to the models for the initial diagnosis and for ongoing management of dementia in East Sussex.

There appears to be some fragmentation with a lack of integration across the care pathway. There is a view that there needs to be more development of services that move across the primary/secondary care boundaries.

There are practical problems with the care pathway in terms of attending memory assessment clinics and the information provided beforehand by some referring GPs.

Communities are becoming more dementia friendly. There are opportunities to develop dementia friendly communities even more, to change people's attitudes and to give practical advice for the general public. There is a lack of knowledge among some patients/carers locally about where to go for advice and what sources of support are available.



Concerns were expressed about how to help people living alone with dementia.

With the use of 'This is Me' and Butterfly schemes there is the opportunity to improve communication between patients/carers and health and social care professionals to avoid patients/carers having to repeat their story.

There are opportunities to enhance the training of healthcare professionals, OTs and Social Workers by raising awareness of simple environmental changes and adaptations in the home.

There is the opportunity to identify the unmet needs of carers and clients sooner and provide support earlier to reduce stress. There is the recognition of the importance of more practical, hands on support for carers.

There is limited published evidence about user and carer views of the different aspects of the dementia care pathway.

There needs to be a local systematic process of capturing user and carer views, especially with regard to the service provided in care homes and acute/community hospitals.

There is the potential to offer younger people with early-onset dementia more opportunities and choices.

## Section 6. The Financial Cost of Dementia

- The social and healthcare costs of dementia are set to rise over the coming years as the prevalence of dementia increases.
- It is important to bear in mind the timescales over which the return on investment will be calculated in any health economic analysis of a programme designed to improve the management of dementia.
- The costs to Government include the provision of early assessment and treatment. These can be set against the potential savings from reduced spending on care homes and acute care.
- Early intervention with supported home care can reduce the cost of care home placements.
- The extent of savings depends on the modelling assumptions.
- The costs of early assessment and treatment are expected to be outweighed by later cost savings.
- The average cost per case of a person with dementia increases as the condition becomes more severe. The majority of costs fall on the social and unpaid care sectors. Economic models do not fully include the opportunity costs and externally imposed costs to carers.
- There are substantial funding implications to ESCC of implementing the Care Act 2014 and its associated financial pressures in future years.
- Financial abuse of the vulnerable elderly is a growing problem that drains their own financial assets and ultimately increases the financial burden on society as a whole.<sup>10</sup>

## Section 7. Conclusions

Key themes of the JSNA are:

1. The number of people locally who have dementia, as well as living with milder degrees of cognitive impairment, will increase substantially over the next few decades. This is around a 57% increase in the number with dementia in the next 15 years, mainly due to a greater number of older people aged 80 and over. As a community we will need adequate resource to deal with this challenge and to provide services more efficiently and sustainably.
2. National targets for dementia diagnosis rates have resulted in notable increases in the number of diagnosed cases in each of the three CCGs in East Sussex though there is still room for improvement. Having identified that a person has dementia this must be followed by an equal commitment and support for their post-diagnostic care. This will encourage earlier diagnosis in future and ensure people and their carers live well with dementia.
3. Most of the hidden cost of supporting those with dementia falls on unpaid carers. With more care being provided at home, pressure on carers may increase. We will need to support, advise and empower carers to fulfil their role without a detriment to their own quality of life.
4. Whilst it is important to maintain independence for longer, there needs to be appropriate escalation of care and planning for this when needed. The financial costs of meeting this will fall mainly on adult social care.
5. Dementia services are provided by a range of agencies-acute and primary care, mental health services, social care and third sector. Better cohesion and collaboration is needed via well-co-ordinated information, advice, advocacy and outreach services.
6. People with dementia and their carers do not always receive equal access to services which support all their mental and physical health needs.
7. There is a need for increased training for paid and unpaid carers, for residential care staff, and health and social care professional as appropriate to their role.

A gap analysis appears in Table 47. This has been used to inform the recommendations.

## Section 8. Recommendations

Recommendations appear on pages 184 to 193. These have been subdivided into those that are strategic and relate mainly to commissioners and those that are more operational and relate to providers of services. Please see [Section 8. Recommendations](#).



## Section 1. Context/ Setting the scene

This section describes the scale of the problem of dementia in the population. The methods used to undertake the needs assessment are summarised. There is a description of the term dementia and the evolving concept of Mild Cognitive Impairment. The national and local policy drivers for improving the management of dementia are outlined. The section concludes with a description of the risk factors for developing dementia and how these can be potentially modified.

### 1.1 Introduction

Dementia is a syndrome caused by a number of progressive disorders. It affects memory, thinking, behaviour and the ability to perform everyday tasks. Alzheimer's disease is the most common type of dementia. Others include vascular dementia, dementia with Lewy bodies and fronto-temporal dementia.<sup>11</sup> It mainly affects older people. One in 14 people over 65 years and one in six over 80 years in the UK have a form of dementia. It is estimated that people live on average 7-12 years after diagnosis.

Nationally, there is an increasing focus on dementia since the **National Dementia Strategy**, 'Living Well with Dementia', was introduced in 2009 (Department of Health).<sup>12</sup>

Dementia is an important issue because it affects a large proportion of people and the absolute numbers are increasing as the population is ageing. It places pressure on all aspects of the health and social care system.

An estimated 25% of acute hospital beds are occupied by people with dementia, who have longer lengths of stay, and more readmissions. Approximately two-thirds of care home residents are estimated to have dementia and one in three people will care for someone with dementia in their lifetime.

Evidence suggests an increasing number of people are likely to develop dementia within East Sussex and this comes at a time when both the NHS and East Sussex County Council (ESCC), with a higher than average population over the age of 75, need to make significant cost savings.

This needs assessment links in with other ESCC, CCG and NHS priorities. These include the East Sussex Health and Wellbeing Strategy and joint frameworks relating to carers, people with functional mental health (psychiatric) problems and people with learning disabilities.

The needs assessment will inform the commissioners and providers about current and future unmet needs, assets and gaps in relation to dementia care across the County, and will enable the development of local action plans to meet these needs.

The main focus will be the development of dementia in people aged 65 and over. The needs of younger patients with early onset dementia have been included where this is not covered elsewhere in ESCC strategy.

## 1.2 Methods

This needs assessment was undertaken between October 2015 and May 2016.

The work was overseen by the Dementia Needs Assessment Steering Group which met on four occasions. Membership was as follows:

- Martina Pickin, Public Health Consultant, ESCC (Chair).
- Nick Kendall (Public Health Practitioner, ESCC),
- Kim Grosvenor (High Weald, Lewes and Havens Clinical Commissioning Group),
- Nigel Blake-Hussey (East Sussex Clinical Commissioning Groups and Adult Social Care, East Sussex County Council),
- Deborah Becker (Sussex Partnership Foundation NHS Trust),
- Sally Hemmings (East Sussex Dementia Action Alliance),
- Sally English (Operations ESCC),
- Elaine Lindfield (Dementia Care Lead, East Sussex Healthcare NHS Trust and Eastbourne Dementia Action Alliance),
- Angela Colosi (Assistant Director of Nursing ESHT),
- Lucy Frost (Dementia Lead Nurse Consultant, Sussex Community NHS Trust).

The group also consulted with:

- Martin Packwood (Head of Strategic Commissioning - Mental Health),
- Tamsin Peart (Adult Social Care Carers Commissioner, ESCC),
- Barry Atkins (Head of Service - Strategic Commissioning, Older People and Carers),
- Jenny Tuck (Strategic Commissioning Manager, ASC ESCC),
- Amelia Culshaw (Senior Training and Development Consultant, ASC ESCC),
- Richard Rogers (Pharmacist, Care Home in Reach Team, Sussex Partnership NHS Foundation Trust),
- Jed Hewitt (Chief Pharmacist, Sussex Partnership NHS Foundation Trust),
- Eileen Callaghan (Head of Medicines Management, Hastings and Rother CCG, Eastbourne, Hailsham and Seaford CCG),
- Paul Wilson (Head of Medicines Management, High Weald, Lewes, Havens CCG),
- Clare Hall, specialist paramedic practitioner, South East Coast Ambulance Service,
- Prof Sube Banerjee, Professor of Dementia & Associate Dean, Brighton & Sussex Medical School,
- Dr.Mokhtar Isaac, Consultant in Old Age Psychiatry Eastbourne, East Sussex Dementia Clinical Lead,
- Dr.Emma Costello, dementia lead GP, HWLH CCG,
- Dr.Lindsay Hadley, dementia lead GP, H&R CCG,
- Dr.Joerg Bruuns, dementia lead GP, EHS CCG.

The steering group agreed a project initiation document [PID] which outlined the objectives and defined the scope of the needs assessment:

### Objectives

- To inform the future development of dementia provision in East Sussex.
- To identify what is working well at each step of the patient journey.
- To summarise unmet needs in the context of the Delivery Plan for Dementia Care.
- To identify inequalities in the health and social care systems, how these may affect people with dementia with protected characteristics and their carers.

### Scope:

- Summarise local epidemiology.

- ➔ Collect the views of local stakeholders.
- ➔ Summarise Commissioners' views of gaps and barriers to development in local services.
- ➔ Summarise local service provision for memory assessment, diagnosis and management.
- ➔ Include a description of new innovations in dementia management in primary care.
- ➔ Include a description of routine GP prescribing for dementia at CCG level.
- ➔ Describe secondary care NHS provision and bed utilisation for dementia.
- ➔ Describe the process for finding new cases, including case finding in care homes.
- ➔ Describe care services in the community as provided by/commissioned by Adult Social Care [ASC ] ESCC.
- ➔ Describe Care home direct provision by ESCC, or its commissioned providers.
- ➔ Describe the current state of End of Life Care for people with dementia.
- ➔ Describe workforce planning and training needs from a strategic perspective.
- ➔ Suggest recommendations to inform future planning.

The steering group agreed that user/carer views would *not* be sought, but that these would be considered when consulting on the draft recommendations and may be sought in any further local work arising from the JSNA.

### **1.2.1 What is a needs assessment and how is it produced?**

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

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

### **1.2.2 Approaches to health assessments are:**

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

This needs assessment was produced by

- 1) reviewing data from a number of different sources,
- 2) evaluating the published research, strategies, national documents, examples from other areas and
- 3) speaking to professionals involved with the dementia pathway.

HealthWatch East Sussex was consulted on behalf of people with dementia and their carers and have given an undertaking to provide further input into the JSNA process in future.

Services commissioned to support East Sussex residents with dementia and their carers are outlined in Appendix 3. The purpose was not to create a directory of services but to identify gaps.

### **1.2.3 Stakeholder consultation**

An online consultation [Strengths, Weaknesses, Opportunities, Threats] analysis with a selected group of local stakeholders was undertaken in November and December 2015. Representatives of the following organisations were invited to respond to an on-line questionnaire hosted by ESCC.

- ➔ NHS Trusts: Sussex Partnership NHS Foundation Trust; East Sussex Healthcare NHS Trust; Sussex Community Trust;
- ➔ NHS Clinical Commissioning Groups [CCGs]: High Weald, Lewes Havens CCG; Eastbourne, Hailsham and Seaford CCG; Hastings and Rother CCG;
- ➔ East Sussex County Council: Adult Social Care Mental Health; East Sussex County Council, Carers Break & Engagement Service;
- ➔ District Councils: Wealden & Rother DC;
- ➔ Voluntary sector: Rotherfield St Martin; Know Dementia; Alzheimer's Society; Age concern; Age UK; 3VA; Care for the Carers;
- ➔ Independent sector: independent trainer; Home Instead Senior Care Provider

Respondents were asked:

- ➔ Strengths: In your view, what are the strengths in local services for people with dementia and their carers in your area? Please refer to your CCG locality area or service area.
- ➔ Weaknesses: Is there anything you think that is not working well at the moment? Are there any gaps?
- ➔ Opportunities: How do you think services for people with dementia and their carers could be improved in your area? Please refer to your CCG locality or service area.
- ➔ Threats: Within your organisation's workforce plans, will you have sufficient 'trained and confident' staff to provide high quality support to people with dementia and their carers over the next 3-5 years?

In the report there are text boxes containing selected case vignettes about people with dementia or their carers. These are reproduced with their permission.

A sense check of the report's recommendations was then undertaken in June 2016 with a selected group of local stakeholder organisations.

### **1.2.4 Other JSNAs**

This needs assessment is concerned with the East Sussex population. A Brighton & Hove City Council dementia needs assessment, published in 2014, is also of relevance to some East Sussex residents, and was consulted prior to undertaking this work.<sup>13</sup>

## 1.3 About Dementia

### 1.3.1 What is dementia?

The World Health Organisation defines dementia as:

*“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. Consciousness is **not** clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. Dementia occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.”*

One in every 79 people (1.3%) of the UK total population and one in 14 of the total population aged 65 and over has dementia. About one in a 100 aged 65-69; one in 25 aged 70 to 79 and one in six aged 80 and over has dementia. Dementia is a condition that has been estimated to affect over 850,000 people in the UK.<sup>1</sup>

Dementia is an umbrella term used to describe a group of progressive symptoms: memory loss; changes in personality, and difficulties in day-to-day living. Symptoms are characterised by a widespread impairment of mental function.

The symptoms experienced by people with dementia can be categorised in the following three groups:

- ➔ **Cognitive dysfunction:** characterised by problems with memory loss, language, attention, thinking, orientation, calculation, and problem-solving.
- ➔ **Psychiatric and behavioural problems:** changes in personality, emotional control, social behaviour, depression, agitation, hallucinations, and delusions.
- ➔ **Difficulties with activities of daily living:** problems with a range of activities such as driving, shopping, eating, and dressing.<sup>14</sup>

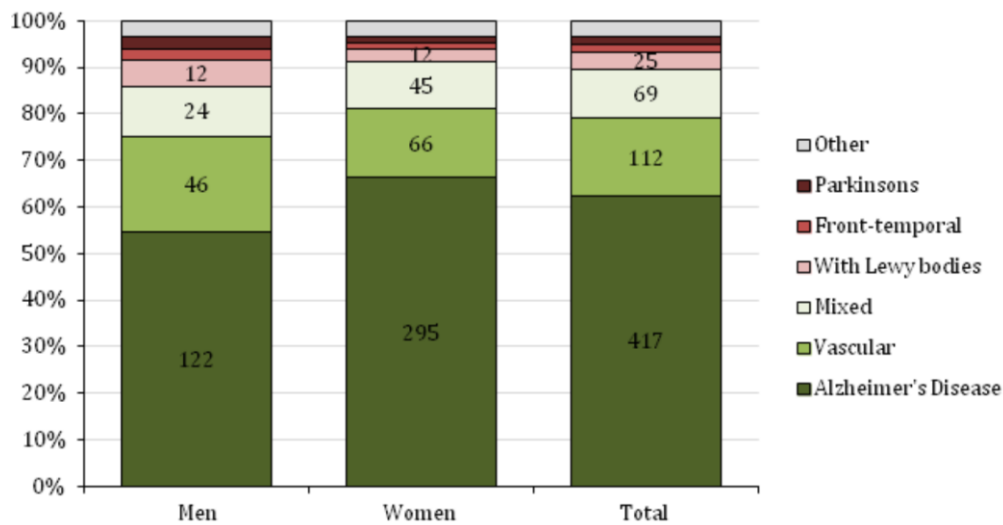
### 1.3.2 Types of Dementia

There are many causes of dementia:

- ➔ 62% is due to Alzheimer's disease,
- ➔ 17% to vascular dementia,
- ➔ 10% is mixed.
- ➔ The remaining 11% is dementia with Lewy bodies, fronto-temporal dementia, Parkinson's disease and other forms of dementia.

The relative contribution of the different conditions causing dementia in men and women are shown in Figure 1.

**Figure 1 Number of people in the UK with dementia subtypes, thousands**



Kings College London & London School of Economics, 2007

### 1.3.3 Early-onset dementia

According to the Alzheimer's Society there are over 40,000 younger people (i.e. under the age of 65) who have dementia in the UK.<sup>15</sup> This amounts to about one in 1400 people aged 40 to 64. Often referred to as 'early-onset dementia' or 'young-onset dementia' or 'working-age dementia', these younger people with dementia experience similar symptoms to older people with dementia but may have specific needs and requirements.

Younger people who develop dementia are more likely to be in work themselves, to have a partner who works, to have children, to be more physically active, and to have financial commitments such as mortgages. Services need to consider the specific needs and interests of younger people, which may well be different from those designed for the over 65s.

Younger people tend to have different sub-types of dementia than over 65s. The Alzheimer's Society indicates the following breakdown of the sub-types of dementia among younger people:

- ➔ Alzheimer's disease - around 33%
- ➔ Vascular- 20%
- ➔ Fronto-temporal dementia - 12%
- ➔ Alcohol-related - 10%
- ➔ Dementia with Lewy bodies- 10%
- ➔ Rarer forms of dementia (e.g. caused by Parkinsons) - 20%

### 1.3.4 Mild Cognitive Impairment [MCI]

Mild cognitive impairment is a syndrome defined as cognitive decline, greater than expected for an individual's age and education level, but that does not interfere notably with activities of daily life. Prevalence in population-based epidemiological studies ranges from 3% to 19% in adults older than 65 years. Some people with mild cognitive impairment seem to remain stable or return to normal over time, but more than half progress to dementia within 5 years.

Mild cognitive impairment can be regarded as a risk state for dementia, and its identification could lead to secondary prevention by controlling risk factors such as systolic hypertension. The type of mild cognitive impairment that mainly affects memory has a high risk of progression to Alzheimer's disease, and it could be an early [prodromal] stage of this disorder. Other definitions and subtypes of mild cognitive impairment need to be studied as potential early phases of Alzheimer's disease and other types of dementia.

The causes of mild cognitive impairment are not yet completely understood. Experts believe that many cases of mild cognitive impairment— but not all — result from brain changes occurring in the very early stages of Alzheimer's disease or other dementias.

### 1.3.5 Co-morbidities

As dementia is a disease of older age, many people with dementia will have other comorbidities. The most common long term conditions among older people are hypertension, depression, asthma, diabetes and coronary heart disease, and 25% of all over-60-year-olds have two or more long term conditions.<sup>16</sup> Therefore it is not surprising that many dementia patients also have these conditions.

Some long-term conditions might be specifically associated with dementia, but the evidence is not conclusive. A large cross-sectional study of older people in Spain found that 70% of dementia patients had at least one additional condition, and 48% had two or more. On average, people with dementia had 2.7 additional conditions.<sup>17</sup> The same study found that in the population they studied a range of medical problems were significantly more common in those with dementia than those without. In decreasing order of likelihood these conditions were:

- Anxiety and neuroses (three times as likely)
- Parkinson's Disease
- Chronic Skin ulcers
- Anaemia
- Retinal disorders
- Cerebrovascular disease
- Cardiac arrhythmias
- Thyroid Disease
- Prostatic hypertrophy in men (twice as likely)

However, a large cross-sectional study in the USA did not find a significantly different number of co morbidities, or different prevalence of common conditions, between patients with dementia and without dementia.<sup>18</sup> The average number of additional conditions for patients with dementia was 2.4.

In the UK, depression and anxiety are commonly associated with dementia.<sup>19</sup> A narrative literature review suggested that 20% of dementia patients in contact with services have depression.<sup>20</sup>

The recent report *Dementia and Comorbidities: Ensuring Parity of Care from the International Longevity Centre* demonstrates that a failure to prevent, diagnose, and treat depression, diabetes and urinary tract infections in people with dementia could be costing the UK's health and social care system up to nearly £1 billion per year.<sup>21</sup> Failure to prevent, diagnose, and treat comorbidities in people with dementia is leading to this group having a reduced quality of life and an earlier death than people who have the same medical conditions, but who do not have dementia. It highlights how:



- ➔ Hospital in-patients with dementia are over three times more likely to die during their first admission to hospital for an acute medical condition than those without dementia.
- ➔ Four of the five most common comorbidities that people with dementia are admitted to UK hospitals for are [potentially] preventable conditions - a fall, broken/fractured hip or hip replacement, urine infection and chest infection.

Six key areas which appear to be leading to the discrepancy in health outcomes for people with dementia and comorbidities are:<sup>21</sup>

1	Atypical symptoms. People with dementia often present atypical symptoms which may lead to carers and medical professionals interpreting these problems as worsening dementia and neglecting other conditions as a potential cause.
2	Communication difficulties between medical professionals/carers and people with dementia, and between medical professional themselves, leading to lower standards of care.
3	A failure by the health system to recognise the individual as a whole leading to the optimisation of care for dementia, while the individual continues to deteriorate because of poor management of a comorbid condition or vice versa.
4	A knowledge gap of hospital staff and carers in caring for people with dementia and comorbidities.
5	Poor medication management relating to how people with dementia's medications are prescribed, monitored, administered and/or dispensed.
6	A lack of support to aid self-management and poor monitoring of comorbidities by health professionals.



## 1.4 policy context

### 1.4.1 Introduction

This section summarises the strategic drivers from the points of view of central and local government. Key commitments are summarised below

It covers the National dementia strategy, quality outcomes for people with dementia, and summarises the Prime Minister's challenge of dementia 2020. It provides a summary of the implications of the Care Act for local authorities and a summary of NICE guidelines for dementia.

### 1.4.2 The Prime Minister's challenge of dementia 2020

The **Prime Minister's challenge on dementia 2020** set out more than 50 specific commitments that aim to make England the world-leader in dementia care, research and awareness by 2020.

The implementation plan<sup>22</sup> sets out how these commitments will be met. It sets out priority actions, and the organisations responsible, across 4 themes:

- risk reduction
- health and care
- awareness and social action
- research

This plan was developed in partnership with a range of stakeholders, including people with dementia and carers. There is now a detailed roadmap to delivering the plan which has the following key commitments:<sup>23</sup>

	Commitment
1	An international dementia institute established in England.
2	Improved public awareness and understanding of the factors, which increase the risk of developing dementia and how people can reduce their risk by living more healthily. This should include a new healthy ageing campaign and access to tools such as a personalised risk assessment calculator as part of the NHS Health Check.
3	In every part of the country people with dementia having equal access to diagnosis as for other conditions, with an expectation that the national average for an initial assessment should be 6 weeks following a referral from a GP (where clinically appropriate), and that no one should be waiting several months for an initial assessment of dementia.
4	Every person diagnosed with dementia having meaningful care following their diagnosis, which supports them and those around them, with meaningful care being in accordance with published National Institute for Health and Care Excellence (NICE) Quality Standards. Effective metrics across the health and care system, including feedback from people with dementia and carers, will enable progress against the standards to be tracked and for information to be made publicly available.
5	GPs playing a leading role in ensuring coordination and continuity of care for people with dementia, as part of the existing commitment that from 1 April 2015 everyone will have access to a named GP with overall responsibility and oversight for their care.
6	All hospitals and care homes meeting agreed criteria to becoming a dementia-friendly health and care setting.
7	All NHS staff having received training on dementia appropriate to their role. Newly appointed healthcare assistants and social care support workers, including those providing care and support to people with dementia and their carers, having undergone training as part of the national implementation of the Care Certificate, with the Care Quality Commission asking for evidence of compliance with the Care Certificate as part of their inspection regime. An expectation that social care providers provide appropriate training to all other relevant staff.
8	Alzheimer's Society delivering an additional 3 million Dementia Friends in England, with England leading the way in turning Dementia Friends in to a global movement including sharing its learning across the world and learning from others.
9	Over half of people living in areas that have been recognised as Dementia Friendly Communities, according to the guidance developed by Alzheimer's Society working with the British Standards Institute. Each area should be working towards the highest level of achievement under these standards, with a clear national recognition process to reward their progress when they achieve this. The recognition process will be supported by a solid national evidence base promoting the benefits of becoming dementia friendly.
10	All businesses encouraged and supported to become dementia friendly, with all industry sectors developing Dementia Friendly Charters and working with business leaders to make individual commitments (especially but not exclusively FTSE 500 companies). All employers with formal induction programmes invited to include dementia awareness training within these programmes.
11	National and local government taking a leadership role with all government departments and public sector organisations becoming dementia friendly and all tiers of local government being part of a local Dementia Action Alliance.
12	Funding for dementia research on track to be doubled by 2025.
13	Increased investment in dementia research from the pharmaceutical, biotech devices and diagnostics sectors, including from small and medium enterprises (SMEs), supported by new partnerships between universities, research charities, NHS and the private sector. This would bring world class facilities, infrastructure, drive capacity building and speed up discovery and implementation.
14	Dementia research as a career opportunity of choice, with the UK being the best place for Dementia Research through a partnership between patients, researchers, funders and society.
15	Increased numbers of people with dementia participating in research, with 25 per cent of people diagnosed with dementia registered on Join Dementia Research and 10 per cent participating in research, up from the current baseline of 4.5 per cent.
16	Cures or disease-modifying therapies on track to exist by 2025, their development accelerated by an international framework for dementia research, enabling closer collaboration and cooperation between researchers on the use of research resources – including cohorts and databases around the world.
17	Open access to all public funded research publications, with other research funders being encouraged to do the same.
18	More research made readily available to inform effective service models and the development of an effective pathway to enable interventions to be implemented across the health and care sectors.

### 1.4.3 Earlier national strategy and policy drivers

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The **National Dementia Strategy**, 'Living Well with Dementia' <sup>12</sup> provided a 5 year plan for dementia care services. The Strategy identified 17 key objectives which should be implemented at a local level, Table 1.

**Table 1: Key objectives of the National Dementia Strategy (2009)**

	Objective
1	Improving public and professional awareness and understanding of dementia: addressing stigma
2	Good-quality early diagnosis and intervention for all: establishing a clear care pathway for people who may have dementia
3	Good-quality information for those with diagnosed dementia and their carers
4	Enabling easy access to care, support and advice following diagnosis: providing a dementia advisor
5	Development of structured peer support and learning networks
6	Improved community personal support services: support for people with dementia living in their own homes
7	Implementing the Carers' Strategy: needs assessments and respite breaks for carers
8	Improved quality of care for people with dementia in general hospitals
9	Improved intermediate care for people with dementia
10	Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers
11	Living well with dementia in care homes: defined care pathways, specialist in-reach services and inspections
12	Improved end of life care for people with dementia: involvement of people with dementia and their carers in plans for their end of life care
13	An informed and effective workforce for people with dementia: basic training and CPD for all relevant staff
14	A joint commissioning strategy for dementia
15	Improved assessment and regulation of health and care services and systems are working for people with dementia and their carers: inspections of care homes and other services
16	A clear picture of research evidence and needs
17	Effective national and regional support for implementation of the Strategy

In 2010 the Department of Health published an implementation plan for the strategy, called '**Quality Outcomes for People with Dementia**'<sup>24</sup>. It focused on the following four priorities

- ➔ **Priority 1** Good-quality early diagnosis and intervention for all (updated to 'timely' diagnosis)
- ➔ **Priority 2** Improved quality of care in general hospitals
- ➔ **Priority 3** Living well with dementia in care homes
- ➔ **Priority 4** Reduced use of antipsychotic medication.

Using the National Dementia Strategy quality outcomes<sup>25</sup> and NICE guidance<sup>28</sup>, what people should be able to say about their care is summarised in Figure 2:

Figure 2: NICE quality standards



Source: Department of Health, 2010

#### 1.4.4 The Care Act 2014

The **Care Act 2014**<sup>26</sup> outlines eight new responsibilities for local government, summarised below:

- ➔ Councils have a duty to provide **preventative** services to maintain health rather than reacting to a crisis.
- ➔ **Information and advice** is to be made available to support service users to make considered and informed choices regarding care early on. Service users and their carers are allocated personal care budgets and given the right to manage their own care should they wish to.

- Emphasis is placed on ensuring that duty of care extends to unpaid **carers**; ensuring needs are assessed, information and advice provided; they are able to access to services and pathways established for raising concerns. The carer is afforded rights which are independent of the financial capabilities or needs of the dependent.
- There is greater emphasis on **integration** of care between health, social and voluntary sector providers. There is also a new duty to create a service market of diverse and high quality service providers.
- National **standardised eligibility criteria** have also been introduced for local authority funded care to reduce discrepancy between areas/authorities.
- Increased **oversight for quality and financial security of services**, and protection of care provided when service users move from one area/authority to the next.
- **Safeguarding** for adults at risk of abuse or neglect.
- Ease of **transition** from child to adult services.

### 1.4.5 The Better Care Fund

The **Better Care Fund**<sup>27</sup> was introduced in July 2013 and consisted of a £3.8 million pooled budget to fund integration of health and social care services. A 2014 amendment stipulates the £1million NHS contribution will be commissioned through Out of Hospital or reducing emergency admission initiatives. Providers can apply for funding from this budget to support integration plans.

### 1.4.6 National guidelines and standards

The 2006 NICE Guidelines "*Dementia: supporting people with dementia and their carers in health and social care*"<sup>28</sup> made recommendations on the diagnosis, management, and care of people with dementia as well as support and interventions for carers. An integrated approach is required from agencies if patients with dementia and their carers are to benefit. The following areas are highlighted as priorities for implementation:

- **Non-discrimination** – There should be equitable access to services for all people with dementia.
- **Valid consent** – Health and social care professionals should always seek valid consent from people with dementia.
- **Carers** – Carers of people with dementia should receive an assessment of needs and, where appropriate, receive psychological therapy.
- **Coordination and integration of health and social care** – Care should be coordinated and integrated across all agencies, with a combined care plan put in place.
- **Memory services** – Memory services should be the single point of referral for a potential diagnosis of dementia.
- **Structural imaging for diagnosis** - Structural imaging should be used to assess suspected dementia and to help identify the type of dementia.
- **Behaviour that challenges** – People with dementia who develop distressing behaviour should be offered an assessment to establish the likely factors that may generate, aggravate or improve such behaviour.

→ **Training** – Staff working with older people in the health, social care and voluntary sectors should have access to dementia-care training.<sup>29</sup>

→ **Mental health needs in acute hospitals** - Hospitals should provide services that address the specific needs and health of people with dementia who use their facilities.

It is recommended that commissioners also refer to the NICE Commissioning Guide for Dementia Care.<sup>30</sup> In 2014 the Care Quality Commission published their themed review of care for people with dementia as they move between care homes and hospitals, *Cracks in the Pathway*.<sup>31</sup> These are summarised in Table 2. Overall, they found more good care than poor care in the 20 hospitals and 129 care homes they visited, but found that the quality of care for people with dementia varied considerably, and that transition between services needed to be improved. They found aspects of variable or poor care in how a person's needs were assessed; how the care met people's physical and mental health, and emotional and social needs; the arrangements for how information was shared when people moved between services; staff's understanding and knowledge of dementia care; people with dementia (or their families and carers) not being involved in decisions about their care and choices about how to spend their time; and the way providers monitored the quality of dementia care.

**Table 2: Summary of CQC Cracks in the Pathway report findings**

Summary of CQC report findings	
1	<ul style="list-style-type: none"> <li>The needs of people with dementia are not always adequately assessed to ensure that they are met at all stages of their care pathway.</li> <li>Assessments do not always consider how the type of dementia affects a person in their daily life, or identify how staff can support them.</li> <li>In hospitals, assessments focused on a person's physical health needs, with less consideration given to mental health, emotional and social needs.</li> <li>Assessments to identify and manage pain are variable, putting people with dementia at risk of experiencing pain unnecessarily.</li> </ul>
2	<ul style="list-style-type: none"> <li>Available guidance is not used effectively to support dementia care. Where changes in a person's condition or behaviour were not identified or managed appropriately, they were more at risk of poor care.</li> <li>Personalisation, putting people at the centre of their own care, helps improve the experiences of people with dementia.</li> <li>Failure to manage known risk factors, including falls and urinary tract infections, can lead to avoidable admissions to hospital.</li> </ul>
3	<ul style="list-style-type: none"> <li>The environment has a significant impact on a person's wellbeing. Environmental changes and having different people looking after them can be particularly distressing to people with dementia.</li> <li>Affording privacy, dignity and respect to people with dementia is part of helping to maintain their personal identity.</li> </ul>
4	<ul style="list-style-type: none"> <li>Arrangements to share information between care homes and hospitals are not good enough. Often, relevant information is not shared or acted on when people are moved between care homes and hospitals. As a result, their needs are not met.</li> <li>Access to support from a range of health and social care professionals is required to maintain people's health and mental wellbeing while living in care homes and hospitals. Their involvement helps people to avoid unnecessary admissions to hospital and supports their discharge from hospital.</li> <li>The voluntary and community sectors have a key role in supporting people with dementia and their families, friends and carers. Staff and providers could do more to signpost people to these services.</li> </ul>
5	<ul style="list-style-type: none"> <li>There are not always enough well-supported and trained staff (and with the right values) to care for people with dementia. Not all staff are equipped to understand what good dementia care looks like. Some care is task-based and this ignores people's emotional and psychological care needs.</li> <li>Training for staff who care for people with dementia is not routinely evaluated for its impact on the care itself.</li> <li>People with dementia and their families told us that staff who understood their needs was the most important thing.</li> </ul>
6	<ul style="list-style-type: none"> <li>Arrangements to make sure that people with dementia are supported to make decisions about their care are not effectively applied.</li> <li>Good care for people with dementia involves the family, friends and carers in decisions and choices about their care.</li> </ul>
7	<ul style="list-style-type: none"> <li>A culture based on strong values supports good dementia care, but this is not yet established in all organisations.</li> <li>Providers are not routinely using systems to monitor effectively the quality of dementia care and inform improvements.</li> </ul>

The report concluded that a person with dementia “is likely to experience poor care at some point along their care pathway” and identified three actions to improve assessments of dementia care:

- ➔ Appoint a new national specialist adviser for dementia care.
- ➔ Train inspectors across all inspecting teams to understand what good dementia care looks like so that their judgements of the performance of providers are consistent and robust.
- ➔ Include a separate section in hospital inspection reports that shows how well the hospital cares for people living with dementia.

## 1.5 Risk Factors for Dementia

### 1.5.1 Introduction

Prevention of dementia is an important aspect of a comprehensive dementia strategy. This area has recently been reviewed in NICE guidelines: Dementia, Disability and Frailty in Later Life: mid-life approaches to delay or prevent onset.<sup>32</sup>

The guidelines include recommendations about factors that can be changed including smoking, lack of physical activity, alcohol consumption, poor diet and being overweight. The guidelines observe that while national and local policies for non-communicable conditions are already in place, they rarely include prevention of dementia, disability and frailty in their scope.

### 1.5.2 Preventing dementia

The Blackfriars consensus report summarises the known risk factors for dementia.<sup>33</sup> This consensus recognised the overlap between risk factors for vascular disease and dementia, and the potential for effective approaches to prevent non-communicable diseases (e.g. cardiovascular disease) to improve brain health in the population.

Dementia is not an inevitable aspect of ageing. The aim is to delay the onset of dementia, disability and frailty, increasing the amount of time that people can be independent, healthy and active in later life (successful ageing).

The profile of the risk factors for dementia has changed greatly over the last decades with both increasing and decreasing prevalence of the risk factors mainly relating to vascular disease ie smoking lack of exercise and unhealthy diet, diabetes and the metabolic syndrome. It has been suggested that up to 30% of cases are potentially preventable.<sup>34</sup> Genetic factors play a much greater part in early-onset dementia.

There is emerging evidence of the influence of cognitive, physical and social engagement protecting, or compensating for, existing neuropathology of the brain.<sup>35 36 37</sup> Cognition has been improving within the population.<sup>38</sup> There have been major changes in many Western and high-income societies so the occurrence of dementia may be expected to change between generations.

Risk factors and protective factors for dementia are briefly summarised in Table 3. [Adapted from Solomon et al].<sup>39</sup>



**Table 3: Risk factors for dementia**

	Risk Factors	Protective Factors
<b>Genetic</b>	<ul style="list-style-type: none"> <li>• Familial aggregation</li> <li>• Certain genes can reduce potential benefits from dietary interventions</li> <li>• Downs syndrome</li> </ul>	<ul style="list-style-type: none"> <li>• Certain genes have been proposed</li> </ul>
<b>Vascular &amp; metabolic</b>	<ul style="list-style-type: none"> <li>• Cerebrovascular lesions</li> <li>• Cardiovascular diseases</li> <li>• Diabetes mellitus and pre-diabetes</li> <li>• Hypertension</li> <li>• High BMI (overweight and obesity)</li> <li>• High serum cholesterol</li> </ul>	<ul style="list-style-type: none"> <li>• None known</li> </ul>
<b>Lifestyle</b>	<ul style="list-style-type: none"> <li>• Smoking</li> <li>• High alcohol intake</li> <li>• Diet</li> <li>• Saturated fats</li> <li>• Low B vitamins</li> <li>• High Homocysteine</li> </ul>	<ul style="list-style-type: none"> <li>• Healthy lifestyle: physical activity; moderate alcohol intake;</li> <li>• Increased consumption of fruit and vegetables, nuts, low-fat dairy products and whole grains</li> <li>• Mediterranean diet: combination of several foods and nutrients separately suggested to have beneficial effects towards cognition: combination of these may increase effect</li> <li>• Poly Unsaturated Fatty Acids and fish-related fats</li> <li>• Foods containing high levels of flavonoids: berries, dark chocolate and soy beans have high levels of flavonoids have anti-inflammatory and anti-oxidant properties, may help decrease oxidative stress and inflammation</li> <li>• Foods containing high levels of carotenoids: carrots, dark leafy greens, tomatoes and sweet potatoes</li> <li>• Vitamins B6 and B12, folate</li> <li>• Antioxidant vitamins (A, C and E)</li> <li>• Vitamin D [removing amyloid]</li> <li>• Selenium intake</li> </ul>
<b>Psychosocial</b>	<ul style="list-style-type: none"> <li>• None known</li> </ul>	<ul style="list-style-type: none"> <li>• High levels of education and higher socio economic status</li> <li>• High level of complexity of work</li> <li>• Rich social network and social engagement</li> <li>• Mentally stimulating activity</li> </ul>
<b>Drugs</b>	<ul style="list-style-type: none"> <li>• None known</li> </ul>	<ul style="list-style-type: none"> <li>• Antihypertensive drugs</li> <li>• Hormone Replacement Therapy (HRT)</li> <li>• NSAIDs (Non-Steroidal Anti-Inflammatory Drugs)</li> <li>• Drugs preventing amyloid deposition</li> </ul>
<b>Others</b>	<ul style="list-style-type: none"> <li>• Depression</li> <li>• Traumatic Brain Injury</li> <li>• Occupational exposure (to heavy metals)</li> <li>• Infective agents e.g. HIV</li> </ul>	<ul style="list-style-type: none"> <li>• None known</li> </ul>

### 1.5.3 Future developments in prevention of dementia

The evaluation of prevention interventions is complicated by the long timescales, mode of diagnosis, and a lack of reliable biomarkers.<sup>40</sup> Three large multicentre trials are currently taking place in Europe and the results will inform the case for preventive interventions. These interventions look at nutritional guidance, physical activity, cognitive training and social activity, and management of metabolic and vascular risk factors;<sup>41</sup> omega 3 fatty acids;<sup>42</sup> and cardiovascular risk factors, comprising treatment of hypertension, hypercholesterolemia, diabetes and reducing overweight, smoking cessation, and stimulating physical exercise.<sup>43</sup>

Advances in drug treatments for Alzheimer's disease are also in the early stages.<sup>44</sup>

#### **1.5.4 Preventing cardiovascular (CVD) and metabolic disease risk factors:**

Lifestyle and behavioural risk factors (smoking, physical inactivity, poor diet and obesity) reflect the combined effects of an individual's current and past choices and circumstances.

There is renewed interest in the association of diet and nutrients with brain function in both healthy individuals and those with cognitive impairment, as there is the potential for modifying these. Clinical trials to date have mostly focussed on single interventions testing a specific pathological pathway thought to be involved in the onset of dementia such as oxidative stress, vascular impairment, or inflammation. Very often these trials have led to negative findings.

A more comprehensive approach is to focus on nutritious dietary patterns known to have beneficial effects on human health such as the Mediterranean diet. The Mediterranean diet typically consists of high consumption of vegetables, moderate consumption of fish and wine, low consumption of dairy products and meat, and high intake of mono-unsaturated fatty acids from olive oil as the main source of fat.<sup>45</sup> The Dietary Approach to Stop Hypertension [DASH] is a dietary pattern characterised by increased consumption of fruit and vegetables, nuts, low-fat dairy products and whole grains, with proven beneficial effects on cardio-metabolic functions and emerging evidence of protective effects on cognition.<sup>46</sup> The PREDIMED trial is the first large scale trial testing the effects of Mediterranean like dietary interventions in participants at higher vascular risk of several health outcomes including cognitive function.<sup>47</sup>

Ongoing research is collecting evidence evaluating the potential effects of vitamin and mineral supplementation in mid and later life, to prevent the onset of dementia and mild cognitive impairment.<sup>48</sup> A recent systematic review found no evidence that prescribing statins prevents the onset of dementia.<sup>49</sup> Small effects on cognitive decline, or on the incidence of dementia, may have a significant impact on healthcare costs and the overall population burden of dementia. Robust assessments are needed about the size of the effects of interventions, and of the 'dose' and duration necessary to achieve an effect.

The fear of cognitive decline and dementia may be powerful motivators for people to try preventive interventions. Nutritional supplements and brain training activities are actively promoted by those with commercial interests. It is important for people to know whether the time and money they might invest in trying to prevent cognitive decline is likely to be well spent. Information about potential adverse effects is also important.<sup>45</sup>

The NHS Health Check programme aims to identify and reduce some of the risks of developing vascular dementia. The priorities in the Health Check work programme include:

1. Raising awareness on how to reduce the risk of onset and progression of vascular disease.
2. Promoting the evidence base for dementia risk reduction and health inequalities.
3. Enhancing the dementia component of NHS Health Check.

The proportion of East Sussex residents who have received an NHS Health Check in the period April 2015 to March 2016 [11%] is higher than the SE Regional [8.6%] and England average [9.0%]. Source: PHE Fingertips.<sup>50</sup>

The following statistics about risk factors in the East Sussex population are taken from the Health Survey for England 2014.<sup>51</sup>

### 1.5.5 Smoking

Smoking has been clearly demonstrated to be a risk factor for dementia. Quitting is thought to reduce risk back to normal background levels.<sup>52, 53</sup> Nationally, cigarette smoking decreased in those in middle age between 2004 and 2014, showing a decrease of 6 percentage points for 45-54 year olds and one percent for those aged 55-64. Smoking prevalence in East Sussex is similar to the Regional and England values. [Table 4]

### 1.5.6 Obesity

The proportion of the population who are overweight or obese increases with age. Within the 45-64 age group it is 12 percent higher for men than women. There is evidence that overweight and obesity in mid-life can increase the risk of dementia.<sup>54, 55</sup> Obesity prevalence in East Sussex is 22%, similar to the figure for England, 23%. Excess weight prevalence in East Sussex for the period 2012-14 was 64.5%, slightly higher than the S.E. Regional (63.4%) and similar to national (64.6%) proportions.<sup>56</sup> Obesity levels are predicted to increase to between 41-48% of men, and to 35-43% of women by 2030.

### 1.5.7 Physical activity

It is recommended adults undertake at least 150 minutes moderate intensity physical activity, or 75 minutes vigorous activity per week, or an equivalent combination of these. In 2012 this was met by 66 % of 45-54 year olds and 55% of 55-64 year olds.

Physical activity has been shown to prevent cognitive decline with ageing and the progression of dementia at all stages of the disease.<sup>57</sup> Despite well documented benefits of physical activity, participation drops with increasing age. The Active People Survey 2011/12 showed only 14.8% of adults aged 55+ engaging in three 30 minute sessions per week.<sup>58</sup> [This contrasts with a figure of 30.1% in 2005/6].

The Active People Survey also suggests that there is a much lower proportion of women undertaking recommended levels of physical activity than men. The Active People's Survey in 2014 estimated that 26.7% of adults in East Sussex were *inactive* (less than 30 minutes per week). This is similar to the values reported for the Region and for England. The percentage of physically active adults, exercising for 30 minutes, 5 or more times a week, is reported in the East Sussex Health profile 2015 as 57.5%.

### 1.5.8 Alcohol consumption

Drinking more than the recommended limit for alcohol increases a person's risk of developing common types of dementia such as Alzheimer's disease and vascular dementia. The NHS recommended limits are now a maximum of 14 units each week for men and women, spread over 3 or more days - although lower limits have been suggested for older people because their bodies handle alcohol differently.

The ONS Report on Adult Drinking in Great Britain, based on the Opinions and Lifestyle Survey in Great Britain in 2014, reported 58% of the population drank alcohol in the week before being interviewed. Almost 1 in 5 high earners drink alcohol on at least five days per week. Nine per cent drink more units in one day than the recommended weekly amount. Young people were less likely to have consumed alcohol: less than half [48%] of those aged 16 to 24 reported drinking in the previous week, compared with 66% of those aged 45 to 64.<sup>59</sup> Alcohol consumption was highest for those aged 55-74 in 2014, with 27% of 45 to 54 year olds and 29% of 55 to 64 year olds drinking more than 14 units per week, in excess of the new guidelines on the upper limit of consumption from the CMO.<sup>60</sup>

Of adults who are drinking alcohol in East Sussex, it is estimated around 20% are drinking at levels of 'increasing risk' of alcohol-related illness and around 7% are drinking alcohol at levels with a 'high risk' of alcohol-related illness. There is little variation at a district/borough level with the estimated percentage of increasing risk drinkers ranging from 19.3% in Eastbourne to 20.6% in Wealden, and the percentage of high risk drinkers ranging from 6.4% in Rother and Lewes to 6.9% in Hastings.<sup>61</sup>

People who regularly drink excessive amounts of alcohol over a long period of time are at risk of developing Alcohol Related Brain Damage, one form of which is Korsakoff's syndrome, a dementia specifically related to alcohol.<sup>62</sup>

### **1.5.9 Poor nutrition in middle age**

The proportion of those in middle age consuming the recommended amount of fruit and vegetables (five portions daily) was: 28% in 2003 and 27% in 2013.

### **1.5.10 Diabetes**

Diabetes is a risk factor for cerebrovascular disease and the subsequent development of dementia with growing evidence linking Type 2 diabetes with an increased risk of dementia.<sup>63</sup>

The recorded prevalence of diabetes in East Sussex for those aged 17 and over (6.0%) was higher than the Regional figure but lower than the England figure in 2013/14, (Table 4). It has been steadily increasing in all three CCGs, albeit more slowly in HWLH.

In 2014/15, the QoF prevalence of diabetes was 6.6% in H&R CCG, 6.3% in EHS CCG, and 5.4% in HWLH CCG compared with SE Region 5.8% and England 6.4%.

The following are estimates in 2014 of the number of undiagnosed cases of diabetes in the East Sussex CCG populations.

In NHS Hastings and Rother CCG there were 9 767 people over 17 years of age diagnosed with diabetes. An estimated further 3100 people remain undiagnosed, suggesting the total number of adults with diabetes is around 12 800.

In NHS Eastbourne, Hailsham and Seaford CCG there were 9 561 people over 17 years of age diagnosed with diabetes. An estimated further 3 200 people remain undiagnosed, suggesting the total number of adults with diabetes is around 12 700.

In High Weald Lewes Havens CCG there were 7 287 people over 17 years of age diagnosed with diabetes. An estimated further 2 600 people remain undiagnosed, suggesting the total number of adults with diabetes is around 9 900.

### **1.5.11 High Blood Pressure:**

High blood pressure is an important cardiovascular risk factor contributing to vascular dementia. In 2014, 27 % of adults aged 45-54 and 45% of adults aged 55-64 had high blood pressure. Rates of high blood pressure increase with age. Men have more high blood pressure than women until the age of 75.

### **1.5.12 Human Immunodeficiency Virus [HIV] dementia:**

Due to improved survival rates with HIV infection, the cumulative prevalence of HIV dementia has risen. There are 493 East Sussex residents diagnosed with HIV infection and accessing treatment centres. Approximately 1 in 4 people are estimated to be unaware of their HIV infection.

A small proportion of individuals with HIV infection may not have received optimal early diagnosis and are therefore at an increased risk of developing HIV-induced dementia.

### 1.5.13 How does East Sussex compare with England regarding CVD Risk factors?

Table 4 summarises the cardiovascular risk factor profile at East Sussex level compared with the SERegion and England:

- ➔ The PHE dementia profile includes a section on the prevention of dementia.<sup>64</sup>
- ➔ East Sussex is doing well with regard to offering people a Health Check.
- ➔ There is a relatively high recorded prevalence of hypertension and stroke.
- ➔ There is the potential to identify more people with diabetes in the local population.

**Table 4: Cardio-vascular risk factor profile in East Sussex:**

Compared with benchmark								
<div> <div>Lower</div> <div>Similar</div> <div>Higher</div> <div>Not compared</div> </div>								
Indicator	Period		England	South East region	Bracknell Forest	Brighton and Hove	Buckinghamshire	East Sussex
Smoking Prevalence in adults - current smokers (IHS)	2014		18.0	16.6	16.9	23.1	15.1	17.4
Percentage of physically active and inactive adults - inactive adults	2015		28.7	25.1	20.3	19.2	22.0	26.6
Excess Weight in Adults	2012		63.8	63.1	66.2	49.2	64.4	65.0
Admission episodes for mental conditions (Narrow) - 40-64 yrs	2014/15		299.6	227.7	196.5	308.4	222.1	247.9
People receiving an NHS Health Check per year	2015/16		9.0	8.6*	9.5	6.7	9.0	11.0
Hypertension: Recorded prevalence (all ages)	2014/15		13.8	13.5	11.1	9.8	13.4	16.6
Stroke: Recorded prevalence (all ages)	2014/15		1.7	1.7	1.3	1.3	1.6	2.4
Diabetes: Recorded prevalence (aged 17+)	2014/15		6.4	5.7	5.3	4.1	5.9	6.1
CHD: Recorded prevalence (all ages)	2014/15		3.2	2.9	2.4	2.2	3.0	3.8
Depression: Recorded prevalence (aged 18+)	2014/15		7.3	7.3	8.1	8.6	7.2	9.0

Source: Public Health England, 2016

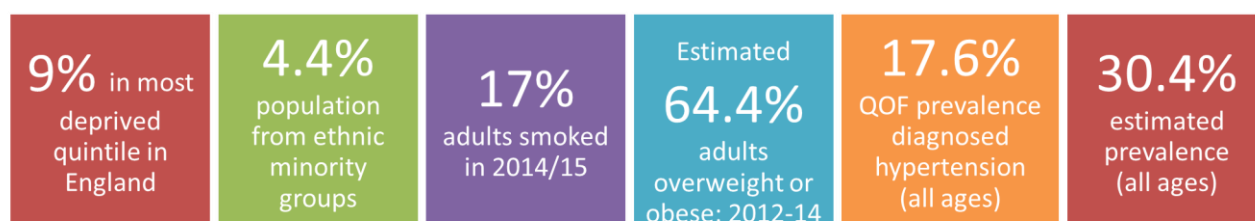
### 1.5.14 Cardio Vascular Disease [CVD] risk factors at CCG level:

Public Health England produced a set of cardiovascular disease profiles for each clinical commissioning group nationally.<sup>65</sup>

#### **Hastings and Rother CCG:**



#### **Eastbourne, Hailsham and Seaford CCG:**



#### **High Weald Lewes Havens CCG:**



### Summary: National Evidence and Policy

- One in every 79 people (1.3%) in the UK has dementia and one in 14 of the UK over 65 population has dementia.
- Late onset dementia and early-onset dementia have different underlying causes.
- People with dementia have other co-morbid conditions that can complicate their management.
- The *Prime Minister's challenge on dementia 2020* set out more than 50 specific commitments that aim to make England the world-leader in dementia care, research and awareness by 2020. The recent implementation plan sets out how these commitments will be met.
- The strategic drivers, from the points of view of central and local government, have included the National Dementia Strategy 2009, and the NICE quality outcomes for people with dementia.
- NICE guidelines for dementia management highlight best practice from the patient's perspective.
- The recently introduced Care Act has major implications for local authorities in terms of duties and resource implications.

### Summary: Risk factors for Dementia

- The risk factors for cardio vascular disease [CVD] are predisposing factors for vascular dementia.
- Compared to the other CCGs, smoking rates are highest in H&R CCG which has the highest levels of deprivation.
- Levels of undiagnosed hypertension, diabetes and those drinking alcohol at "increasing risk" are similar across the three CCGs.
- East Sussex is doing well with regard to offering people a health check to address these CVD risk factors.
- Evaluating how much impact modifying these CVD risk factors will have in preventing new cases of dementia in future is challenging.
- A recent epidemiological study in the USA has shown the benefits of optimising cardiovascular function in the prevention of dementia



This section describes the current structure of the East Sussex population and how this is expected to change over the next 15 years. The latest evidence about the number of newly diagnosed cases [incidence] and the expected number of people who are and will be living with dementia [prevalence] are summarised. Local estimates of numbers of cases are presented. The adverse effect on survival for a person diagnosed with dementia is described. The differences in presentation and risks of dementia are summarised for groups with protected characteristics and there is consideration of the potential inequalities that can arise.

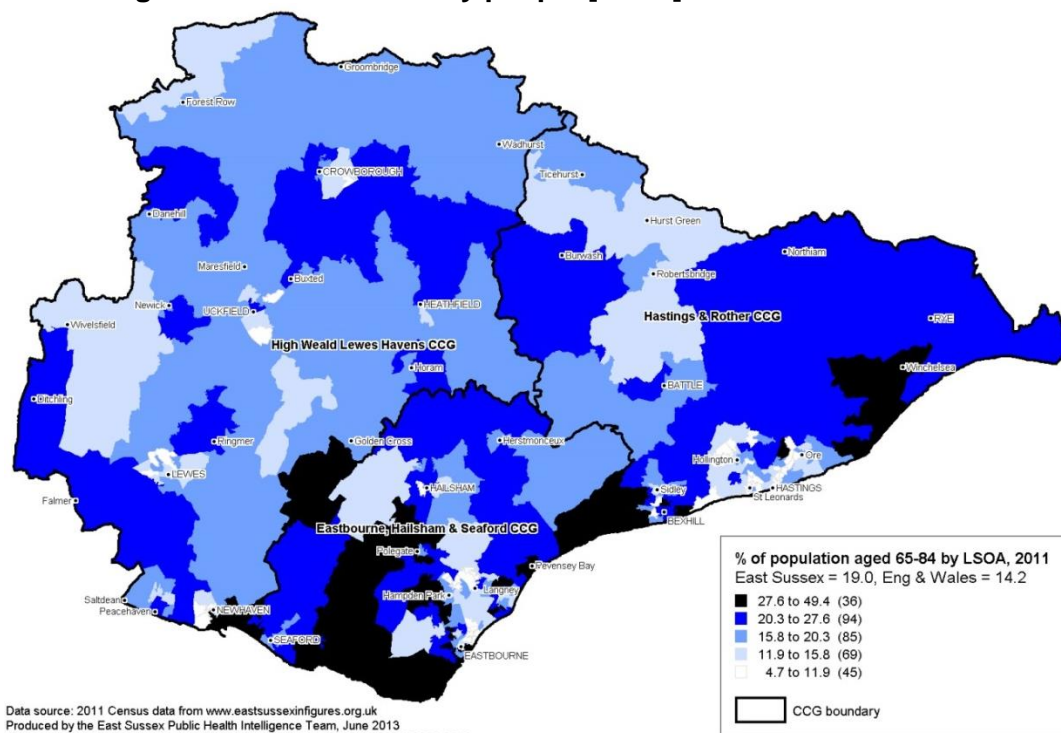
One key aim of this needs assessment is to identify where there are inequalities among people diagnosed with dementia and the support given to their carers. Inequalities in health include: how the predisposing risk factors for dementia are distributed in the population, how people access services once their memory problems and other symptoms appear, and how well people adapt to living in the community having been formally identified as having dementia.

There are 541,468 people resident in East Sussex, according to the latest mid-year population estimates for 2016. Of these, there are 138,063 people aged 65 or over. There are 61,540 males and 76,522 females aged 65 or over. [Source ESiF Jan 2016].

## Age

Dementia disproportionately affects people aged 65 and over. The risk continues to increase as people get older. Figure 3 shows where people aged 65 to 84 live in East Sussex.

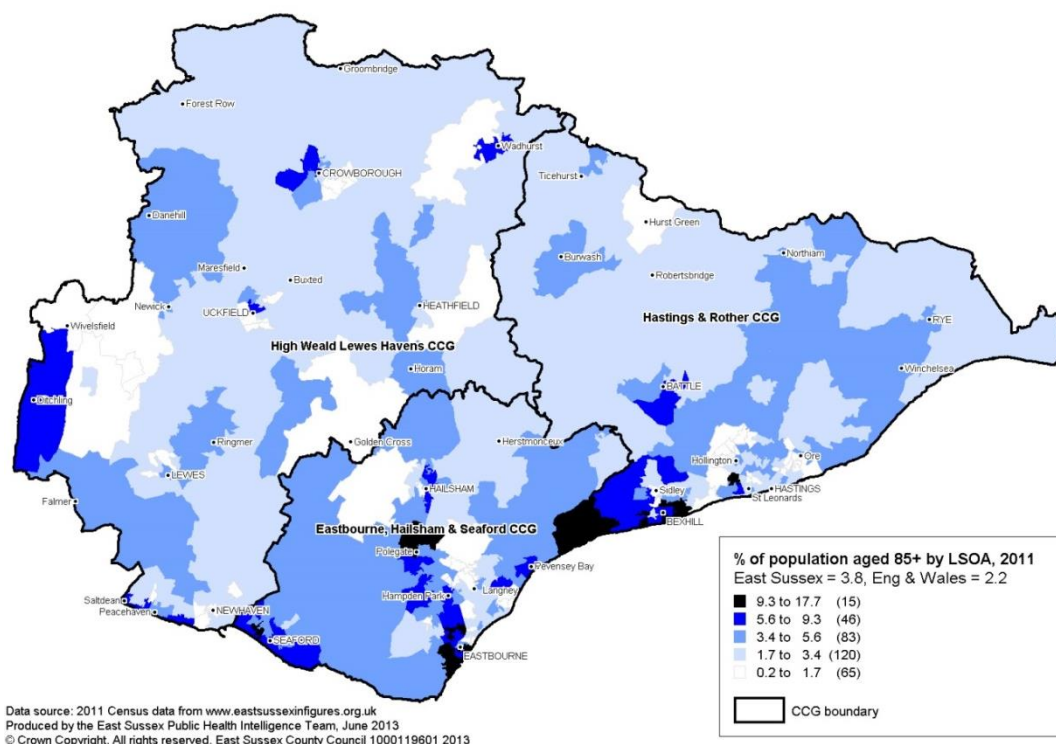
### Figure 3: Where do elderly people [65-84] live in East Sussex?





The coastal towns of Eastbourne, Bexhill, Hastings and Rye have the highest proportions of people aged 65 to 84 living there. Figure 4 shows that there are pockets of very elderly persons living in East Sussex.

**Figure 4: Where do very elderly people [85+] live in East Sussex?**



The number of older people aged 65 and over in East Sussex is shown projected at county, district and borough level until 2030 in Table 5.<sup>iii</sup> The greatest projected increase in number is in Wealden LA and the least in Hastings LA.

**Table 5: Population projections**

	2015	2020	2025	2030
East Sussex	135,500	148,300	164,300	185,100
Eastbourne	24,700	27,000	29,600	33,700
Hastings	17,500	19,400	21,600	24,400
Lewes	25,100	27,900	30,900	34,800
Rother	28,700	31,100	34,300	38,500
Wealden	39,100	43,100	47,900	53,800

Source: POPPI<sup>66</sup>

Table 6 shows changes in the number of people in East Sussex, aged 65 and over, projected to the year 2030, in five year age bands. The increase is of the order of 50 000 people in total over the next 15 years.

<sup>iii</sup> Population estimates are prepared using a number of data sources, including the 2011 Census Population, the mid-year population estimates from the Office for National Statistics (ONS) and the counts of postal addresses.

**Table 6: Changes in the number of the population aged 65 and over**

	2015	2020	2025	2030
People aged 65-69	40,400	35,600	39,200	45,800
People aged 70-74	30,400	39,400	35,100	38,800
People aged 75-79	24,100	28,100	36,700	33,000
People aged 80-84	18,900	20,700	24,600	32,300
People aged 85-89	12,900	14,100	16,000	19,400
People aged 90 and over	8,800	10,400	12,700	15,800
<b>Total population aged 65+</b>	<b>135,500</b>	<b>148,300</b>	<b>164,300</b>	<b>185,100</b>

Source: POPPI <sup>66</sup>

The number of people in East Sussex aged 65 and over, those aged 85 and over, and their relative proportion of the population, are projected to increase substantially from 2015 to 2030, Table 7. In the medium term, ONS estimates that the population aged 65+ will increase by 2% per year to 2020/21, representing a 12% increase between 2014/15 and 2020/21.

**Table 7: Changes in the proportion of the population in East Sussex who are elderly and very elderly**

	2015	2020	2025	2030
Population aged 65+ (% of total)	135,500 (25.1%)	148,300 (26.5%)	164,300 (28.3%)	185,100 (30.8%)
Population aged 85+ (% of total)	21,600 (4.0%)	24,500 (4.4%)	28,700 (4.9%)	35,200 (5.9%)
Total East Sussex [all ages]	540,600 (100%)	559,800 (100%)	580,900 (100%)	601,100 (100%)

Source: POPPI <sup>66</sup>

In East Sussex, the changes in the proportion of the population aged 65 and over, between 2015 [25.1%] and 2030 [30.8%], are greater than the expected changes in the South East Region, [18.9% in 2015 and 23.7% in 2030 respectively]. The changes in the proportions aged 85 and over, between 2015 [4%] and 2030 [5.9%] are greater than in the South East Region [2.7% in 2015 and 4.4% in 2030 respectively].

**Table 8: Projected changes in the elderly population for men and women in East Sussex:**

	2015	2020	2025	2030
<b>MALES</b>				
Males aged 65-69	19,200	16,900	18,800	22,100
Males aged 70-74	14,400	18,600	16,500	18,500
Males aged 75-79	11,000	13,200	17,100	15,400
Males aged 80-84	8,200	9,200	11,200	14,800
Males aged 85-89	4,900	5,800	6,800	8,600
Males aged 90+	2,500	3,300	4,400	5,800
<b>Total males aged 65+</b>	<b>60,200</b>	<b>67,000</b>	<b>74,800</b>	<b>85,200</b>
<b>FEMALES</b>				
Females aged 65-69	21,100	18,700	20,500	23,700
Females aged 70-74	15,900	20,800	18,600	20,400
Females aged 75-79	13,100	14,900	19,600	17,600
Females aged 80-84	10,700	11,500	13,300	17,500
Females aged 85-89	7,900	8,200	9,200	10,900
Females aged 90+	6,200	7,100	8,200	10,000
<b>Total Females aged 65+</b>	<b>74,900</b>	<b>81,200</b>	<b>89,400</b>	<b>100,100</b>

Source: POPPI <sup>66</sup>

Table 8 shows the projected increases in the number of men and women aged 65 and over until 2030 in five year age bands. In absolute terms, there is expected to be an increase of 25,000 men and 25,200 women.

These increases in numbers and relative proportions within the population highlight the future challenges of providing adequate dementia care in East Sussex.

### 2.1.2 Life expectancy:

PHE have reported on recent trends in life expectancy in older age.<sup>67</sup> Men can now expect to live for a further 19 years at age 65, 12 years at age 75, 6 years at age 85 and 3 years at age 95. Women can expect to live for a further 21 years at age 65, 13 years at age 75, 7 years at age 85, and 3 years at age 95. In East Sussex life expectancy at 75 is 13 years for all persons, ranging from 12.2 years in Hastings LA to 14 years in Lewes LA.

### 2.1.3 People Living Alone:

The number of people living alone has major implications for dementia care. The further the disease progresses, the more intensive the care required becomes. People living alone are at greater risk of accidents in the home, are likely to be admitted to a care home earlier than those living with another person and are more vulnerable.

The percentage of *all households* occupied by a person aged 65 and over living alone in East Sussex was 16.2% (37 635 out of 231 905) at the Census in 2011. The proportion is higher than all other authorities in the region [except the Isle of Wight]. The proportions of *all pensioners* living alone by local authority were: Eastbourne 35%; Hastings 35%; Lewes 31%; Rother 31%; Wealden 28%(Table 9). In England this proportion was 32% at the Census in 2011.

**Table 9: Men and women living alone in the projected East Sussex population:**

	2015	2020	2025	2030
Males aged 65-74 predicted to live alone	6,720	7,100	7,060	8,120
Males aged 75 and over predicted to live alone	9,044	10,710	13,464	15,164
Females aged 65-74 predicted to live alone	11,100	11,850	11,730	13,230
Females aged 75 and over predicted to live alone	23,180	25,437	30,683	34,099
<b>Total population aged 65-74 predicted to live alone</b>	<b>17,820</b>	<b>18,950</b>	<b>18,790</b>	<b>21,350</b>
<b>Total population aged 75 and over predicted to live alone</b>	<b>32,224</b>	<b>36,147</b>	<b>44,147</b>	<b>49,263</b>

Source : POPPI<sup>66</sup>

Over the next 15 years there are predicted to be substantial increases in the numbers of men, and women, particularly in those aged 75 and over, of the order of 17,000 more people living alone in the county.

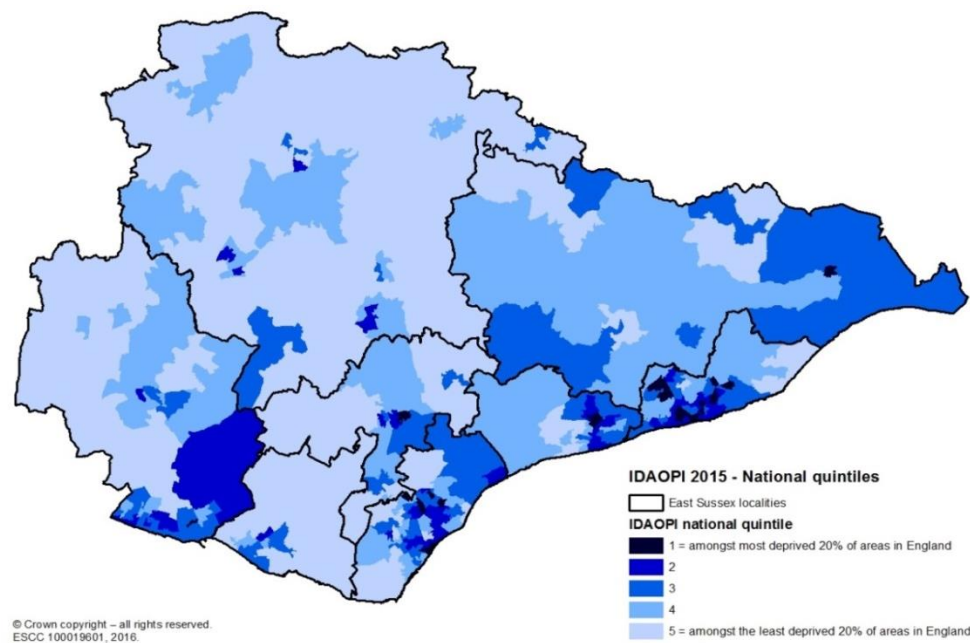
### 2.1.4 Population net migration:

It is estimated that 1,130 people aged 65 and over moved into East Sussex from other areas within the UK in 2015, slightly fewer [1,230] than in the previous year [Source ESiF]. Eastbourne LA had a slightly greater net influx of people in this age group [340] compared to Rother [320] and Wealden [260] local authorities in 2015.

### 2.1.5 Income Deprivation in Older People [IDAOPI index]:

The areas with the most income deprived elderly persons living in East Sussex are shown in Figure 5. These areas do not necessarily correspond to areas with the highest proportions of the elderly population. Elderly people living in these areas are more likely to require assistance with funding their care.

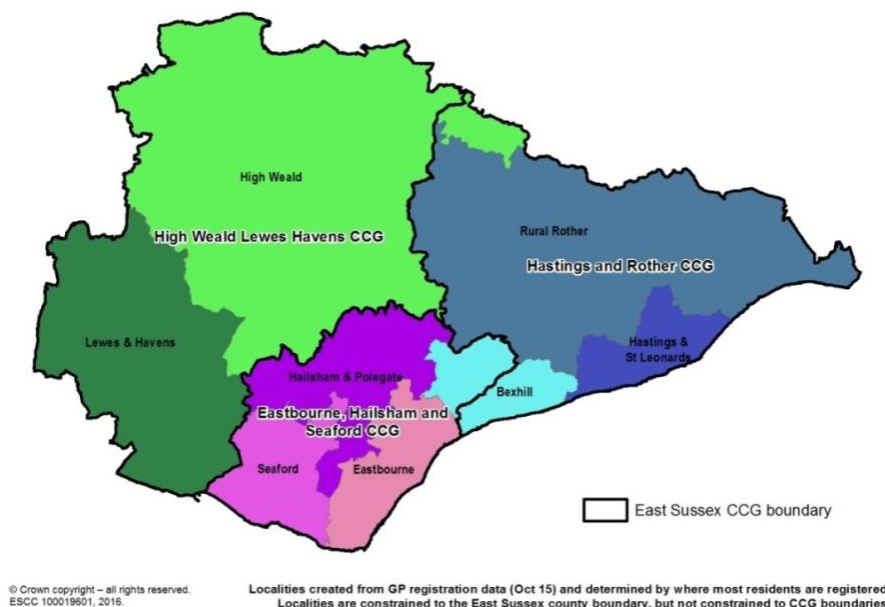
**Figure 5: Income Deprivation in Older People [IDAOPI index], 2015**



Elderly people living in the most deprived areas [national quintile] are concentrated largely along the coastal strip, particularly in Hastings, St Leonards, parts of Eastbourne and in Newhaven and Peacehaven.

The corresponding eight localities in East Sussex which are used to define the areas where community teams operate are shown in Figure 6.

**Figure 6: East Sussex localities**



## 2.2 Incidence of dementia

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

A Medical Research Council [MRC] Cognitive Function in Ageing Study [CFAS] project has been looking at the changes in the epidemiology of dementia over the last 25 years. Over the last two decades there have been considerable changes in diagnostic practice. The MRC CFAS study is the first study in the world where identical methods have been used to compare incidence, the number of new cases in a population developing over a given time period, and how incidence differs between areas with greater and lesser degrees of deprivation.

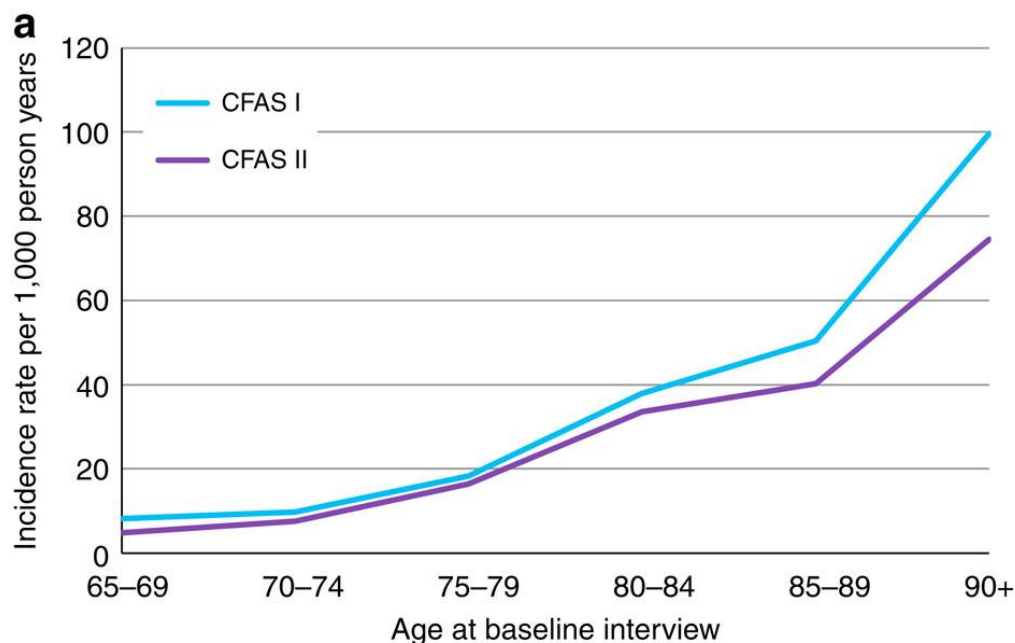
The first Cognitive Functioning and Ageing Study (CFAS I) was based on a randomly selected sample of people aged 65 years and older who were interviewed and diagnostically assessed for dementia. The same study design was repeated in the CFAS II study in 2008-2011. The CFAS II study now reports a 20% drop in incidence (95% Confidence Interval: 0% to 40%) with a reduction in incidence in men across all ages above 65.<sup>68</sup>

Figure 7 shows, on a natural scale, how the incidence of dementia [shown as a rate per 1000 person-years] increases substantially with age and how this has changed between the two studies over twenty years. Person-years allows for the fact that a proportion of people will die before they reach the age at the top of the age band. Two people living for 6 months give an equivalent risk of one person developing dementia over a year.

A higher incidence was found in the more deprived areas in the CFAS II study (comparing the *most* versus the *least* deprived area. This is described by the ratio of the dementia incidence rate in the highest compared to the lowest area. The incidence rate ratio [IRR] comparing the incidence rate of the most deprived area to the least deprived areas is 1.5 [95% CI: 1.0 -2.2]. This relationship with deprivation was not found in the earlier CFAS 1 study. Table 10 shows the changes in incidence rate between the two studies.

In two European studies, previous findings of a higher risk of dementia in women were confirmed, with much of the observed drop in incidence and prevalence being driven by a drop in men's rates.<sup>69 70</sup>

**Figure 7 Dementia incidence rates in CFAS 1 and 2**



Source: CFAS II study

**Table 10: Changes in Incidence rate per 1,000 person years, (95% confidence intervals) between CFAS I and II studies**

	CFAS I			CFAS II		
	Rate	95% CI	IRR (95% CI)	Rate	95% CI	IRR (95% CI)
Overall rate	20.1	(16.8–24.0)		17.7	(15.2–20.6)	
Cambridgeshire	19.1	(14.0–26.2)	1	16.0	(12.2–21.0)	1
Newcastle	16.7	(11.7–23.6)	1.0 (0.5–1.6)	20.6	(16.1–26.4)	1.3 (0.9–1.9)
Nottingham	24.8	(19.0–32.3)	1.3 (0.8–2.0)	16.4	(12.6–21.4)	1.0 (0.7–1.5)
Least deprived	19.7	(14.6–26.5)	1	14.0	(10.7–18.3)	1
Middle	21.0	(15.9–27.8)	1.1 (0.7–1.6)	18.7	(14.7–23.8)	1.3 (0.9–1.9)
Most deprived	18.8	(14.0–25.2)	1.0 (0.6–1.5)	20.6	(15.8–26.8)	1.5 (1.0–2.2)

Source: CFAS II study

IRR: Incidence Rate Ratio, the ratio of the dementia incidence rate of the highest compared to lowest areas

### 2.2.1 Estimated incidence (new cases per year) of dementia In East Sussex population

Applying the dementia incidence figures from the CFAS 2 study to the East Sussex population projections shows the expected increase in new cases of dementia arising from 2,507 per year in 2015, to 2,796 per year in 2020, Table 11.

*A more conservative estimate of the number of new cases arising per year would be 1,490 cases per year in East Sussex, using the age-specific incidence values from the lower end of the confidence intervals from the CFAS 2 study, compared to the figure of 2,507 cases in Table 11.*

This expected increase has important implications if increased awareness of dementia encourages earlier presentation; there may be more referrals to memory assessment clinics with the expectation of support in the community for these earlier diagnosed cases.

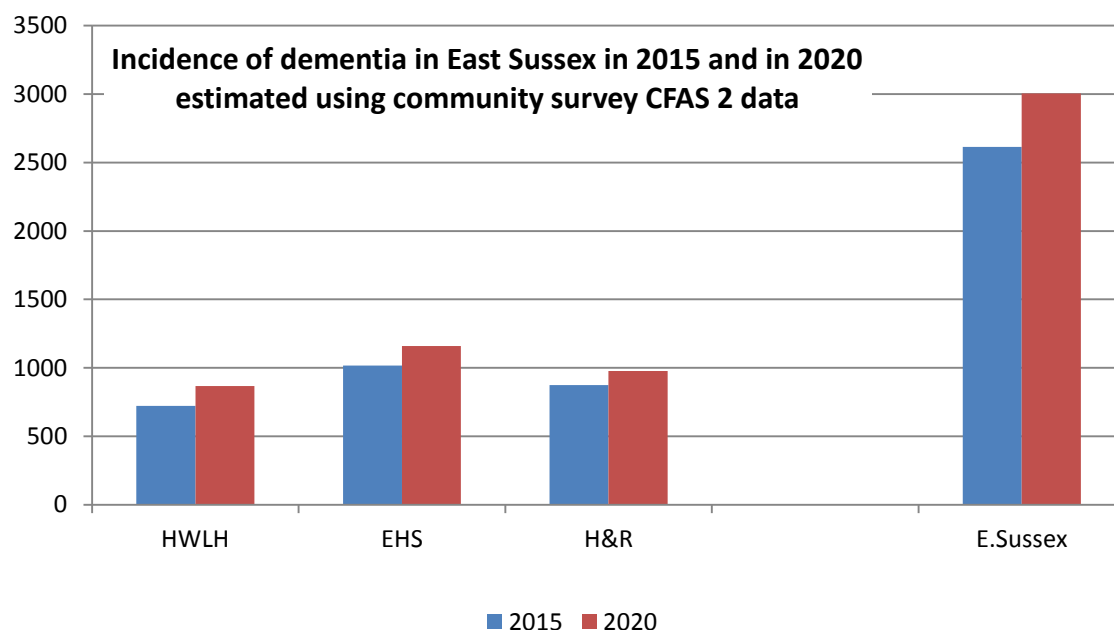


**Table 11: Projected incidence in East Sussex residents (using CFAS 2) estimates**

	2015	2020
Incident cases, community: male	888	1017
Incident cases, community: female	1619	1779
<b>Total ESCC</b>	<b>2507</b>	<b>2796</b>

The annual number of new cases in each CCG in 2015 and in five years time is illustrated in Figure 8: This estimate takes into account the ageing of the population in East Sussex.

**Figure 8: New cases of dementia in East Sussex CCGs using (CFAS 2) community survey estimates:**



Source: ESIF ESCC population projections; CFAS 2 for incidence

### 2.2.2 Symptomatic New Cases:

A different way of looking at incidence of dementia is to count those people who have presented to their doctor with symptoms.

Age-sex specific incidence rates of symptomatic cases can be derived from the MRC GP practice database. These incidence rates are much lower than those found in community surveys such as the CFAS study above.<sup>71</sup> The estimated number of *new symptomatic cases per year* presenting to GPs in East Sussex is shown in Table 12. These are the numbers of people that could be expected to present *with symptoms* to their general practices, as part of routine care, and the potential for earlier diagnosis. As can be seen, these estimates are much lower than the number in the population estimated in section 2.2.1 above.

**Table 12: Increase in symptomatic new cases of dementia in East Sussex**

	2015	2020
Incident cases with symptoms male	217	245
Incident cases with symptoms female	416	445
<b>Total ESCC</b>	<b>633</b>	<b>690</b>

Source: Rait et al for incidence estimates; ESIF ESCC for population projections

## 2.3 Prevalence of dementia

**Prevalence is the proportion of a population with a condition at any given time. Prevalence of dementia is the result of both incidence (new cases) and mortality.**

Dementia prevalence in those aged 65 and over in the period 2008-2011 was predicted to be 8.3% of the population, if the CFAS I prevalence estimates were used. However, this was found to be 6.5% in the CFAS II study, a statistically significant difference. There was decreased prevalence in both sexes.<sup>72</sup>

The reason for the reduction in prevalence is attributed to people's increasingly healthier lifestyles over the intervening years compared with those at the same age in the previous CFAS1 study, with less smoking, lower alcohol consumption, healthier diet and greater levels of exercise. Studies from elsewhere in Europe suggest decreases in dementia prevalence in men and stability in women.<sup>73</sup>

CFAS 2 prevalence rates, applied to the predicted future UK population, indicate that there will be 1.1 million people with dementia in 2025 and 2.1 million in 2050. In older age groups, women have higher rates of dementia than men. Possible explanations for this difference are:

- only very healthy men, who are less likely to get dementia, survive to very old age,
- men with dementia may have a shorter survival (which would explain differential prevalence, but not incidence).

Overall there are twice as many women with dementia as men because women tend to live longer. The rising prevalence of dementia with age is shown in Table 13.

**Table 13: Consensus estimates of prevalence rates by age group, Dementia UK 2014**

Age group	Female	Male	Total
60-64	0.9%	0.9%	0.9%
65-69	1.8%	1.5%	1.7%
70-74	3.0%	3.1%	3.0%
75-79	6.6%	5.3%	6.0%
80-84	11.7%	10.3%	11.1%
85-89	20.2%	15.1%	18.3%
90-94	33.0%	22.6%	29.9%
95+	44.2%	28.8%	41.1%

Source: Dementia UK 2014

### 2.3.1 Case severity

The severity of dementia is generally categorised as mild, moderate or severe. At any given time about 55% of the population affected will have mild dementia, 32% moderate and 13% severe dementia. The proportion of people with severe dementia increases with age.<sup>74</sup> In 2014/15, women aged 65 and over were more likely than men to have been assigned to a dementia-related care group [or cluster]. The proportion of women with cognitive impairment or dementia with *moderate* need was 1.2% vs 0.8% in men, with *high* need 0.4% vs 0.3% in men, and with *high physical need or engagement* 0.2% vs 0.1% in men.<sup>75</sup>



### 2.3.2 Uncertainty about prevalence estimates

While there are likely to be fewer people currently living with dementia than had previously been estimated, it is difficult to predict what future numbers will be. Improved lifestyle factors may not be maintained; we know that obesity rates among the under 65's are higher now than they were and are predicted to increase. However, the increasing ageing of the population alone would suggest that dementia prevalence is likely to increase.

The Alzheimer's Society now takes the view that previous prevalence estimates are a **worst case scenario**. The Department of Health has commissioned a review to reach a new consensus on prevalence rates. This will reduce the total number of people in England currently estimated to have dementia from 670,000 to 620,000.

In the Rotterdam Study new (incident) dementia cases in people aged 60-90 fell by a quarter between 1990 and 2000, although the finding was not statistically significant.<sup>76</sup> Two cross-sectional studies in Sweden showed that whilst prevalence is stable, survival is increasing, and from this inferred a decreased incidence.<sup>69</sup>

### 2.3.3 Changes in the estimated prevalence of dementia in East Sussex

Table 14 shows how the number of people diagnosed with dementia is predicted to increase in the next 15 years, age-specific prevalence rates applied to East Sussex population projections. This reflects the increase in size of the elderly population, particularly those aged 85 and over.

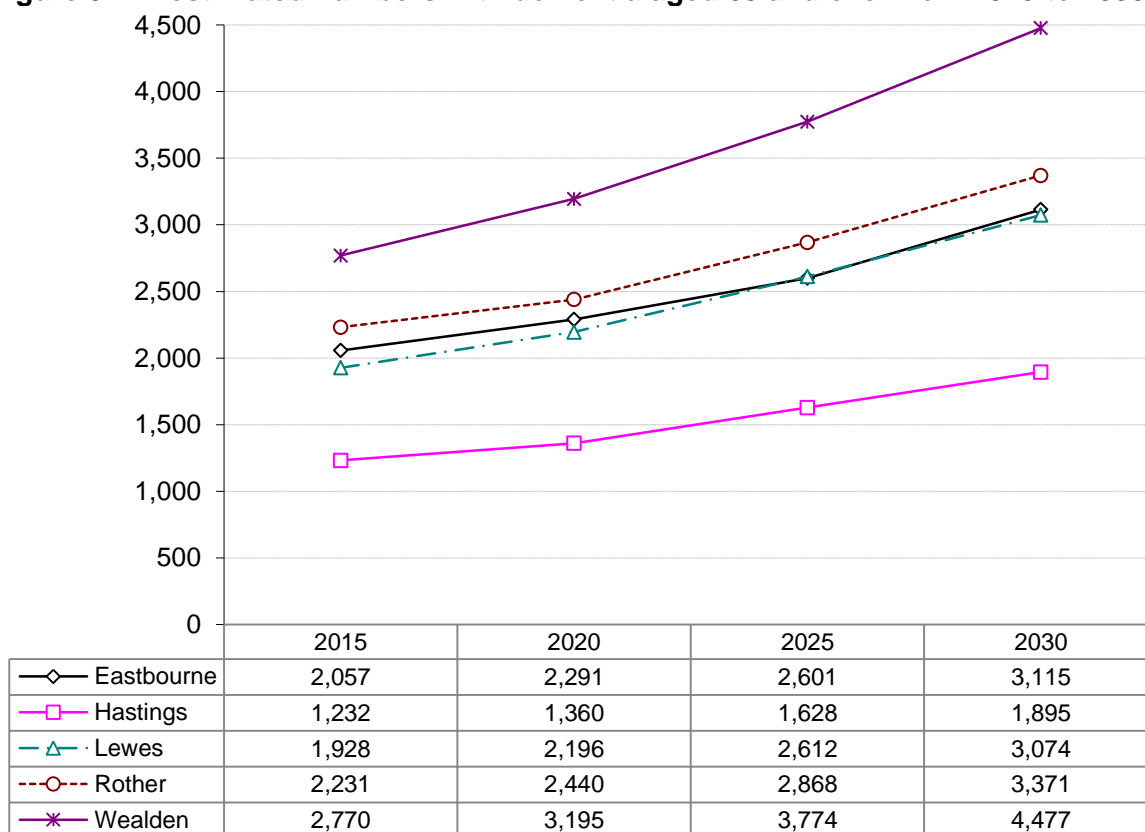
**Table 14: Projected number of people who will develop dementia in East Sussex by age group**

	2015	2020	2025	2030
<b>MALES</b>				
Males aged 65-69	288	254	282	332
Males aged 70-74	446	577	512	574
Males aged 75-79	561	673	872	785
Males aged 80-84	836	938	1,142	1,510
Males aged 85-89	818	969	1,136	1,436
Males aged 90+	698	921	1,228	1,618
<b>Total males aged 65+</b>	<b>3,648</b>	<b>4,331</b>	<b>5,171</b>	<b>6,254</b>
<b>FEMALES</b>				
Females aged 65-69	211	187	205	237
Females aged 70-74	382	499	446	490
Females aged 75-79	852	969	1,274	1,144
Females aged 80-84	1,423	1,530	1,769	2,328
Females aged 85-89	1,754	1,820	2,042	2,420
Females aged 90+	1,903	2,180	2,517	3,070
<b>Total Females aged 65+</b>	<b>6,524</b>	<b>7,184</b>	<b>8,254</b>	<b>9,688</b>
<b>Total population</b>	<b>10,172</b>	<b>11,515</b>	<b>13,425</b>	<b>15,942</b>

Source: POPPI66

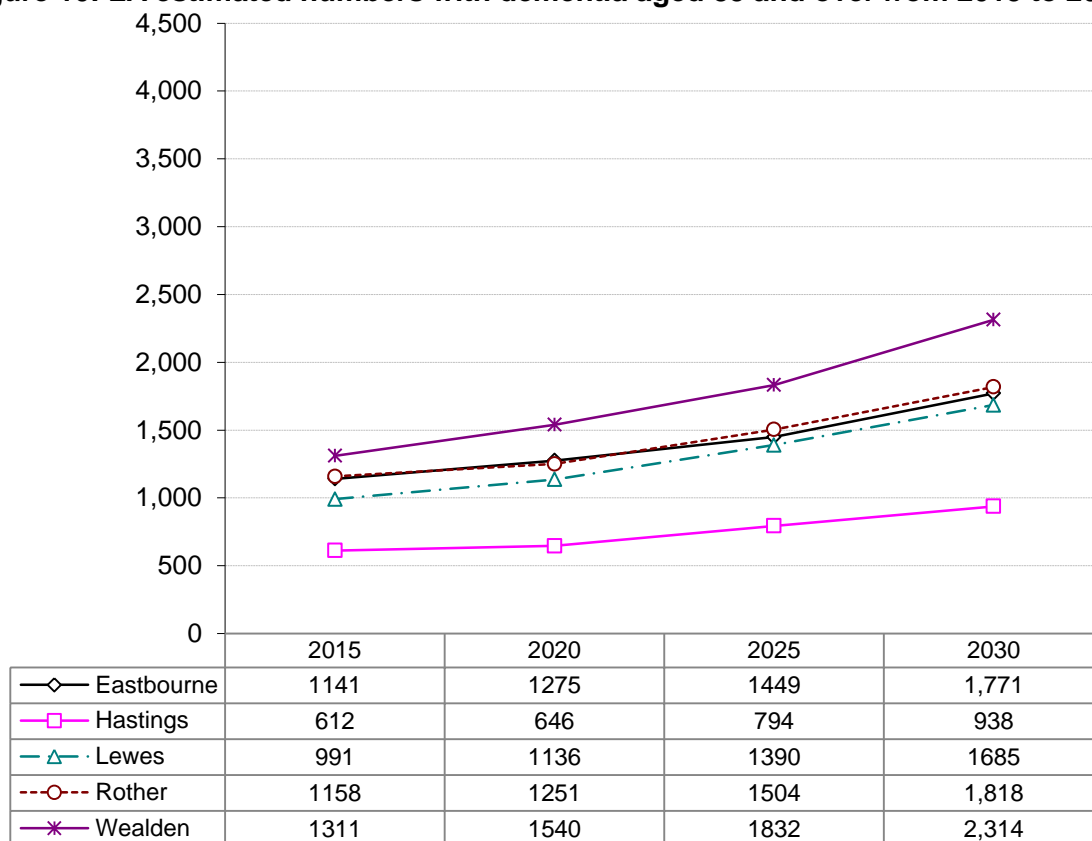
In East Sussex, the total rises from 10,172 cases in 2015 to an expected number of 15,942 by 2030. The increasing numbers are shown at District and Borough level for persons aged 65 and over, and 85 and over, Figures 9 and 10. There is a predicted increase in cases in all districts, with a greater increase in absolute terms in Wealden district.

**Figure 9: LA estimated numbers with dementia aged 65 and over from 2015 to 2030**



Source: POPPI

**Figure 10: LA estimated numbers with dementia aged 85 and over from 2015 to 2030**



Source: POPPI

Differences in the interpretation of projected prevalence estimates are discussed in the Alzheimer Society Dementia Update Report 2014.<sup>77</sup> This considers the relative contributions of reductions in the risk factors for vascular dementia at a population level. There is a suggestion that new cases of dementia will become more evident in the very elderly (the concept of compression of cognitive morbidity). It concludes that it is no longer reasonable to assume that the age-specific prevalence (and incidence) of dementia in the UK will remain stable over the next 40 years. No growth is the least likely of a range of possible scenarios. The possible scenarios in future are:

- a) an **overall reduction** in total numbers affected (assuming a very substantial decline in age-specific incidence and prevalence, more than offsetting any increases expected because of population ageing),
- b) **no growth at all** assuming, as observed between CFAS I and II [Matthews et al, 2013], that the expected growth in numbers from population ageing is completely offset by declining prevalence,
- c) a **more modest increase** than that outlined in the projections, (assuming that the growth in numbers from population ageing is *partly* offset by declining age-specific prevalence).

Which of these scenarios plays out will depend upon the success of continuing efforts to improve public health. Those who will be old in 2050, were born around the 1970s, and are now in their third and fourth decades of life. This is a crucial 'sensitive period' where efforts to prevent, detect and control obesity, hypertension, diabetes and dyslipidaemia (high cholesterol) are likely to have maximum positive impact upon brain health and dementia risk in later-life.

### 2.3.4 Early Onset Dementia

The expected number of prevalent cases of *early onset dementia* [onset between the ages of 30 and 64 years of age] in the East Sussex population at present is estimated at approximately 85 men and 62 women. These numbers are predicted to increase to 95 men and 67 women respectively with early onset dementia by the year 2030.

Source: Projecting Adult Needs and Service Information [PANSI], accessed 19/07/16.<sup>78</sup>

### 2.3.5 Screening for Dementia

The National Screening Committee does not recommend population screening for new cases of dementia in the general population.<sup>79</sup> Screening for dementia would involve calling everyone in the population above a certain age to be tested before they present with symptoms to GPs, and then recalling them after a given time period.

## 2.4 Co-morbidities and long term conditions

People with dementia usually have other medical problems. People with vascular dementia are more likely to have other vascular problems, such as coronary heart disease, peripheral vascular disease and diabetes.

People with dementia and co-morbidities are at risk of receiving worse care because of the complexity of their management. However, co-morbidities also provide an opportunity for integration between services.

### 2.4.1 Parkinson's disease

Many people with Parkinson's disease have dementia. The proportion of people with Parkinson's disease who have dementia is estimated to be 30%.<sup>80</sup> The proportion rises to 75% for people who have had Parkinson's disease for more than 10 years. Just over three per cent (3.6%) of people with dementia have Parkinson's disease.<sup>81</sup> This is equivalent to about 360 people across East Sussex having both dementia and Parkinson's disease. This may be an underestimate because of under diagnosis of both conditions.

### 2.4.2 Falls

People with dementia are four to five times more likely to experience falls than older people without similar significant impairment.<sup>82</sup> People with dementia have physical and mental changes which make them more likely to have falls.

Dementia pathways and the specific needs of people with dementia need to be considered when developing falls prevention interventions and services.<sup>83</sup>

### 2.4.3 Burns

Burns in people with dementia are significant injuries with prolonged lengths of stay. A study from Australia shows the incidence of burns has not decreased over the past 10 years despite efforts to prevent them.<sup>84</sup>

### 2.4.4 Visual Impairment

Sight loss is also common in dementia. This will further complicate the management of the dementia patient as well as increasing the likelihood of falls. It is estimated that about 10.8% of 75 to 79 year olds, 20% of 80 to 84 year olds, 35.3% of 85 to 89 year olds and 53.1% of 90 year olds have partial sight and blindness.<sup>85</sup> The ProVIDe study is looking at potentially correctable visual impairment in people with dementia by improving refraction [new glasses] or consideration for cataract surgery.<sup>86</sup>

### 2.4.5 Incontinence

Incontinence is another significant co-morbidity that is common in dementia. People with dementia, compared to those who do not have dementia, are three times more likely to have urinary incontinence and four times more likely to have faecal incontinence.<sup>87</sup>

## 2.5 Survival with dementia and mortality

Dementia is associated with significantly early death. This is due to both the dementia itself, as well as the difficulty in managing other medical problems. Observed differences in mortality between people with and without dementia may change over time, as can the overall rate of mortality in the population.

Rait et al studied survival from when dementia was first noted in a person's primary care record compared with survival in people without dementia.<sup>71</sup> The study looked at the period between 1997 and 2007 for people who could be followed up in the participating GP practices for 10 years (or until they died). The average age at diagnosis of dementia was 83.2 years and, of these, two thirds were female.

Table 15 shows how long people survived from a new diagnosis with dementia compared with those who did not have dementia. The median number of years survival is shown following a diagnosis of dementia (red shading) and for those that did not get dementia (white line), together with the inter quartile range (25% dying and 75% dying). The values for 'all' are taken from the ONS life tables.

**Table 15: Median number of years survival in study following a diagnosis of dementia**

Years to dying		Lower quartile	Median	Upper quartile
Age when diagnosed	Proportion dying	25%	50%	75%
60-69	No Dementia	>10yrs	>>10yrs	>>>10yrs
	Dementia	3.1yrs	6.5yrs	10.0yrs
	All (from ONS)	11.2yrs	18yrs	23.4yrs
70-79	No Dementia	5.1yrs	>10yrs	>>10yrs
	Dementia	1.8yrs	4.5yrs	7.4yrs
	All (from ONS)	5.1yrs	10.0yrs	14.4yrs
80-89	No Dementia	2.6yrs	5.9yrs	9.9yrs
	Dementia	1.3yrs	3.0yrs	5.3yrs
	All (from ONS)	1.4yrs	4.4yrs	8.2yrs
90+	No Dementia	1.3yrs	3.0yrs	5.3yrs
	Dementia	0.6yrs	1.8yrs	3.3yrs
	All (from ONS)	0.8yrs	2.2yrs	3.4yrs

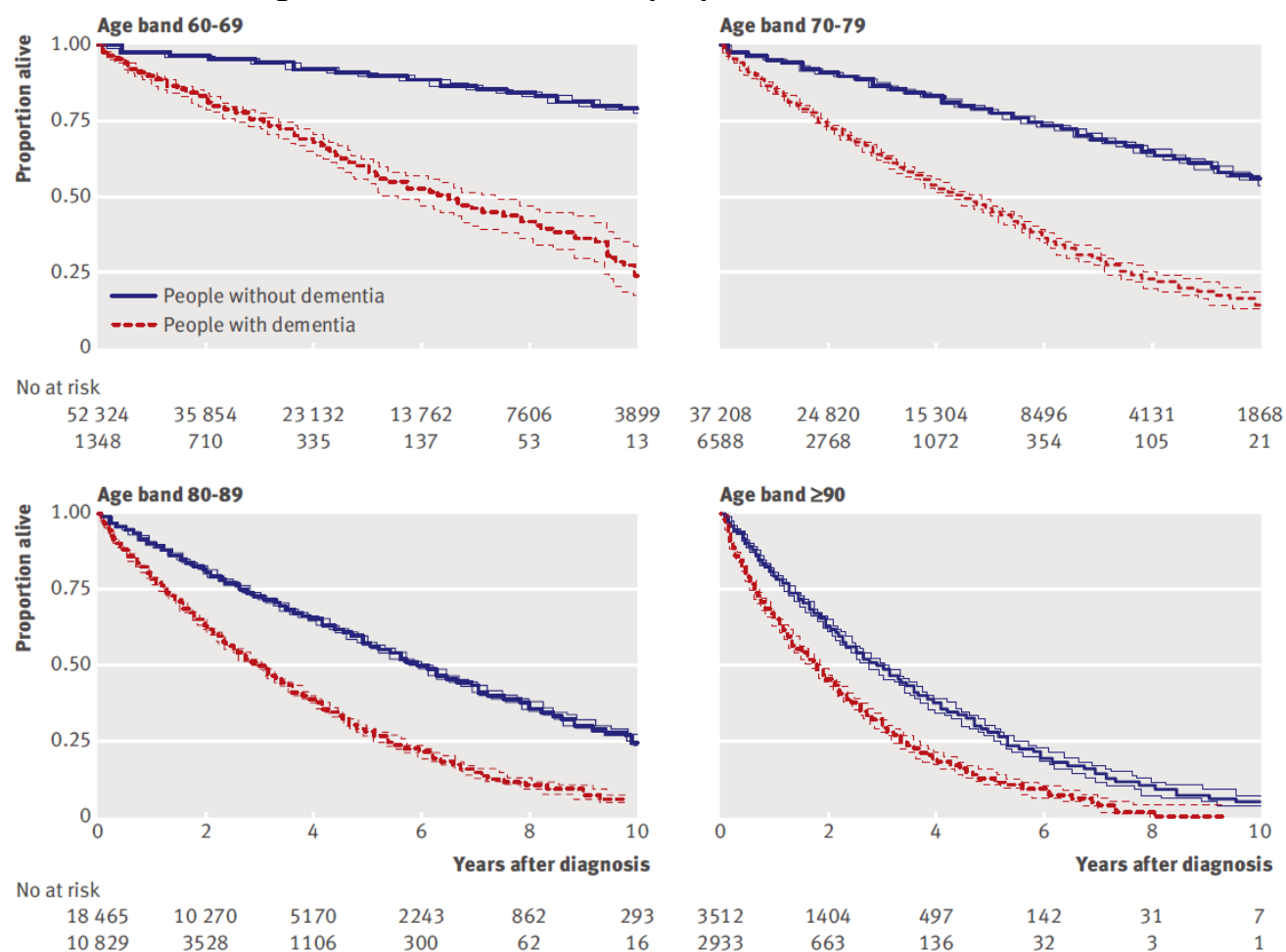
Source: Rait et al,2010

>10, greater than 10, >>much greater than 10, >>>very much greater than 10. Study stopped after 10 years and the duration of survival is implied both from projection and national survival rates.

For those aged 80-89, following a diagnosis of dementia, 50% had died within 3 years [inter quartile range 1.3 to 5.3 years], compared with 5.9 years for those who did not develop dementia [interquartile range 2.6 to 9.9 years].

Figure 11 illustrates survival with and without dementia for 10 year age bands 60 to 69, 70 to 79, 80 to 89 and over 90 years. The space between the blue (no dementia) and red (dementia) survival curves indicates how many years of life are lost, on average, over the 10 years of the study by someone with dementia.

**Figure 11: Survival curves of people with dementia**



Source: Rait et al,2010

The x axes on the graphs for 60-69 and 70-79 also cover a ten year time period.  
 'No. at risk' is the number of people still at risk during each subsequent two year time period.

In addition to age and sex, the study looked at other risk factors; deprivation: smoking; alcohol; diabetes; hypertension; cardiovascular disease; cerebrovascular disease; and high cholesterol. These increased the likelihood of dying early by the same amount whether or not the patients had dementia. However, the study did suggest that risk factors for cardiovascular disease, associated with progression of vascular dementia, were managed less comprehensively in those with dementia compared to those without dementia.

Increasing case recognition of people with dementia is likely to identify more mild cases who will appear to live longer. The average age at which people actually die may not change if early diagnosis is solely associated with longer awareness of dementia, rather than necessarily resulting in longer survival. Early diagnosis does allow more appropriate support for patients and carers that can significantly improve their quality of life and better management of co-morbid problems could increase survival.

## 2.5.2 Survival analysis using the Mental Health Minimum Dataset [MHMDS]

The Mental Health Minimum Data Set (MHMDS) contains individual patient record-level data about the care of adults and older people using secondary mental health services. The

MHMDS covers services provided in hospitals, outpatient clinics and in the community, where the majority of people in contact with mental health services are treated.

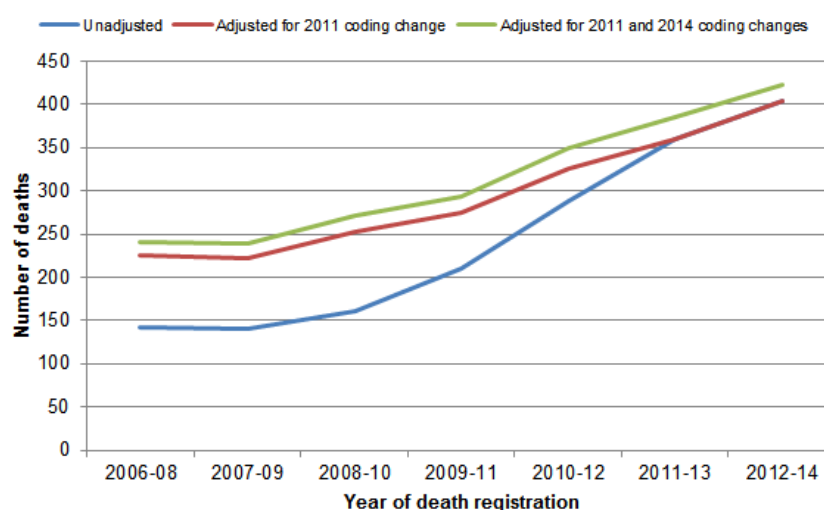
Recently, a national survival analysis of people with dementia has been carried out on the patients observed in the MHMDS,<sup>75</sup> from April 2012 until March 2015. Patients' survival was assessed from when they were first recorded as being in one of the three dementia care groups [clusters] of increasing severity: cognitive impairment or dementia at moderate need, high need, or with high physical need/engagement. All causes of death were counted in each care group, not just the deaths recorded as due to dementia. Survival was defined as the time from the initial assessment to the date of death, or to the end of the study period for those who were still alive. Results of this survival analysis provided:

- a median survival time from when patients are first assessed as having cognitive impairment, or dementia at *moderate* need, is 3 years 6 months .
- median survival from first assessment for those at *high* need is 2 years 3 months.
- median survival from first assessment at high *physical need or engagement* is 1 year and 8 months.

### 2.5.3 Deaths due to dementia in East Sussex

The Primary Care Mortality Database was searched for deaths of East Sussex residents attributable to dementia, using ICD-10 underlying cause of death codes F01 and F03. The year recorded is the year of death registration. Coding changes have been taken into account. [For an explanation of dementia comparability ratios, please see Ref.<sup>88</sup>] The numbers attributable to dementia have increased from 142 for the period 2006-08 to 404 for the period 2012-14 [using three year rolling averages]. The gradual increase in deaths attributable to dementia is shown in Figure 12.<sup>iv</sup>

**Figure 12: The increasing number of deaths attributed to dementia in East Sussex**



<sup>iv</sup> Currently deaths are certified by the attending doctor. They fill out a **medical certificate of the cause of death (MCCD)**. In 'standard' cases, where the death is due to known natural causes, the relative then takes this to the registrar who registers the death. However if the death is as a result of an accident, suicide, violence, neglect (by self or others), or industrial disease, or the cause of death is not known, the death is referred to the coroner who decides whether it requires investigation by inquest. One role of the certifying doctor is to capture the underlying cause of death - WHO definition:

- the disease or injury that initiated the train of events directly leading to death, or
- the circumstances of the accident or violence that produced the fatal injury

Therefore certifying practitioners are asked to start (on line 1a of the MCCD) with the direct cause of death, then work back through the sequence of events or conditions that led to death on subsequent lines, until the one that initiated the fatal sequence. That way the condition on the lowest completed line will have caused all of the conditions on the lines above it. It is this initiating condition which is generally selected as the underlying cause of death, following the ICD-10 coding rules. ONS death statistics on deaths from particular conditions generally use just the underlying cause of death codes.



The county of East Sussex had *lower* directly standardised mortality rates for dementia than some other upper tier local authorities in the Region, (Table 16). In terms of the colour coding used, the yellow bars indicate similar to England, light blue higher and dark blue lower than England as the benchmark.

Standardisation allows comparison between populations with different age distributions against a reference population. In the direct method of standardisation, 'age-adjusted rates' are derived by applying the mortality rates seen in a given population, for each age group, to a standard reference population, in this case England.

**Table 16: Age-standardised mortality from dementia**

**Directly Age-Standardised Rate of Mortality: People with dementia aged 20+** 2013 Directly standardised rate - per 100,000

Area	Count	Value		95% Lower CI	95% Upper CI
<b>England</b>	70,937	187.2		185.8	188.6
South East region	12,179	177.0		173.9	180.2
Bracknell Forest	96	157.9		127.8	192.9
Brighton and Hove	273	156.8		138.6	176.8
Buckinghamshire	574	153.2		140.9	166.3
East Sussex	1,009	166.6		156.4	177.3
Hampshire	2,143	193.8		185.6	202.2
Isle of Wight	334	219.1		196.2	244.0
Kent	1,931	163.9		156.7	171.4
Medway	281	188.6		167.1	212.1
Milton Keynes	201	171.8		148.8	197.4
Oxfordshire	909	190.7		178.5	203.5
Portsmouth	312	244.0		217.6	272.8
Reading	191	232.9		200.9	268.5
Slough	110	201.0		165.1	242.5
Southampton	282	196.7		174.3	221.2
Surrey	1,597	170.0		161.7	178.6
West Berkshire	178	178.0		152.7	206.2
West Sussex	1,379	167.6		158.8	176.7
Windsor and Maidenhead	210	187.5		162.9	214.8
Wokingham	169	168.7		144.2	196.2

Source: Public Health England (Office for National Statistics Mortality File)

The effect of people dying from dementia on achieving the expected national diagnosis targets is an important local issue as this affects the overall diagnosed number at any point in time [and from this the observed prevalence]. There is a limited understanding of survival rates among people diagnosed with the symptoms of dementia locally, although a figure of 12% dying per year on dementia registers in HWLH CCG has been estimated.



## 2.6 People with protected characteristics

### 2.6.1 Ethnicity and dementia

Nationally, there is currently no evidence that rates of dementia by ethnic group are any different from the general population. Studies of sufficient size and robustness have not yet been undertaken that would provide reliable results to detect a difference in prevalence between ethnic groups. In the absence of evidence, dementia prevalence and incidence are taken to be the same in all ethnic groups as the whole of the UK. This is the approach of Alzheimer's UK and the National Strategy.

Some ethnic groups have low levels of knowledge and understanding of dementia, and there are additional challenges faced in providing culturally sensitive services.

A recent literature review concluded that there appear to be system-wide issues with diagnosing dementia.<sup>89</sup> People from certain minority groups may be less willing to seek help. When they do, some health professionals may not consider the diagnosis of dementia as readily. Diagnostic and screening tools need to be culturally appropriate, otherwise there is the potential for over diagnosis or misclassification. A recent paper about people from the South Asian community identifies the potential of interventions to influence attitudes about seeking medical help for memory problems, as potentially more beneficial than focussing on knowledge about dementia.<sup>90</sup>

A study from Tennessee in the USA<sup>91</sup> showed a greater proportion diagnosed with dementia in African-Americans than Caucasians. The increase in dementia appeared to be largely mediated through increased prevalence of stroke and diabetes.

It is likely that dementia will be more common among Asian and Black Caribbean elders in England in future. The report *Black, Asian, and Minority Ethnic Communities and Dementia-where are we now?* concludes<sup>92</sup>:

*"In the UK, there has been very little work done on the impact of dementia in black and minority populations despite some of these communities being at higher levels of risk than the indigenous white population. There are increasing indications that the prevalence of dementia in Black African-Caribbean and South Asian UK populations is greater than the white population and that the age of onset is lower."*

Policy guidance on understanding the issues for black and ethnic communities has not yet found its way into practice when implementing the UK National Dementia Strategy. High blood pressure, diabetes, stroke and heart disease, all risk factors for vascular dementia, are more common in these communities.<sup>93</sup> Numbers of Black and Minority Ethnic (BME) populations are expected to increase in coming years, particularly in the 65 and over age group, as these populations age. Nationally it is estimated that dementia in BME groups will increase seven-fold by 2051, compared to the two-fold increase in the rest of the population.

### 2.6.2 Ethnicity in East Sussex

The proportion of the county's population from Black and Minority Ethnic (BME) groups increased from 5% in 2001 to 8% in 2011. East Sussex remains less ethnically diverse than nationally and regionally, where the proportions of the population from BME groups are 20% and 15% respectively.

In East Sussex, the most recent population estimates (2011) for the population aged 65 and over show that 99.0% of the population are White British and 1.0% are from a BME group. The current numbers in minority groups in East Sussex are relatively small, (Table 17).<sup>94</sup>

**Table 17: Numbers in ethnic minority groups in East Sussex**

	White	Mixed/ multiple ethnic group	Asian/ Asian British	Black/African/ Caribbean/ Black British	Other ethnic group
People aged 65-74	57,971	219	401	107	68
People aged 75-84	40,799	111	146	56	19
People aged 85 and over	19,762	53	35	9	7
<b>Total population aged 65+</b>	<b>118,532</b>	<b>383</b>	<b>582</b>	<b>172</b>	<b>94</b>

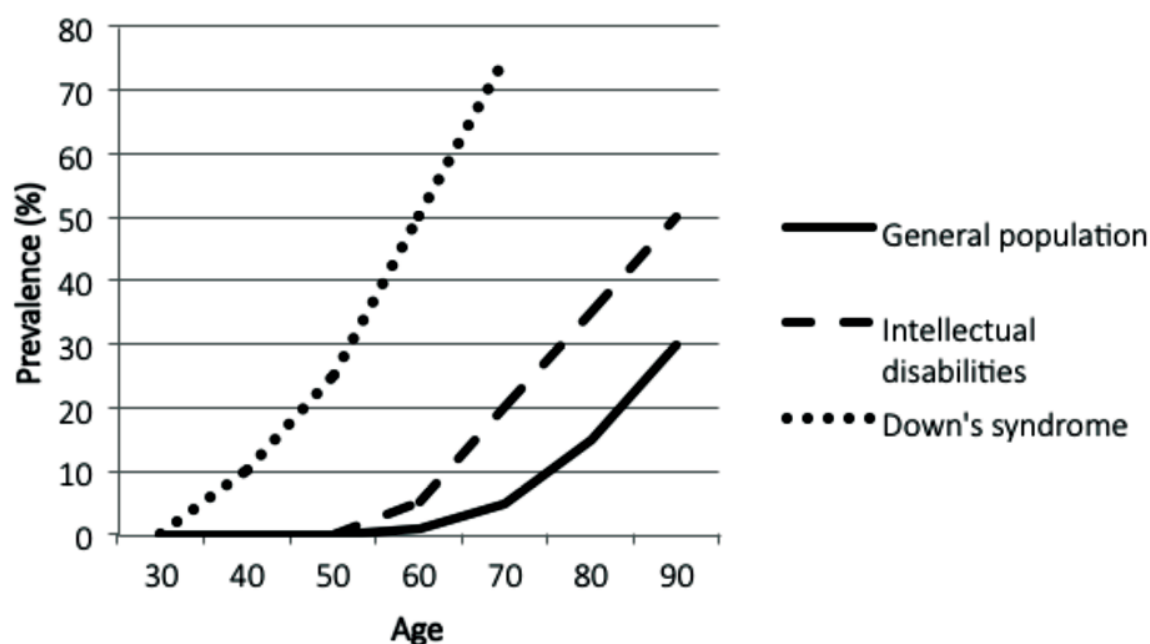
Source: POPPI

### 2.6.3 Dementia and people with learning disabilities

Dementia is more prevalent among people with a learning disability than the general population. As people are living longer the numbers of people with a learning disability who develop dementia are increasing. It has been predicted that the proportion of people with a learning disability over 65 years of age will have doubled by 2020, with over a third of all people with intellectual disabilities being over 50 years of age by that time.<sup>95</sup>

People with a learning disability are five times more likely to develop dementia compared to the general population. People with Down's Syndrome are at particular risk of developing dementia. Figure 13, compares the age-related prevalence rates of dementia in people with Down's syndrome with those with other intellectual disabilities, and the general population.<sup>95</sup> By the age of 70, over 70% of people with Down's syndrome will have dementia compared with fewer than 10% of the general population.

**Figure 13: Comparison of dementia prevalence in learning disability groups**



While many of the symptoms of dementia are the same for people with a learning disability as with the general population, there are a number of features which are different.<sup>96</sup> People with a learning disability:

- may present with different symptoms in the early stages;
- are less likely to receive a correct or early diagnosis of dementia and may not be able to understand the diagnosis ;
- may experience a more rapid progression of dementia ;
- may already be in a supported living environment ;
- may have already learned different ways to communicate ;
- will require specific support to understand the changes they are experiencing, and to access appropriate services after diagnosis and as dementia progresses.

In order for people with learning disabilities to live well with dementia and to access services effectively, public sector organisations are required to put reasonable adjustments into place to ensure this group are not disadvantaged. This may involve making physical adjustments to buildings, altering policies and procedures, staff training, and service redesign.

The Improving Health and Wellbeing of people with learning disabilities report provides a number of case studies from across the UK.<sup>97</sup> Examples cover:

- clear pathways for people with a learning disability and improved access to appropriate memory clinics;
- learning disability training for staff working with older people, and dementia awareness training for learning disability staff ;
- establishing networks for staff to share good practice, provide support and learn from each other;
- adaptations to community/hospital buildings and refurbishments to create dementia friendly environments;
- screening services for people with Down's Syndrome;
- information and training for carers and people providing support to people with dementia;
- easy read booklets for people with learning disabilities about dementia.

The recent review by the Royal College of Psychiatrists highlights the importance of an integrated care pathway for the assessment, diagnosis, and support for people with learning disabilities. The elements of an excellent service are listed as:

- Demographics are known, including having a database of all adults with intellectual disabilities which includes identification of people with Down's syndrome and those in out of area placements;
- A multi-agency dementia strategy;
- A multi-agency care pathway for assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia;
- A multi-disciplinary approach to assessment and diagnosis and support;
- Prompt access to assessment and diagnostic services including baseline assessment for people with Down's syndrome by the age of 30;
- Person-centred dementia care;
- Effective care management and review system;
- Prompt access to the full range of medical, psychological, therapeutic and social interventions;
- All living and day service environments are dementia friendly;
- The person is supported to remain in their familiar home with additional supports provided in a timely manner;
- Support is available to family carers and service providers;
- There is a capable workforce able to deliver excellence in dementia care;
- End of Life care follows the requirements of the National End of Life Strategy.

The importance of person centred care in the management of dementia is also highlighted by NICE and the Alzheimer's Society, with due consideration given to the needs and preferences of the person with a learning disability. It is important to ensure that people with

a learning disability and those caring or supporting them, understand the consequences of a diagnosis of dementia. In their priorities for implementation, NICE highlight that: “*People with dementia should not be excluded from any services because of their diagnosis, age or coexisting learning disabilities.*”

As life expectancy increases for people with complex disabilities and dementia, parent carers may develop dementia themselves which will affect their own ability to provide care. Many parent carers are single parents, which is an additional risk factor delaying identification.

## 2.6.4 People with learning disabilities in East Sussex

It is recognised that people with intellectual disabilities are at a greater risk of developing dementia at an earlier age than the general population [Fig 12 above]  
Predicted increases in the number of people in East Sussex with a learning disability are shown in Table 18:

**Table 18: Number in population of East Sussex with a learning disability**

	2014	2015	2020	2025	2030
People aged 65-74	1,479	1,524	1,637	1,610	1,830
People aged 75-84	851	860	983	1,244	1,324
People aged 85 and over	401	412	472	559	692
<b>Total population aged 65 and over predicted to have a learning disability</b>	<b>2,731</b>	<b>2,796</b>	<b>3,092</b>	<b>3,412</b>	<b>3,846</b>

Source: PANSI

Predicted increases in the number of people predicted to have a *moderate or severe* learning disability are shown in Table 19

**Table 19: Number in the East Sussex population with a moderate/ severe learning disability**

	2014	2015	2020	2025	2030
People aged 65-74	242	249	262	260	297
People aged 75-84	89	89	102	129	134
People aged 85 and over	38	39	44	52	63
<b>Total population aged 65 and over predicted to have a moderate or severe learning disability</b>	<b>369</b>	<b>377</b>	<b>408</b>	<b>441</b>	<b>494</b>

Source: PANSI

## 2.6.5 Adults with a learning disability, receiving Social Care in East Sussex

In the 12 months between 1st December 2014 and 30th November 2015 there were a total of 1,272 working age adults with a Primary Support Reason (PSR) of Learning Disability Support, and 170 older people with a PSR of Learning Disability Support received Long Term Support.<sup>v</sup> Of these, 220 people had a medical diagnosis recorded in their record, of

<sup>v</sup> Long Term Support encompasses any service or support which is provided with the intention of maintaining quality of life for an individual on an ongoing basis, and which has been allocated on the basis of eligibility criteria/policies (i.e. an assessment of need has taken place) and is subject to regular review.

which, 90 had Down's syndrome and five have fragile X syndrome. In the 12 months 1st December 2014 to 30th November 2015, a total of 40 working age adults were admitted to permanent residential / nursing care, of these, 2 had a health condition of dementia recorded. Source: Adult Social Care Dept.ESCC.

### **2.6.6 Sexual orientation**

A recent survey in East Sussex estimates that three per cent of the total population describe themselves as lesbian, gay, bisexual and transgender [LGBT], with one percent each of gay men, lesbian or gay women, or bisexual people.<sup>98</sup> Lesbian, gay, bisexual and transgender people with dementia are at risk of health inequality and face challenges that heterosexual people do not. Older LGBT people are more likely to be single and live on their own than heterosexual people.<sup>99</sup> They are less likely to have children or see family members, so that without this support, as they get older, they are more likely to need Adult Social Care. They may also fear prejudice and discrimination from generic support groups and residential care staff, which may put them off from seeking help with their dementia.<sup>100</sup> People may be unwilling to declare their sexuality on admission to residential care.<sup>101</sup> Older people's services, including care homes, need to ensure staff are trained to meet the needs of LGBT people, including those with dementia.

The needs of LGBT people in East Sussex were reviewed by the Adult Social Care department, ESCC.<sup>102</sup> The report identified a lack of gay friendly provision in the independent residential sector and in extra care housing. Voluntary sector support services were often not seen as inclusive of LGBT people.

Estimates of the UK LGBT population generally vary between 5 to 7% of the overall population;<sup>103</sup> the Office of National Statistics (ONS) estimate is lower. All estimates are likely to be underestimates as LGBT people may be reluctant to 'come out' to policy makers and researchers, seeing little benefit in doing so and fearing discrimination and harassment. The Census has not collected information on sexual orientation or gender identity.

A London-based study found that age discrimination may also come into play through the commonly held perception that older people are heterosexual and even asexual. This is compounded by a social stereotype of LGBT people as being young and active. One result is invisibility of older LGBT people in health and social care provision for older people. In common with people of all backgrounds, LGBT people wish to be with others who are like-minded. For example, sharing activities in many care environments may have implications for LGBT residents. Sensitive approaches to reminiscence/ life review are needed, especially in group situations. LGBT older people want to be able to meet with friends and to have partner relationships respectfully supported. Age Concern Opening Doors participants emphasise the importance of being included in the care of loved ones. For transgender people specifically, there are also particular physical health and personal care matters that must be acted on appropriately: attention to hormone replacement regimes; intimate care, skin and hair care; attention to personal choice of clothing, style and privacy.<sup>102</sup>

There are legal requirements about confidentiality of personal identity that providers need to be aware of and ensuring their staff comply with these requirements.<sup>104</sup> Safety can be a real concern for LGBT users of social care. There is anxiety about other service users or staff passing on information that may lead to hostile behaviour. This can lead to emotional deprivation for LGBT people living in extra care housing, or nursing and residential situations.

Assumptions of heterosexuality and 'family norms' can also affect LGBT people as carers. Some carers report feeling the need to conceal a long-term relationship, referring to it only as a friendship in order to avoid any prejudicial attitudes of professionals in their partner's

life. LGBT carers need support, acknowledgement and involvement. LGBT partners who are not married, or in civil partnerships, can find they have limited rights in relation to decision-making and involvement.

The importance of viewing LGBT people's needs, to provide for these adequately and to combat these people's valid concerns has been emphasised.<sup>105</sup> It is important for there to be culturally appropriate services for people of sexual minorities where people can expect compassionate, non-judgemental responses and respect for confidentiality.

## Summary: The Local Picture:

- East Sussex has an ageing population. The total number of people aged 65 and over will increase substantially from 135,500 in 2015 to 185,100 by 2030.
- The number and proportion of elderly and very elderly people living with dementia will increase more than elsewhere in the Region. The situation will be complicated by the forecast increase in numbers living alone.
- An estimated 10,172 people in East Sussex currently have dementia (either diagnosed or undiagnosed). This is equivalent to 1.88% of the population, or 1 in every 53 people, in East Sussex.
- The expected number living with dementia in East Sussex will have risen to 15,900 by 2030. The greatest growth of dementia cases will be in people over 85 years old.
- More intensive case finding will identify people in the community with early cognitive [memory] problems before they present with more advanced symptoms. Different epidemiological studies give different estimates of the extent of undiagnosed cases in the population, depending on the method of case ascertainment.
- People with dementia have reduced survival compared to those who do not have dementia of the same age group, in all age groups over 65.
- Preventive efforts to reduce the risks of cardiovascular disease in middle age are ongoing in East Sussex and should reduce the number of cases which are attributed to vascular dementia. The extent to which these efforts will counteract the predicted rise in the number of cases of people who will be living with dementia is unknown.
- The proportion of the total East Sussex population from ethnic minority groups is relatively small in East Sussex (eight per cent), with only one per cent in those aged 65 and over. There is some evidence that people from BME groups are at greater risk of developing dementia and may present differently to services.
- The number of People With Learning Disabilities living to old age is expected to increase. People with Down's syndrome have an earlier onset of dementia.
- It is difficult to be clear about how many people there are in the LGBT group in the elderly. The number is likely to increase in future. It is important that all staff working in all clinical care settings, including care homes have received cultural awareness training.
- There are a small number of people with a learning disability who are at a greater risk of developing dementia. Most of these people are already known to the adult social care department in ESCC. There is a local care pathway to meet their needs.



## Section 3. What should be provided for people with dementia and their carers?

This section describes patient and professional barriers to diagnosing dementia in a timely way. Variation in the rates of diagnosis of dementia between general practices in East Sussex CCGs is shown. Current interventions to improve rates of diagnosis and management at the CCG and GP practice level are covered. The increasing number of carers, and the importance of support to carers are outlined. Initiatives to encourage the development of dementia friendly communities in Europe and locally are summarised, including the appropriate use of assistive technology. Published evidence of different ways of providing services to diagnose and manage people with dementia is summarised and the performance of the current Memory Assessment Services in East Sussex is compared.

### 3.1 Timely Diagnosis of Dementia

#### 3.1.1 Introduction

A clinical diagnosis of dementia is a gateway to allow people with dementia and their carers to make informed decisions about the future. The benefits of timely diagnosis are considerable. Across dementia services the terminology has evolved from “early diagnosis” to “timely diagnosis”. People with dementia and their carers are usually aware that something is not right. Misunderstanding about the condition and unhelpful coping strategies can lead to significant anxiety and detrimental care. For some people it may take months for them to be ready to receive a diagnosis of dementia. Some carers report being in denial about the problem.

The manner in which the diagnosis is shared, and the support available afterwards is equally important. Receiving a diagnosis of dementia is life changing. For some people it is unexpected and for others it confirms their fears or relieves uncertainty. The diagnosis should be delivered in a sensitive manner. Following a diagnosis people with dementia and their carers should have access to appropriate advice, information and support. The Prime Minister’s Challenge on Dementia described a target of achieving 67% diagnosis rate with appropriate diagnostic support by 2015.

#### 3.1.2 Barriers to early diagnosis

From a study by the Social Market Foundation five principal reasons emerged to explain the delay between developing symptoms and seeking medical advice, as well as principle factors explaining why GPs may fail to diagnose or delay referral for diagnosis.<sup>106</sup>

	Patient Barriers	Health professional barrier
1	Lack of knowledge about Alzheimer’s and the closeness of the symptoms to those of ageing	The low importance that some GPs attach to the diagnosis of dementia.
2	The gradual appearance of Alzheimer’s and the inability to treat problems as acute and serious.	Lack of time to make a proper diagnosis.
3	Fear of Alzheimer’s and the denial of the disease and its implications.	The complexity of diagnosis of dementia and insufficient knowledge of the condition.
4	The lack of trust in the health system with regards to medical practitioners.	A lack of clear accountability and responsibility for diagnosis across the health care system.
5	The lack of support, either from family or friends, or professional support	Inadequate assessment tools



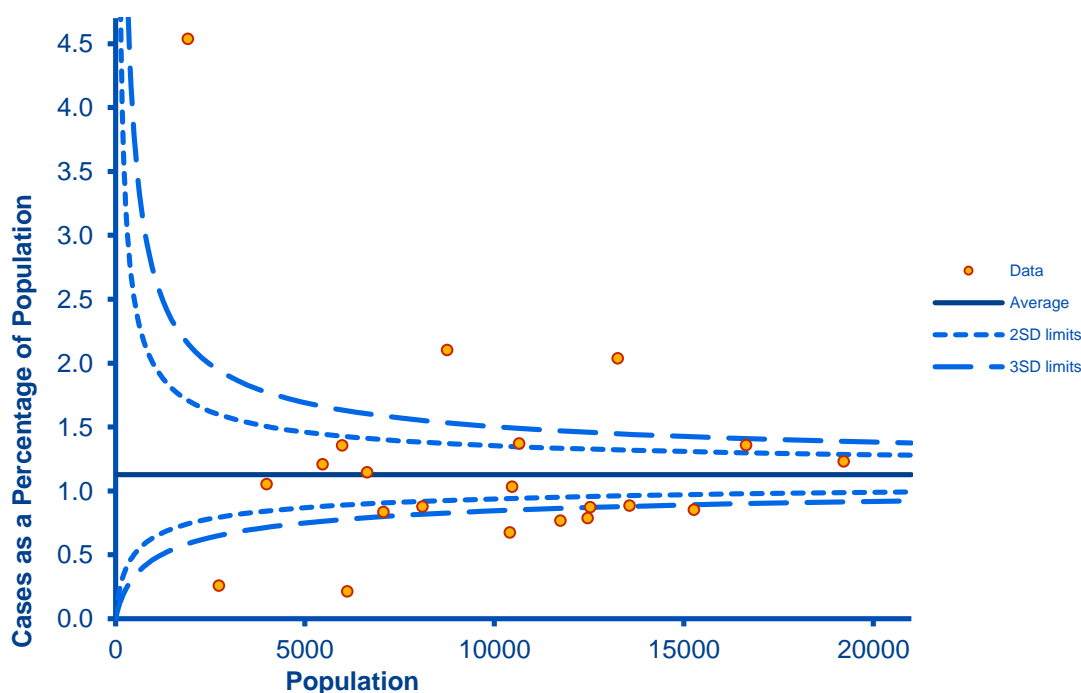
### 3.1.4 How many cases of dementia are being diagnosed?

Nationally it is recognised that many cases of dementia are still under diagnosed. Without a formal diagnosis, people are unable to gain access to *specialist* dementia services and get the support they need during the early stages of the disease. Primary Care should aim to diagnose as large a proportion of the expected dementia cases as possible with appropriately skilled and knowledgeable practitioners undertaking this work. The ASC information system has not specifically collected information about dementia.

GP practices maintain a register of patients known to have dementia. A record is made of those seen during the previous year and who are actively monitored. The data are reported on Quality and Outcomes Framework QOF dementia indicators. Not all cases of dementia on a GP practice list will be formally diagnosed and accessing support. According to the Quality and Outcomes Framework (QoF), there were a total of 544,461 people registered with GPs in East Sussex. The proportion of the East Sussex total population on the dementia registers in 2014/15 was 1.0%. The percentage of the total population in England on the registers was 0.74%. This mainly reflects the difference in structure of the East Sussex population.

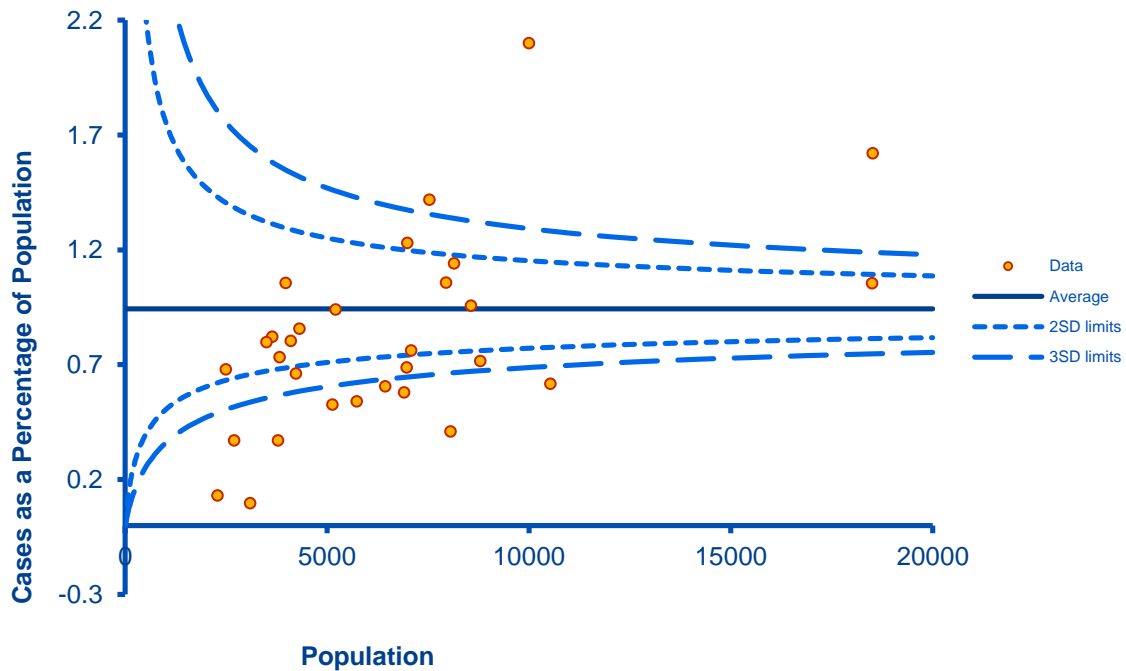
Variation in the rate of diagnosis of dementia between CCGs in East Sussex is also reflected at individual practice and ward level. The statistical process control [SPC] charts, in Figures 14, 15 and 16, show the variation in diagnosed prevalence according to the size of the GP practice. The boundaries illustrated show where there is more variation in the proportion diagnosed compared with other practices in the same CCG. Some smaller practices have low numbers of dementia cases [diagnosed prevalence], particularly in H&R CCG. In EHS CCG there are some medium sized practices with relatively lower proportions diagnosed compared to other practices in the CCG. Where there are outlier practices these clearly merit closer consideration to explain the variation. This could be on account of different practice populations, or differences in clinical practice.

**Figure 14: Dementia diagnosed prevalence EHS CCG**



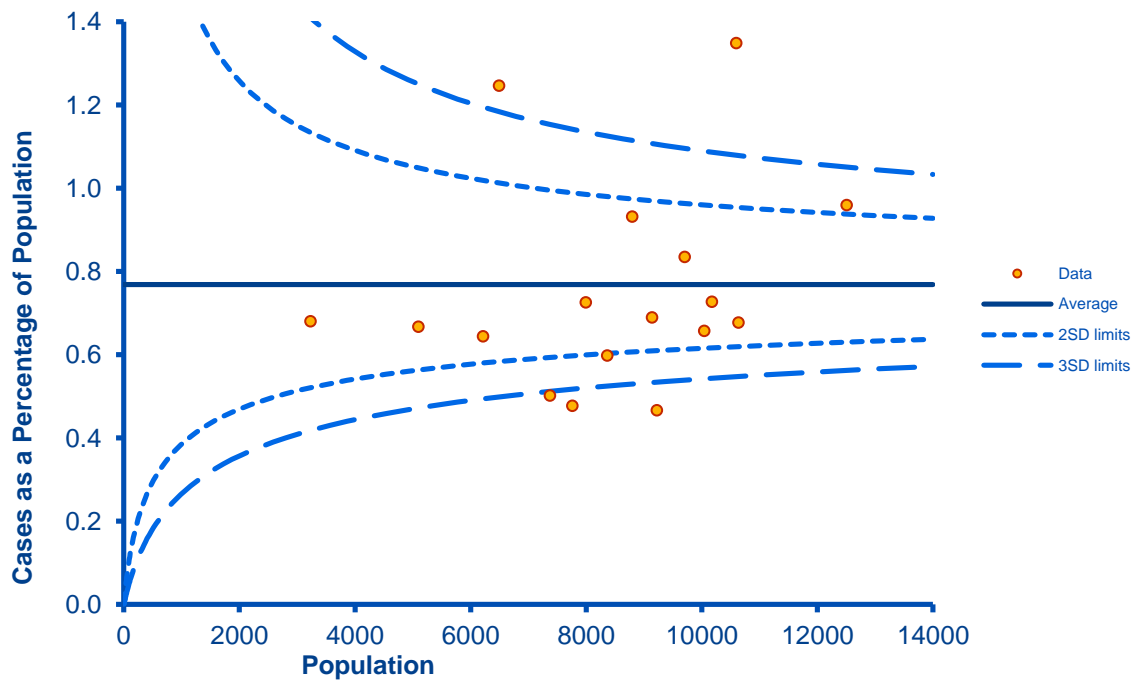
Source: QoF 2015

**Figure 15: Dementia diagnosed prevalence H&R CCG**



Source: QoF 2015

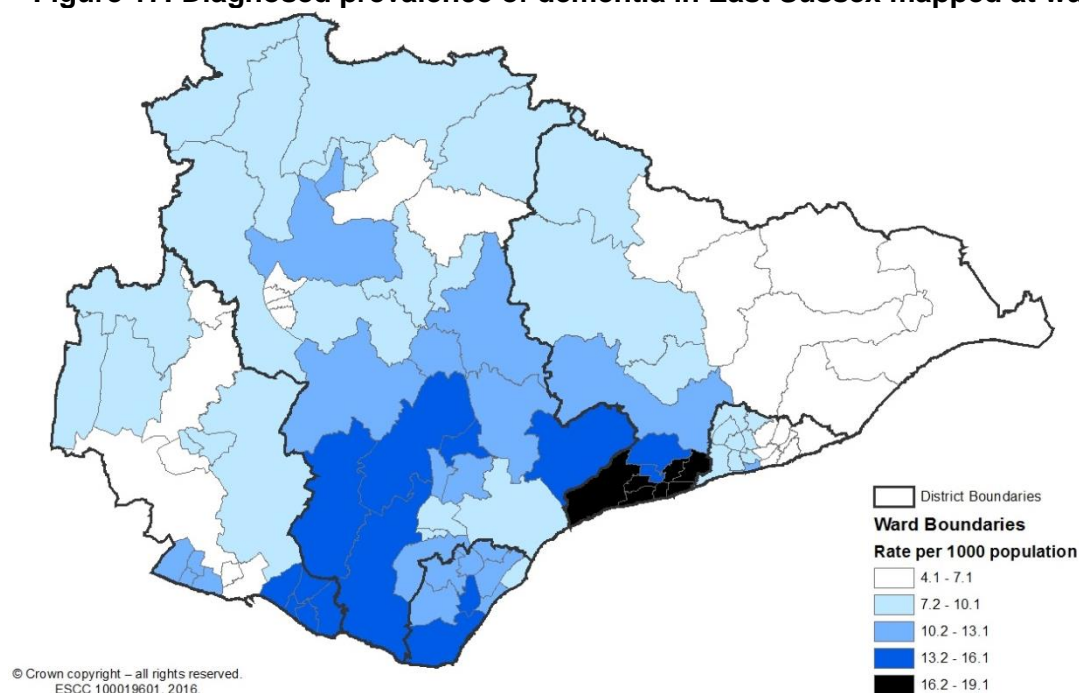
**Figure 16: Dementia diagnosed prevalence HWLH CCG**



Source: QoF 2015

Figure 17 shows prevalence estimates at ward level in quintiles: the East Sussex wards are ranked according to their prevalence values and sub-divided into fifths. There is a very low recorded prevalence in wards in the Rye area and a much higher recorded prevalence in Bexhill and Eastbourne.

**Figure 17: Diagnosed prevalence of dementia in East Sussex mapped at ward level**



### 3.1.5 How accurate are the dementia estimates likely to be?

The NHS primary care dementia calculator gives estimates of the expected prevalence of dementia for local CCG areas and individual practices. The calculator uses national estimates of prevalence, and also takes into account the number of older people living in local residential care and nursing homes. Table 20 shows the expected prevalence of dementia in East Sussex in all CCGs.<sup>vi</sup>

**Table 20: CCG *adjusted* dementia prevalence figures for East Sussex**

CCG	Number of patients registered (all ages)	Adjusted national dementia prevalence (number)	Adjusted National Dementia Prevalence (%)
High Weald, Lewes, Havens CCG	Total 168 155 82230 male 85925 female	2 544	1.51%
Eastbourne, Hailsham and Seaford CCG	Total 191 113 92104 male 99009 female	4 000	2.09%
Hastings & Rother CCG	Total 185 193 90623 male 94570 female	3 459	1.87%
<b>Total</b>	<b>544 461</b> <b>264957 male</b> <b>279504 female</b>	<b>10 003</b>	<b>1.84%</b>

Source: Primary Care Web team prevalence calculator, accessed 21 Sept 2015.

<sup>vi</sup> The CCG *adjusted expected* prevalence figure includes an adjustment that takes into account nursing and residential homes in the area.

Table 21 shows that there is under diagnosis in all three CCGs; it identifies the number of cases aged 65 and over that would need to be diagnosed in each CCG to reach the Government target of diagnosing 67% of all expected cases in each CCG.

**Table 21: Gap to reach ambition of 2/3 of expected cases diagnosed in the population**

	ENGLAND	South of England	South East	NHS Eastbourne, Hailsham and Seaford	NHS Hastings & Rother	NHS High Weald Lewes Havens
Sum of Dementia Registers (ALL AGES) latest available	439,275	122,977	40,252	2,507	2,030	1,524
Sum of Dementia Registers (65 + only) latest available NUMERATOR	425,556	119,864	39,203	2,435	1,958	1,494
Estimated Dementia Prevalence (65 + only) CFAS II DENOMINATOR	639,003	191,188	62,454	3,752	3,236	2,594
EAS1: Dementia Diagnosis Rate INDICATOR	66.6%	62.7%	62.8%	64.9%	60.5%	57.6%
Diagnoses needed on dementia register to meet ambition 66.7%	426,116	127,487	41,646	2,502	2,158	1,730
GAP to reach ambition of 2/3 diagnosed	560	7,623	2,443	67	200	236
GAP to diagnose all 100%	213,550	71,3510	23,261	1,317	1,278	1,101

Source: HSCIC June 2016

### 3.1.6 Do people with dementia want to know about a diagnosis of dementia?

Published evidence suggests that the majority of people with mild dementia want to know their diagnosis.<sup>107</sup> Some researchers advocate that diagnosis should be disclosed in all situations where the person with dementia shows both the desire and ability to know.<sup>108</sup> However, if the diagnosis is disclosed at the wrong time, or in the wrong manner, there can be negative consequences.<sup>109</sup>

The benefits to sharing a diagnosis include:

- ➔ confirming suspicions and ending uncertainty
- ➔ increasing understanding of problems
- ➔ giving access to support
- ➔ promoting positive coping strategies

→ facilitating planning and fulfilment of short term goals

### **3.1.7 Trends in dementia diagnosis**

**Nationally, from the new dementia quality and outcomes framework data in December 2015, 97% of patients with a recorded diagnosis of dementia were aged 65 or over for whom the diagnosed dementia prevalence was 4,245 per 100 000.**

All commissioning regions nationally have seen recorded prevalence increase. Since 2009/10 in all three East Sussex CCGs in (High Weald Lewes Havens, Eastbourne Hailsham and Seaford, and Hastings & Rother) there has been an increase in the numbers of dementia cases on GP practice QoF registers. This is attributed to a combination of better formal recording of cases, implementation of effective Memory Assessment Services across the county, as well as an increase in the number of new cases resulting from the ageing population. Data harmonisation exercises have been undertaken in general practices<sup>110</sup> and there are further planned initiatives to identify undiagnosed cases in care homes.

Expected prevalence figures include the very early stages of dementia which may be very mild (but identifiable in MRC CFAS research). These patients are unlikely to be diagnosed formally by their GP, Memory Assessment Services or in hospitals until their symptoms worsen. Almost all cases of severe dementia are likely to have been identified.

Fewer than 5% of dementias are in the under 65s (early onset dementia) who may also be diagnosed late, as dementia is so uncommon in this age group.

**The national dementia lead has noted that it is important to interpret the expected prevalence data with caution. The data should not be used for performance management purposes but can be used to assist in estimating the local challenge and the progress being made.**

There is no reason why we would expect to see a relationship between the rurality of a GP practice and the practice diagnosis rates.

### **3.1.8 DiADeM (Diagnosis of Advanced Dementia Mandate in Care Homes)<sup>111</sup>**

The Yorkshire and Humber Dementia Strategic Clinical Network has developed a new protocol 'DiADeM' to support GPs to diagnose dementia for people living with advanced dementia in a care home setting. DiADeM is designed to be used only with those patients living with advanced dementia within a care home setting for whom a trip to memory services is unlikely to be feasible and/or make a difference to ongoing management. The use of this case finding tool is being actively considered by CCGs locally, although this does pose ethical dilemmas as to the real benefit for the patients identified in this way.

## 3.2 What interventions can improve progress at a CCG level?

A systematic review did not find enough evidence to support the use of population screening for dementia.<sup>112</sup>

### 3.2.1 Interventions at CCG level

The national dementia lead identified key themes from those CCGs which were making greatest progress. These were:<sup>113</sup>

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

Voluntary and community sector organisations are key partners in the development of strategic plans and as service providers. Investments in this sector are key components of local dementia strategies. Interventions which were used in successful CCGs were:

- ➔ High levels of Enhanced Service for Dementia (DES) amongst GPs;
- ➔ Coding reconciliation exercises and monitoring of QOF performance;
- ➔ Commissioning dementia advisor services to support timely diagnosis and post-diagnostic support;
- ➔ Training of health care professionals;
- ➔ Training for carers;
- ➔ Advance care planning;
- ➔ Access to respite care.

### 3.2.2 What actions have been taken at CCG level in East Sussex to improve diagnosis and management of dementia?

#### Post-diagnostic Support Services

Sufficient Dementia Advisors have been commissioned for all those diagnosed in EHS and H&R CCG areas to be referred and provided with information, advice and support. The aim (in line with the national initiative) is to encourage more referrals for diagnosis by ensuring that post-diagnosis support is available.

Referrals are made from the Memory Assessment Service (MAS) to Dementia Advisors at the time of diagnosis. The proportion of referrals made that were converted to the case load of the Dementia Advisor Service in 15/16 for each CCG were: 100% in EHS, 98% in H&R and 86% in HWLH CCG.

## Care Home In-reach

A dementia-specialist Care Home In-Reach service is commissioned from SPFT and works by invitation from a care home. The service is encouraging diagnosis and improved care by providing Care Home staff with specialist training and also guidance on the management of specific patients exhibiting Behavioural and Psychological Symptoms of Dementia (BPSD).

## Commissioning for Quality and Innovation [CQUIN] in East Sussex Hospital Trust [ESHT]:

A national commissioning quality initiative [CQUIN] is in place at East Sussex Hospital Trust [ESHT] for identifying patients who may have dementia, and referring them for further advice or follow-up (to the Memory Assessment Service). On receipt of discharge summaries from ESHT, GPs are expected to act on recommendations and refer to the MAS if appropriate. ESHT performance on this CQUIN in 2014/15 has generally fallen short of targets. Please see the later section 4.8.4: [How well has Commissioning for Quality and Innovation \(CQUIN\) for dementia been implemented?](#)

An evaluation of the Memory Assessment Service pilot highlighted that very few GP referrals to the MAS were initiated as a result of ESHT recommendations. This could be because the patient's acute symptoms had resolved and therefore did not need referral, or because no definitive follow up/tracking action was taken in the practice.

## Mental Health Liaison

Mental Health liaison services have been in place across both General Hospital sites in East Sussex since 2008. There is no formal requirement for the liaison services to bring to the attention of the GP that dementia may be suspected in their patient and a referral to the Memory Assessment Service MAS recommended. The national CQUIN should result in ESHT identifying people with possible dementia and making recommendations on discharge.

### 3.2.3 Interventions to increase diagnosis of dementia at GP practice level

One randomised controlled trial compared usual practice with a combination of an electronic tutorial (from a CD rom), decision support software (built into electronic medical records to prompt diagnosis) and practice-based workshops to increase diagnosis at GP practice level.<sup>114</sup> Decision support software and practice-based workshops significantly improved detection rates. The electronic tutorial did not improve diagnosis rates.

One study distributed guidance about coding of dementia to 23 practices in London.<sup>115</sup> The guidance involved a simple five point process.

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

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



## GP practice level interventions in East Sussex

Directed and National Enhanced Services are additional services which a GP practice can choose to deliver to its patients over and above their basic GP service contract. The Directed Enhanced Service for dementia (introduced in 2014/15) requires GPs to undertake opportunistic assessments of at risk patients using some basic memory questions followed by more detailed questioning if concerns are found. Where appropriate, patients are then referred onwards, and offered care planning; a health check of carers is also undertaken.<sup>116</sup>

All practices participated in the national Quality Outcomes Framework. All GP practices in East Sussex CCGs now have a dementia register [DEM1] as they do for managing other long term conditions. The DEM2 indicator shows the proportion of patients who have had an annual review of their dementia care by their GP practice. Both the Direct Enhanced Service (DES) and the National Enhanced Service (NES) have been implemented locally. Practices have signed up to one or both enhanced services.

Significant differences in practice dementia diagnosis rates remain however. There is a new Locally Commissioned Service in H&R and EHS CCGs, please see [4.4.2 New Dementia Locally Commissioned Service \[LCS\]](#)

## Directed Enhanced Service [DES]

Take up of the Directed Enhanced Service [DES] in 2014/15 was high: in EHS CCG this was 95%; in H&R CCG 97%; and in HWLH CCG 82%. In practices which took up the DES, their diagnosis rates increased between October 2014 and March 2015 by, on average: EHS = 6.2%; H&R = 2.2%. The increase was 11.8% in HWLH CCG in the four practices which solely took up the DES.

## National Enhanced Service [NES]

Take up of the National Enhanced Service [NES] in 2014/15 was: 60% in EHS CCG; 62% in H&R CCG and 76% in HWLH CCG. Of those practices which took up the NES, their diagnosis rates increased by on average: EHS CCG by 8.6%; H&R CCG by 4.5%. In HWLH CCG the increase in prevalence was 7.2%. More than half of these practices had also signed up to the DES as well. In contrast, in those practices which did not take up the NES, their diagnosis rates increased by on average: 2.1% in EHS CCG; and 0.8% in H&R CCG.

## Data Harmonisation

National and local guidance were issued to all practices on how to undertake 'data harmonisation' on their systems to identify those who could be safely coded and reported on QOF registers as having dementia. Take up of the 'data harmonisation' exercise by CCGs in 2014/15 was: 67% in EHS and 63% in H&R CCG. The uptake was 65% of practices in HWLH CCG between 2014/15 and 2015/16 [including up to May 2016.] Of those practices which did undertake 'data harmonisation' in 2014/15 their diagnosis rates increased by, on average: 5.8% in EHS; 2.8% in H&R and 4.9% in HWLH CCG. In contrast, of those practices which did not undertake this exercise their diagnosis rate increased, on average by: 3.0% in EHS and 1.2% in H&R CCGs. There were no data available for HWLH.

## Dementia Partnerships

Dementia Partnerships is an NHS England sponsored specialist knowledge website to share knowledge and learning in the field of dementia. The Partnership has published a resource which details 10 key steps to improving timely diagnosis.<sup>117</sup>

These steps are:

1. Understand demand	Describe prevalence, incidence, diagnosis rates and population projections
2. Improve access to memory assessment	Ensure that supply matches demand. There needs to be sufficient memory assessment services to allow the diagnostic pathway to operate efficiently. An inefficient process is likely to dis-incentivise referral
3. Build capacity and support in the community	Strong local leadership, good support, appropriate treatment, skilled workforce and timely and accessible information
4. Drive improvement; monitor and review	Use incentives and manage performance
5. Ensure transparency about access and standards	Provide up-to-date data, information and intelligence to practitioners about performance
6. Educate; promote	Primary care staff about the prevalence, diagnosis rates, diagnostic pathway and support available
7. Recognise; assess; refer	Proactive, responsive primary care services
8. Find cases	Opportunistic case finding, especially with complex cases and care home residents
9. Check coding	Accurate coding on the GP Quality Outcomes Framework dementia register
10. Review prescribing	Ensure appropriate prescribing of anti-dementia drugs and anti-psychotics

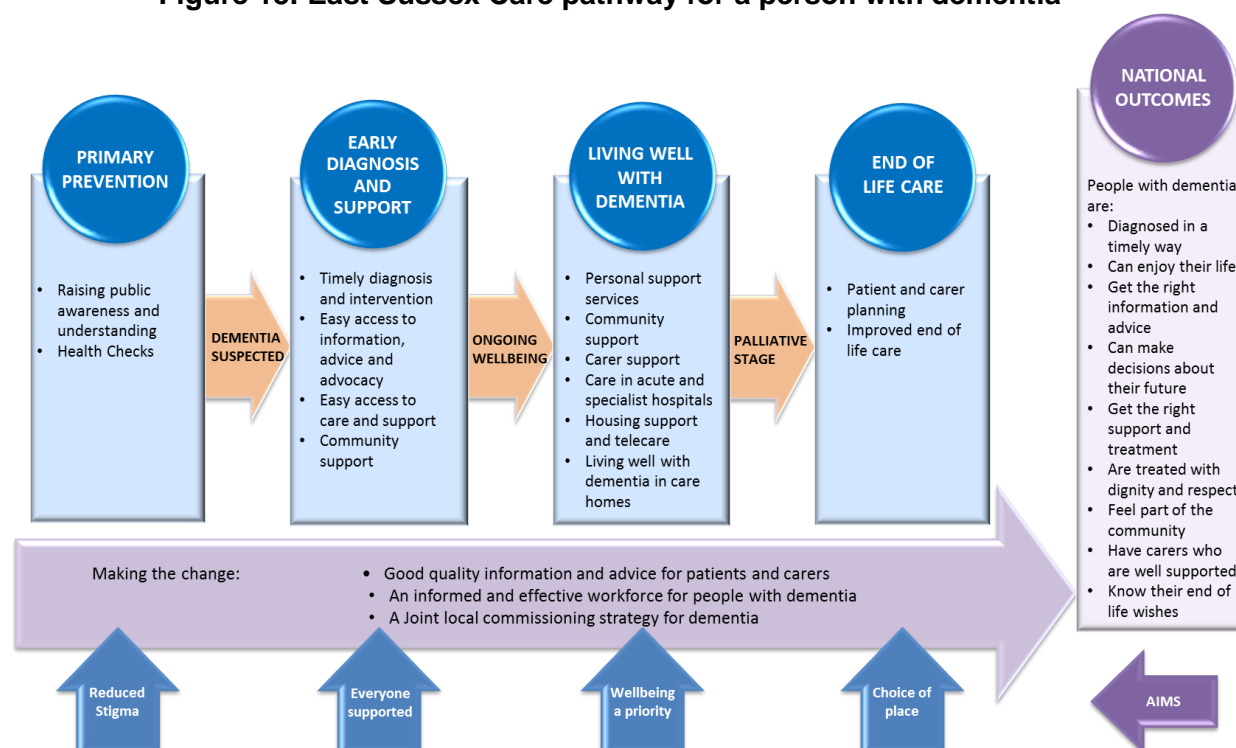
### 3.2.4 Risk prediction algorithms:

Risk prediction algorithms are still being developed to help practices identify patients on their list who are at greater risk of developing dementia. Using routinely collected GP data, UCL have developed a computer algorithm that could help predict the risk of patients developing GP-diagnosed dementia over the next 5 years. The algorithm was found to work well in predicting risk among the 60 to 79 year old age group but not in the 80 to 95 age group. With a low threshold of 1% risk of getting dementia, the risk algorithm had a sensitivity of (78%) and specificity of (73%). With thresholds set at 2% or above the risk algorithm had higher specificity (85%), meaning fewer people were falsely predicted to get dementia, but a lower sensitivity (58%), meaning the algorithm did not pick up so many cases. Some potential risk factors could not be included in the algorithm.<sup>118</sup>

### 3.2.5 What is the care pathway for a person with dementia in East Sussex?

Figure 18 illustrates the East Sussex dementia care pathway from primary prevention through to end of life care. This is summarised in the Sussex End of Life Care and Dementia Care pathway.<sup>119</sup> The four aims of the dementia pathway are reducing stigma, supporting everyone, making wellbeing a priority and dying in the right place. These can be measured by the nine national outcomes.

**Figure 18: East Sussex Care pathway for a person with dementia**



### 3.2.6 How should the pathway work in practice?

A recent publication from London clinical networks describes how the care pathway after diagnosis for a person with dementia should work.<sup>120</sup> This guidance describes who should be involved in the plan, why and when should it occur, what it should contain, how should it be shared, and what resources are available.

### 3.2.7 What do local GPs think of the local care pathways?

A clinical review was undertaken in consultation with GP practices in HWLH CCG which highlighted a number of problems with the care pathway:<sup>121</sup>

- ➔ There are problems with early recognition and diagnosis
- ➔ There are differing perceptions as to the dementia advisor service. Some describe the service as working well and others believe that this type of service does not provide the necessary levels of support required by people with Dementia and their carers.
- ➔ There is a deficit in care co-ordination.
- ➔ More work is required in respect of service integration to avoid patients falling between any gaps in services.
- ➔ People may well be ending up in hospital unnecessarily because of a lack of Advance Care Plans.

Selected comments from the clinical review of practices in HWLH CCG are summarised below:

### Prevention

- When a patient with MCI is referred back to GP, GP's don't know what to do with the patient. As the patient does not fall under any support service/teams, they have no one to contact and don't go anywhere.
- GPs can be reluctant to diagnose more patients as it is time-consuming and an added responsibility. It will add 'x' amount of time for doing: reviews, communication, diagnosis, counselling and after care.
- The system needs to be more pro-active, whereas it is currently re-active. There needs to be services which are able to provide a preventative service.
- When family raises concerns where possible someone from the surgery will call that person in for a health review relevant to known conditions and will conduct a memory assessment at the same time.
- Patients with suspected memory problems can be put into one of two groups: they are either worried, coming in very early and having no memory deficit, or they are in denial and only come after having been referred through anonymous phone calls by concerned friends or relatives.

### Access to clinics

- There is currently the issue that if the GP knows that a person is dementing, but the person scores well on the GP COG or an equivalent test, then MAS will refuse to see the patient (as the patient must reach a certain score). Patients can pass the short tests done by GP's if they are trying hard and concentrating, but it is when they are tired that falls/accidents occur and can lead to crisis.
- There is a difficulty trying to see patients early. However GP's are seeing more patients who want to come in and discuss their memory problems so that they can address it.
- There seem to be two referral routes depending on the patient. There is one route for those patients who are un-cooperative (such as patients who don't want assessment); and another service for those patients who will go for assessment.
- Some patients have to travel long distances to get an assessment which acts as a barrier for assessments.
- For simple cases MAS are fine in regards to getting an early diagnosis and follow ups are going well. However the more complex cases are trickier.
- Having to visit the hospital can be intimidating, being able to have GPs give diagnosis or diagnosis given in home/familiar environment would be less intimidating.
- Dementia should be in primary care, like diabetes, there should be dementia clinics in the practice.

### Post diagnosis management

- After a diagnosis of dementia is given to the patient they are then left in a state of limbo.
- GPs are confused about what teams do what and think the structure is very complicated. There is lack of clarity on who in the community is there to support certain needs.
- Patients are bombarded with information, then support drops off.

## Feedback from practices in H&R and EHS CCGs:

Following the introduction of the new Memory Advisory Service [MAS], a qualitative report was prepared from an on-line questionnaire to GP practices in June 2014.<sup>122</sup> The report does not quote the response rate by practices to the survey, nor comment on sources of bias which could potentially have influenced the findings. Extracts from the executive summary are provided below. In response to the key question:

Question	Response
Would you say that the quality and standards of service achieved over time have improved/deteriorated?	Both the Bexhill Consortia and the [Sussex Partnership Foundation] Trust improved the quality and standards of service they delivered over time. [The report concludes that] these improvements appear considerably greater and more complete in respect of the Bexhill Consortia.

Question	Response
During the period since services were introduced, how well did your MAS provider help improve your knowledge and understanding of the new referral process and care pathway?	The Bexhill Consortia was most successful at improving knowledge and understanding,
How would you rate your knowledge and understanding of the MAS referral pathway and care pathway now?	Results for the Bexhill Consortia are by some way the best with over 40% considering their knowledge and understanding of referral pathways to be now 'excellent'.
Since the MAS Services were introduced, have the number of patients you have referred for routine diagnosis of dementia changed?	The introduction of new MAS has increased the numbers of referrals being made for a dementia diagnosis across East Sussex, although it appears that the extent of this phenomenon is most marked in the CCG area served by the Bexhill Consortia, followed by where the Trust [SPFT] is the provider.
Since the MAS Services were introduced, has the stage at which you have referred patients who may have dementia changed?	Patients do appear to be being referred for dementia diagnosis earlier than before MAS was introduced, in particular in areas served by the Bexhill Consortia and Trust.
Feeding back on referrals made/ information requirement	This appears to have been most successfully achieved by the Bexhill Consortia, with the Trust doing less well but none-the-less doing so better than 'average' in the view of 70% of GP respondents.
Communicating progress with arrangements to see the patient	Communications about arrangements to see patients was most successfully achieved by the Bexhill Consortia, with the Trust communicating reasonably well or at an average level of expectations.
Time taken to see patients	The Bexhill Consortia's timescales were considered 'excellent' by over half of GPs respondents, the Trust scored 'average' with some views that they were above or below this level of expectation.
Sensitivity to patients/ respect for patients dignity	Sensitivity to patients and respect for their dignity appear to be generally better across providers than on many of the other indicators of quality and standards, although the highest performance against this measure appears to be by the Bexhill Consortia, with the Trust also doing well.
Diagnosis and discharge information/ management and treatment plans	The quality of such plans provided by the Bexhill Consortia are above average or excellent in around 85% of instances, with the Trust's GP respondents indicating these were 50/50 'average' or 'above average'.

### **3.2.8 What other anecdotal information is there about how well the local care pathway is working?**

There are anecdotal reports from the primary care pilot service of patients identified as requiring memory assessment not being able to attend their initial screening, or the Memory Assessment Service [MAS], because they live alone and have forgotten to attend. The primary care pilot project in Bexhill is collecting further evidence about this and providing assistance. Unless there is support, patients will forget that they have appointments or have no insight into the need for them. Some people have been sent appointments by the SPFT provided service, and where these have been ignored, the case has been closed.

Advanced Care Planning is the process whereby a number of possible decision options ['what if' scenarios] are discussed with the patient/client. Advanced decisions to refuse treatment (ADRT), lasting power of attorney, and preferred place of care plan can all be

considered part of an advanced care plan. According to Adult Social Care in ESCC the opportunity to make decisions about the future is often missed until it is far too late, when the patient no longer has sufficient mental capacity to make decisions. There are new initiatives to increase awareness of Advanced Care Planning among service providers in East Sussex.

Wherever feasible, people with dementia should be integrated within main stream services and their local community. This is especially important in East Sussex which has many people living in rural areas where access to services is more of a challenge.

Further comments on the care pathway can be found in the stakeholder consultation [5.3.1 Strengths:](#) and [5.3.2 Weaknesses](#)

### **3.2.9 Dementia Service maps:**

The Dementia Roadmap<sup>123</sup> aims to provide high quality information about the dementia journey, alongside local information about services, support groups and care pathways so as to assist primary care staff to support people with dementia and cognitive impairment, their families and carers. The main audience is staff working in primary care, including GPs, nurses and practice managers.

There is also the One Space map for CCGs in East Sussex, although anecdotally this is not regularly used.



## 3.3 Support for people with dementia and their carers

### 3.3.1 Introduction

One of the most important components of the journey for someone with dementia is the support they receive. Support is necessary for both the person with dementia and their carer to help them live well with the condition and to manage the progression of symptoms.

With good support a person with dementia is able to maintain their identity and self-worth. Good support can also help ameliorate the impact on carers' physical and mental health associated with the caring role.

### 3.3.2 What is the impact on carers?

Research on carers has found that those providing care are more likely to be in poor health than those not providing care.<sup>124</sup> Emotional and mental health problems tend to be more often associated with the role of care giving than physical health problems. Nationally, carers providing *substantial* levels of care are twice as likely to have mental health problems as those providing a lower level of care (27% against 13%).

In addition to poorer physical and mental health, carers often suffer from social isolation, with fewer opportunities to get paid employment or education, to have time to themselves or with friends.

### 3.3.3 What is the evidence of the importance of providing carer support?

Dementia carers are a large and growing group. Interventions with multiple components can reduce the burden on the care giver and delay the person being cared for being put in an institution.

Carer education, emotional support and cognitive reframing have been shown to be effective in reducing carers' stress. The START [STrategies for RelaTives] randomised controlled trial has recently shown the cost-effectiveness and benefits of a brief support intervention, in terms of reduced carer anxiety and depression, in both the short and medium term. The support was implemented by psychology graduates under supervision.<sup>125</sup>

A key question is whether carer support requires clinical professional input, or whether support models can be delivered less expensively. The difficulty is balancing diffuse awareness-raising about carers' needs with specific targeted responses to carers' needs. With financial challenges of an ageing population and limited budgets, this is an important challenge.

Having a co-resident carer exerts a 20-fold preventative effect on the likelihood of a person entering a care home. A brief programme of carer support and counselling at diagnosis alone has been demonstrated to reduce care home placement by 28%, with a median delay to placement of 557 days compared with those not receiving the intervention."<sup>9</sup>

A randomised controlled trial in a Dutch programme of respite provision for people with dementia, coupled with carer support and advice, found that the programme achieved significant delays in transfer to residential care.<sup>126</sup>

Support for family carers has been recognised as a crucial element in services for people with dementia in the *National Dementia Strategy*. Carers have a legal right to have their



needs assessed by local authorities and to be given a support plan, setting out how their needs will be met.<sup>127</sup> Carers needs can be very different. For example, younger carers who are of a different generation than those being cared for may not be living locally and may have very different expectations of what care can reasonably be given to an older person. The Dementia Alliance Carers Call to Action,<sup>128</sup> recognises the unique experiences and challenges of people caring for someone with dementia.

### **3.3.4 How many carers are there in East Sussex? What is being done to assist them?**

East Sussex has a total of 59,500 unpaid carers, representing 11% of the total population of East Sussex. [Source 2011 Census.]

Ten percent of all carers in England are estimated to be caring for someone with dementia. The majority of carers in East Sussex are of working age, with 26 per cent aged over 65. Of all carers in East Sussex, 58 per cent are women.

This subject is covered in detail in the following ESCC documents:

- ➔ East Sussex Carer's Strategy Refresh,<sup>129</sup>
- ➔ Comprehensive Needs Assessment for Carers,<sup>130</sup>
- ➔ Carer's Investment Strategic Context,<sup>131</sup>
- ➔ The East Sussex Carer's Breaks Evaluation,<sup>132</sup>

### **3.3.5 What are the objectives of the East Sussex Carers' Strategy?**

The objectives of the East Sussex carers strategy are to provide better prevention and early intervention and access to universal carers' services. These can prevent stress and avoidable injuries. The strategy aims to :

- ➔ Build community resilience through peer support, and a raised awareness of carers;
- ➔ Encourage self management/self care: carers have a vital role as partners in care and in supporting self care for long term conditions;
- ➔ Develop proactive and joined up responses to people that require care and support across traditional organisational and geographical boundaries;
- ➔ Provide a streamlined point of access. This ensures carers can access the right information and services at the right time to avoid crises and sustain their caring role;
- ➔ Develop primary care led urgent care: support to carers to prevent admissions (of both the carer and the cared for);
- ➔ Develop integrated Local Health and Social Care Teams;
- ➔ Encourage carer identification and intervention, with carer recognition as an expert partner in care.

The increasing numbers of carers of all types in East Sussex is summarised in Table 22 taken from the East Sussex Carer's Strategy Refresh, 2013.<sup>129</sup> The number of carers in Wealden District is greater than in the other Districts and Boroughs in East Sussex.

**Table 22 Rising number of carers in East Sussex**

	ENGLAND	SOUTH EAST	East Sussex	Eastbourne	Hastings	Lewes	Rother	Wealden
Total numbers of carers in 2011	5,430,016	847,353	59,409	10,518	9,442	11,501	11,261	16,687
Carers as a % of all East Sussex Carers 2011			11% of total E.S population	18%	16%	19%	19%	28%
Total numbers of carers in 2001	4,877,060	737,751	50,993	8,767	8,635	9,695	9,553	14,343
Rise in number of carers in a decade:	552,956	109,602	8,416	1,751	807	1,806	1,708	2,344
% increase 2001 to 2011	11%	15%	17%	20%	9%	19%	18%	16%
2011 Provides 1 to 19 hours unpaid care a week	3,452,636	577,114	39,537	6,678	5,708	8,000	7,279	11,872
% 1 to 19 hours	64%	68%	67%	63%	60%	70%	65%	71%
2011 Provides 20 to 49 hours unpaid care a week	721,143	96,883	6,745	1,261	1,321	1,197	1,250	1,716
% 20-49 hours	13%	11%	11%	12%	14%	10%	11%	10%
Provides 50 or more hours unpaid care a week	1,256,237	173,356	13,127	2,579	2,413	2,304	2,732	3,099
% 50+ hours	23%	20%	22%	25%	26%	20%	24%	19%

Source: Census, 2011

## 3.4 Dementia Friendly Communities

This section describes what a dementia friendly community is, and how people can be supported to live in the community. The progress that has been made in developing dementia friendly communities in East Sussex and examples of best practice both locally and elsewhere in Europe are described.

### 3.4.1 Why are dementia friendly communities important?

People with dementia may have bad experiences when they are out and about. This can lead to a fear of leaving their home. These experiences can arise because people in the community, shops, businesses and public services misunderstand dementia. This can result in a cycle where people with dementia and their carers find it difficult to feel part of their community and become increasingly isolated. In order to make people with dementia and their carers feel valued and able to participate, communities need to understand, adapt and become dementia friendly.

### 3.4.2 What is a dementia friendly community?

Dementia friendly communities are recognised as important in improving the everyday lives of people with dementia and raising awareness of the condition. The term has become widely used in UK policy and represents an amalgamation of:

- a) evidence regarding environments that facilitate functioning and reduce mental distress in the cognitively impaired.**
- b) enhancing the role of people with dementia within their communities via methods of increasing access to various facilities and reducing stigma in society.**

There is no clear prescription of what a dementia friendly community *should* look like. The Alzheimer's Society has been working with the British Standards Institute in the recognition of dementia friendly communities. <sup>vii</sup> **Current outputs** from this work include:

- ➔ Dementia friendly Financial Services Charter;
- ➔ Dementia friendly Employers' Guide;
- ➔ Dementia friendly Arts Venue Guide;
- ➔ Dementia friendly Technology Charter;
- ➔ Accessing and Sharing Information publication;
- ➔ Maintaining Personal Wellbeing pledge;

**Further work** is planned for:

- ➔ Dementia friendly Retail Guide, Spring 2016;
- ➔ Dementia friendly Transport Pledge, Summer 2016;
- ➔ Housing Charter, Summer 2016;
- ➔ Dementia friendly Faith Guide, Autumn 2016;
- ➔ Air Transport Pledge, Winter 2016;

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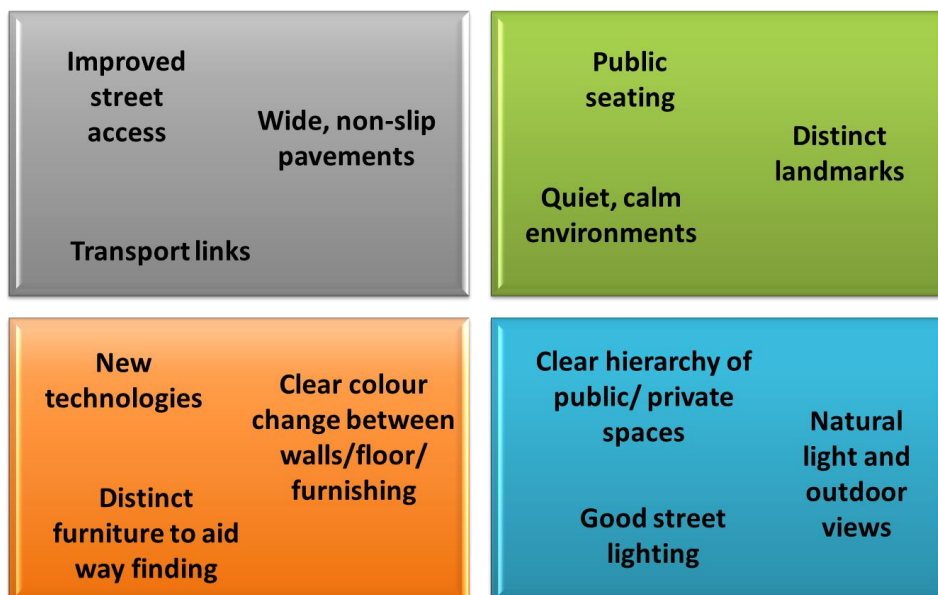
<sup>vii</sup> **BSI PAS1365: A code of practice for dementia-friendly communities**

The PAS1365 document is a code of practice which provides more detailed guidance and structure for communities around what 'dementia-friendly' looks like and what the key areas for action are in working to achieve a dementia-friendly community. The code provides recommendations on:

- Who needs to be involved in setting up a dementia-friendly community
- Aims that should be central to all dementia-friendly communities
- Areas for action to focus on and the processes needed for a dementia-friendly community to operate successfully
- The positive changes for people with dementia that we would expect to see from a dementia-friendly community

To achieve this will require working with the voluntary and community sector and small businesses. There is the opportunity for housing and urban planning departments, as well as design of residential and inpatient units, to incorporate facets of a dementia friendly environment.

For example, designers and planners can give consideration to the following:<sup>133</sup>



As part of the **Enhancing the Healing Environment** [EHE] programme, the King's Fund developed resources and assessment tools for hospitals, care homes, primary care premises and specialist housing providers to become more dementia friendly.<sup>134</sup> The assessment tools are based around five design principles:

1. Meaningful Activity
2. Legibility
3. Familiarity
4. Way finding
5. Orientation

These are known to enable the following outcomes: easing decision-making; reducing agitation and distress; encouraging independence and social interaction; promoting safety; enabling activities of daily living. The specific assessment tools available are:

- ➔ Is your care home dementia friendly? – for use in care homes;
- ➔ Is your health centre dementia friendly? – for use in health centres and GP premises;
- ➔ Is your housing dementia friendly? – for use in any 'housing with care' setting; including extra care housing, retirement communities, sheltered housing and very sheltered housing;
- ➔ Is your ward dementia friendly? Is your hospital dementia friendly? – one tool for use in wards and clinical areas and the other for areas such as Outpatients.

The SE Strategic Clinical Network are working on a framework for dementia friendly GP practices.

### 3.4.3 Peer support and befriending services

Both the goals of living well with dementia and dementia friendly environments/communities can be supported by peer support, befriending and community based activities, largely

provided by the voluntary and community sector. Peer support and befriending services have the added benefit of supporting the caregiver, as well as the person with dementia.

A national evaluation of peer support networks<sup>135</sup> highlighted their ability to enhance community engagement and dementia awareness. People with dementia and their carers spoke about the positive aspects of identifying with other people in a similar position, and the unique quality in peer-to-peer relationships: decreased isolation, increased confidence emerging from discussing struggles and triumphs. Peer support was useful immediately post diagnosis, often filling a needs gap, and the flexibility of support was seen as a strength. Peer support networks worked better when they were supported by a strong infrastructure and worked well in collaboration with other services such as dementia advisors.

Dementia or memory cafés consist of regular forums where people with dementia and carers can get together and share experiences. There is little formal quantitative evaluation<sup>136</sup> but their widespread popularity is an indicator that they are well received and meeting a need.<sup>137,138</sup> Befriending services are also popular. Trained volunteers help people with dementia access activities or help provide respite for carers, and have been shown to increase quality of life.

#### **3.4.4 Cost-effectiveness of befriending services**

A cost-effectiveness analysis has shown that befriending services compare favourably with other health care interventions. They have an incremental cost-effectiveness ratio [ICER] of £2,800 per Quality Adjusted Life Year [QALY], as compared to £13,172 per QALY gained for a person having cataract surgery.<sup>139</sup> There is an *increase* in costs across all sectors (health and social care, voluntary sector, family care costs) however, so this intervention may not be cost-effective to society as a whole.<sup>140</sup> A systematic review of interventions for supporting caregivers concluded that well designed educational interventions or interventions with multiple components were effective at improving caregiver quality of life and preventing depression.<sup>141</sup>

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

The Dementia Friendly Communities programme has primarily focused on *geographical* communities. Other important communities include social networks (e.g. friends and family), support groups (e.g. day services and dementia cafés), community groups or clubs, workplaces and ethnic, cultural or faith communities. Many of these are not confined to a geographical location. For example, a person from Eastern Europe may feel more part of their Eastern European community rather than a specific geographical area. The community of carers is equally important. A diagnosis of dementia can change the communities and social networks that a carer identifies with and, as dementia progresses, the carer's community becomes increasingly important.

#### **3.4.6 What support do people with dementia want from their community?**

- ➔ **Awareness** – Most people with dementia and their carers want members of the community to have a basic understanding of what dementia is and how it affects people.
- ➔ **Support groups** – These are highly valued by people with dementia and their carers.
- ➔ **Clear information** – Navigating services in the community for people with dementia and their carers is challenging. Simple changes such as making

signage dementia friendly and bus timetables easier to read could make a significant difference.

- **Advice** about signage and the physical environment has been suggested by Innovations in Dementia.<sup>142</sup>

### 3.4.7 Meaningful activities

- **Activities need to be pitched at the right level:** People with dementia want to be able to do activities, such as singing or walking in the community. People with mild dementia want to be able to undertake activities with others at a similar stage of the condition and not with people with advanced disease.
- **Improving social interaction, mental stimulation and physical activity** are areas that can be useful for improving quality of life, reducing depression and may also impact upon inappropriate use of anti-psychotic medication.
- There is a view that activities that specifically **appeal to the needs of men** deserve more attention.
- **Dementia friendly sporting** activities are now being actively promoted.
- Sussex Community Trust and the Dementia Research Unit at the Brighton and Sussex Medical School will evaluate the possible benefits of **music therapy**.<sup>143</sup>
- **Activities in care homes:** One study found that people living in care homes with dementia spent less than 12 minutes in every day undertaking constructive activities, other than watching television.<sup>144</sup> Examples of constructive activities include **social stimuli (e.g. real or simulated pets), music or art**.<sup>145</sup>
- Some innovations include '**living room theatre**',<sup>146</sup> and **dance therapy**.<sup>147</sup>
- Transport: Communities need **public transport which is accessible** and supported by helpful staff. The ability to access and use services in a community often depends on good transport links.
- Local facilities: people with dementia and their carers rely more than most on the **availability of local amenities**.

### 3.4.8 What progress has been made in developing dementia friendly communities in East Sussex?

Areas/communities aim to achieve dementia friendly status with the support of local Dementia Action Alliances [DAAs]. There are 7 Local DAAs in East Sussex: Hastings & St Leonard's DAA; Rye & District DAA; Bexhill DAA; Eastbourne DAA; Havens DAA; Lewes and Wealden DAA.

### Hastings & St Leonards DAA

They have run a number of Dementia Friends (awareness) sessions including with Hastings Borough Council staff and councillors. There are plans to run 12 dementia friends sessions in the coming year and to roll out a programme for getting businesses 'buy in' to working towards being dementia friendly. In addition a number of public events will be held to raise public awareness.

### Rye & District DAA

This was launched last year and held an event in September to mark Older People's Day. They too are keen to raise awareness through dementia friends sessions and to work with local businesses to help secure better access for those living with dementia.

### Bexhill DAA

They are running regular dementia friends sessions and hope to work more this year with local businesses. They have combined with the De La Warr to host relaxed screenings – 6 were held in 2015/16 and they are seeking funding to run a further 6 screenings in 2016/17. They also have an allotment where people with dementia and their carers can 'pop in' and spend some time. They have made good links with local businesses, namely Hastings Direct and a local firm of solicitors.

They have provided small amounts of money to purchase garden tools and a bench for the allotment. They run a regular fortnightly singing group which has proved very popular and self-sustaining. This is run through volunteers and is highly valued by those living with dementia and their carers, as witnessed from the very positive feedback.

The Bexhill Museum project is a good example of creative working with the local community. The Museum is hosting an exhibition on Stuff and Objects, which looks at the impact objects have on our wellbeing. Part of the project involves groups of people with dementia and their carers, and outreach work to museum staff and Bexhill college students. The museum also holds a number of reminiscence boxes for loan, and offers an outreach service to care homes.

### Eastbourne DAA

This brought together 74 interested parties who discussed issues affecting people with dementia. There was an activities group, a dementia friendly communications group and one working on helping people who get lost/wander. These groups will continue to plan activities, provide information, and improve things for people with dementia in Eastbourne.

The DAA is also enabling dementia friends sessions in April 2016, with help from Asda, for shops and businesses around the Sovereign Harbour area to become dementia friendly. Eastbourne Borough Council funded the EDAA until March 31, 2016.

**3VA** is a Council for Voluntary Service, providing support for voluntary and community organisations across the Eastbourne, Lewes District and Wealden areas of East Sussex. It is currently starting area forums and hoping that the Eastbourne one will incorporate dementia as an area that needs to be supported.

The Towner Art Gallery Eastbourne has a monthly session for people with dementia and their carers. Inspired by a project in New York, Open Ended offers sessions for people with memory loss problems and their carers.



### Wealden DAA

Wealden Strategic Partnership has provided funding for the Wealden Alliance which held a launch event in May 2016 at Hailsham Civic Community Hall.

The Wealden DAA will work to take practical actions to improve the lives of people with dementia, and their families, by running dementia awareness workshops across Wealden. The Wealden DAA will support action plans established for specific towns and villages. Local forums will be set up around the district including Hailsham, Uckfield, Crowborough & Hurstmonceux.

The DAA has been working with Dementia Friends champions to raise awareness of dementia in the various businesses and voluntary sector organisations within the area, including Freedom Leisure facilities. Freedom Leisure have been working on setting up dementia friendly courses/activities.

Dementia friendly film screenings: The Wealden DAA have been successful in partnership with Hailsham Pavilion, in obtaining funding from South East Films Hub and the British Film Institute Film Audience Network to be able to put on 12 Dementia Friendly Screenings at the local cinema. The screenings will run once a month, on a Friday, for a year.

### Lewes DAA

Lewes is in the early stages of setting up a local Dementia Alliance. In September 2016, Lewes invited local people, businesses and stakeholders who were interested in supporting and being involved in making Lewes a dementia friendly community to sign up to Lewes DAA/steering group. The steering group have begun shaping the aims of Lewes DAA and members have agreed to regular future meetings to show they are committed to making Lewes Dementia Friendly.

### Havens DAA

A public meeting was held in April 2015 leading to the formation of a steering committee meeting monthly. Havens DAA is working towards creating a Dementia Friendly Community along the coastal strip – Newhaven to East Saltdean. Havens DAA have been working with HWLH CCG/ESCC to create more LDAA's across the county and providing free Dementia Friends Awareness sessions to local – councils, offices, shops, community groups, banks, solicitors etc.

## 3.4.9 Dementia friendly schools/generation in East Sussex

The concept of a dementia friendly generation is being actively promoted by the Alzheimer society. In neighbouring West Sussex, schools are currently involved in a dementia friendly schools initiative, as well as 950 children through the Junior Citizen programme. In East Sussex, Rotherfield Primary School intends to start some sessions from next school year. The Scout Group have started training the scouts. Rotherfield St.Martin will also be contacting the local Community College to run some sessions next year.

## 3.4.10 Prevention of financial abuse in the community

People with dementia are at higher risk of financial abuse because it affects the ability to make decisions and judge risk. People with impaired cognition may also find it difficult to understand new methods of financial transactions for example online banking, telephone banking and cash machines. Financial abuse is a growing problem.<sup>148</sup> Scams can be a major factor in the decline of health in older people. The Care Act recognises the significant threat that financial abuse poses to adult health and wellbeing and places a responsibility for protection on Local Authorities. Loss of assets and finances may result in individuals being unable to contribute to their health and social care costs in old age, increasing the financial burden on society for future care provision. East Sussex Safer Community Partnerships action plan includes helping to protect the vulnerable elderly from serious organised crime and fraud.

### 3.4.11 Living well with dementia

Underpinning the idea of person-centred care is the idea of supporting people to accept their diagnosis, cope with the inevitable strains and maintain as good a quality of life as possible. Red and Yellow Care and the Alzheimer's Society have jointly published a document that outlines 6 facets of 'a good life with dementia'<sup>149</sup> and addresses some of the factors that affect quality of life. These are:

- respecting identity;
- embracing the now;
- sustaining relationships;
- valuing contrast (between good days and bad days);
- supporting agency (risk versus restriction) ;
- maintaining health.

These are described more fully in: Appendix 1: 'Six Paths to a Good Life with Dementia'  
[Appendices](#)

### 3.4.12 What good examples do we have from other areas?

The Joseph Rowntree Foundation gives examples of grassroots dementia friendly work from communities across Yorkshire.<sup>150</sup> Case studies include making York Railway Station and Airedale General Hospital dementia friendly; working with Trading Standards to prevent doorstep crime by providing befriending services, arranging family reconciliations, helping change locks and undertake home safety-checks. Other initiatives include working with supermarkets and department stores to ensure signage is clear and staff understand dementia; as well as teaching children in schools about dementia.

Bruges in Belgium is a leading example of a dementia friendly city.<sup>151</sup> This includes local dementia choirs, dementia friendly "safe havens" (shops and businesses where people with dementia and carers can stay if in distress), specialist dementia counsellors and a database for police to track vulnerable dementia sufferers.

Hampshire has promoted the use of a help card scheme.<sup>152</sup> This allows people with dementia to give a card to anyone they come into contact with which explains their conditions and any specific individual needs. It is part of a wider scheme called Communication Awareness Care.

The Alzheimer's Society has published guidance for the financial sector about how to become dementia friendly.<sup>153</sup> The document calls for financial services to sign up to the dementia friendly financial services charter and meet a number of stated commitments. The Health and Social Care Partnership has developed a Dementia Resource Suite for Schools.<sup>154</sup> The document is intended for head teachers and subject leads to use in order to create a dementia friendly generation. The resource suite provides information for schools about how to communicate the key messages about dementia education in schools. Liverpool Museums House of Memories Project is a highly successful dementia awareness project, run in collaboration with the health and social care sector. The project includes training, inclusive activity days, digital apps, and Buddy Schemes.

The Dulwich Picture Gallery Visual to Vocal – is an ongoing inter-generational project involving people with dementia and their carers to bring painting to life through song. Atmag.org, a website for **art therapy in museums and galleries**, has many case studies of successful projects involving people with dementia and museums and galleries in order to enhance wellbeing.

Equal Arts Project Gateshead, had the aim of engaging people with dementia and their carers in local arts/cultural venues. An independent evaluation by Northumbria University demonstrated that participants showed an increased sense of wellbeing after the project. The positive impact arts and culture can have on older people is supported by recent research, by ComRes. This shows the different ways older people (aged 65+) value arts and culture:

- **76%** said it is **important in making them feel happy**
- **57%** said it is important in **helping them meet other people**
- **60%** said it is important in **encouraging them to get out and about**

Arts and cultural activities could potentially help to tackle key social issues such as loneliness and isolation, which can increase during the winter months, with longer nights and colder weather making it harder for older people to get out and about. The Alzheimer's Society has produced a brochure *Becoming a Dementia Friendly Arts Venue: A Practical Guide*.<sup>155</sup>

## 3.5 Using Assistive Technology (AT)

### 3.5.1 Potential uses of assistive technology

The term assistive technology (AT) covers a range of technological devices and solutions designed to support people to live independently in their home, in safety, and with dignity.<sup>156</sup>

**AT can be used to support independent living by:**

- ➔ Reducing hospital stays by enabling earlier discharge;
- ➔ Monitoring the safety of persons with dementia who live alone;
- ➔ Using reminder systems e.g. medication;
- ➔ Using home security and social alarm systems.

As well as promoting independence and autonomy, AT can enable people to manage potential risks around the home, reduce the need for early entry into care homes and hospital, facilitate memory and recall, and reduce stress on carers. It covers a range of electronic devices to support people with dementia.<sup>157</sup> One form of AT is alarm systems usually activated by a neck or wrist-worn pendant. Any alerts are usually monitored by a call centre who will then contact the resident, their family, carer or emergency service, depending on the seriousness of the situation.

**Examples of telecare include:**

- ➔ Flood sensors – These can be fitted on skirting boards or floors. The system can shut off the water and raise the alarm.
- ➔ Gas sensors – These can detect if the gas is left on, shuts off the gas, and raises the alarm.
- ➔ Bed or chair sensors – These can detect if a person doesn't get up in the morning or stands up and doesn't return in a set time. Sensors in or around the bed activate when someone gets up in the night and call assistance.
- ➔ Falls – These sensors worn on the hip can detect the impact of a person falling.
- ➔ Door sensors-These can be set up to trigger an alarm if the front door is opened, e.g. during specified times such as night time.

### 3.5.2 Concerns about the application of Assistive Technology [AT]

Some concerns have been raised about the application of AT. The Alzheimer's Society identified the following potential issues:<sup>158</sup> risk of social exclusion as AT may replace human contact; potential threat to independence; people's lives or living environments may become more complicated; focus on a person's problems and not promoting their strengths. AT may be employed without the full consent of the person with dementia; data protection issues; people may feel stigmatised by AT.

The evidence base on the efficacy of AT is still limited and mixed, with relatively few robust studies published.<sup>159 160</sup> Fleming and Sum highlight a number of issues about the studies conducted: small samples, high drop-out rates, very basic statistical analyses, lack of adjustment for multiple comparisons, and poor performance of the technology. More specifically:

Independence, prompts and reminders: once the evaluation moved from the laboratory, significant practical and methodological problems emerged. Generally, the reported use of the technology made little difference to practical outcomes.

Safety and security: The very weak evidence showed that common problems were associated with lack of acceptance by the user, difficulties with use, and technical reliability. Careful assessment was required to discover the likely benefit of the technology to an

individual; there was a strong suggestion that the window of opportunity was quite small for the successful application of technology.

Telecare and telehealth: Although the literature did not seem to support the use of technology (in the form available) to enhance communication *initiated by the person with dementia*, it provided some promise that *remote, carer- initiated communication* could be used for assessment and simple therapeutic interventions.

Therapeutic interventions: There was little convincing evidence to support the use of Snoezelen technology (multi-sensory stimulation exposure) over other activities to improve the wellbeing of people with dementia. The effects of simulated presence therapy appeared modest and short lived.

Another review reports a lack of scientific evidence either for, or against, the use of Skype for clinical tele health.<sup>161</sup>

Examples of best practice from across the UK and international settings demonstrate the potential impact of AT to enable people with dementia to maintain their abilities for longer, support activities of daily living, improve their quality of life, and provide support for carers.<sup>162 163 164</sup> How well, and how efficiently these various alarm systems are responded to when they are activated will greatly influence how cost-effective the assistive technology is in the local context. An evaluation of an AT pilot programme in Finland<sup>165</sup> found that the technology increased the amount of time elderly people spent in their home by an average of eight months, demonstrating the potential to postpone the need for institutional care.

### 3.5.3 Missing Persons

In the whole of Sussex, during the period 2015/16, there were 87 people aged over 65 who were reported missing to Sussex Police. The majority went missing from their own home or neighbourhood. Of these, 24 were recorded as having dementia, and four of these were East Sussex residents with dementia.<sup>166</sup> Tracking devices using satellite technology, Global Positioning Systems (GPS) can be used to locate people who have gone missing. Sussex Police Missing Persons Unit report that they have made 27 referrals for consideration of a GPS device, since the scheme began. About half have been allocated a GPS system. Some people have refused to have a GPS, whilst other families have preferred to review their overall care arrangements instead. Routine data are not collected about how often these GPS systems are used in practice. The case history on P.97 illustrates that AT can improve the quality of life of the patient and carer and delay the need for residential care.

### 3.5.4 In conclusion:

A person-centred approach is required to employing assistive technology, with solutions tailored to the individual and in consultation with the end-user, their family and/or carers. Telecare should be introduced in the early stages of dementia so that the patient is able to understand how the equipment works and becomes familiar with it, before their dementia progresses.<sup>167</sup>

### Case history use of a GPS system in an active person with dementia

Mr x was born and raised in the old town of Hastings and the surrounding area. He spent much of his youth exploring the hills and countryside. He enjoyed walking and cycling for most of his life. He married and had two children. His wife and children also enjoyed and shared his love of walking and cycling. When he retired he and his wife would go out most days either on their bikes or walking.

When Mr x was diagnosed with Alzheimer's disease, his wife, daughter and son in law decided to sell their homes and buy a house with an annexe. This they thought would give Mr x time to get used to a new environment and give his wife maximum support with caring for Mr x. The families moved in the autumn and all went well. Unfortunately his wife died suddenly just before Christmas.

Mr x barely seemed to notice that his wife was not around anymore. He wanted to spend all day out walking or cycling. He started to say that he was having trouble getting home sometimes. On occasions he was turning up at his old address. This was causing his family some concerns as once or twice they had to report him as missing to the Police. This made Mr x angry (he had no insight at all into his memory problems). Mr x had started to visit the house where he grew up in. He would walk in (as if he still lived there) and sit down with the family. The Police became involved and fortunately his daughter knew the family who were most understanding. They would call Mr x's daughter when he turned up and she would go and pick him up.

Mr x's daughter and son in law decided to purchase a GPS system. It looked just like a watch and Mr x was more than happy to wear it. They chose not to explain that it was a GPS system. It was linked to their computer at home. They would just switch on their computer and could see exactly where Mr x was which gave them peace of mind. Mr x was happy as he was still able to go for his walks and a lot of tension was relieved at home. Mr x used this system for about eighteen months with success. One day while his daughter was monitoring him he disappeared off the screen. He walked through a railway tunnel and was picked up by the Railway Police. He was then introduced to residential care for his own safety. He is now settled in a home in Hastings old town.

**His daughter said without a doubt he would have had to go in to residential care much earlier for his safety if it had not been for the GPS system.**

### 3.5.5 Local Telecare project in East Sussex<sup>168</sup>

The pilot telecare project in East Sussex was conducted over a six month period from September 2014 to Spring 2015, involving 18 Clients and 17 Carers. The study included a range of ASC clients. Some were eligible for social care funding, others were self-funding individuals. People were living in a variety of different situations with family carers, or living alone, with or without formal Home Care, or in residential accommodation. Although the participant numbers were relatively small, and the pilot project was time limited, the project demonstrated the potential for comprehensive Telecare solutions to offer significant benefits in three key areas:

- ➔ Reduction in Carer stress and perceived ability to cope better with a caring role;
- ➔ Continued independence of client continuing to remain independently in their own home for as long as possible;
- ➔ Delay in movement to higher cost levels of care. Three cases demonstrated the potential for significant savings to be accrued over time as a result of delaying transfers to higher levels of care.

The following recommendations reflect the findings of the pilot project:

1. Assistive Technology assessment and intervention should form part of **all** assessments for clients and carers
2. The ASC directorate in ESCC should promote Telecare solutions to self-funders and carers, and specifically target teams working with clients with Dementia
3. ASC should work with local voluntary groups to promote Telecare solutions to residents who may come into contact with funded services
4. ASC should work with NHS colleagues in establishing a single point of access to Telecare services, which would increase the prescribing base and provide preventative support earlier on in the patient journey
5. Dementia awareness training should be required for assistive technology providers, in particular focussing on communication skills for customer facing staff
6. Telecare and Assistive Technology training should continue for appropriate ASC front facing staff
7. Where possible, installations and maintenance call outs to a client with dementia should be undertaken jointly with an ASC worker



## 3.6 Evidence Based Models of Care

### 3.6.1 Introduction

This section describes models of best practice for the community care of people with dementia. There are opportunities to consider new integrated models for dementia care where there are complex care pathways.

### 3.6.2 Integrated Care Models

The NHS 5 year strategy aims to enhance Out Of Hospital Care and Primary and Acute Care Systems. Integrated care seeks to focus the different services around the individual for more integrated and effective treatment. Recent examples of best practice in commissioning for dementia management have been reviewed in: Models of Dementia Assessment and Diagnosis Indicative Cost Review and are considered below.<sup>7</sup>

### 3.6.3 The Gnosall primary-care based memory clinic

This is a primary care-based service with specialist secondary care input to the GP practice. A primary care based 'elder care facilitator' (ECF), typically a health visitor, collates relevant information, supported by the practice manager, through contact with the patient, clinical notes and test results. These are presented to the assessing clinician at the assessment appointment.<sup>169</sup> A diagnosis is obtained on the day when possible. The patient retains their own care plan on a data stick. The service includes input from a psychiatrist with a special interest in the elderly. A clinic is provided at the practice one half day a month, with ongoing support and telephone advice in between. The service has been positively evaluated and has reported increases in its diagnostic rates to circa 100% of the estimated prevalence of dementia. It is planned that there will be a 24 hour decision making helpline for carers and an urgent care call out service until 10 p.m. in future. The cost of this pathway is currently estimated at £396 per patient.

### 3.6.4 The Bristol CCG dementia diagnosis and care in primary care model

In Bristol diagnosis rates for dementia were low, there were bottle necks at the memory clinic with insufficient filtering of referrals and long waiting times for the memory clinic. People were being delayed in getting the right advice and treatment. As a consequence GPs had become deskkilled at managing and supporting people with dementia. A pilot scheme assessed whether GPs could be supported to diagnose straightforward dementia cases. Following a positive evaluation, the service is now being rolled out to GPs in the whole of Bristol. This is supported by an enhanced service. Practices are being paid for the clinical time to do the additional work previously undertaken in secondary care.

The service is now commissioned as the Dementia Wellbeing Service. It aims to shift dementia from predominantly secondary care to primary care. There is a focus on prevention and care planning. There is extra capacity in the services which provides ongoing support to patients with dementia navigators. The service still has a one stop memory clinic for complex cases of dementia. Results to date show that 80% of cases are now diagnosed in Primary Care. There are no delays for the memory clinic due to capacity issues.

### 3.6.5 Northumberland, Tyne and Wear

In this service model, secondary care contracts with GPs with a Special Interest [GPwSI] for diagnostic assessments and reviews. Initial referrals to the memory protection service are

screened by a nurse practitioner who triages the referrals. Once all results and assessments are complete a diagnostic appointment is offered either with a consultant or the GPwSI. All patients receive a CT scan as a minimum, in accordance with NICE guidelines. The cost of this pathway is estimated at £877 per patient.

### **3.6.6 Rotherham, Doncaster and South Humber**

This is a self-contained, specialist-led assessment, diagnosis, and follow-up service. The cost of this pathway is estimated at £491 per patient.

## 3.7 Memory Assessment Services in East Sussex

### Introduction

In East Sussex, almost every person who has a formal diagnosis of dementia will have been through a memory assessment service. General practitioners normally make the initial referral. The memory assessment service is an outpatient service where the person with suspected dementia and their carer have first contact with specialists to discuss the diagnosis, treatments, services available and their possible future needs.

### 3.7.1 Memory Assessment Service providers [MAS] in East Sussex

There are two different memory assessment services commissioned and provided in East Sussex.

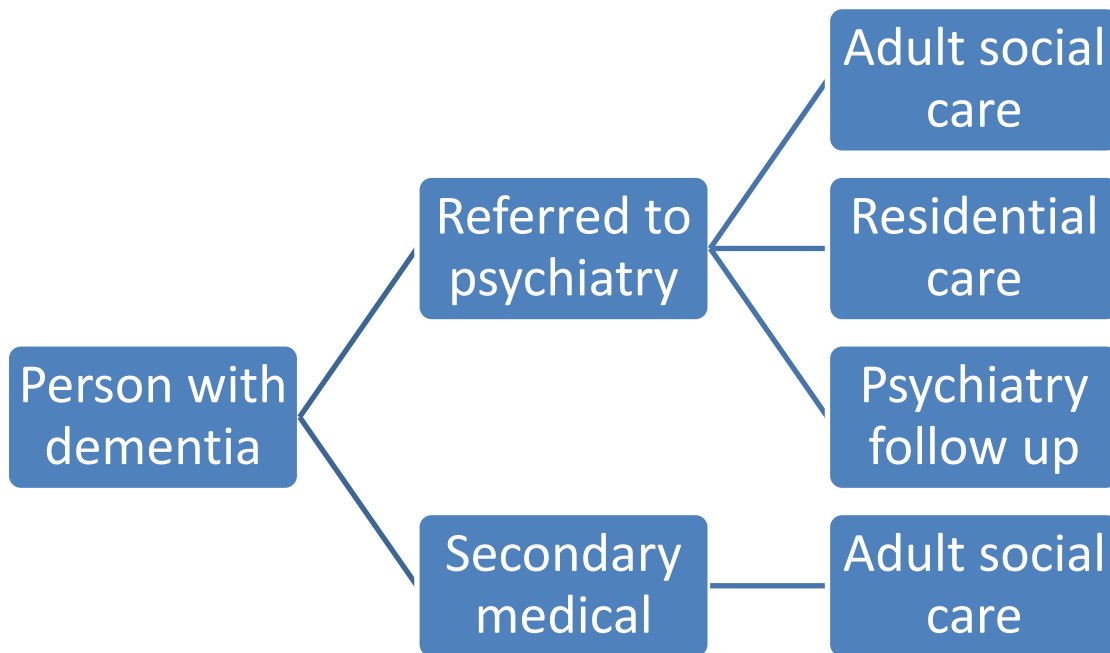
- ➔ The service in the East of East Sussex is an independent, GP social enterprise company-led service (ICC Memory Assessment Service [ICC MAS]), covering Hastings and Rother CCG and Eastbourne, Hailsham and Seaford CCG.
- ➔ In the West of the county, the memory assessment service is provided by Sussex Partnership Foundation Trust, SPFT, for High Weald Lewes and Havens CCG.

More complex, management of people with the behavioural and psychiatric symptoms of dementia is provided by Sussex Partnership Foundation Trust to complement the above two MAS services in the East and West of the county.

### 3.7.2 Primary Care led [MAS] Service East Sussex

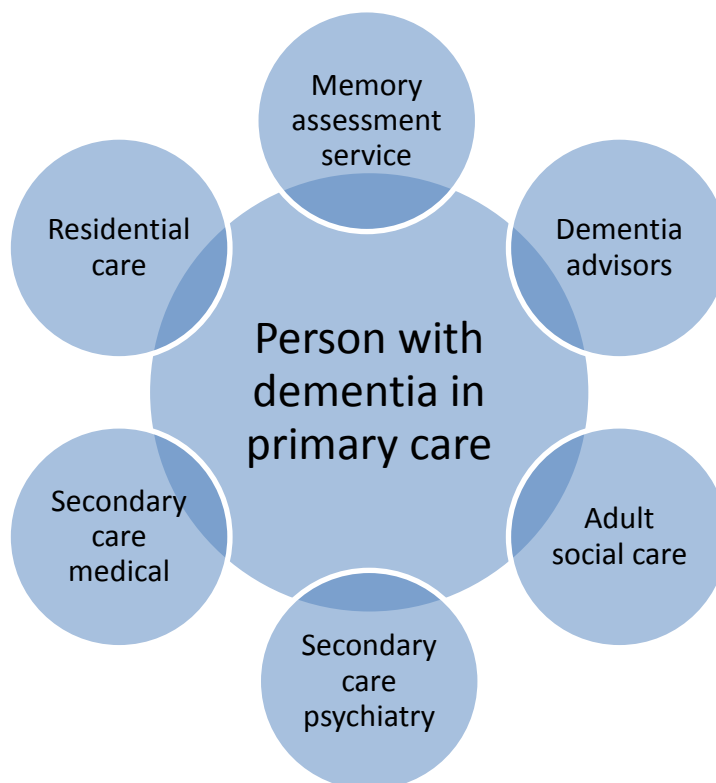
The ICC-MAS memory assessment service, is delivered at GP practice level. Its main aims are to deliver an accessible, flexible and responsive service for patients whilst providing an ongoing educational resource for GPs and practice nurses in the process. The service is enabling a shift of resources from secondary to primary care. Once the patient has been seen by the MAS GPs and practice nurses are key in co-ordinating and planning the patient's ongoing care. The scheme has diagnosed over 2 000 patients to date since its inception in 2012. The service has been formally evaluated by Bradford University and the evaluation is ongoing. The memory assessment service *before* the implementation of the MAS is shown in Figures 19, and *after* in Figure 20.

**Figure 19 What happened prior to the primary care MAS service?**



Prior to the introduction of the MAS, a person with suspected dementia would be referred to the specialist psychiatric service in secondary care by their GP. Alternatively they would present initially as an acute admission to secondary care (old age medicine service in the acute hospital) and then be referred on.

**Figure 20 Integration with a primary care based service**



In the new service the initial assessment service is based in the patient's own GP practice. Onward referral to secondary care can be made as appropriate.

### 3.7.3 Performance of the MAS services

The number of referrals in to the MAS from GPs in EHS CCG [651] and H&R CCG [530] were approximately equal to the number of commissioned appointments [632] and [588] in the year 2015/16. The number of referrals from GPs [536] in HWLH CCG was approximately equal to the number of commissioned appointments [504].

Commissioners have assumed in the past that all referrals to the memory assessment service would convert to a confirmed dementia diagnosis. It is now clear that this is not the case. The proportions of the referrals to the MAS *not resulting in a confirmed dementia diagnosis* were: EHS = 23%; H&R = 20%; and 39% in HWLH CCG in 2015/16.

There is variation between practices both in their utilisation of the MAS service and in the 'conversion' rates. This may reflect different referral thresholds and diagnostic practices. Detailed evaluation of the pilot phase of MAS in East Sussex indicates that the diagnosis of dementia has been taking place earlier, as is evidenced by increasing numbers who are in the mild to moderate stages of disease severity.

By 2020 there is an expectation that the average waiting time for an initial assessment from an appropriate GP referral will be six weeks. Having attended the MAS, 90% of eligible patients are being referred onward to the Dementia Advisor Service. This is a formal written referral. The Dementia Advisor Service provided by the Alzheimer's Society is a key part of post diagnostic support provision in East Sussex. Not all recommendations by the MAS to attend the Dementia Advisor service are taken up at the outset by patients and carers for personal reasons, though the number taking up this offer increases with time. Two external issues impact on the effectiveness of memory assessment services' performance.

#### Incomplete referral information

In 2015/16, 51% of referrals in EHS and H&R CCGs were submitted with incomplete information. Significant administrative time is required to source the necessary patient information to enable the diagnostic process to start, with associated delays for patients being offered appointments.

#### Referrals that are not dementia diagnosis

A national estimate of the number of referrals not resulting in a dementia diagnosis is of the order of 40%. [Source: Freedom of Information request to 11 mental health trusts in England between Nov 2015 and Feb 2016].

Tables 23 and 24 show the number of completed diagnostic episodes and number diagnosed with dementia in the Memory Assessment Services since their inception and in the financial year 2015/16.

**Table 23 MAS Diagnostic Episodes & Dementia Diagnoses Oct 12–Mar 16:**

CCG	Oct 12-Mar 16 Completed Diagnostic Episodes	Oct 12-Mar 16 Diagnosed with Dementia
Hastings & Rother CCG	1,289	910
Eastbourne Hailsham & Seaford CCG	1,225	801
High Weald Lewes & Havens CCG	1,206	765
<b>Total</b>	<b>3,720</b>	<b>2,476</b>

Source: ASC ESCC

**Table 24: MAS Episodes and Diagnostic Activity 2015-16**

CCG	15/16 Completed Diagnostic Episodes	15/16 Diagnosed with Dementia	% Conversion
Hastings & Rother CCG	497	336	68
Eastbourne Hailsham & Seaford CCG	551	383	70
High Weald Lewes & Havens CCG	426	258	61
<b>Total</b>	<b>1,474</b>	<b>977</b>	<b>66</b>

Source: ASC ESCC

This shows that the proportion of referrals **not** diagnosed with dementia after referral to a memory assessment clinic in East Sussex during 2015/16 was 34% which compares very favourably with the national benchmark of approximately 40%.

### **3.7.4 Memory Assessment Services (MAS) Waiting times by CCG**

The performance of the memory assessment services for the year 2015/16 is shown in Tables 25 and 26. The contract specifies that patients should be seen *within 5 days* of a completed referral. There are difficulties offering some patients an appointment and some patients did not attend [DNA].

**Table 25: Time between completed referral received and first offered appointment date 2015/16**

	HWLH CCG	EHS CCG	H&R CCG	Total
Within 5 days	260	340	282	882
Not within 5 days	89	140	27	256

Source: ASC ESCC

**Table 26: Time between first appointment and clinic discharge date 2015/16**

	HWLH	EHS	H&R	Total
Within 12 weeks	332	390	340	1062
Not within 12 weeks	101	161	156	418

Source: ASC ESCC

The waiting time to be discharged from the clinic may be increased by the time taken to adjust the dose of medication, whilst some patients may have a further secondary care referral (on account of a more complex presentation).

The proportion of referred patients who did not attend clinics [DNA proportions] was 4% in EHS, 6% in H&R, and 2% in HWLH CCGs in 2015/16.

### **3.7.5 Evaluation of Memory Assessment Services:**

Prior to the commissioning the GP provider-led MAS provided service in H&R and EHS CCGs, all the existing provider services were formally compared. The evaluation specifically looked at the following criteria: earlier diagnosis, better recognition of dementia, reliability of diagnosis, prescribing, onward referral, waiting times, numbers of attendances, location of attendances, deployment of professional staff, and cost per episode. The evaluation showed that the GP-led memory assessment service performed very well. A summary report is available.<sup>122</sup>

### 3.7.6 Future development in East Sussex

While the best practice examples in Section [3.7 Evidence Based Models of Care](#) are helpful they do not give sufficient definitive information as to what would be most cost effective in the local context. Continued implementation of the GP-led approach to diagnosis from the primary care-led MAS and Bexhill pilot projects, as well as formal evaluation of the Buxted Golden Ticket project, will help inform local decision making. Please see: [Improving dementia management in Primary Care](#). The advantages and disadvantages of a primary care-led dementia service are summarized in Table 27.

**Table 27: Pros and cons of an E. Sussex primary care-led dementia service**

What are the pros of a primary care provided service?	What are the cons of a primary care provided service?
Avoids need for an initial referral to specialist services GPs are generalists and have a holistic approach to management	GPs are generalists not specialists Need to see enough patients to develop / maintain skills, consistency, reliability Requires specific training: GPwSI; MSc course or diploma
Convenient for patients and carers Geographically local and accessible	
Potential to be cheaper	Requires access to brain imaging by GPs
Patients know the primary care team Access to existing patient information; easier to code and include on practice registers	
Compatible with generic primary care model of management of long term conditions	
Specialist services reserved for atypical/complex and crisis cases	May result in referral of the same case at a later date to secondary care so reducing any net saving

The advantages and disadvantages of a secondary care led dementia service are summarized in Table 28:

**Table 28: Advantages and disadvantages of a secondary care led dementia service**

What are the pros of a specialist secondary care provided service?	What are the cons of a specialist secondary care provided service?
More suitable for quality control via Memory Service National Accreditation Programme	Stigma of referral to Mental Health Services
Quality can be assured and delivered consistently	Perpetuates the view that management of dementia is a specialist condition
	Longer time from referral to diagnosis
Includes assessment of atypical / complex /early onset presentations	More expensive
	Too standardised to save on costs
Well established in many areas	Not individualised
	Not necessary for more advanced



	presentations of dementia
	Patients presenting with non-dementia problems eg with physical illness, depression, Mild Cognitive Impairment potentially divert resources away from those with dementia

### Summary: Carers Section

A person with dementia and their carer need to understand the condition and manage the progression of symptoms.

Dementia can have a devastating effect on family relationships. The psychological stress and physical strain experienced by carers increases as the dementia progresses.

East Sussex has a total of 59,500 unpaid carers, representing 11% of the total population of East Sussex. Ten percent of all carers in England are estimated to be caring for someone with dementia.

The number of carers in East Sussex has been increasing and will be expected to increase substantially in future.

### Summary: Dementia Friendly Communities

- Dementia friendly communities are recognised as important in improving the everyday lives of people with dementia and raising awareness of the condition. Apart from geographical communities, communities also include support groups [day care, dementia cafes], community groups, ethnic, cultural and faith communities.
- Dementia friendly communities can now choose to work towards and be recognised by the BSI specification. There are examples of best practice in England and Europe which are being implemented locally
- One of the first dementia friendly communities in East Sussex was Bexhill-on-Sea; another is Rotherfield. Dementia Action Alliances are developing dementia friendly communities in East Sussex.
- Innovative programmes with local museums and arts based therapies have been

### Summary: Assistive Technology

- The published evidence about the use of telecare is equivocal.
- Information from Sussex Police identifies the scale of the problem of missing persons aged over 65, some of whom have dementia.
- A case history of the local use of a GPS system shows how the appropriate use of assistive technology can enable a person with dementia and their family to maintain their quality of life and delay their transfer to a care home.
- A small successful local pilot study of the use of assistive technology suggests its use is likely to increase. It showed a reduction in carer stress, while three cases demonstrated the potential for significant savings to be accrued over time as a result of delaying transfers to higher levels of care.
- Technical solutions need to be tailored to the individual and to their carers.

## Summary: Memory Assessment Services

- Recently published examples of the different service models of best practice nationally have been put forward for local consideration. Models of dementia care best practice differ in their estimated cost per case, ranging from £396 to £877 per case.
- It is unclear which service model would offer best value for money in the long run, locally.
- Some care pathway models require additional commitments to resourcing including staffing, diagnostic imaging and ongoing clinician training.
- There is a primary care-led memory assessment service in the Hastings and Rother and Eastbourne, Hailsham and Seaford CCGs, which is well-established. A different service model is being piloted on a small scale in Buxted, part of HWLH CCG.
- There are pros and cons for either adopting a primary care led or a secondary care led model of dementia care.
- The majority of the management of dementia can take place in primary care.
- Studies have shown that people want to know their diagnosis. A diagnosis of dementia is a gateway to allow people with dementia and their carers to make informed decisions about the future.
- Barriers to early diagnosis are found among health care professionals as well as factors within the patient and their families.
- The local health and care community in East Sussex has a coherent plan of work to improve dementia care and to improve early diagnosis.
- There is variation in the proportion of expected cases of dementia diagnosed between CCGs in East Sussex from **61.8% in Eastbourne, Hailsham and Seaford CCG to 55.1% in High Weald, Lewes and Havens CCG**. This variation is also reflected at individual practice level within CCGs.
- All three CCGs in East Sussex (High Weald Lewes and Havens, Eastbourne Hailsham and Seaford, Hastings & Rother) have shown an increase in the numbers of dementia cases on GP practice QoF registers.
- There is variation between GP practices in the number of referrals to the memory assessment service [MAS]. There is variation in the 'conversion' rates: the number of diagnosed cases of dementia resulting from the referrals varies between CCGs and between practices within CCGs.
- Working relationships are positive, and it appears that values and ambitions are shared.
- Exercises to improve the quality of coding of clinical records in the majority of GP practices have been undertaken and achieved increases in the diagnosed prevalence rates.
- The rate at which people who have been diagnosed with dementia die and how this affects achieving the NHS targets [for diagnosing 2/3 of the expected number of cases in the population at any given time] is not yet clearly understood locally

## Section 4. Services provided for people with dementia

The hierarchy of care needs of people with differing degrees of severity of dementia is presented as a pyramid from self-care to the most complex needs. How these needs are met by health and social care service provision forms the main focus for this section. Routine primary care for managing dementia is described, together with an overview of two primary care pilot projects.

The challenges for the SEC ambulance service [SECAMB] at the interface between primary and secondary care are covered. This is followed by a description of acute in-patient care for people with dementia. Social care provision both at home and in care homes follows. Gaps in the social care system are identified. End of Life care is briefly summarised. A summary of prescribing for people with dementia at CCG level is given, and the ways in which medicines management initiatives are helping to improve the safety and efficacy of prescribing are included. Opportunities for developing the health and social care workforce conclude the section.

### 4.1 Introduction

Remaining independent at home in their community for as long as possible is important for many people with dementia and their carers. High quality, person-centred community services are essential to achieve this aim.

### 4.2 Trends in primary care service delivery

Over the past 20 years health service planners have tried to shift healthcare from reactive acute care to proactive community care. The potential benefits of high quality community care are that people with dementia are able to receive flexible healthcare closer to home, and are more likely to stay at home for longer, preventing institutionalisation in acute hospitals or in care homes.

One of the biggest challenges for community services is delivering joined up, integrated, health and social care. Services have tended to become more fragmented over the past few years making integration more difficult. Integrated healthcare allows services to work with each other to ensure people with dementia receive high quality healthcare. This can be more efficient as expertise is shared, and duplication reduced.

### 4.3 What support services do we have in East Sussex?

Community services that have been commissioned to support people with dementia and their carers across East Sussex are shown in Appendix 3. Some services are specialist services provided specifically for people with dementia and others more generic. Specialist services in East Sussex include: day care, residential care, support via voluntary organisations funded by East Sussex County Council, specialist in-patient care, mental health liaison services between hospital and community services, and specialist diagnosis via the Memory Assessment Service. Many people with dementia are supported within mainstream services such as home care and residential care.

Figure 21 identifies service provision in relation to level of need. The area where we need to focus most is on developing the services at the bottom of the triangle; these should be

aimed at the large numbers of people who are at risk of developing dementia- related problems and where investment in relatively low level services could prevent the need for more specialist services later on.

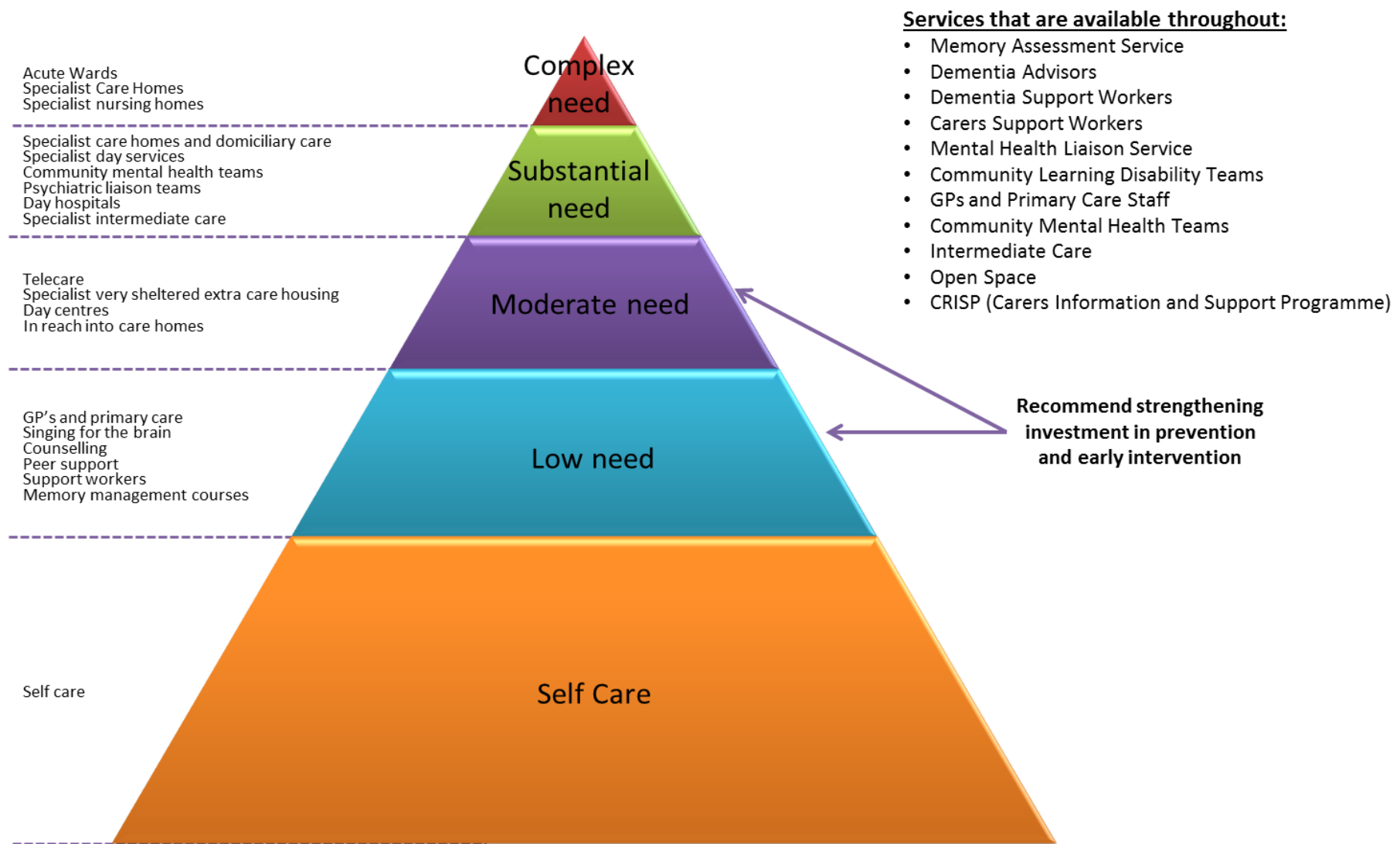
## 4.4 What impact have primary care provided services had on dementia care?

### 4.4.1 The Quality Outcomes Framework [QoF]

The Quality Outcomes Framework (QOF) for dementia pays GP practices for managing dementia by:

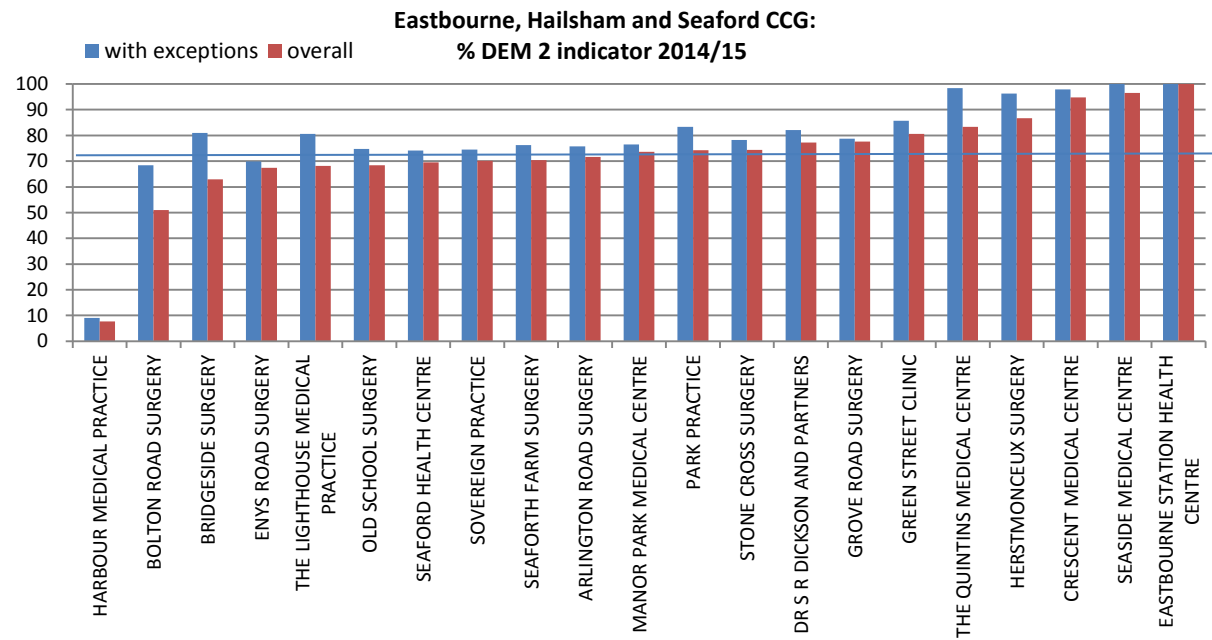
- 1) keeping a **register** of people with dementia [DEM01],
- 2) undertaking an **annual review** of people with dementia [DEM 02]
- 3) ensuring people who are newly diagnosed have the **appropriate investigations** [DEM03].

**Figure 21: How services function according to the needs of people they are supporting**



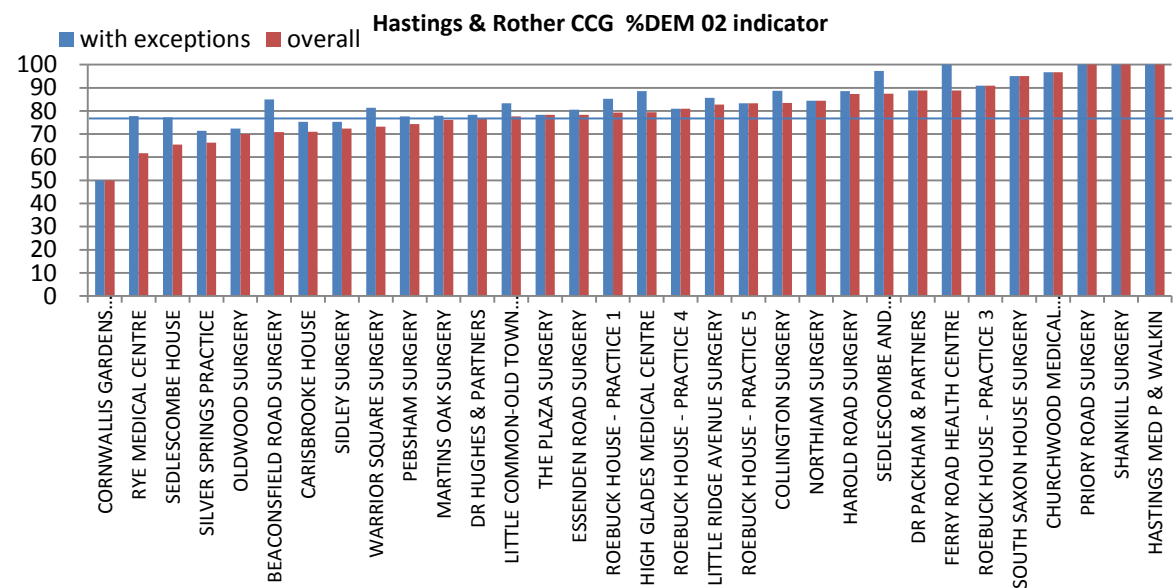
Figures 22 to 27 show the performance of GP practices by CCG in carrying out an annual review review of patients on the dementia register [Dem 02] and in doing baseline blood tests [Dem 03]. They show good achievement for most practices, although there is variation between CCGs and at individual practice level. With exceptions means that the register excludes those for whom it would be inappropriate to undertake an annual review of management e.g. those who are terminally ill. The fact that a patient has had an annual review does not prove whether the review resulted in improved care outcomes of care though this is implied as it indicates care is better organised.

Figure 22: Proportion of patients on dementia register who have had an annual review EHS CCG



Source: HSCIC QoF

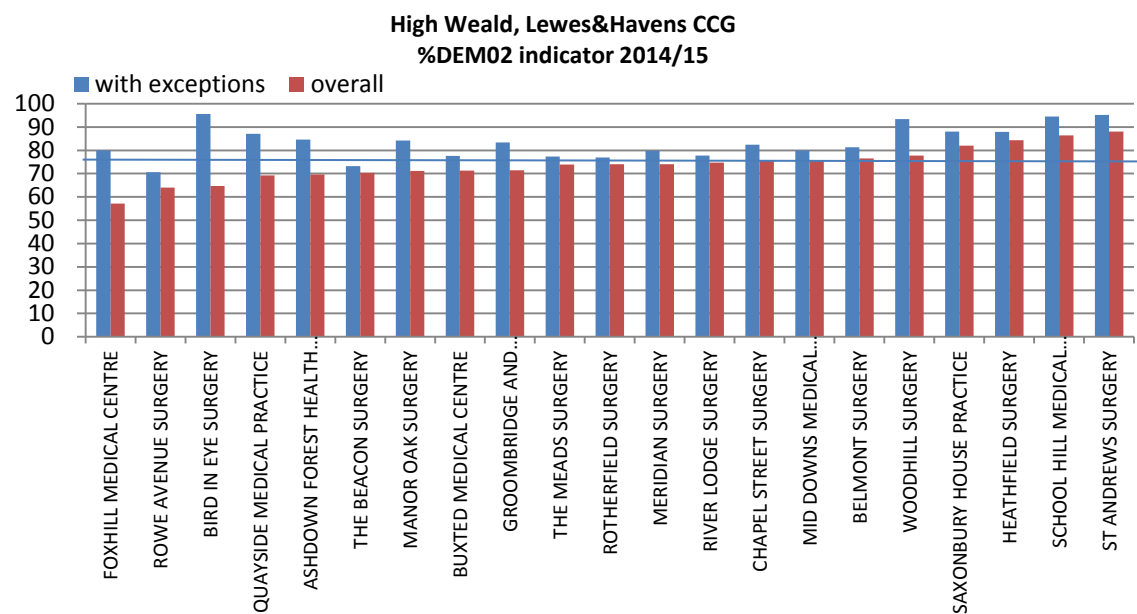
Figure 23: Proportion of patients on dementia register who have had annual review H&R CCG



Source: HSCIC QoF



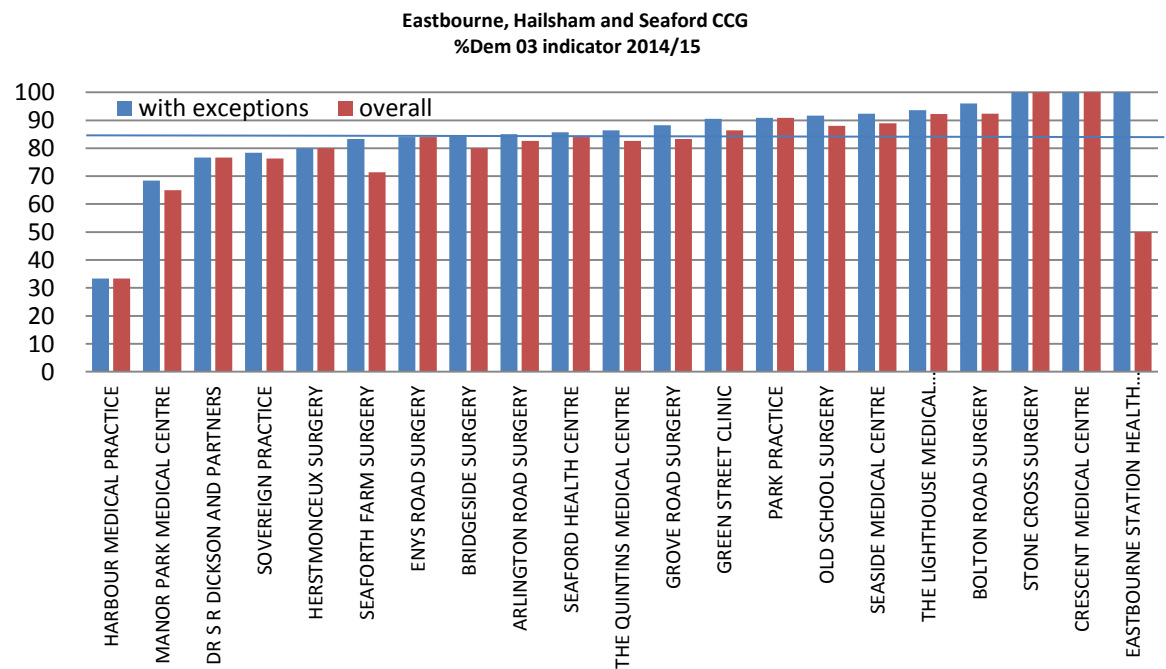
**Figure 24: Proportion of patients on dementia register who have had annual review  
HWLH CCG**



Source: HSCIC QoF

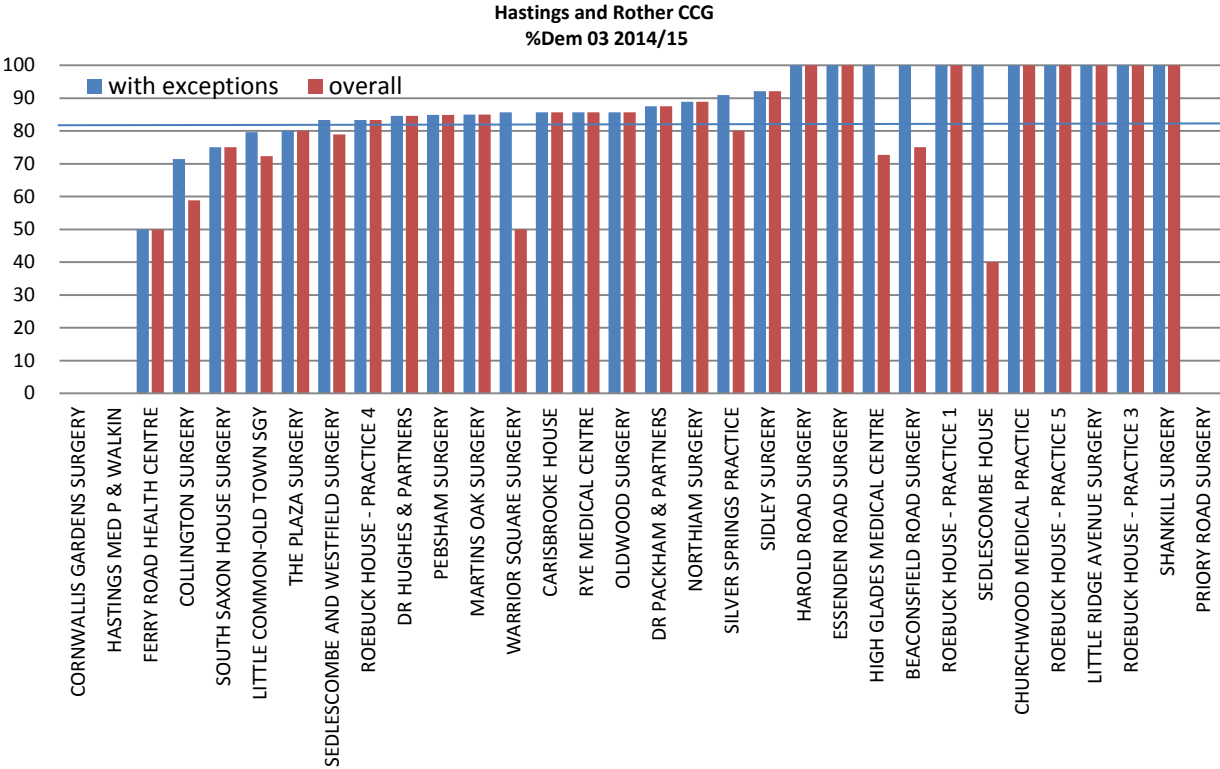
In each CCG, there are a few practices that have not managed to carry out a review of their dementia patients. Dementia patients should receive that same level of attention in terms of annual reviews of their dementia care as for other long term conditions. The DEM 3 indicator shows the proportion of patients who have had their baseline clinical blood tests for treatable causes of dementia undertaken by their GP practice.

**Figure 25: Proportion of patients on dementia register who have had their baseline  
blood tests EHS CCG**



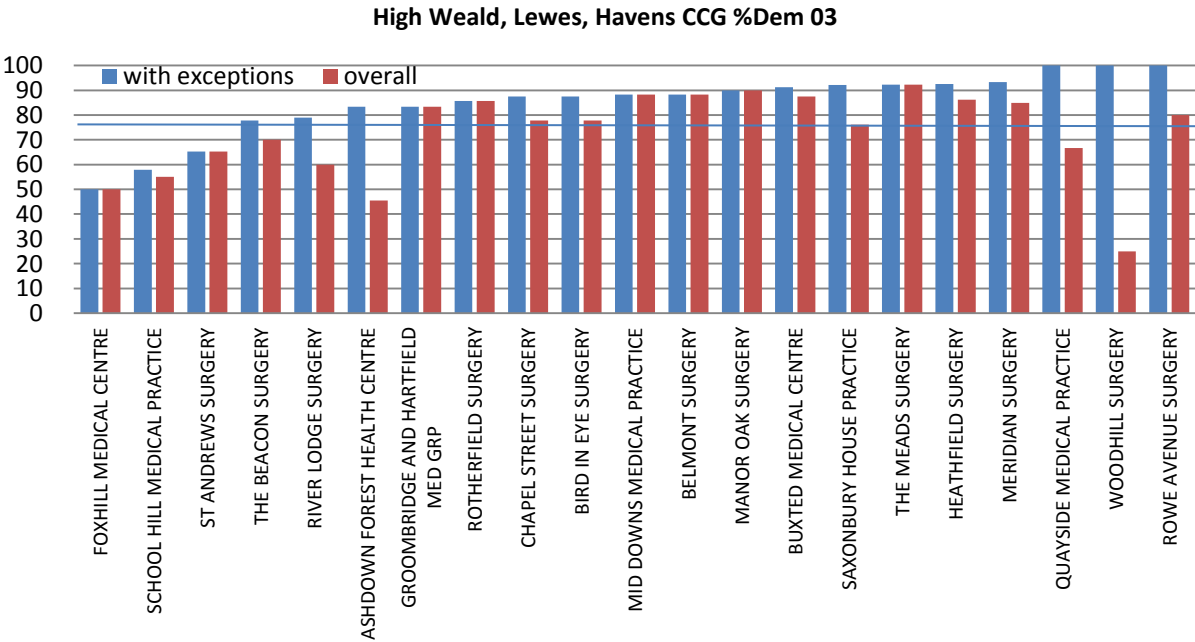
Source: HSCIC QoF

Figure 26: Proportion of patients on dementia register who have had their baseline blood tests H&R CCG



Source: HSCIC QoF

Figure 27: Proportion of patients on dementia register who have had their baseline blood tests HWLH CCG



Source: HSCIC QoF

In a few practices some people with dementia do not have a record of having had the baseline tests that would be expected in the clinical work up of a person with dementia. This could be because the results have not been entered in the clinical record, or because they have not been done. This needs following up at individual practice level. Some practices have a large proportion of exceptions reported.

#### 4.4.2 New Dementia Locally Commissioned Service [LCS]

A new locally commissioned service specifically for managing dementia is being designed in Eastbourne, Hailsham & Seaford and Hastings & Rother CCGs. The new service will assist GP practices in contributing to system-wide improvements by supporting timely diagnosis, supporting individuals diagnosed with dementia and their carers, and improving integrated working with health and social care organisations. **The aims of the Service in 2015/16 are to encourage GP practices to:**

- identify patients at clinical risk of dementia
- offer an assessment to detect for possible signs of dementia in those at risk
- offer a referral for diagnosis where dementia is suspected
- provide advanced care planning in line with the patient's wishes
- increase the health and wellbeing support offered to carers of patients diagnosed with dementia.

For the purposes of this Enhanced Service, **'at-risk' patients are:**

- patients aged 60 or over with cardiovascular disease (CVD), stroke, peripheral vascular disease or diabetes
- patients who are over 60 and have a 'high-risk' of CVD, for instance because of smoking, alcohol consumption or obesity
- patients who are over 60 with a COPD diagnosis
- patients aged 40 or over with Down's syndrome
- other patients aged 50 or over with learning disabilities
- patients with long-term neurological conditions which have a known neurodegenerative element, for example Parkinson's disease.

**There are ongoing discussions about the practicalities of identifying dementia among at-risk persons in primary care.**

#### 4.4.3 How can community, primary care and secondary care services be delivered in a more integrated way?

Delivering joined up, integrated Health and Social Care services has been identified as a priority by people with dementia, their carers and professionals. Not having a comprehensive understanding of the different services offered by individual organisations, means that professionals may find it difficult to advise people with dementia and their carers about which services they would benefit from most.

People with dementia and their carers have expressed a desire to have a single point of contact, rather than having to access each agency separately. A dementia advisor programme is currently operating in East Sussex providing a single point of contact and working to achieve a more joined up integrated service for people with dementia.

## 4.5 What evidence is there to recommend specialist support in primary care?

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

### 4.5.1 Dementia Advisors

A national evaluation found that dementia advisor services were able to meet the needs of people with dementia and their carers.<sup>170</sup> Dementia Advisor and Peer Support Network services had a significant role in enabling people with dementia and carers to re-shape their lives, and in signposting people with dementia and carers to appropriate services and support. East Sussex has currently opted for the dementia advisor model. HWLH CCG is engaging in procuring a new type of post-diagnosis support service with Admiral Nurses.

### 4.5.2 Admiral Nurses

Admiral Nurses have a specialist mental health clinical background. Their role includes clinical casework with carers of people with dementia (PWD), which may be long or short term, depending upon need and consultancy work with other professionals. Nursing interventions are based on a research based stress management model, which deals with carers' needs. These can be broadly summarised as information needs, emotional support needs and skill needs (coping with problem solving). Admiral Nurses assist, and support carers by providing:

- ➔ Assessment of physical and mental health of the carer and the Person With Dementia [PWD] and subsequent meeting of those needs identified.
- ➔ Enhancing the level of carer understanding in relation to diagnosis, symptoms behaviours, treatments and approaches to care.
- ➔ Facilitating access to professional care and resources available to the carer and PWD.

The evidence base around their cost-effectiveness is evolving.<sup>171</sup> East Sussex CCGs are currently exploring how the role of the clinical/mental health nursing function might contribute to the dementia care pathway in East Sussex.

### 4.5.3 Cognitive Stimulation Therapy [CST]

Cognitive skills are the skills the brain uses to think, learn, remember, solve problems and communicate. Cognitive Stimulation Therapy [CST] has been shown to help the memory and thinking skills of people with mild to moderate dementia. CST includes activities that involve cognitive processing. Activities are usually group-based with an emphasis on enjoyment, including discussing current news, music or singing, word games and practical activities. The programme usually lasts twice a week for several weeks. There can be a need for continuation meetings after the formal group has finished ensuring that the benefits last.

People with dementia who took part in CST said there was an improvement in their quality of life.<sup>172</sup> CST is a cost-effective intervention.<sup>173</sup> NICE guidance states "People with mild-to-moderate dementia of all types should be given the opportunity to participate in a structured, group cognitive stimulation programme. This should be commissioned and provided by a range of health and social care staff with appropriate training and supervision, and offered *irrespective of any drug prescribed* for the treatment of cognitive symptoms of dementia."<sup>28</sup> East Sussex piloted a Memory Support Service with the Alzheimer's Society and Sussex Partnership Foundation Trust offering a variation on CST. Uptake of this service was very poor and the CCGs decided not to extend the pilot. In its place, H&R and EH&S CCGs have commissioned additional GP practice orientated Community Support Workers and a programme of Cognitive Stimulation sessions. In HWL&H CCG a voluntary sector organisation, Know Dementia, has been commissioned to provide 'Café' drop-in type support and cognitive stimulation post diagnosis.

## 4.6 Improving dementia management in Primary Care

From April 2016 there is a new Locally Commissioned Service for general practices in EHS CCG and H&R CCG being introduced. Please see [4.4.2 New Dementia Locally Commissioned Service \[LCS\]](#).

There are two pilot projects being undertaken in primary care East Sussex, the Bexhill primary care support workers pilot project and the Golden Ticket project.

### 4.6.1 Bexhill primary care community support workers pilot project

The Bexhill project evolved from the primary care led-MAS service. It involves attaching Community Support Workers [CSW] to selected general practices in Bexhill. Examples of how the pilot is working in practice are given in the two case studies below.

#### Case 1:

Mr.A is an 89 year old man living alone. A new carer was identified, a friend who lives locally and had expressed concerns that Mr.A continues to drive despite a diagnosis of Dementia and reported a recent motor accident involving him. The Carer described multiple caring roles and stated she could no longer manage to maintain the level of support she provided to him (shopping, correspondence and banking). The carer stated the patient lacks insight to his memory loss and had declined offers of additional /alternative support.

The Surgery Support Worker (SSW) visited the Patients home and:

- The Patient agreed to support with correspondence, a letter was found from DVLA for on road driver assessment 19/01/2016. The Patient appeared to lack capacity to fill in the required documentation.
- **MAS contacted who reported that the Patient is closed to them due to non-attendance at appointments.**

The outcome from the Surgery support worker intervention was that the Surgery Support Worker (SSW) helped the client complete and return the DVLA forms; the GP was contacted for re referral to MAS; and the Carers Assessment of need was completed and a support plan put in place.

#### PLANS:

- Surgery Support Worker (SSW) would continue to support the Patient through initial screening events and Memory Assessment Appointments.
- SSW would support the Patient through Driver Assessment and refer to the Carers Breaks and Engagement Service, ESCC would explore additional support services.

## Case 2

Mr.B is a 69 year old gentleman living alone. There were concerns over self-neglect, not functioning well, multiple health conditions, alcoholism, suspected early onset dementia. All attempts at engaging with the gentleman, and getting him to the surgery had been unsuccessful. He was non compliant with his, with no prescriptions submitted for 2 years.

The Community Support Worker [CSW] visited the gentleman and explained why they were visiting. He had been the main carer for his wife who had MS and cancer. Since her death 2 years ago he had lost interest in life. He said he had nothing to do and had no interests in anything; he just sat in his chair all day watching tv.. He had had a fall before Christmas and it had made him nervous of going out. He neglected visiting the GP due to difficulties getting there. The CSW explained that we could support him with visiting GP, to which he agreed. Appointments were made for bloods, a flu injection and a GP visit. They also discussed shopping and cooking. His son would bring in the food and he uses the microwave to heat ready meals.

He was supported with blood tests and a follow up appointment made with GP. The GP explained that the blood results were abnormal and asked the CSW to escort gentleman to hospital for immediate blood transfusion.

CSW escorted him to the hospital and settled him in, then telephoned to inform his son of his admission. CSW telephoned the hospital later in the afternoon for an update. The Patient was kept in hospital. He was in ITU in an induced coma. The nurse informed the CSW that if he had not been brought in when we was he would not be alive now. He was still in hospital at present. The GP was kept updated. Social care on duty was informed of the situation. Follow up after discharge was to be discussed.

### 4.6.2 HWLH CCG The Golden Ticket project, Buxted

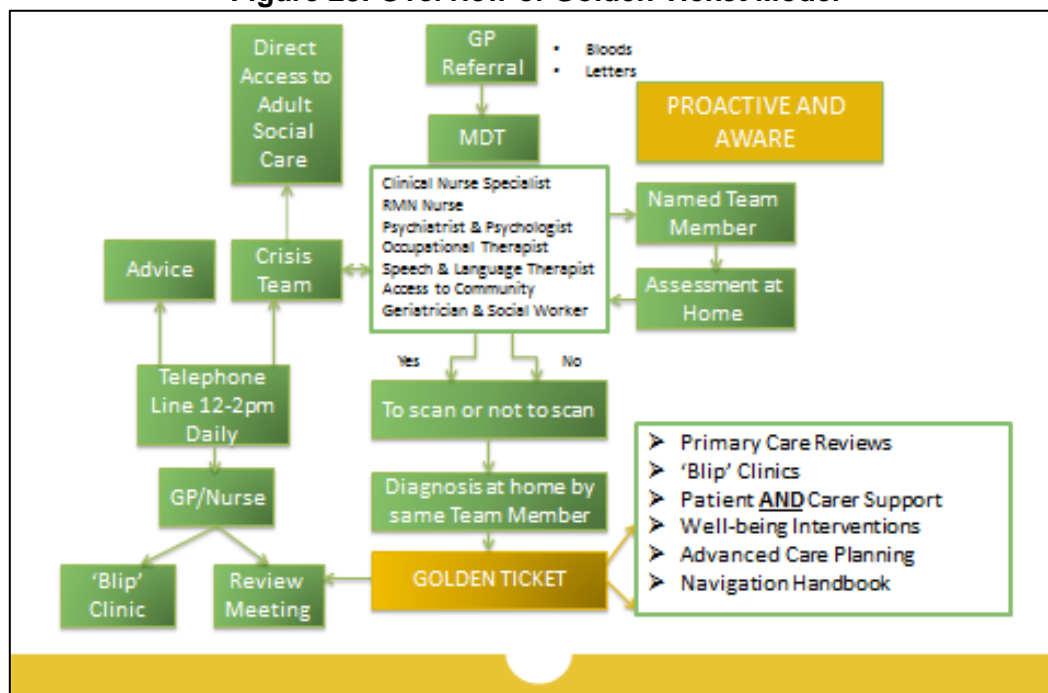
Buxted Medical Centre was the focus for the Golden Ticket dementia transformation pilot project in HWLH CCG. The 12 week project involved early identification and case finding in primary care. A review of the evidence informed the project design, referring to a four stage timeline of disease progression.<sup>174</sup> The project had the following objectives:

1. To **encourage help-seeking and help-offering** (referral for diagnosis) by changing public and professional attitudes, understanding and behaviour;
2. To **make early diagnosis and treatment the rule** rather than the exception; and achieve this by locating the responsibility for the diagnosis of mild and moderate dementia in a specifically commissioned part of the system that can:
  - a) **make the diagnoses well**,
  - b) **break those diagnoses sensitively** and well to those affected,
  - c) **provide individuals with immediate treatment, care and peer and professional support** as needed;
3. To **enable people with dementia and their carers to live well** with dementia through the provision of good-quality care for all from diagnosis to the end of life, in the community, in hospitals and in care homes.

### 4.6.3 How does the Golden Ticket scheme work?

An overview of the Golden Ticket is in Figure 28. The GP refers the patient for a multi-disciplinary team assessment. Members of this team contribute information to make the initial diagnosis, which is formally made by a clinician from SPFT.

**Figure 28: Overview of Golden Ticket Model**



There are primary care review meetings (within 2 weeks after diagnosis, then 6 monthly and annually). Blip clinics are set up for when changing circumstances require a timely response (weekly). There is a direct point of contact with the practice nurse. Medication reviews are undertaken by a pharmacist. Information, advice and support comes from a Dementia guide (within 2 weeks after diagnosis or part of the review schedule). Advanced care planning is supported by the dementia guide and signed off by the GP. Peer support and a carer's café are provided. A personalised handbook is given to the patient.

There are four core interventions for:

1. **physical wellbeing** (once a month);
2. **emotional wellbeing** (once a week);
3. **memory wellbeing** (once a month);
4. **occupational wellbeing** (once a month).

There is an out-of-hours team covering weekends and evenings.

#### **4.6.4 Evaluation of Golden Ticket Project (Qualitative evidence)<sup>175</sup>**

The service was piloted with 40 patients in total. A qualitative service evaluation was undertaken to find out whether the project had improved the quality of life for those living with dementia. The aim was to capture the patient and carer experience within the pilot service and to understand how the service had begun to impact on their lives. The evaluation used interviews, observations and surveys to understand how patients, carers and staff demonstrated, or reported, improvements in their wellbeing and/or healthcare services.

Most people reported an improvement in their sense of wellbeing and confidence to self-manage. Specifically, there was some evidence to suggest that:

- ➔ **Quality of life** for patients living with dementia improved
- ➔ People involved felt able to **live more independently**
- ➔ Access to **information and advice** improved
- ➔ **Wellbeing interventions** were beneficial to patients and carers
- ➔ **Mental health and wellbeing** improved for patients involved
- ➔ **Carers' experience** and reported outcomes improved



- The Golden Ticket workforce believed one model offered an improved **patient experience**.

It is interesting to note that some users did not find the Golden Ticket document as useful as was expected. Some were still uncertain as to who to contact in a crisis situation. Two examples of case histories of patients and carers who have benefitted from the project are given below:

#### Case 1:

##### **Before his diagnosis B. had been self-employed and ran a plant nursery.**

B. had been living with dementia and was being cared for by his wife. He expressed his concerns about his wife and other carers and said "I appreciate the fact that carers are involved in the Golden Ticket and I worry about those who do not have a carer."

B. wrote some heartfelt, touching feedback about his and others' experience because he was so passionate about what had been delivered. The letter describes how he longed for normality and how the service had enabled him to be so. He worries about getting a lot worse with his condition but he says he is "not as bad as he was... I (now) get input from other things... the Golden Ticket has helped me to socialise".

Amongst the things that B. enjoyed particularly were the café sessions and physical exercise classes. Of the latter, he said "we know there are limited numbers but we aren't turned away."

When asked about the future B. said "I hope it continues, I hope I don't go completely nutty or *ga-ga*. I want to keep my mind active; I have to have a reason to get up in the morning. I have found it (the Golden Ticket) really useful and I have met a good crowd."

#### Case 2:

K. cares for her husband J. who lives with severe dementia. Her husband wouldn't be able to respond to the interview questions. K has power of attorney for J., who received his diagnosis back in 2013. K [stated] that they had received a lot of support over the years. "We can pay for carers - we have a live in carer and night carer too."

Although the couple were able to support themselves, having the Golden Ticket in the background should they need it was helpful. She said "there is somewhere I can go to (for help), it is more obvious now."

According to K, J. had displayed challenging behaviour as a result of his condition and had previously hit a night carer.

"When you don't know what is happening you are in a tailspin. It is difficult giving up privacy and letting others do things and I know it is hard because he prefers me doing it...J. wants his wife and no one else."

When asked about how the Golden Ticket had featured in their life, K explained: "J. is partially blind and deaf. He has never been one to mix with people - he won't go to a circle and sing songs, he isn't a typical case and we can't take full advantage. We have gone to a couple of coffee mornings and he has been enjoyable and polite. His idea of time has gone and he has no idea what time of day it is." She also said "lots of people care and show they care. They show their support which is very, very, valuable. The whole package is very, very, good and that feeling of support is gold."

There is **no quantitative evidence** evaluating the programme to date-this is awaited from an external academic body [BSMS]. A full business case of the Golden Ticket is expected to proceed to the HWLH CCG governing body.

## **4.7 What challenges does dementia pose for the South East Coast Ambulance Service [SECAMB]?**

There is limited information at present about how the SEC ambulance service is dealing with the challenge of dementia, but the service is looking into the issues. Most emergency calls for people with dementia are not specifically for a dementia crisis, but for another associated problem, such as a fall or head injury. It can often be difficult for ambulance staff to assess if a person with dementia who has had a fall is more confused than usual. [Increased confusion in someone who has fallen can indicate serious pathology.] This can result in transfers to hospital for assessment and admission.

### **4.7.1 Does the SEC ambulance service collect information about people with dementia?**

SECAMB do not routinely collect information on the numbers of patients that have dementia, however when community specialist teams upload care plans to the Intelligence Based Information System [IBIS] there is a section for them to tick the patient's long-term conditions. They are able to run a report that shows how many [of the crews] identified dementia. IBIS (Intelligence Based Information System) [recorded] patients count for a small percentage of [all] the patients SECAMB attend. When the ePCR (electronic patient clinical record) is active across the ambulance Trust, SECAMB will have more accurate data.

### **4.7.2 Is there a process in place if an ambulance crew suspects, undiagnosed dementia?**

Ambulance clinicians receive some education on dementia at university. Specialist Paramedics (Paramedic Practitioners) have more in-depth knowledge as part of their 'care of the older person' module. The Urgent Care Handbook which is being issued across the Trust has a section on Dementia & Delirium. It summarises Symptoms /Signs/ Circumstances, Red Flags and Cautions, Treatment, and Referral Management. For patients with suspected undiagnosed dementia it signposts to the GP for referral to the Memory Clinic.

### **4.7.3 Is there Commissioning for Quality and Innovation [CQIN] in place to encourage referrals by SEC ambulance crews?**

There is no 2015-16 CQUIN in place specifically regarding dementia. However in Surrey, SECAMB are developing a screening tool that aims to identify vulnerable elderly patients that have actual or potential long-term conditions, who are *not currently under the care of a community team and/or do not have a care plan on IBIS*. The tool supports decision making and prompts staff to refer to a community care team, directing them to community based, urgent care hubs. The tool helps to integrate the ambulance service with urgent care systems and with the wider healthcare community.

### **4.7.4 Training in the Mental Capacity Act and other dementia awareness training?**

SECAMB report that ambulance clinicians have training on Mental Capacity as part of their education. In the Urgent Care Handbook there is a section on Mental Capacity which details when the MCA should be used, how to conduct a capacity test, and key principles of mental capacity. SECAMB are considering revising an existing pocket book aide memoire that staff can use whilst assessing mental capacity/making best interest decisions (including the use of proportionate restraint) and how to document the findings. [Any development of tailored training regarding the application of MCA would need to include its use for patients with dementia.]

### 4.7.5 Improving communication on transfer to hospital

The use of medical passports 'this is me' from the Alzheimer Society, as well as the use of similar communication aids [prescription in a bottle], will help improve communication from community to hospital care when handed over to the appropriate staff.

## **4.8 Hospital [Secondary] Care<sup>176</sup>**

Most people with dementia and their carers will have had experience of being admitted into hospital or having been seen in Accident and Emergency departments. Assessment in Accident and Emergency departments can be frightening for the patient especially if they are confused. Once admitted, like other people, people with dementia can be moved between several wards and may experience a lack of person-centred care.<sup>177</sup> An example of best practice in an acute trust can be found in New Cross Hospital, Wolverhampton.<sup>178</sup>

Hospital admission is often the time in a person's journey when life-changing decisions are made. Their care needs are re-assessed and it may result in a move from their current home to a long-term care facility. Ensuring that hospital care is of high quality and that the person with dementia, their carer and their family feel supported in making difficult decisions about their future care is very important. Organising personal care can take weeks, resulting in extended admissions and the associated risks of a prolonged hospital stay.

### 4.8.1 In-Patient Care

#### **East Sussex Hospitals Trust [ESHT ]**

ESHT has six Care of the Elderly Consultants. There is a pathway of care for the dementia patient in the trust. One ward at the Conquest Hospital, Hastings, is for dementia care of more complex cases. ESHT also has a Dementia Care Team which consists of a Dementia Care Lead (nurse) and two Band 3 Support Workers on a 6 month secondment. A Business Case is also recommending an additional Band 6 staff (of any profession) one or both of whom could become Admiral Nurses.

A recommendation from the last national dementia audit was for there to be a dementia care champion, nominated and trained, within every ward/department. This is a constant moving target on account of staff turnover in ESHT. Over 180 champions have been educated on the six day course.

The trust has embedded the 'This is Me' care passport and has *recently* implemented the 'Butterfly Scheme' whereby a person with dementia is identified by a butterfly symbol and to highlight their care needs. Ongoing awareness training is made available for staff in hospitals that adopt the scheme.

The Carer Survey (CQUIN) results about carer satisfaction are predominantly positive. In the last two years the Trust achieved a mean score of 68% satisfaction, although ward moves across the emergency floor are problematic. ESHT have implemented a system to enable relatives to stay with the person with dementia while in hospital if they wish.<sup>179</sup>

Occupational Therapists [OT]s have developed reminiscence boxes which are made available to wards. Fiddle muffs and blankets for sensory or activity support are also now in place and the OT's have also developed a sensory and activity garden. Five volunteers have now been engaged to provide companionship, talk, read or undertake activities with people on the wards.

The trust works closely with the Patient Advisory Liaison Service [PALS], the ward and ASC staff, as well as the new multi-disciplinary community frailty teams.

The Enhancing the Healing Environment [EHE] audit has been undertaken every six to nine months during the past two years in all acute ward areas and community services. The EHE audit findings are taken into account during the rolling programme of hospital refurbishment working with ward matrons, to make the care environment more dementia friendly.<sup>134</sup>

There has been a proposal to introduce a specialist medical and mental health unit [shared care ward] in Eastbourne DGH, although the published evidence about this is equivocal.<sup>180</sup> A randomised controlled trial showed no convincing benefits in health status or service use but recommended using carer and patient satisfaction scores as more appropriate measures of success in future studies.<sup>181</sup> Whilst there may be greater satisfaction for carers in these specialist wards, there may be more problems in locating all complex cases in one place and in maintaining consistent best practice.<sup>182</sup>

### **Brighton and Sussex University Hospitals [BSUH]:**

Patients in the western part of East Sussex access acute in-patient services in Haywards Heath, Princess Royal Hospital [PRH] and Brighton, Royal Sussex County Hospital [RSCH]. Poynings ward is an 8 bed specialist dementia unit at PRH and Emerald ward is a 15 bed specialist shared care dementia unit in RSCH. The management of dementia in BSUH has been reviewed in the Brighton & Hove JSNA.<sup>13</sup>

### **Maidstone and Tunbridge Wells Trust [MTW]**

Patients from HWLH CCG in the north of the county are admitted to Maidstone and Tunbridge Wells hospitals.

### **Sussex Partnership Foundation Trust [SPFT]**

Mental health liaison services have been in place across both ESHT general Hospital sites in East Sussex since 2008. Liaison services are provided to patients in Accident and Emergency [A&E], or admitted by ESHT. Liaison OTs and nurses assess in-patients in Eastbourne DGH and The Conquest Hospital in Hastings as to patients' suitability for Milton Grange [ESCC intermediate care facility]. SPFT also provides a liaison service to patients in BSUH hospitals. There is no formal requirement for patients seen by SPFT liaison services, and where dementia may be suspected, to bring this to the attention of the patient's GP [or recommend a referral to MAS.] GPs should be being informed on discharge as a result of the CQIN initiative.

#### **4.8.2 How are in-patient beds for dementia in East Sussex being used?**

NHS dementia beds currently were provided on two sites by SPFT and were under-occupied.

The number and usage of in-patient dementia beds was reviewed in detail in the Business Case for Reconfiguration of Acute Dementia Services.<sup>183</sup> [Trust clinicians assessed the average length of stay required to achieve the clinical objectives for patients needing dementia ICU admission as 8 weeks, with a maximum of 12 weeks, after which further benefits are unlikely to accrue.] CCG Governing bodies agreed to a wholly new model of bed-based dementia services, following formal public consultation on options. These beds are being consolidated onto a single site with re-investment in a new and wider range of community- based urgent care services, including step-up and step-down beds aimed at providing alternatives to admission.

### 4.8.3 What are the reasons for delayed discharge for people with dementia?

One of the main reasons for stay in hospital being prolonged is the need for adult social care services to arrange for long term, often care-home based packages through a comprehensive process of assessment. This involves patient and family choices, and having to agree financial contributions. A proportion of patients could have their admission avoided in the first place if a wider range of community based acute services were available.

### 4.8.4 Commissioning for Quality and Innovation (CQUIN) for dementia?

Commissioning for Quality and Innovation (CQUIN) payments enable commissioners to link a proportion of a provider's income to the achievement of locally agreed goals. Some CQUINs are nationally agreed, while others are agreed locally. In 2013/14 there was a national dementia CQUIN which incentivised the identification of patients with suspected dementia in hospital to ensure prompt referral.<sup>184</sup> This includes finding people with dementia, assessing and investigating their symptoms and referring for support. The funding is divided into three parts:

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

The third part of this must include a monthly audit of carers of people with dementia the findings of which are reported to their Board at least twice per year. The content of this audit is for local determination but must include a question on whether carers of people with dementia feel adequately supported. Data from the carers' audits are shown below:

For ESHT:

- ➔ As a carer, how did you find the support offered to you by the staff? **81.5% satisfaction.**
- ➔ Were you provided with a care passport (This is Me)? **48%.** Mean (average) satisfaction, **64%.**

Source: Meridian database, ESHT.

The national dementia CQUIN requires each NHS provider to have a dementia lead.

The terminology changed to include delirium as well as dementia.<sup>185</sup> Targets have been set for 90% of eligible patients to receive an assessment, and for 90% of positive assessments to be referred on to the Memory Assessment Service. The monitoring data for the Dementia Assessment and Referral are described with the acronym **FAIRI (Find, Assess/Investigate, Refer/Inform)**.<sup>186</sup> Three measures are reported - the number and proportion of patients aged 75 and over admitted as an emergency for more than 72 hours:

1. to whom case finding is applied following an episode of unplanned care to either hospital or community services; **[Find]**
2. who, if identified as potentially having dementia or delirium, are appropriately assessed; **[Assess/Investigate]**
3. where the outcome was positive or inconclusive, have a care plan on discharge meeting locally agreed standards and shared with general practice. **[Refer/Inform].**

### 4.8.5 What effect have the CQUIN schemes had on dementia care in East Sussex?

Table 29 shows how EHST performance on this CQUIN fell short of the expected target to identify people on admission in Q4 2014/15 but had improved in Q3 in 2015/16. On receipt of discharge summaries from ESHT which identify suspected cases, GPs are encouraged to act on the recommendations and refer on to the Memory Assessment Service [MAS].

**Table 29: Performance of acute trusts on Find, Assess/Investigate Refer Measures**

	Number of cases identified	Number of emergency admissions	Percentage of cases identified (i)	Number of cases with diagnostic assessment	Number of cases with positive case finding question	% cases with diagnostic assessment (ii)
<b>Quarter 4 2014-15</b>						
All providers of NHS funded care	170,504	189,308	94%	34,825	36,754	94.8%
Brighton & Sussex University Hospitals NHS trust	482	515	94%	89	89	100%
East Sussex Healthcare NHS trust	1,273	1,524	84%	198	210	94%
<b>Quarter 3 2015-16</b>						
<b>NHS Acute (Foundation and Non Foundation Trusts)</b>	<b>163,835</b>	<b>181,912</b>	<b>90.1%</b>	<b>29,198</b>	<b>30,716</b>	<b>95.1%</b>
<b>Community Service and Other Providers</b>	<b>4,986</b>	<b>5,714</b>	<b>87.3%</b>	<b>1,266</b>	<b>1,320</b>	<b>95.9%</b>
Brighton & Sussex University Hospitals NHS trust	410	442	93%	102	102	100%
East Sussex Healthcare NHS trust	1,404	1,536	91%	265	275	96%

Source: NHS England

Evaluation of the Memory Assessment Service [MAS] pilot, looking at whether referrals were initiated as a result of ESHT recommendations, highlighted very few GP referrals were ever received. In ESHT, where a patient has been diagnosed with dementia as a result of an acute admission, under some consultant teams in ESHT there is no primary care or follow up support being provided in the community. Refer and inform indicator (iii): the data have not yet been posted. From April 2015 the mandatory data set includes community service providers, as well as acute trusts. By Q3 in 15/16, neither SPFT nor SCT trusts had submitted FAIRI performance data.

### 4.8.6 How many people are admitted to hospital?

The number of admissions is influenced by how people with dementia and their carers make use of primary care services. Rates of admission are also affected by differences in referral patterns within the primary and secondary care sectors across East Sussex. In-patient hospital admissions are reported through Hospital Episodes Statistics (HES). The data provide some information on use of acute hospital services by people with diagnosed



dementia. There will also be undiagnosed cases admitted. Data are presented on all East Sussex residents who have been admitted over two financial years 2013/14 to 2014/15. Admissions are defined as Finished Consultant Episodes (FCEs). The following analyses have looked at ICD dementia codes F00 to F03, G30 and G31 for dementia and have excluded persons under the age of 30. Admissions of East Sussex residents in the last two financial years are summarised in the Table 30.

**Table 30: Admissions of East Sussex residents with any diagnosis of dementia**

2013/14	3,498
2014/15	4,041

Source: SUS

The total of 7,539 in two years represents 7.0% of all emergency admissions [107 609] of East Sussex residents during the years 2013/14 and 2014/15. Not all admissions of people with dementia are coded as having dementia, even where this is already known to be present, so this is likely to be an underestimate. The diagnostic label of dementia may be applied following a subsequent transfer between organisations. A person could be admitted more than once, as shown in Table 31:

**Table 31: Patients with dementia having repeated admissions between 2013-15**

Number of repeat admissions	Number of patients
1	994
2	312
3	99
4	42
5	19
6 or more	16
TOTAL	1,482

Source: SUS HES data

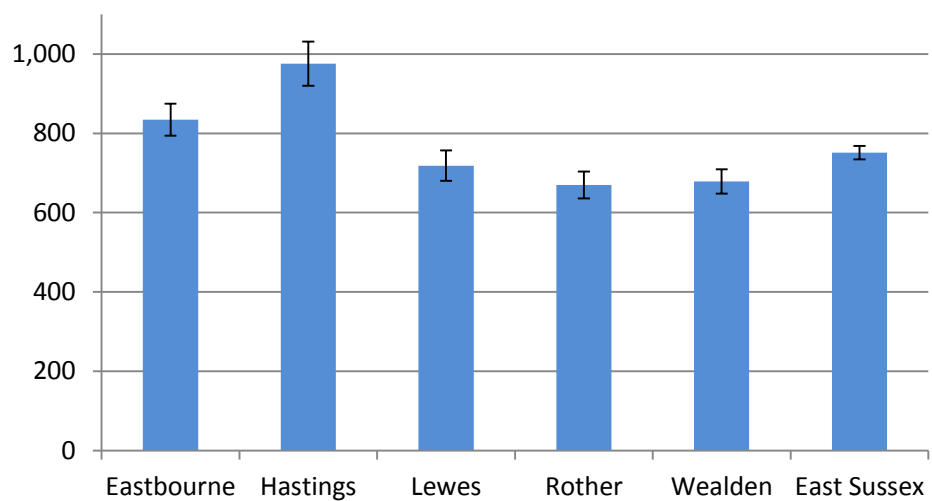
1,482 East Sussex residents with a dementia diagnosis had more than one admission during 2013/14 and 2014/15 and two patients were admitted 12 times each over the period.

**4.8.7 What are the rates of admission for dementia by Local Authority?**

Age-standardised admission rates for people with dementia per 100,000 population are shown by LA in Figure 29. All those where dementia has been coded anywhere in the care record, for persons aged 30 years and over, using 2013/14 & 2014/15 pooled data were included.



**Figure 29: Age-Standardised Rate of admission for dementia per 100,000 [with 95% confidence intervals]**



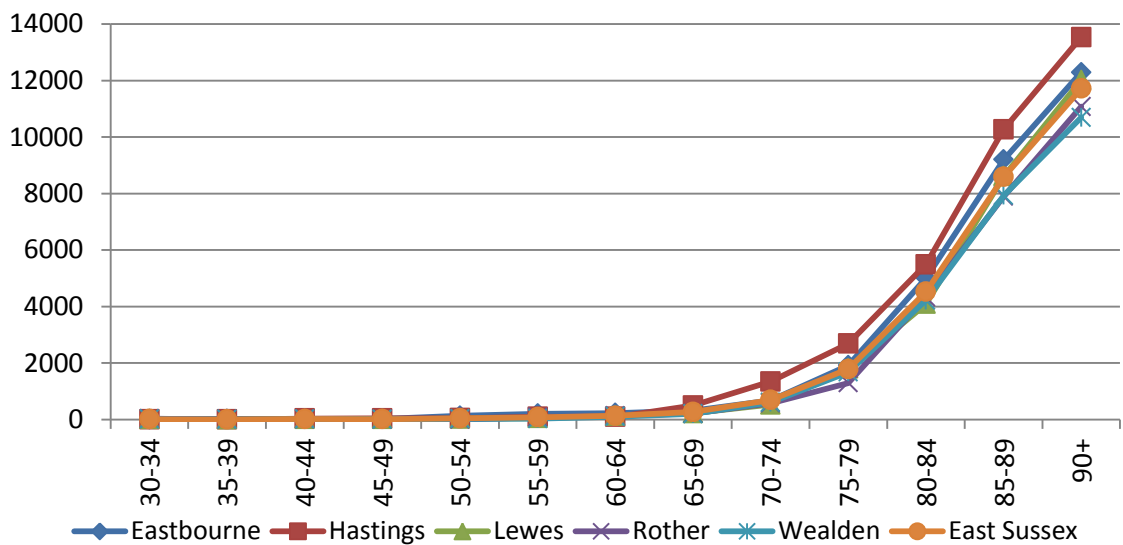
Source: SUS HES data

In East Sussex there were approximately 751 people with dementia admitted per 100,000 residents over these two financial years 13/14 and 14/15. There are significantly higher rates of admission in Hastings and Eastbourne local authorities. This could reflect either different service provision or patterns of service utilisation. There is the potential for more cost-effective provision of care in the community which has been recognised locally in the recent successful business case.<sup>187</sup>

**4.8.8 What are the age-specific rates of admission by Local Authority?**

Figure 30 shows the age-specific rates of admission per 100 000 are broadly comparable between local authorities and increase rapidly from 70 years. There are higher age-specific rates of admission for all age groups in Hastings local authority and lower rates in Rother and Wealden.

**Figure 30: Age-specific rates of admission by Local Authority**

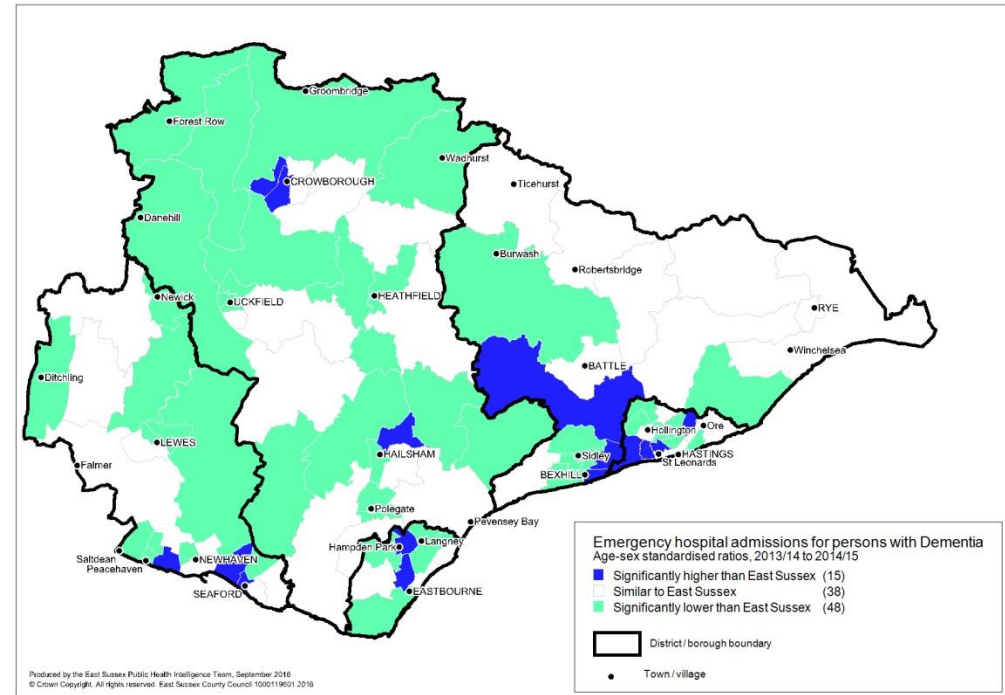


Source: SUS HES data

4.8.9 Where do most admissions come from?

Figure 31 shows at ward level where there are more, or fewer, emergency hospital admissions for persons with dementia (ICD-10: F00-F03, G30, G31 in any diagnosis position) than expected. All lengths of stay are included in the analysis. The areas with significantly higher admissions rates than expected compared to East Sussex are coloured in blue, and areas significantly lower than expected are shown in green. Admission rates are highest in Peacehaven, Seaford, Hailsham, Crowborough, St.Leonards and Crowhurst ward.

Figure 31 Emergency hospital admissions for persons with dementia 2013/14 to 2014/15



4.8.10 What are the main reasons for admission to hospital in East Sussex?

Table 32 shows the main reasons for admission of people with dementia are for the management of their co-morbidities [other medical conditions]. Cognition, perception, emotional state and behaviour as reasons for admission only appear tenth in the following list. These co-morbid conditions include urinary tract infections, fractured neck of femur, pneumonias, and head injury as the top four. Lower down the list come general symptoms and signs, neurological and musculoskeletal problems, cardiovascular and cerebrovascular disease.

Table 32: Main reasons for hospital admission of people with dementia

Reason	2013/14	2014/15	Grand Total
Urinary system	245	292	537
Injuries to the hip and thigh	264	245	509
Influenza and pneumonia	200	306	506
Injuries to the head	226	242	468
General symptoms and signs	229	212	441
Nervous and musculoskeletal systems	183	166	349
Circulatory and respiratory systems	119	111	230

Other forms of heart disease	82	114	196
Cerebrovascular diseases	86	108	194
Cognition, perception, emotional state and behaviour	72	84	156
Other diseases of intestines	74	80	154

Source: SUS HES data

The recently introduced PHE Fingertips comparator suggests that East Sussex has a relatively higher rate of short stay admissions for dementia [1 night or less] than the rest of England.<sup>188</sup> Further analysis would be required to establish the reasons and whether a proportion of these were potentially avoidable.

**4.8.11 Which Hospitals are East Sussex residents with dementia admitted to?**

Table 33 shows the main hospitals where East Sussex residents with dementia are admitted.

1. **In ESHT:** there are more admissions to Eastbourne Hospital than to the Conquest Hospital. There are fewer admissions to the community hospitals. There are much longer lengths of stay in community hospitals, with the exception of Bexhill Hospital. Please see below.
2. **In BSUH:** there are more admissions to the Royal Sussex County Hospital than to the PRH hospital. There are relatively longer lengths of stay than in ESHT.
3. **In MTW:** the number of admissions and length of stay is comparable to the PRH
4. **In SPFT:** these are admissions to EMI wards with relatively prolonged lengths of stay.

**Table 33: Hospital admissions where any ICD code of dementia recorded 2013-15**

Trust	Hospital		Average length of stay [days]
<b>EAST SUSSEX HEALTHCARE NHS TRUST [ESHT]</b>	EASTBOURNE DISTRICT GENERAL HOSPITAL	2,991	8.2
	CONQUEST HOSPITAL	2,496	8.9
	MEADOW LODGE	51	35.9
	CROWBOROUGH WAR MEMORIAL HOSPITAL	39	39.6
	UCKFIELD HOSPITAL	37	25.6
	BEXHILL HOSPITAL	36	4.3
	RYE MEMORIAL CARE CENTRE	4	29.0
	FIRWOOD	4	26.0
<b>BRIGHTON AND SUSSEX UNIVERSITY HOSPITALS NHS TRUST [BSUH]</b>	ROYAL SUSSEX COUNTY HOSPITAL RSCH	671	11.8
	PRINCESS ROYAL HOSPITAL	410	9.6
	SUSSEX EYE HOSPITAL	15	0.1
	SUSSEX ORTHOPAEDIC TREATMENT CENTRE	6	2.2
	HURSTWOOD PARK CENTRE	4	7.8
	BRIGHTON GENERAL HOSPITAL	4	0.0
	LEWES VICTORIA HOSPITAL	1	0.0
<b>MAIDSTONE AND TUNBRIDGE WELLS NHS TRUST</b>	THE TUNBRIDGE WELLS HOSPITAL	408	9.6
	THE MAIDSTONE HOSPITAL	21	11.6
<b>SUSSEX PARTNERSHIP NHS FOUNDATION TRUST [SPFT]</b>	ST ANNE'S CENTRE & EMI WARDS	73	76.1
	BEECHWOOD UNIT	62	60.0
	BRUNSWICK WARD	11	68.1
	HEATHFIELD COMMUNITY CENTRE CLINIC	10	51.2
	THE HAROLD KIDD UNIT	1	63.0
	DEPARTMENT OF PSYCHIATRY	1	
	LANGLEY GREEN HOSPITAL	1	
	SALVINGTON LODGE (THE BURROWS)	1	11.0
<b>QUEEN VICTORIA HOSPITAL NHS FOUNDATION TRUST</b>		61	0.8
<b>KING'S COLLEGE HOSPITAL NHS FOUNDATION TRUST</b>		12	2.3
<b>SURREY AND SUSSEX HEALTHCARE NHS TRUST</b>		10	9.1

Source: SUS HES data

Table 34 shows the number of admissions by provider by CCG. Most admissions for EHS and H&R CCG registered patients are to ESHT, whereas the majority of admissions of patients registered with HWLH CCG are to BSUH and MTW trusts.

**Table 34: Number of admissions during 2013-15, by provider, by CCG**

	EHS CCG	H&R CCG	HWLH CCG	Grand Total
East Sussex Healthcare NHS Trust	2789	2490	357	5636
Brighton And Sussex University Hospitals NHS Trust	112	18	838	968
Maidstone And Tunbridge Wells NHS Trust	2	5	408	415
Sussex Partnership NHS Foundation Trust	65	58	26	149
Queen Victoria Hospital NHS Foundation Trust	6	14	35	55
Other	31	22	40	93
<b>Grand Total</b>	<b>3005</b>	<b>2607</b>	<b>1704</b>	<b>7316</b>

Source: SUS HES data

Table 35 shows that where dementia has been recorded as the main reason for the admission (primary reason) there is a longer mean length of stay [LOS] than where this is for a co-morbid condition.

**Table 35: How long do people with dementia stay in hospital? Mean LOS in days.**

	2013/14	2014/15	Grand Total
Dementia recorded as main reason	29.6	32.4	31.0
Dementia appearing anywhere in the record	8.8	9.6	9.3
<b>Grand Total</b>	<b>10.0</b>	<b>10.7</b>	<b>10.4</b>

Source: SUS HES data

Most of the admissions for people with dementia are as an emergency; about 10% of all admissions are for elective procedures (Table 36).

**Table 36: How many people with dementia are admitted as an emergency?**

	Main reason	Any position in record	Grand Total
Elective	19	713	732
Emergency	325	6290	6615
Other	6	125	131
#N/A	55	6	61
<b>Grand Total</b>	<b>405</b>	<b>7134</b>	<b>7539</b>

Source: SUS data

It is recognised nationally by the health and Social Care Information Centre [HSCIC] that for nearly half of in-patient episodes of people with known dementia, the fact that they are already known to have dementia, their dementia diagnosis is not recorded.

#### 4.8.12 Management of dementia by the community dementia teams

##### **Sussex Community Trust [SCT]**

In Autumn 2015, Sussex Community Trust [SCT] took over the community inpatient beds in: Lewes Victoria Hospital; Newhaven Hospital; Crowborough Community Hospital and Uckfield Community Hospital. There are **no** specialist dementia services in High Weald, Lewes Havens CCG, although community teams *do* accept referrals of people with dementia.

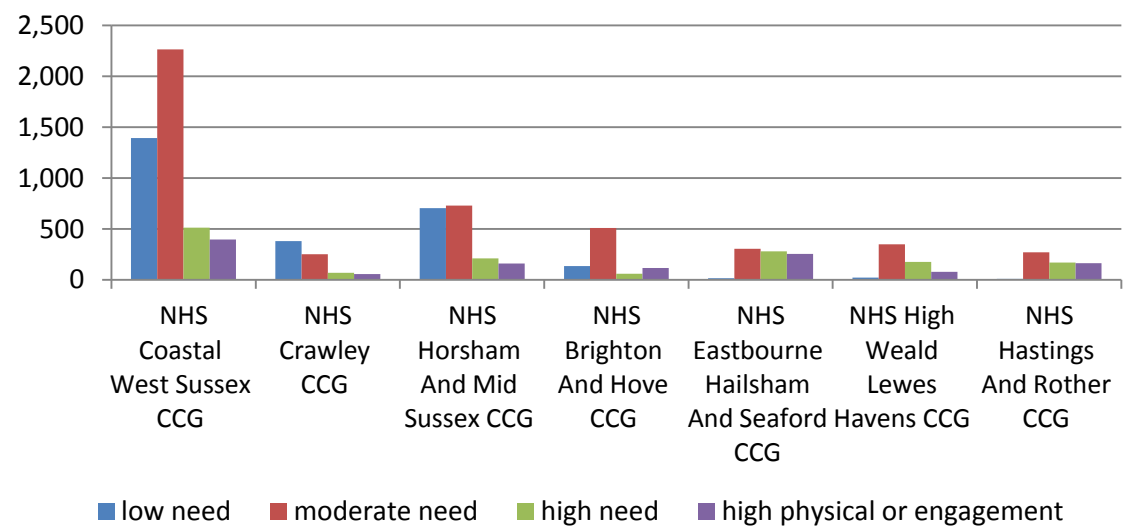
## Sussex Partnership Foundation NHS Trust [SPFT]

The Specialist Older People Mental Health [OPMH] service is community-based and provides assessment and treatment for older adults with both functional mental health problems and dementia. The service provides support for in-patients with dementia and their carers; education around dementia care for staff, and outreach support to community hospitals; intermediate care and day services across East Sussex. OPMH liaison nurses and OTs continue to provide in-reach to Lewes Victoria, Crowborough Memorial, Uckfield Community Hospitals and Bexhill Irvine Unit. There is a liaison doctor for Milton Grange local authority dementia care home.

A dementia specialist Care Home In-reach Service is commissioned from SPFT.<sup>189</sup> The in-reach team are invited to attend care homes. The team provides staff in those homes with specialist training workshops and bespoke practice development in a facilitative, supportive style. Workshops include person-centred care, effective communication, dealing with challenging behaviours, life stories, meaningful activity, use of anti-psychotic drugs, physical health care, working with families, sexuality and dementia, end of life care, activity profiling, care planning, assessment tool training (to consider pain, depression and behavioural and psychological distress in people with dementia who are unable to vocalise their needs), organisational abuse, and doll therapy. Further evidence about how this service has been working can be found in their annual report.<sup>189</sup>

Figure 32 illustrates the dementia caseloads of SPFT community teams by case severity for CCGs in Sussex. There are substantially more patients with low and moderate needs on SPFT caseloads in West Sussex, Horsham and Mid-Sussex, and Brighton & Hove CCGs than in the three East Sussex CCGs. Source ASC ESCC.

**Figure 32 Numbers of dementia patients on SPFT caseloads, indicative report Aug ‘15**



## 4.9 Social care

### 4.9.1 Introduction

Caring for someone with dementia at home is challenging. For many carers this is a 24 hour a day responsibility, seven days a week, with little respite. The needs of each person with dementia are different and changing. Each carer-patient relationship is unique and evolves over time. It is important to consider the impact on relationships, as well as individuals within those relationships. Much of the research has considered the impact on marital relationships and less commonly the relationships between adult children and their parents, or other

relationship patterns such as those influenced by ethnicity, sexual orientation, disability and divorce.<sup>190</sup>

Some people need help with washing, dressing and toileting, others with eating. Providing personal care can be difficult for carers and is a common source of daily anxiety.<sup>191</sup> Relationships with families are important but can become easily strained.

Support with personal care at home can be provided by the local authority, depending on an assessment of need and eligibility, and subject to financial assessment. Social care can help the individual client with their personal care needs and give carers some respite during the day. Without this support carers are likely to burn out in a relatively short period of time.

Simple modifications can make the home environment more dementia friendly and safer, helping both the person with dementia and their carer.<sup>192</sup> These may include aids and adaptations following advice from an occupational therapist or physiotherapist.

#### **4.9.2 What are the implications of the Care Act?**<sup>193</sup>

Local Authority Adult Social Care [ASC] Departments have a responsibility to promote wellbeing and assess the needs of a person and their carer.<sup>26</sup> The Local Authority works with other agencies and providers to support people with dementia to live safely and independently within their own homes and in the local community for as long as possible.

#### **4.9.3 Principle of promoting wellbeing**

Local authorities must promote wellbeing when carrying out any of their care and support functions for a person, and that person should be enabled to participate as fully as possible in decisions at every stage in their care. This is a shift from local authorities to providing particular services, to the *concept of 'meeting needs'* – now a core legal duty. It recognises that everyone's needs are different and personal to them and assumes that the individual is best placed to judge their own wellbeing, and what wellbeing means to them. The new legislation recognises that new models of care and support are emerging all the time, and embraces innovation and flexibility, unlike previous legislation that focused primarily on traditional models of residential and domiciliary care.

Wellbeing is described in the act as:

- ➔ personal dignity including respect
- ➔ physical and mental health and emotional wellbeing
- ➔ protection from abuse and neglect
- ➔ control by the individual over day-to-day life (including over care and support provided and the way it is provided)
- ➔ participation in work, education, training or recreation
- ➔ social and economic wellbeing
- ➔ domestic, family and personal relationships
- ➔ suitability of living accommodation.

The assessment and eligibility process is the key interaction between the local authority and an individual. It is a critical intervention in its own right, which can help people to understand their situation and access support when they require it. Local authorities must undertake an assessment for any adult, including a carer (see below), who appears to have any level of needs for care and support, irrespective of whether the local authority thinks the individual has eligible needs. The individual should be supported to participate as fully as possible in decisions, perhaps by family, friends or carer. This can be by an independent advocate if the local authority thinks the person has substantial difficulty in involvement in decisions and the



person has no one else available to help them. The purpose of the assessment is to identify the needs and how these impact on the wellbeing and outcomes that an adult wishes to achieve in their day to day life.

Assessment must seek to establish the total extent of a person's needs before their eligibility for assistance is determined and the impact of those needs on the individual's wellbeing (day to day life). Assessments may be carried out in different formats. Where appropriate, an assessment may be carried out over the phone or online, although a local authority must make sure it has fulfilled its duties around safeguarding, independent advocacy, and assessing mental capacity. If this process does not give sufficient information, a face-to-face assessment must be arranged. Assessments can be carried out by a range of people from different backgrounds, including social workers, occupational therapists, and rehabilitation officers, as well as care managers or first contact staff. Anyone carrying out an assessment must be appropriately trained, have the necessary skills and be competent to do so. Local authorities should consider whether additional relevant expertise is required on a case-by-case basis, taking into account the nature of the needs of the individual, and the skills of those carrying out the assessment.

#### **4.9.4 Assessment of those who may lack capacity**

Where an individual lacks capacity, the local authority must carry out supported decision making, involving the person as far as possible. It must carry out a capacity assessment and take 'best interests' decisions. In cases where a person refuses, a local authority is not required to carry out an assessment, unless it has established that the adult *lacks mental capacity* and that carrying out a needs assessment would be in their best interests. The authority must also carry out an assessment where it considers the person is or is at risk of being abused. The local authority must carry out an assessment if the person requests one at a later time. Local authorities must consider *all* the adult's care and support needs, *regardless of any support being provided by a carer*. Any support from a carer must not be considered until *after* it has been determined that the adult has eligible needs. The local authority is not required to meet any needs which are being met by a carer who is willing and able to do so, but it should record where that is the case. This ensures that all of the adult's needs are identified and the local authority can respond appropriately if the carer feels unable or unwilling to carry out some or all of the caring they were previously providing. The requirements of the Mental Capacity Act and access to an Independent Mental Capacity Advocate apply for all those who may lack capacity.

#### **4.9.5 Carer's assessment**

The Care Act places a duty on the Local Authority to assess the needs of carers in their own right and to enable carers to lead a healthy, active fulfilling life.<sup>26</sup> Local authorities should not *assume* that others are willing or able to take up caring roles. Where an individual provides care for another adult, local authorities must carry out a carer's assessment if it appears that the carer may have any level of needs for support. A carer's assessment must establish the carer's needs for support and how these impact on their wellbeing – as well as the sustainability of the caring role, including the practical and emotional support provided. It must consider the carer's future needs for care and support, and their ability and willingness to provide care *now* and *in the future*. A carer's assessment should be accompanied by information and advice specific to the carer's requirements.

#### **4.9.6 National Eligibility Criteria**

The Care Act introduces a national eligibility threshold for adults with care and support needs which consists of three criteria, all of which must be met for a person's needs to be eligible. The eligibility threshold has been set at a level which is intended to allow local authorities to maintain their existing access to care and support. It is based on identifying:

1. whether a person's needs are due to a physical or mental impairment or illness

2. to what extent a person's needs affect their ability to achieve two or more specified outcomes
3. whether and to what extent these have a significant impact on their wellbeing.

The Eligibility Regulations set out a range of outcomes, and local authorities must consider whether the adult is unable to achieve two or more of these outcomes when making the eligibility determination - "being unable" to achieve an outcome includes any of the following circumstances, where the adult:

1.	is unable to achieve an outcome without assistance
2.	is able to achieve it without assistance but doing so causes significant pain, distress or anxiety
3.	is able to achieve it without assistance but doing so endangers, or is likely to endanger the health and safety of the adult, or others
4.	is able to achieve it without assistance but takes significantly longer than would normally be expected

The outcomes are:

- ➔ managing and maintaining nutrition;
- ➔ maintaining personal hygiene;
- ➔ managing toilet needs;
- ➔ being appropriately clothed;
- ➔ being able to make use of the adult's home safely;
- ➔ maintaining a habitable home environment;
- ➔ developing and maintaining family and other personal relationships;
- ➔ accessing and engaging in work, training, education or volunteering;
- ➔ making use of necessary facilities or services in the local community including public transport, and recreational facilities or services, and
- ➔ carrying out any caring responsibilities for a child.

#### 4.9.7 Care planning and review

If the local authority has a duty to meet a person's needs, it must help the person decide how their needs are to be met by preparing a care and support plan, or support plan for carers. The plan must describe what needs the person has and which needs the local authority is to meet. The plan must consider any needs that are already being met, by a carer for instance. In addition, it must include a tailored package of information and advice on how to delay and/ or prevent the needs the local authority is not meeting.

The Act specifies that plans must be kept under review and local authorities should establish systems to do this, including seeking cooperation with other health and care professionals who may be able to inform the authority of any concerns about the ability of the plan to meet needs. The review should be person-centred and is an opportunity to take stock of outcomes and to consider if the plan is working. The review could be a self-review, or carried out by a carer, a provider or another authorised professional, and then signed-off by the local authority. It is expected that authorities should conduct a review no later than every 12 months, with an initial 'light-touch' review after 6-8 weeks. Where circumstances have changed it may be necessary to undertake a revision of the care plan, and if appropriate, a needs assessment and financial assessment. This should be proportionate, taking into consideration what is already known of the person. In some cases a complete change of plan may be required, whereas in others only minor adjustments may be needed.

#### **4.9.8 Meeting needs**

Local authorities must establish whether the person meets the ordinary residence requirement in that they ordinarily live in the local authority's area. In the case of the carer, the person for whom they care must be ordinarily resident in the authority's area. Individuals can complain and challenge a decision and there is a formal appeal system. The local authority must produce a written record of their decision and the reasons for it.

#### **4.9.9 What support can be made available?**

The types of support available include:

- ➔ Information and advice;
- ➔ Practical support within the home;
- ➔ Equipment or adaptations within the home that can maintain or improve independence;
- ➔ Assistive Technology (AT) to help people to do things, maintain safety or reduce risks;
- ➔ Supporting people to participate in community activities;
- ➔ Rehabilitation by community therapists, or Reablement Officer, to maintain or improve general levels of functional ability;
- ➔ Devising Emergency Care Plans that can be activated at times of unforeseen crises;
- ➔ If someone lacks the mental capacity, arranging for managing finances should there be no one else to do this.
- ➔ Discussing and planning for the future;
- ➔ Planning and arranging moves to either Extra Care Sheltered Housing, or residential care, should this be necessary;
- ➔ Enabling and supporting people to be safe and free from harm.

Adult Social Care departments also provide, or commission, community services such as day centres and memory cafés for people with dementia and their carers.

#### **4.9.10 Funding social care**

The direct costs of managing dementia fall mainly on local authority adult social care services. These costs can be for providing one-to-one home care, community or residential and nursing care, with long-term residential and nursing care forming the majority of costs.<sup>194</sup>

#### **4.9.11 Personal Budgets**

A person with dementia will have an assessment of their needs and finances. Based on these two components, the person may be eligible for free, or part-funded, personal care. Many people with dementia and their families/carers may not be eligible for Adult Social Care ASC Packages of Care (PoC).

People with dementia who have been assessed as having eligible needs will have a personal budget as part of their care and support plan that identifies the cost of their care and support and the amount the local authority will make available, regardless of their care setting. Person-centred care and support planning means that a person can choose to receive part of, or their entire personal budget, as a direct payment, depending on how much control and responsibility they wish to take over the arrangement of their care and support. The local authority must inform the person which, if any, of their needs may be met by a direct payment and provide appropriate information and advice on how to use and manage this. Personal budgets have been welcomed as part of a person-centred approach to providing personal care. If people are not eligible then the person and their family can still have Adult Social Care ASC support to access services as a self-funder/private client.

There remain significant challenges in the social care system, namely lack of funding overall to meet the needs of an increasing ageing population and strict eligibility criteria which are set nationally and enacted locally. This is in the context of more complex clients with long-term conditions, more people being managed in the community, the number of older carers increasing, and more people living alone.

#### **4.9.12 Importance of the home environment and housing needs**

Assessment of housing needs of people with dementia is fundamental as it enables a person to live as safely as possible and as long as is feasible in the community.<sup>195</sup> Dementia and housing: an assessment tool for local commissioning has been developed by PHE, the Alzheimer society and the LGA. It is intended to help local partner organisations identify what needs to happen to ensure future local commissioning decisions for health and wellbeing are based on an understanding of:

- ➔ The importance of the **physical home environment** to the health and wellbeing of people with dementia, their families and carers
- ➔ The contribution that **housing-related services** and interventions can make to the wellbeing of people with dementia, their families and carers
- ➔ The contribution the **housing workforce** can make to the wellbeing of people with dementia, and what is needed to develop this workforce,
- ➔ The **perspective and housing needs of people with dementia**, their families and carers, and the support needed to ensure this is central to decision making.

#### **4.9.13 Home Care**

Many people with dementia want to live at home for as long as possible and home care is a key factor in enabling them to do so. The report Dementia & Homecare: Driving Quality & Innovation provides clear recommendations, practical ideas and suggestions for improvement.<sup>196</sup> It is important to:

1. Champion homecare as the key facilitator of dementia care and information;
2. Deliver a personalised approach focused on outcomes for the individual & their family;
3. Give greater flexibility for homecare providers to innovate and shape care with and for the individual;
4. Recognise and realise the value of homecare to reduce risk & lessen the negative impact of dementia progression;
5. Prioritise homecare as a cost-effective form of intervention;
6. Ensure sufficient time to deliver the care people with dementia need in the way they want;
7. Develop consistent and reliable homecare services;
8. Help providers to implement & experiment with technology;
9. Develop research on care, as well as cure.

#### **4.9.14 Care Homes**

Care homes, whether residential or nursing, provide short term respite as well as long-term care for people who can no longer live independently in the community. Often this is decided during or after an admission to hospital. A substantial proportion of residents living in care homes have dementia or significant memory problems. Many people with dementia do not have an opportunity to visit the care home they are placed in. Arranging a care home admission can be associated with considerable worry and guilt for carers. It can also be a significant source of delay in discharging a person from an acute hospital bed.

There are several good and bad examples of dementia provision in care homes as found in The Alzheimer's Society report on care homes called *Low Expectations*.<sup>197</sup> The report describes the low expectations people have about the quality of care provided in care homes and the quality of life for residents. The report argues that our expectations need to increase in order to improve standards of care. An example of best practice in care home management is given by Merevale residential home.<sup>198</sup>

Care homes fall under the Care Quality Commission [CQC] inspection regime. The CQC is the independent regulator of health and social care in England and is responsible for monitoring, inspecting and regulating health and social care services. Inspection reports and ratings are publicly available on their website. Additionally, the ESCC Adult Social Care Quality Monitoring Team [QMT] is responsible for monitoring the contractual compliance of current care managed contracts, and acting as a key interface for safeguarding and complaints activity. The QMT team works by developing good working relationships with providers. They are developing a Care Governance Framework to monitor and assess the quality of care services provided by the independent sector. The aim of the team is to monitor and improve a range of care services in terms of:

- quality
- performance
- keeping to contractual agreements
- value for money

The QMT manages the Preferred Provider Schemes and any updates and notifications to the suspension list when care providers are temporarily suspended from taking on new work.

#### 4.9.15 Respite Care

Respite may be defined as “a pause, temporary cessation, or an interval of rest”. Respite can also mean when there is physical separation of the carer from the care giving situation. Respite care can take various different forms: home-based respite, day opportunities in day centres, live-in care, and residential respite in care homes.

There is a difference between *home care*, usually a short visit, focused on meeting the personal care needs of the person with dementia and *home-based respite care*. The latter is where a care worker comes into the home to give the carer a break and enable them to go out.

National and international reviews of the literature have indicated that, whilst respite care is highly valued, uptake is poor.<sup>8</sup> This may be because carers are unaware of what's available to them. There are also other barriers to accessing respite:

- ➔ There is a stigma associated with using respite care. Carers may have feelings of guilt and a perceived failure in the fulfilment of their duty. There can be apprehension that the person with dementia will become angry, resentful or distressed.
- ➔ Respite care is less likely to be required where other family, social care or health service support is available. Those looking after people with higher personal care needs are more likely to seek respite.

The objective evidence of the benefit of respite care is conflicting.<sup>8</sup> A study of the use of respite for people with dementia found that staff providing care are a key feature of respite success.<sup>8</sup> Staff attributes that tend to be well regarded by carers include: showing respect; providing emotional support; being willing to listen and talk to the carer; relieving the family's feelings of guilt; providing education and information. The carer needs to be able to hand over the care of the person being cared for and staff should place themselves in a supportive role to the carer.

No respite model appears to be superior to another. National research has recommended that a range of services should be available to enable carers to have a choice over the timing, flexibility and length of respite break.<sup>199</sup>

While some carers prefer in-home care respite, as this is less disruptive to the carer's routine, other carers do not like having strangers in their home. Carers have expressed a wish to be able to specify which staff will provide the care. Maintaining the stability of the same respite care staff is important for building rapport. A facilitator may help individual carers to identify activities they can participate in to make best use of their respite time and which are most likely to improve their wellbeing. Carers have been known to perform household tasks that require two people rather than take a proper break.

Adult day care may be sociable for the person with dementia, but for the carer this can incur a considerable amount of extra work and preparation. Given that people with dementia have declining health status over time, respite care may be moderating the negative effects of the caring role in an otherwise deteriorating situation. Using respite earlier has been shown to delay institutionalisation due to a greater opportunity to receive support and acclimatise to the caring role.<sup>200</sup>

## **4.10 What support services are available for carers in East Sussex?**

### **4.10.1 Investing in support for carers**

Investing in support for carers is covered in the East Sussex Better Together [ESBT] Carers Investment Strategy.<sup>201</sup> The ESBT vision supports carers in sustaining their caring role with the aim of preventing the need for alternative high cost services from both social care and health care.

The range of services commissioned on behalf of carers is summarised according to the ESBT Six Box Model in East Sussex, (please see Appendix 2). The range of services commissioned for carers is shown in Table 37; some of these support services are generic and not specific to carers of people with dementia.

### **4.10.2 Dementia-specific support services in East Sussex:**

Most carer services are available county-wide. There are pilot services in two local areas specifically relating to dementia care. These are:

- 1) in HWLH CCG, The Golden Ticket project in Buxted, which ended in December 2015.
- 2) in H&R CCG the primary care pilot project with Bexhill practices, funded until March 2017.



**Table 37: Range of services commissioned on behalf of carers**

<b>Healthy Living and Wellbeing</b>	WRAP (Wellness Recovery Action Planning) – allows carers to explore safe and simple tools to help maintain their wellbeing and support, when facing challenges
	Dementia Supper Clubs – 8 monthly clubs held in pubs across the county for people with dementia and their carers to socialise with support provided by ASC
	Singing for the Brain - Singing groups for people with dementia & their carers
	Telephone counselling-provided by The Association of Carers for housebound & bereaved carers.
<b>Proactive Care</b>	Care for the Carers – East Sussex Carers Centre - Support and activities to enable carers to build resilience, develop coping strategies, build networks of support and help carers to maintain their health & wellbeing.
	Carers Breaks and Engagement Team-This started out as a DH Demonstrator Site project funded to provide flexible short breaks to carers of people with dementia. Following successful evaluation, the service continued and has now expanded to support all adults with care and support needs through short term interventions to facilitate access to sustainable activities and services in the community. This is now mainstreamed and jointly funded by the CCGs and Adult Social Care. The Bexhill pilot will link this service directly with primary care and the localities.
	Dementia Support Service - group and 1:1 support plus information & advice, CrISP (Carers Information & Support Programme) – a validated programme for carers of people with dementia.
	Improving Carers Experience Project-Information and training for carers of people with functional mental health problems providing practical information and strategies to promote wellbeing in the cared-for person and the carer themselves, as well as peer support.
	Counselling – delivered by volunteer counsellors at a range of national venues.
	Carers' Toolkit - training to equip carers with skills and information on a wide range of caring issues, which will improve their health and wellbeing, and ensure they have a better knowledge of the support services available to them.
	Volunteer support and counselling for carers of hospice patients.
	Headway – Information, support and healthy activities for carers of people with Acquired Brain Injury.
<b>Crisis Intervention</b>	Motor Neurone Disease Association - Sitting service, peer support groups, info & advice.
	CRESS - Provision of replacement care in an emergency. Agreed emergency plan to provide replacement care to the cared for person if carer experiences unexpected event that prevents them from caring, e.g. accident/illness.
<b>Maintaining Independence</b>	British Red Cross - Short term and crisis intervention – promotion of health and well-being to carers and support via companionship, conversation and practical support and/or enabling the carer to take a short break whilst they support the cared for person. Trained volunteers actively support carers to find opportunities to attend social groups, training or help, seek employment through networking.
	Respite – replacement care, providing breaks for carers can be home based, residential or through activities in the community, or day care service. It can also enable carers to attend their own healthcare appointments and training relating to their caring role.
	Volunteer Respite in the home – regular weekly break for carers.
	Computer Help at Home – support to use a range of technology, email, Skype, smart phones/TVs, tablets, research conditions, book health appointments, online shopping etc.
	Talk & Support - telephone support service providing Carers with emotional support, signposting to additional support and professional counselling when needed. It provides peer support opportunities between Carers and former Carers and between volunteers.
	Carers Personal Budgets – Direct Payments to carers to enable them, to meet their eligible support needs.
	Ambitions - vocational support to carers and former carers in relation to employment, education and training, and volunteering opportunities.



### 4.10.3 Carers Assessment

Carers Support Plans are produced following a carer's assessment, except in cases where only information and advice have been provided.

Carer reviews are undertaken at the same time as a review of the needs of the person being cared for.

Carers can re-contact the ASC department for an annual review, or an unscheduled review, if needed.

The proportion of adult carers in East Sussex who report having as much social contact as they would like (37.5%) is similar to other local authorities in the region and is summarised in Table 38. There were only very few respondents to the survey in East Sussex (less than 20) so it is difficult to draw any meaningful conclusions.

**Table 38: Social contact reported by carers**

Social Isolation: % of adult carers who have as much social contact as they would like			2014/15	Proportion - %	
Area	Count	Value		95% Lower CI	95% Upper CI
England	-	38.5		38.0	39.0
South East region	-	35.5		33.8	37.2
Bracknell Forest	-	44.2		39.2	49.2
Brighton and Hove	-	42.6		37.8	47.4
Buckinghamshire	-	38.9		35.5	42.3
East Sussex	-	37.5		33.6	41.4
Hampshire	-	28.5		24.7	32.3
Isle of Wight	-	31.4		27.8	35.0
Kent	-	33.9		30.2	37.6
Medway	-	41.0		37.7	44.3
Milton Keynes	-	33.1		26.7	39.5
Oxfordshire	-	38.5		35.1	41.9
Portsmouth	-	47.1		44.0	50.2
Reading	-	36.6		31.8	41.4
Slough	-	39.0		32.9	45.1
Southampton	-	49.5		44.6	54.4
Surrey	-	35.8		33.4	38.2
West Berkshire	-	38.8		34.1	43.5
West Sussex	-	36.1		32.2	40.0
Windsor and Maidenhead	-	36.5		31.7	41.3
Wokingham	-	33.8		29.8	37.8

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

Source: Personal Social Services Survey of Adult Carers in England, 2014/15

National data from the Personal Social Services Survey of Adult Carers in England, 2014-15 report that just over half of carers felt they were looking after themselves well in terms of sleep and nutrition.

### 4.10.4 Safeguarding

Caring for another person can be very rewarding but also very demanding. Sometimes people who are being cared for can harm or abuse their carer; this can happen because they have a condition that changes their behaviour. When a carer is managing a challenging situation, this can lead to them abusing or neglecting the person they care for, whether this is intentional or unintentional. Adult abuse issues are dealt with in ESCC by the Local Safeguarding Adults Board.<sup>202</sup>

### 4.10.5 Home Care in East Sussex

Home Care is purchased from the independent sector as part of the Community Services Contract. There are currently six areas with a lead provider in each area. There is an approved provider list that provides additional choice and capacity. These providers of services should be able to work with any client group, including people with dementia. The majority of the support in East Sussex is purchased within the independent sector, whether

for people with dementia, older people, people with a learning disability, or physical disability.

Reablement is about helping people regain the ability to look after themselves following illness or injury. The reablement approach to care in East Sussex is provided by the joint community reablement teams. These are multi-disciplinary teams, which are employed as a first option for new entrants, and can help after discharge from hospital of a person with dementia.

There are many day opportunities commissioned, with some solely supporting people living with dementia at varying levels of severity. The provision of day care has moved to the independent and voluntary sector in recent years, as ESCC has closed its own in-house services. Overall demand has reduced.

#### 4.10.6 Extra care housing<sup>203</sup>

##### Definition

Extra care housing is housing with care, primarily intended for older people, where occupants have specific tenure rights to occupy self-contained dwellings and where they have agreements that cover the provision of care, support, domestic, social, community or other services. Unlike people living in residential care homes, extra care residents are **not** obliged to obtain their care services from a specific provider, although services (such as some domestic services, costs for communal areas including a catering kitchen), might be built into the charges residents pay.

*“A fundamental feature of housing with care is that it is a housing model. Whilst on-site services may – and indeed should be – co-ordinated effectively, legally, the housing is a separate entity from the care – if it were otherwise, schemes would be liable to registration as care homes. Occupants have security of tenure and housing rights afforded by their occupancy agreements and cannot be required to move, unless in breach of the occupancy agreement.”*

Extra care housing can accommodate people with dementia and provides an alternative to residential care in a safe, secure environment. It also offers the potential for considerable cost benefits to both Adult Social Care [ASC] departments and the NHS.<sup>204</sup> ESCC ASC has led on this agenda in partnership with Borough and District councils and registered providers (Housing Associations).

People in the early to moderate stages of dementia may be successfully accommodated in extra care housing, although this will depend on individual circumstances. Many of those people who develop dementia after moving into extra care are able to stay there until they die. Some people need to move on to nursing home care. A local estimate of the proportion of older people living in extra care schemes who have dementia is between 15% and 20% per scheme. [Source: strategic commissioner ASC ESCC]. An even higher proportion [25%] has been reported in the literature.<sup>203</sup> People with an assessed care need are referred by Adult Social Care to affordable *rented* places in extra care schemes. However, there is no requirement for people who choose to *purchase* extra care housing, either outright or with shared equity, to have a care need although this is the intended market.

##### Current provision of extra care housing

There are 8 recently developed extra care schemes in East Sussex. At the time of writing, places were being allocated in three of these schemes. They are located as follows:

1. Hastings and Rother CCG: four schemes with a total of 188 units.  
➔ The Marlborough, St Leonards has 40 units all rented–due back in operation in Autumn 2016, following a serious fire.

- ➔ The Orangery, Bexhill has 58 units (42 rented, 16 shared ownership).
- ➔ Newington Court, Ticehurst (this is the only rural scheme) has 35 units, all rented.
- ➔ St Bartholomews, Rye has 55 units (40 for rent, 15 shared ownership).

2. **Eastbourne Hailsham and Seaford CCG**: two schemes with a total of 107 units.
  - ➔ Cranbrook, Eastbourne has 62 units (52 rented, 10 shared ownership).
  - ➔ Bentley Grange, Hailsham has 45 units (35 rented, 10 shared ownership).
3. **High Weald, Lewes and Havens CCG**: two schemes with a total of 80 units.
  - ➔ Margaret House, Uckfield has 39 units (29 rented, 10 shared ownership).
  - ➔ Downlands, Peacehaven has 41 units (30 rented, 11 shared ownership).
  - ➔ Source: Strategic Commissioning Manager, ASC ESCC.

### 4.10.7 Sheltered housing

Sheltered housing is an established service model. There is a considerable amount of sheltered provision across East Sussex. Some of this provision is owned by Boroughs and Districts, some by registered providers and some is in private ownership. There are different tenure options available. The breakdown of provision across all types of tenure is: Hastings and Rother CCG, 76 schemes; Eastbourne, Hailsham and Seaford CCG, 86 schemes; High Weald, Lewes, Havens CCG, 69 schemes.<sup>205</sup> Figures are not available in ESCC for the number of people with dementia and currently living in sheltered housing.

### 4.10.8 Provision of residential/nursing care for people with dementia in East Sussex

There are relatively more care home beds per head of population aged 65 and over in the H&R CCG area than in EHS and HWLH CCG areas. Similarly there are more beds in care homes which will accept patients with dementia in H&R CCG area. This highlights a historical pattern of provision in East Sussex with a higher number of homes in the coastal strip and higher population density compared to the more rural and northern parts of the county.

Table 39 shows care home bed availability in East Sussex, the rate of bed provision per head of population aged 65 and over, and bed provision in care homes which specifically state they will accept people with dementia for each CCG.

**Table 39: Care home beds in East Sussex**

		Number of beds	Population 65+	Rate of provision per 1000 persons aged 65+
HWLH CCG	Total care home beds	1843	36,010	51
	Dementia included	903		25
EHS CCG	Total care home beds	2538	47,787	53
	Dementia included	1353		28
H&R CCG	Total care home beds	2774	44,004	63
	Dementia included	1539		35

Source: service placement team ASC ESCC and Public Health

### 4.10.9 Respite care [residential]

There is limited provision in East Sussex of EMI [Elderly Mentally Infirm] residential/nursing care, for respite and long term care. There is a programme of bookable, rolling respite provision in East Sussex. Funding is allocated as part of the client’s personal budget. The

client/carer receives written confirmation of how many weeks funding they *can* access per annum. They are then free to book their own respite. In practice, it is not always feasible to continue to use the same care home for respite care on each occasion. Respite beds can usually only be booked two weeks in advance. Whether one can be found depends on what's available in the sector at the time. There are issues in people getting access to respite care. This is primarily due to bed capacity and not due to availability of funding. More homes are closing than are opening. Planning applications may not be considered by district councils or are contested. Finding a bed is difficult. Although there is respite provision for clients that need dementia nursing in the Havens area it is currently suspended. If people can't access respite locally clients/carers need to look at the wider East Sussex area. It is not uncommon for clients to refuse respite care offered in other areas, even though a bed has been found by the secondary care provider.<sup>206</sup> Clients want a care home near where they live.

#### 4.10.10 ESCC Directly Provided Services (DPS)

##### Intermediate Care

Intermediate care is available to support timely discharge from hospital for people with dementia who would benefit from assessment, rehabilitation, and possible phased return home. In some cases the service can provide an alternative to hospital admission. ESCC directly provides intermediate care beds [both step-up and step-down beds] in Eastbourne: in Milton Grange, with day care, 40 Intermediate Care Services and respite beds; and Firwood House in Hampden Park, with 21 beds Intermediate Care Services with nursing care. ESCC ASC also commission Intermediate Care beds at Bowes in Hailsham. There is ongoing project work between the ESCC ASC department and ESHT NHS relating to all intermediate care bed provision in the H&R and EHS CCG areas. There are also NHS units at Rye Memorial Hospital and the Irvine Unit, Bexhill.

##### Day Care

Warwick House in Seaford, is a day care service for people with dementia. All other residential & day services are provided in the independent sector (private & voluntary) and are spot purchased.

#### 4.10.11 What do we know about the quality of dementia care in care homes in East Sussex?

- ➔ **It is notable that there have been ten care home closures in East Sussex since May 2015.** There are a further two homes, with a total of 59 closed beds, subject to appeal to the CQC, at the time of writing. Reasons for closure have included failed CQC inspections and financial stability.
- ➔ **In the homes which have closed since May last year there were 270 beds, of which 117 were designated as intended for dementia residential or nursing care.** This represents a loss of about 3% of the total capacity in the sector. The remainder of closed beds were for older people's residential or nursing home care.
- ➔ **There are a further ten care homes which are closed to new admissions [three of which are EMI care homes] at the time of writing.**
- ➔ **There have been two suspensions of extra-care housing in May 2016.**

Source: Quality Monitoring Team ASC ESCC.

**4.10.12 How do LA, NHS and self- funded placements differ across East Sussex?**

There is a much higher proportion of elderly persons funding their own care in HWLH CCG than in EHS and H&R CCGs. This reflects the income differential between people living in HWLH and EHS and H&R CCGs.

The term ‘continuing health care [CHC] funded’ refers to where the NHS agrees to fund the cost as part of a package of care. There is a higher proportion of CHC funded beds in HWLH CCG (Table 40) but more spare bed capacity in care homes in H&R CCG.

**Table 40: Sources of funding of care home beds**

	HWLH CCG	EHS CCG	H&R CCG
Total Beds	1,843	2,538	2,774
ASC Funded	18.07%	28.21%	30.10%
CHC Funded	3.04%	2.64%	1.84%
Vacant	4.83%	5.63%	10.56%
Self Funders / Other LA	74.06%	63.52%	57.50%

Source: ESCC ASC dept. Autumn 2015

**4.10.13 Where are people with dementia living in East Sussex?**

The estimated proportions of patients living in the community, or a care home, are summarised for each CCG in Table 41.

**Table 41: Where are people with dementia being cared for?**

	No.in community	No.in care homes	% in care homes
HWLH CCG	1,908	636	25.0%
EHS CCG	2,787	1,212	30.3%
H&R CCG	2,356	1,102	31.9%

Source: NHS Primary Care Web tool, accessed 17th February 2016

A relatively smaller proportion of patients with dementia are cared for in the care home sector in HWLH CCG compared to EHS and H&R CCGs. EHS CCG has the highest estimated numbers of people with dementia living in care homes and also in the community. H&R CCG has the highest proportion of people with dementia living in a care home.

**4.10.14 What are the gaps in the social care system?**

1. There is a **challenge to finding suitable respite** care in East Sussex because of capacity issues.
2. **Capacity issues in the nursing home sector have been exacerbated by care home closures in the past year**, caused by providers failing the CQC inspection and/or financial instability. Many of the closures were in homes providing dementia care. There are a further ten care homes which are not operational, i.e. currently closed to new admissions, [three of which are EMI care homes]. These closures and suspensions cannot have helped the process of discharge from hospital. Evidence is now being collected prospectively in the National Dementia audit to look at the effect of care home closures on bed blocking in the acute hospital sector.
3. **Capacity issues also affect people with dementia with increasing needs in the community and the choices available** to them and their relatives. A recent example of system problems caused by escalating needs is illustrated by the following root cause analysis of a case in ESHT [one of a number of cases of this nature encountered on a regular monthly basis by the dementia lead nurse in ESHT].

### **Case study: problems where behaviour escalates in the community**

A care home patient with an escalation of disturbed behaviour over a period of a few months was taken to A&E as an emergency. A&E assessment was that there was no need for acute hospital admission and the patient was medically fit for discharge.

The care home would not take the patient back after attending A&E due to inability to keep other residents and staff safe.

There were subsequent delays in arranging admission to Moreton House from ESHT. In the interim there was intensive staff resource required in the Clinical Decision Unit to manage the patient.

There is no anticipatory strategy in place that ESHT and SEC Ambulance are aware of, and that can be accessed easily in and out of hours. There is no appropriate single destination with joint clinical and psychiatric care.

Source: dementia lead nurse ESHT



## 4.12 End of Life Care

### 4.12.1 Introduction

One in three people over the age of 65 will die with dementia. It is one of the top five underlying causes of death.<sup>207</sup> It is essential that family members, carers and professionals recognise and understand when the person with dementia is nearing the end of their life. Ensuring that the person with dementia's Preferred Priorities for Care Plan<sup>208</sup> is reviewed regularly will give clinicians the confidence to arrange care in the preferred place. Spiritual and cultural needs should be taken into account at all phases of the care pathway. End of life care is an important part of someone's dementia journey. People with dementia may die because of another illness. For example at the end-stage of dementia people can have difficulty eating, leading to an aspiration pneumonia. There are a number of end of life services available. None of them are specific for dementia but they do include dementia alongside other terminal conditions.

### 4.12.2 End of Life Care Strategy

The End of Life Care Strategy<sup>209</sup> outlined what should be regarded as a "good death". The report suggested the following components.

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

These provide a good measure of how to deliver high quality end of life care in dementia. There have been a number of recent national reports on the subject of end of life care.<sup>210 211 212 213 214 215 216</sup>

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

### 4.12.3 Having a preferred care plan:

Having a preferred care plan gives an opportunity for people with dementia and their carers to document their wishes for their care as they approach the end of their life. In England, if people choose to make an advance care plan this can be:

- An advance statement, which can cover anything to do with future care including the values they want to guide their care, their thoughts on different treatment options, or where they would like to be cared for. It can include all types of wishes, not just those about medical care
- An advanced decision to refuse treatment ADRT. This is a decision to refuse a specific type of medical treatment in the future if the person loses the ability to make his or her own decisions. It is usually legally binding.

Advanced Care Planning works best when there is a supportive discussion with a health or social care professional so that people understand their condition and care options.<sup>217</sup>

Advanced Care Planning can also help to reduce unnecessary emergency admissions to hospital and improve quality of end of life care.<sup>218 219 220</sup>

The Gold Standards Framework and End of Life Register is accepted best practice to support the person with dementia to a 'good death', and focuses on enabling generalists to provide a 'gold standard' of care for all people nearing the end of life in all settings.<sup>221</sup>



A locally commissioned service for palliative care is in place in HWLH, H&R and EHS CCGs. This service encourages clear communication between professionals during the phases of palliative care. Practices are encouraged to use electronic methods, the Summary Care Record and enhanced End of Life Care [EOLC] record to update both the in-hours and Out Of Hours providers whenever there are changes to a patient's care and health status. The service ensures joined-up delivery of care to patients at the end of their life. Professionals can see and contribute to an advance care plan and this helps with implementing the South East Coast Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) policy. Preferred care plans will include the patient's preferred place of care and preferred place of death. There is a multidisciplinary significant event review of the care given at GP practice level after a patient has died.

End of Life Care in HWLH CCG was reviewed by the Care Quality Commission. The CQC undertook benchmarking against national and local End of Life Care priorities. The formal CQC report, which forms part of a national report, is awaited. Other JSNAs have commented on a lack of capacity within community services to allow expedited discharge from hospital for people with dementia who are at the end of their life, to allow them to die in the place of their choice.<sup>222</sup> ESHT end of life care has also been reviewed by the CQC. There is a local guideline in the Hastings and Rother Area for the management of complex cases and predictable specified medical complications at the end life.<sup>223</sup> There is also a rapid discharge service provided by St Michael's Hospice, Hastings, which started in May 2016 but not yet in Eastbourne.

#### **4.12.4 Do people understand and know how to access legal support?**

If someone has dementia it is important that they organise their legal and financial affairs before their mental capacity deteriorates further. Making the correct legal and financial choices is important because it helps carers and public services make decisions which would be consistent with what the person with dementia would have wanted. Legal services include:

- ➔ **Making wills**
- ➔ **Lasting Power of Attorney** (both components 1. property and financial affairs and 2. health and welfare).
- ➔ **Enduring Power of Attorney** (the old style of document referring only to property and financial affairs).

Some people with dementia lose their mental capacity before making a will or arranging a Lasting Power of Attorney. This can have significant consequences: a person with dementia may receive more hospital treatment than they would otherwise have chosen. There is a need to provide people with dementia and their carers with comprehensive legal advice and information shortly after diagnosis in order to allow them to make informed decisions. In other JSNAs, discussion with people with dementia and their carers suggests a lack of knowledge and information about legal support available.<sup>222</sup>

#### **4.12.5 The local position**

It is important to note that the proportion of East Sussex residents with dementia aged 65 and over dying in their usual place of residence [73.0%] was higher than the Regional [70.9%] and England value [67.5%] in 2014.<sup>224</sup>

An indication of how the whole process is working locally is given in: The Dementia Timeline, a project by Dementia Support at the Bridge, Hastings. This gives carers' perspectives on the issues and needs for emotional, practical and medical support and interventions along

the dementia patient journey.<sup>225</sup> The stages vary from case to case and overlap. They include:

- First suspicions;
- I think we need to see the doctor;
- First consultation;
- Assessment;
- Diagnosis;
- 3/6 months post diagnosis;
- Early stages;
- Mid Stages;
- Later Stages;
- Preparation for Residential Care;
- Residential Care;
- Bereavement;
- Post Bereavement.

## 4.13 Medicines Management and Prescribing

### 4.13.1 Introduction:

Many people with dementia take a number of medicines for their long-term medical conditions. These are in addition to a group of drugs prescribed on a shorter term basis for managing the symptoms of dementia. For someone whose memory is impaired, making sure all medicines are taken at the right time, in the right way and watching out for side effects can be challenging. For their carers managing medications can be difficult, especially if the person with dementia has challenging behaviour.

### 4.13.2 What drugs are prescribed to improve or stabilise dementia?

#### NICE clinical guideline dementia (CG 42)<sup>19</sup>

Currently four drugs are recommended as options for managing Alzheimer's disease. Donepezil, galantamine and rivastigmine are recommended for managing mild to moderate Alzheimer's disease. They may only be effective at improving symptoms for between 6 to 12 months although some patients may derive benefit for much longer. Improvements noted have included motivation, anxiety levels and confidence, in addition to daily living, thinking and memory. Memantine is an option for managing Alzheimer's disease for people with severe Alzheimer's disease, or with moderate disease for those people who are intolerant of, or cannot have the three drugs listed above.

Not all people with dementia benefit from these drugs and NICE only recommends continuation where there is ongoing benefit. NICE recommends a number of non-drug treatments such as cognitive stimulation therapy (CST). NICE did not specify which drug is the most cost-effective, but states that treatment should normally be started with the drug with the lowest acquisition cost. Donepezil, galantamine and rivastigmine [AChE inhibitors] should not be prescribed for people with Mild Cognitive Impairment (MCI) unless as part of a properly constructed clinical study.

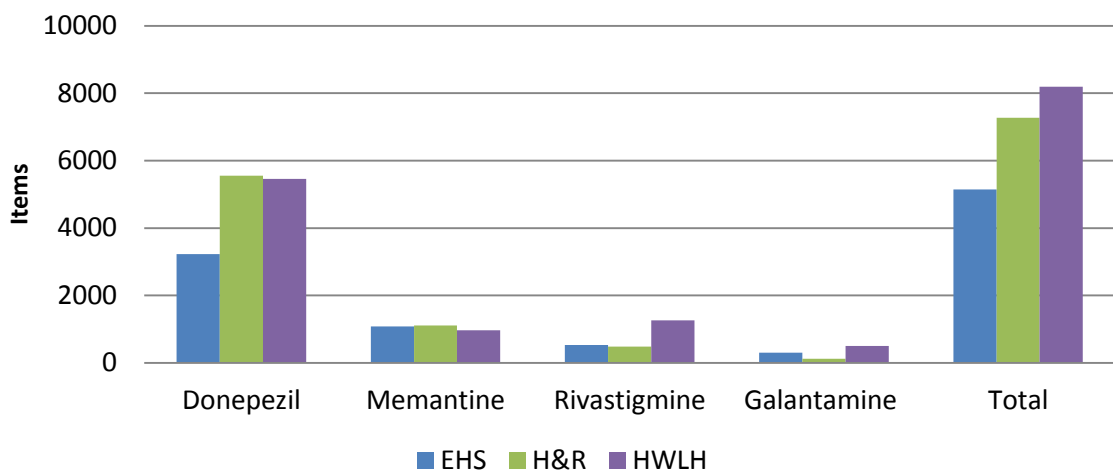
### 4.13.3 Prescribing to manage dementia in East Sussex

The Memory Assessment Service [MAS] initiates treatment and, once stabilised, patients are discharged back to their GPs. Not all cases are managed between GPs and the MAS. Secondary care services, including mental health, manage more complex cases and initiate and stabilise patients on anti-dementia medications. SPFT have a significant case load in secondary care including assessment and management of various complex cases and follow ups.

The H&R and EHS CCG medicines management team has produced Dementia Prescribing Guidance for GPs, aimed at supporting GPs with ongoing care and medication reviews once patients have been discharged from the MAS. HWLH CCG have similarly produced specific information for GPs to support on-going prescribing on patient discharge.

In terms of quantity, donepezil is the most frequently prescribed dementia drug in all E.Sussex CCGs, (Figure 33).

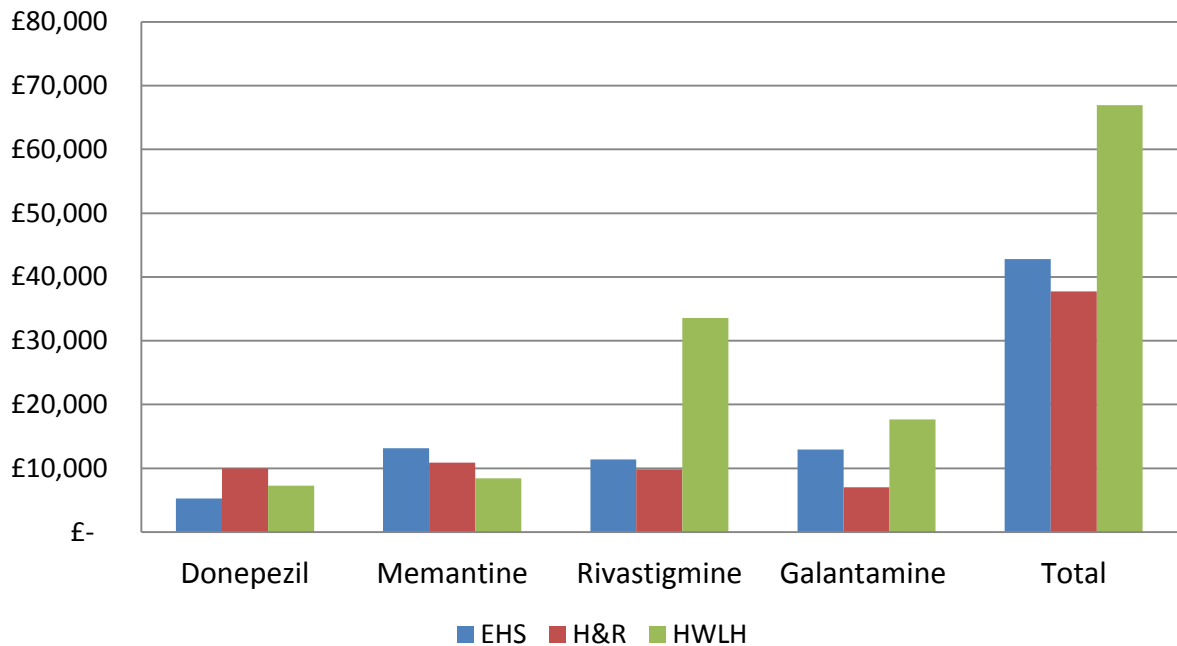
Figure 33: Prescribing of drugs to manage dementia in CCGs in East Sussex 2014/15



Source: HSCIC

In terms of overall cost, in 2014/15 spend was highest in HWLH CCG on rivastigmine and galantamine, Figure 34. The data shown refer only to primary care prescribing<sup>viii</sup>.

Figure 34: Spending on drugs to manage dementia symptoms in E. Sussex CCGs, 2014/15



Source: HSCIC

All patients should be having medication reviews by their own GPs. The Quality Outcomes Framework (QOF) offers remuneration for a practice where 80% of all patients with a repeat prescription have had a medication review in the past 15 months. This review could be undertaken by a GP or pharmacist.

<sup>viii</sup> There is a cohort of legacy patients retained within the MAS under the care of SPFT. Some of the difference in total expenditure can be explained by the continued prescribing for some dementia patients by SPFT and not by their GP. This is marginally greater in EHS CCG [£100k] than in H&R CCGs [£90k] and HWLH CCG [£90k] in 2014-15.

The difference in cost of SPFT prescribing for dementia patients between CCGs is very much reduced in the following financial year 2015-16, though still present: EHS CCG [£41k] H&R CCG [£49k]; HWLH CCG [£40k].

#### 4.13.4 Use of anti-psychotic drugs

The Committee on Safety of Medicines (CSM) in 2004 published guidance highlighting that regular use of anti-psychotics in elderly patients with dementia is associated with a three-fold increase in stroke and a two-fold increase in mortality. In 2009, an independent review of anti-psychotics as part of the National Dementia Strategy concluded that associated risks of prescribing anti-psychotics for these patients far outweighed the benefits. This led to a government pledge to reduce prescribing by two-thirds by November 2011.<sup>226</sup> Antipsychotics should only be used to treat **non-cognitive symptoms**, such as **psychosis and/or agitated behaviour causing significant distress or immediate risk of harm** to the person with dementia or others.

#### 4.13.5 What is the current use of long-term anti-psychotic drugs in E.Sussex? Are these being used appropriately?

NICE guidance gives clear advice about when antipsychotics should be used. "People with Alzheimer's disease, vascular dementia, mixed dementias or DLB with severe non-cognitive symptoms (psychosis and/or agitated behaviour causing significant distress) may be offered treatment with an antipsychotic drug after the following conditions have been met.

There should be a full discussion with the person with dementia and/or carers about the possible benefits and risks of treatment. In particular, cerebrovascular risk factors should be assessed and the possible increased risk of stroke/transient ischaemic attack and possible adverse effects on cognition discussed.

- ➔ Changes in cognition should be assessed and recorded at *regular* intervals.
- ➔ Alternative medication should be considered if necessary.
- ➔ Target symptoms should be identified, quantified and documented.
- ➔ Changes in target symptoms should be assessed and recorded at regular intervals.
- ➔ The effect of co-morbid conditions, such as depression, should be considered.
- ➔ The choice of antipsychotic should be made after an *individual* risk–benefit analysis.
- ➔ The dose should be low initially and then titrated upwards, although it should be borne in mind that only risperidone has a specific licence for use in Alzheimer's disease, (for the treatment of persistent aggression in moderate to severe disease).
- ➔ Treatment should be time limited and regularly reviewed (every 3 months or according to clinical need)."

There have been historic projects on reducing antipsychotic prescribing in dementia in response to the 'Call to Action'. There have not been any *recent* audits of anti-psychotic prescribing in the context of dementia as part of patient medicine reviews in East Sussex.

SPFT have a GP resource pack on their website 'Reducing Antipsychotics in People Living with Dementia' and this has also been made freely available to CCGs. A SPFT pharmacist is working (as part of the care home in-reach team) to assist care homes across Sussex and other pharmacists directly supporting SPFT community mental health teams, including those providing dementia services.

EHS and H&R CCG are commissioning a new Medicines Optimisation in Care homes service (starting April 2016). One of the areas that the pharmacists will be supporting the GPs to review is antipsychotic prescribing in dementia. Practices could be asked to audit patients over 65, with an antipsychotic prescription, whilst excluding those with a diagnosis of schizophrenia or other psychosis. HWLH CCG have developed an integrated pharmacy workforce pilot within general practice which will also support clinical medication reviews in this cohort of patients which they envisage rolling out across the CCG.

#### 4.13.6 What advice/support is there for people with dementia in East Sussex in managing their medications?

There are several community services available to help people with dementia and their carers manage medications. The Medicines Use Review [MUR] service is a commissioned service offered free to patients by community pharmacists. People with dementia and/or their carer can discuss with a pharmacist their medications and possible side effects.

The pharmacist is able to offer advice and support about taking medicines. This can include undertaking domiciliary visits and might include the use of dosette [pill taking] boxes for each day. Medication Administration Records [MAR] prepared by the pharmacy can also help. There is also a New Medicines Service [NMS] for pharmacists to help people with long term conditions who are newly prescribed a medicine. Medication errors can potentially be reduced by pharmacists using new decision support systems.<sup>227</sup> Stopping inappropriate prescribing may also be relevant as the end of life approaches, after a careful consideration of risks and benefits.<sup>228</sup>

Part of the pharmacist's duty is to undertake an Equality Act 2010 assessment where appropriate. This allows people with physical or mental disability to have a "reasonable adjustment" to their medicine services. People with learning disabilities and dementia would be included in this category. The nature of the reasonable adjustment depends on the needs of the person with dementia and their carer. Pharmacies are expected to comply with the Act which includes having wheelchair access. Many are installing induction loop systems for those with hearing difficulties. A pharmacy delivery service offers free delivery for those who are housebound, or have difficulty getting to a pharmacy. This is not a commissioned service, however.

The county-wide Carers Breaks and Engagement service have many examples where people with dementia are given a prescription which they forget to hand in to the pharmacy. There are examples where pharmacies have several months' back log of medications because the patient with dementia has not been at home when the pharmacy has tried to deliver, or have forgotten to collect them. There is no link back to the GP, so the GP is not aware that the patient is not taking the medications prescribed.

***In Norfolk JSNA, discharge from hospital was highlighted as a particularly important period.<sup>222</sup> Anecdotal reports from pharmacists suggested that people with dementia are often discharged from hospital without enough information.*** For example, changes have been made to doses, or drugs stopped without a clear reason or explanation. This is especially important for people with memory problems and their carers who rely on good communication between, and from, professionals.

The issue of hospital discharge has been discussed locally with the community pharmacy lead following the joint ESHT & ESCC JSNA project. A recent pilot study from the Isle of Wight NHS Trust has shown the potential benefits of improved liaison between hospital pharmacist and community pharmacists in reducing admissions over a year, the probability of readmissions within 30 days, and savings on bed days [paper in press].

The Healthy Living Pharmacy concept may enable greater signposting to community services for dementia, and the provision of 'flu immunisation. Community pharmacies support people with difficulties accessing the pharmacy with medicine delivery services. These are not currently commissioned.

Pharmacies have a role in reducing CVD risk in the general population by participating in smoking cessation campaigns. They can also set a good example by being dementia friendly businesses as well as being carer friendly.

## 4.14 Workforce Training and Development

### Introduction

People with dementia and their carers have contact with a wide range of professionals from both health and social care. Most staff are in non-specialist, frontline roles that look after people with a range of health and social problems. In any given week a person with dementia and their carer might interact with the GP receptionist, the pharmacist, their home carer(s), for personal care, or a social worker.

When going to hospital, a person with dementia will meet lots of people as they move through the system, from the ambulance staff, the A&E team, the ward teams, to the discharge team. If any one of these individuals is insufficiently trained in their understanding of dementia, this can impact upon the whole experience of the person with dementia and their carer.

The wider workforce includes those staff working in sheltered living schemes and extra care housing schemes. They too need training so they can sign post people for memory assessment where appropriate, and know about support services that are available.

There are wider benefits of a well-trained workforce. A professional who communicates well with someone with dementia, is more likely to communicate well with other vulnerable people.

#### 4.14.1 What levels of specialist staff and volunteers exist?

There are different levels of specialist staff. These include:

- ➔ Dementia organisational leads – usually responsible for the strategic direction of an organisation.
- ➔ Dementia care coaches - to coach, mentor and role model within an organisation.
- ➔ Dementia specialist nurses – registered nurses who have taken advanced training in dementia care
- ➔ Admiral Nurses – specialist nurses that work with carers and people with dementia
- ➔ Dementia Support Workers – work with people with dementia and their carers to support them, either in the community or hospital. In practice this role may provide more information and advice rather than support
- ➔ Dementia Advisors – provide information and advice to people with dementia and their carers and signpost them to appropriate services.
- ➔ Dementia Friends – non-specialists who have undertaken a short awareness session. This is organised by the Alzheimer's Society and part of the Prime Minister's Challenge.
- ➔ Dementia Friends Champions – non-specialists who have undertaken a one-day training session in order to deliver dementia friends training.

#### 4.14.2 Workforce development

Workforce development is key to improving dementia care in all sectors.

There is a need for training to match an individual's level of learning need, based upon their role in their organisation. Staff who have high direct contact with people with dementia and are involved with delivery of care will need significantly more training than staff who have infrequent or indirect contact. All care home staff and home carers need dementia focused training.



The Skills for Care guide 'Ongoing Learning and Development in Adult Social Care' sets out recommended minimum learning and development areas in which adult care workers should be competent.<sup>229</sup> The guidance cites the following as opportunities for learning and development:

- Classroom delivered training;
- One-to-one knowledge sharing;
- Workshops;
- Workbooks;
- E-learning;
- Research/reading;
- Role play;
- Coaching and Mentoring;
- Observing and shadowing;
- Team discussions and knowledge sharing.

Employers should consider what their workers need to achieve (learning outcomes) to determine the best solution and how best they can support their workers in implementing newly learnt or updated practices. Enabling staff to undertake any training is challenging because of the time commitments involved. This applies to all levels of dementia training alongside mandatory and other specialist topic areas.

There is a range of guidance available to inform the content of dementia training initiatives:

- Common Core Principles for Supporting People with Dementia (Skills for Care & Skills for Health, 2011)
- Qualification & Credit Framework Units at L2 and L3 (accredited with awarding bodies)
- Dementia guidance and resources (Skills for Care)

#### **4.14.3 Tiered approaches to training:**

Health Education England (HEE)<sup>230</sup> has a tiered approach to training and this is the approach taken by Sussex Community Trust and ESCC. It matches the depth of training with the need of the member of staff.

Tier 1 is training to familiarise staff with recognising and understanding dementia, interacting with those with dementia, and being able to signpost people with dementia and carers to appropriate support. Tier 2 training is in-depth training for all staff that work regularly with people with dementia. Tier 3 training is to prepare key staff to lead in transforming care. Table 42 shows how these Tiers match the equivalent social care workforce group.

**Table 42: HEE Tier and matched social care groups**

HEE Tier	Matched social care workforce group
Tier 1: dementia awareness raising, in terms of knowledge, skills, and attitudes for all those working in health and care settings	Group 1: all of the social care workforce-dementia awareness
Tier 2: knowledge, skills, and attitudes for roles that have regular contact with people living with dementia	Group 2: people working in social care who are providing personalised direct care and support to people with dementia
Tier 3: enhancing the knowledge, skills and attitudes for key staff (experts) working with people living with dementia designed to support them to play leadership roles	Group 3: registered managers and other social care leaders who are managing care and support services for people with dementia  Group 4: social care practice leaders and managers who are managing care and support services and interventions with people with dementia which includes social workers, and occupational therapists working in social care

Source: Dementia core skills Education and Training Framework

#### 4.14.4 Dementia Friends Training

Dementia Friends awareness training has been part of the Prime Minister's Challenge and aims to raise awareness of Dementia. People with dementia and their carers feel that the Dementia Friends initiative is a positive step forward, especially in terms of raising awareness and reducing stigma among the public. The steering group advised that Dementia Friends training is good for members of the public but not sufficient for training frontline staff.

### 4.15 Dementia training across East Sussex

#### 4.15.1 Adult Social Care ESCC

East Sussex County Council provides dementia training for its own staff, and for staff from Independent care sector organisations who are delivering services to people with dementia. In addition, training is available to personal assistants [PAs], voluntary sector and unpaid carers. Provision of training is designed to be cost-effective, consistent, and with a clear pathway/programme for staff across East Sussex to access.

Training provided by the Adult Social Care Training team is summarised in internal six monthly reports. These show the total number of people who successfully completed each course and a breakdown of the participants' service delivery roles. ASC provides a pathway of Dementia courses, which develop knowledge and understanding according to the complexity of a person's role and emerging themes:

- Dementia e-learning package;
- Dementia Awareness;
- Dementia - The Role of Communication and Positive Interaction;
- Responding Effectively to the Changing Behaviours of People with Dementia;
- The Use of Medicines for Clients who have Dementia;
- Dementia – Nutrition & Hydration;
- Dementia – Engaging in Meaningful and Purposeful Activities.

Additionally, qualifications recently made available to the Independent Care Sector through the East Sussex Qualification and Assessment Centre (ESQAC) include: Level 2 & 3 Award and Certificate in Dementia Care and Level 2 & 3 Award in End of Life Care. Organisations, for example care homes, that sign the Dementia Pledge commit to providing training that meets the needs of people with dementia.<sup>231</sup>

#### **4.15.2 Mental Capacity Act 2005 and Mental Health Act 1983 amended 2007] training**

Some health care professionals do not have a good understanding of the Mental Capacity Act and Mental Health Act. A lack of understanding amongst professionals could mean that these Acts are not being used to the full benefit of people with dementia. The issue of understanding the MCA has been identified in the Government response to the Select Committee on the Mental Capacity Act.<sup>232</sup>

Adult Social Care in ESCC currently offers the following MCA training pathway:

- ➔ MCA & DoLS e-learning packages;
- ➔ MCA 2005 an Introduction;
- ➔ MCA Who Decides;
- ➔ MCA 2005 Assessing Capacity;
- ➔ Deprivation of Liberty Safeguards [DoLS] under the MCA 2005 – an Introduction

### **4.16 NHS workforce development in East Sussex:**

There is limited information routinely collected to describe current NHS staff development in dementia care.

#### **4.16.1 HWLH CCG**

According to the CCG primary care workforce tutor:

*“At the beginning of the year, we encouraged all our GP practices (all staff: clinical and non-clinical) to complete the on-line foundation level dementia training. This was incentivised through a payment for each staff member that completed the modules and provided proof of completion, although numbers for take up were still low. Our commissioning manager ...has worked very hard in taking forward the dementia agenda, together with our GP lead, and helped design the Dementia Conference to which all GP practice staff in HWLH area were invited to attend. As GP practices are independent contractors they may also access dementia training without CCG knowledge.”*

The Sussex Community Trust workforce training programme is comprehensive and now includes staff working in the community in HWLH CCG area. The learning objectives are summarised in Appendix 4.

#### **4.16.2 EHS and H&R CCG**

Working with the Memory Assessment Service, the CCG are increasing the capacity and skills in primary care to look after those with dementia and facilitating more integration of care.

*“.. basing the service in primary care is about skilling up the workforce,.. breaking down stigma and making dementia just another long term condition [LTC]. The added advantage is also that it is easier for the patients.”*

The primary care MAS has been going for 3 years and has widened the skill mix. The service has spent time doing practice workshops to teach about dementia. It has held two protected learning time sessions both of which evaluated very well and covered around 80 GPs in total. It has developed a guidance document which goes out to GPs when patients are discharged from the service.

In collaboration with the University of Bradford, Department of Dementia Studies, the CCG actively promotes the Postgraduate Certificate for Practitioners with a Special Interest in Dementia Care, preparing students to deliver a memory assessment service. The part-time Post Graduate Certificate is studied over 1 academic year: 60 credits are studied in 2x30 credit modules: assessment and diagnosis of dementia in primary care; pharmacological and psychosocial support for people with dementia in primary care. Part of the course involves the practitioner gaining a greater understanding of their local services.

The course aims to:

- ➔ support participants to develop high level skills in assessment, diagnosis, clinical management and on-going support for people with dementia and their carers
- ➔ enable participants to gain appropriate knowledge and skills in order to seek local approval to work as a practitioner with a special interest in dementia
- ➔ prepare GPs for long term management of patients with dementia

There is an e-learning component with real time tutorials and a dedicated social network for sharing learning. Future plans for the Memory Assessment Service include:

- ➔ Further training of GPs on the next iteration of the Bradford course. There are now 14 GPs and one nurse qualified, with a further nurse and pharmacist in training.
- ➔ Accredited nurse training delivered locally.
- ➔ Improve the remote access
- ➔ Deliver the training in more surgeries
- ➔ Practice learning events
- ➔ Use of IT to carry out assessments.

#### **4.16.3 East Sussex Healthcare Trust [ESHT]**

In ESHT there is a dedicated Dementia Care Lead. A multi-disciplinary / multi-organisational 6 day Dementia Care Champions Programme is in place across both hospital and community sites. Staff can choose to apply and submit for academic accreditation at Levels 4-7. Dementia champions cascade best practice across the trust to general staff.

#### **4.16.4 Brighton Sussex Medical School [BSMS] training:**

There is an MSc, a Post Graduate diploma, and a Post Graduate Certificate in dementia studies offered at Brighton & Sussex Medical School [BSMS]. These are increasing skills among GPs and dementia leads.

## 4.17 What workforce is needed for the future?

The National Dementia Strategy aimed to develop an “informed and effective workforce for people with dementia”.<sup>12</sup> As the number of people with dementia increases, the need for a workforce that is able to deliver high quality care to people with dementia is going to grow.

It is important to ensure that the correct people are recruited in the first instance. Some people naturally find it easier to care for people with dementia than others. The low paid nature of frontline care staff, the negative media coverage and high staff turnover result in poor morale. This has the potential to reduce motivation and efforts to improve services.

Provisional numbers of staff needed could be estimated, although it is difficult to be prescriptive as this depends on the service model.

- A workforce model used in the dementia needs assessment in the Norfolk JSNA<sup>222</sup> uses the following assumptions:
  - Each newly diagnosed person in the community would receive on average 3 sessions with a dementia advisor, dementia support worker or Admiral Nurse, or similar.
  - Each currently diagnosed person in the community would receive on average 2 sessions per year with a dementia advisor, dementia support worker or Admiral Nurse, or similar.

There is no national guidance on the number of dementia specialists needed.

The views of key stakeholders about future staffing issues in East Sussex are covered in a later section, [5.3.4 Future staffing to support people with dementia](#)

### Summary: Service provision secondary care

- Approximately 1 in 3 to 1 in 5 people in hospital have dementia. In the two years 2013/14 and 2014/15, the number of hospital admissions with dementia recorded as a diagnosis represents 7.0% of all emergency admissions of East Sussex residents.
- Most of the admissions for people with dementia are as an emergency. The main reasons for admission are for the management of other medical problems.
- There are higher rates of admission in Hastings and Eastbourne local authorities. This could reflect either different service provision, or patterns of service utilisation. The age-specific rates of admission are broadly comparable between local authorities.
- In ESHT, with the majority of the admissions, there are more admissions to EDGH than to the Conquest Hospital.
- One ward at the Conquest Hospital is for complex care and one ward at EDGH is working toward becoming a complex care ward.
- ESHT has a pathway of care for the dementia patient, as does BSUH [Brighton & Sussex University Hospitals].
- The Royal Sussex County and Princess Royal Hospital deal with the majority of admissions from HWLH CCG in the West of East Sussex. There are specialist dementia wards in RSCH [Emerald Ward] and PRH [Poynings Ward].
- In Sussex Partnership Foundation Trust [SPFT], admissions to the EMI wards have relatively prolonged lengths of stay. It is expected that these will reduce when bed reconfiguration is completed and redesigned community services introduced.
- SPFT provides mental health *liaison* services across both EDGH and the Conquest Hospital sites. Mental health liaison is also provided to both hospitals in BSUH.
- The number of in-patient beds was reviewed in the Business Case for reconfiguration of acute dementia services. NHS dementia beds are currently being provided on two sites by Sussex Partnership Foundation Trust [SPFT] and are under-occupied. A single site consolidation is now taking place in Hastings with the bed numbers at an equivalent occupancy level.
- As part of the business case, investment has been agreed for community-based services including step-up/step-down beds and a community-based crisis team.
- Prolonged lengths of stay in hospital can result from the time for adult social care services to arrange long-term care involving patient and family choices and agreeing financial contributions.

### Summary: Service Provision Social Care

- The Care Act 2014 includes the new responsibility to promote wellbeing, and to undertake an assessment of needs of both client and carers, with review as these needs change.
- There are substantial resourcing implications for ESCC in implementing the Care Act 2014 in future years on account of the ageing population, more community provided care, more people living alone, and more complex cases with multiple co-morbidities.
- A person with dementia and their carer need to understand the condition and manage the progression of symptoms. Dementia can have a devastating effect on family relationships. The psychological stress and physical strain experienced by carers increases as the dementia progresses.
- Support to carers can reduce the adverse impact of caring on the carers' health and wellbeing, as well as preventing carer breakdown. Carer support and counselling at diagnosis has been demonstrated to reduce care home placement.
- Other published needs assessments identified a lack of information and knowledge amongst patients and carers about writing wills and lasting power of attorney.
- The published evidence on the benefit of respite care is conflicting. It may be the most severe cases have been studied in depth and research evidence may not have been of sufficient quality to measure carer burden adequately.
- Carers may not be aware of all support that is available. There may be financial barriers. Carers may be putting off obtaining respite care long after when it is needed. There are also negative outcomes for seeking respite care (guilt, stigma, concerns over quality of care and difficulty in readjustment when the period of respite is over), as well as potential positive outcomes (maintaining relationships, catching up on sleep and rest.)
- Respite may be moderating the negative effects of the caring role in a deteriorating scenario. A range of services should be available to allow carers to have a choice over the timing, flexibility and length of respite break.
- There is a lack of accessible respite care in East Sussex which, although bookable, in practice has to be arranged at short notice and may not be available.
- In the H&R CCG there is relatively more care home provision, a lower proportion of self-funders (57%) of nursing and residential home care, with a higher proportion of clients who are funded by Adult Social Care. In HWLH CCG there is a relatively higher proportion of clients managed in the community and a much higher proportion of people (74%) funding their own nursing or residential home care. EHS CCG has the highest numbers of people with dementia living in care homes and in the community.
- There have been ten care home closures in East Sussex since May 2015 accounting for 270 nursing home beds, of which 117 were designated as intended for dementia residential care. The closure of a further two homes is subject to appeal to the Care Quality Commission. This represents a loss of 3% of the capacity on the sector in the past year. A further ten homes are currently non-operational [closed to admissions]. This will have caused problems with hospital discharge and also for people with escalating needs in the community.
- The extent to which dementia friendly environment recommendations have been implemented in the care home sector across East Sussex is not clear. To clarify this would require specific local audits.



### Summary: End of Life Care

- Early discussions with people with dementia are important so that people can plan ahead for their future care, including palliative and end of life care, while they still can.
- The emotional wellbeing of carers is key during end of life care. Carers need to be supported throughout the end of life phase and in their bereavement.
- The locally commissioned service [LCS] for palliative care in East Sussex will improve communication between professionals both in-hours and out-of-hours.
- A pilot study looking at the methods for reviewing the pathway of End of Life Care was undertaken by the Care Quality Commission in the autumn of 2015 in HWLH CCG. The pilot study report for HWLH CCG, which is part of a national CQC report, is awaited. The CQC findings for ESHT have been published as a separate report.
- CCGs and ESCC continue to implement the Sussex, Integrated End of Life and Dementia pathway. This includes training for professionals and promotion of Advance Care Planning [ACP] at all phases of the pathway as appropriate.
- HWLH CCG is procuring a post-diagnosis support service specifically to assist with Advanced Care Planning for all people with dementia.
- There is limited evidence available to demonstrate how effectively the policy of Advanced Care Planning is being implemented.
- The proportion of East Sussex residents dying in their usual place of residence is higher than the Regional and England average.

### Summary: Medicines management

- Community pharmacists often come into contact with a range of vulnerable people and may be the first health professional to suspect memory loss.
- The Healthy Living Pharmacy concept may enable greater signposting to community services for dementia, and the provision of 'flu immunisation. Community pharmacies support people with difficulties accessing the pharmacy with medicine delivery services. These are not currently commissioned.
- Pharmacists have an important role to play in ensuring that appropriate Medication Use Reviews [MURs] are undertaken and in informing the GP of non-adherence to prescribed treatment. MURs should be further encouraged along with the New Medicines Service.
- Pharmacies can potentially reduce the risk of avoidable medication errors with new prescription checking decision support software and by doing so help to reduce avoidable admissions.
- The quality of communication about medications on discharge between hospital and primary care has been identified in other JSNAs. This issue has been raised locally with the community pharmacists in the course of the East Sussex JSNA process.
- There was more total spending on the more expensive dementia drugs in HWLW CCG than in either of the other two CCGs in the financial year 2014-15. This statement refers only to primary care prescribing.
- New initiatives in East Sussex will improve the quality of prescribing in care homes and are specifically aiming to improve the appropriate use of anti-psychotic drugs.
- Pharmacies have a role in reducing CVD risk in the general population by participating in smoking cessation campaigns. They can also set a good example by being dementia friendly businesses as well as being carer friendly.

### Summary: Service provision in community and primary care

- A range of community support services are already in place, or implementation planned, across East Sussex. These are summarised in Appendix 3.
- Services have been commissioned from the Alzheimer's Society to support people with dementia and their carers. East Sussex has currently opted for the dementia advisor model after diagnosis. There are no Admiral Nurses currently employed by the NHS in East Sussex, although HWLH CCG are going through a procurement exercise for a new post-diagnosis support service.
- All GP practices in East Sussex CCGs participate in the Quality and Outcomes Framework [QoF] and have a dementia register. The performance of practices in East Sussex in doing an annual care review of patients with dementia shows good achievement for most practices.
- A new Locally Commissioned Service [LCS] specifically for managing dementia has been introduced in H&R and EHS CCGs. This will simplify the care plans for individual patients and encourage timely diagnosis.
- NICE guidelines recommend Cognitive Stimulation Therapy for all people with dementia. This was trialled in East Sussex with limited uptake and the resource re-allocated. There is further commissioning of this service from April 2016 in two CCGs, and in a different format in HWLH CCG.
- There is a well-established primary care-led memory assessment service in Hastings and Rother CCG and Eastbourne, Hailsham and Seaford CCG which is also shifting the responsibility for dementia care into the primary care. As part of the primary care led MAS, a second research project is looking at the benefits of community support workers [CSWs] in Bexhill GP practices.
- A separate local research project in Buxted Surgery is evaluating an integrated, multi-disciplinary care model of dementia management in primary care [The Golden Ticket]
- From the HWLH stakeholder consultation, staff identified a lack of a clear care pathway; the need for more GP training; and the lack of a single point of contact for service users or their carers.
- There are **no** specialist Sussex Community Trust dementia services in High Weald, Lewes and Newhaven CCG, although community teams do accept referrals about people with dementia.
- The SPFT Specialist Older Adults Mental Health Service is community based, providing assessment and treatment for older adults with both functional mental health problems and dementia. A dementia-specialist care home in-reach service is commissioned from SPFT.

### **Summary: workforce training and development**

There is a wide range of dementia training available across East Sussex. This training is provided by several organisations and targeted at different staff roles and groups. There are many different levels of dementia specialist staff including dementia specialist nurses, dementia advisors, dementia support workers and Admiral Nurses. Health Education England and Skills for Care have identified nationally recommended levels of tiered dementia training.

Dementia leads, champions and specialist nurses can train others within their organisations and within their sphere of influence.

Every worker involved with people living with dementia should have had basic dementia awareness training to identify early symptoms and have an understanding of support available.

Adult Social Care [ASC], Sussex Community Trust [SCT], SPFT & ESHT each have a detailed programme of training.

It is unclear to what extent the people who have attended any Dementia courses are representative of the workforce in each organisation. This would require a training needs assessment and quality audit.

All training outcomes are *intended* and it is difficult to quantify and measure the impact on practice in any organisation.

CCGs and ASC are continuing to raise the profile of dementia training. There is the opportunity to improve the uptake of dementia training among all relevant staff.

A hospital staff survey reported from another JSNA in Norfolk found that most staff feel they have had insufficient training about dementia including: communication skills, assessing cognition, dealing with aggressive behaviours and recognising pain. Knowledge of the Mental Capacity Act was also identified nationally as a gap by the Government Select Committee.

## Section 5. What people say about services/provision

The published literature of user involvement in dementia care is briefly summarised in this section.

This is followed by the themes identified from an on-line consultation in the autumn of 2015 with a selected group of local stakeholders.

### 5.1 National context and published evidence

The views and perceptions of people with dementia and their carers underpin the principles of person-centred dementia care. The Dementia Engagement and Empowerment Project (DEEP) undertaken by the Joseph Rowntree Foundation<sup>233</sup> found that the development of a dementia ‘service user movement’ was still in the early stages, with only a “small number of groups led by, or actively involving, people with dementia that are influencing services and policies”.

The same report recommends that national and local organisations such as Clinical Commissioning Groups and local authorities need to “**develop and implement involvement plans, allocating resources to develop new groups, link groups together and help them share resources**”. There are several guides on how to consult people with dementia, such as the Department of Health’s *Listen to us: Involving people with dementia in planning and developing services*.<sup>234</sup>

A large proportion of people with dementia feel unsupported, do not feel part of their community, often experience anxiety or depression, and do not feel society is geared to deal with dementia.<sup>235</sup>

A survey undertaken by the Alzheimer’s Society suggests that progress is being made, with almost two-thirds (61%) of respondents reporting that they were living well with the condition. The report also found that quality of life is variable for a significant number of people with dementia.<sup>236</sup>

There is a small and relatively limited evidence base on the views and perceptions of people with dementia and their carers, which is summarised in Table 43

**Table 43: published evidence about user and carer views**

	Description	Evidence
Services	Care homes	<p>Research undertaken by the Alzheimer's society found:</p> <ul style="list-style-type: none"> <li>• There are low expectations about the quality of life of people with dementia in care homes.</li> <li>• Positive views on the quality of care for people living with dementia in care homes</li> <li>• Finding information on care homes can be challenging.</li> <li>• A large number of people with dementia had moved care home after they initially moved in. The most common reason was an increase in needs.</li> <li>• Family members and staff were positive about how homes worked with doctors and family members</li> <li>• Views on opportunities for trips out and how the home worked with volunteers were less positive.</li> </ul> <p>Although family members' views on opportunities for activities in care homes were good, there is further evidence which suggests that older people with dementia living in care homes often have differing views from their carers' and staff on what constitutes a meaningful activity.<sup>237</sup></p>
	Palliative care	<p>A recent review<sup>238</sup> of carers' and professionals' views on end of life care made the following observations:</p> <ul style="list-style-type: none"> <li>• A lack of communication between professional and carer may lead to a poor experience. Professionals should establish the carers' perspectives and wishes on the care of the patient.</li> <li>• Cultural backgrounds, beliefs and experiences of professionals may influence choices over what kind of support and care is desired</li> <li>• Advance care planning may be helpful to all parties, but may not always be desired</li> <li>• Professionals need to be aware of the possibility of elder abuse or poor quality care when supporting people with dementia and should know their responsibilities</li> <li>• Professionals may benefit from skills development and access to resources in seeking to implement a holistic approach to end-of-life care for people with dementia</li> </ul>
	Cognitive Stimulation Therapy	<p>Cognitive Stimulation Therapy (CST) is highly valued by people with dementia, although staff and family carers expressed some concern about effectiveness.<sup>239</sup></p>
	Telecare	<p>There is some evidence<sup>240</sup> that carers of people with dementia view telecare medical support systems (TMSS) positively. Perceived benefits include the ability to self-diagnose patient's conditions; provide reminders, care, and emotional support; and help stabilize the patient's condition and emotions. The study was conducted in Taiwan and may not be as relevant to local populations.</p>
	Assistive Technology	<p>Research from the UK and Israel<sup>241,242</sup> indicates that, despite some ethical concerns, the use of Global Positioning Systems (GPS) to promote safe walking and tracking of people with dementia were acceptable to older people, people with dementia, and their carers.</p> <p>Users of the (GPS) tracking devices, their carers, and professionals should be involved in the design of the devices and in discussions regarding their use.</p>

Interventions	Crisis intervention	<p>One study<sup>243</sup> reported the following to address crises for people with dementia:</p> <ul style="list-style-type: none"> <li>• People with dementia preferred support from family and friends, access to mobile phones and home adaptations to reduce risks</li> <li>• Carers were keen on assistive technology and home adaptations</li> <li>• Both carers and staff valued carer training and education, care plans and well-coordinated care.</li> <li>• Staff emphasized more intensive interventions such as <i>emergency home respite</i> and <i>extended hours services</i>.</li> </ul> <p>Practical interventions such as <i>home adaptations</i>, <i>assistive technology</i>, <i>education and training for family carers</i>, and <i>flexible home care services</i> were highly valued by service users and their families during times of crisis and may help prevent hospital admissions. <i>Specialist home care</i> was highly valued by all groups.</p>
Vulnerable groups	People with a visual impairment and dementia	<p>One study<sup>244</sup> considered the implications for people with dementia and visual impairment. Six themes were identified from a number of case studies:</p> <ul style="list-style-type: none"> <li>• Disorientation, including the inability to orientate oneself due to a lack of memory and visual cues.</li> <li>• Loss of independence</li> <li>• Accepting multiple losses, with acceptance identified as a key coping strategy</li> <li>• Risk of isolation. Day centres and one-to-one interaction were both highly valued</li> <li>• Hallucinations, with over a third of the older adults interviewed experiencing visual hallucinations</li> <li>• Challenges to services. Professionals reported difficulties in coping with patients who developed dementia, and a lack of training</li> </ul>

## 5.2 Stakeholder consultation

### Introduction

An online consultation [SWOT] analysis was undertaken in November and December 2015.

Respondents were asked:

1. Strengths: In your view, what are the strengths in local services for people with dementia and their carers in your area? Please refer to your CCG locality area or service area.
2. Weaknesses. Is there anything you think that is not working well at the moment? Are there any gaps?
3. Opportunities. How do you think services for people with dementia and their carers could be improved in your area? Please refer to your CCG locality or service area.
4. Within your organisation's workforce plans, will you have sufficient 'trained and confident' staff to provide high quality support to people with dementia and their carers over the next 3-5 years?

## 5.3 Methods

The link to an on-line questionnaire was sent to 36 key stakeholders in the health and social care system in East Sussex, with replies being collated from the ESCC website. A total of 27 replies were received after one reminder, giving a (75%) response rate. The responding organisations are shown in Table 44.



**Table 43: Organisations responding to the online consultation**

	Organisation
NHS	Sussex Partnership NHS Foundation Trust
	East Sussex Healthcare NHS Trust
	Hastings and Rother CCG
County and district councils	ESCC Adult Social Care Mental Health
	East Sussex County Council
	Carers Break & Engagement Service
	Wealden and Rother District Council
Voluntary sector	Rotherfield St Martin village
	Know Dementia
	Alzheimers Society
	Home Instead Senior Care - Home Care Company
	Independent Trainer
Independent sector	

## 5.4 Results

A summary of the themes arising from the stakeholder replies is given below under the headings of strengths, weaknesses, opportunities:

### 5.4.1 Strengths

There is a view shared by a number of people that communities are becoming more dementia friendly:

- Small scale services are now willing to work with people with dementia whereas previously excluded.
- Dementia friendly villages: e.g. Rotherfield St.Martin.
- Golden Ticket project-has improved multi-disciplinary working
- 3<sup>rd</sup> Sector Providers: Contributing to dementia friendly communities.
- Supper clubs, singing group and support to Bexhill Dementia Action Alliance.

Other strengths are more support now being provided for carers from the Carers Breaks and Engagement Service and more crisis support from the dementia support workers attached to some GP practices.

There have been ongoing improvements in staff training with well-trained staff and effective further education programmes in primary and secondary care.

There is an active local research programme supported by Brighton& Sussex Medical School and by Bradford University.

### 5.4.2 Weaknesses

#### **Primary care:**

There are differences of opinion about how well primary care is working and which model of primary care should be adopted in East Sussex:

- How about the primary care [MAS] model being used across the whole patch? That leads to upskilled primary care. When primary care is more knowledgeable then all the other things will improve.
- Knowledge of other services, working more successfully with other agencies. Moving resources from secondary to primary care.
- .. there are very different demographics and geography. What suits wealthy rural villages may not be suitable for town centre deprived areas.
- .. We have to make sure that everyone can access the right kind of care and that the primary care workforce is adapted and developed to manage the ongoing support of people with dementia.
- Huge discrepancy in provision within the county. Some surgeries are just not doing dementia properly.
- There are weak links reported between some GP and pharmacies, with patients not collecting prescribed drugs. The situation is made worse if the pharmacy does not inform the GP practice if a home delivery is unsuccessful.

#### **Lack of knowledge:**

There is a lack of knowledge among patients/carers about where to go and sources of advice.

- What is already available is not being well communicated or advertised.
- There is a wealth of experience and support from 3rd sector organisations out there which is just not being tapped into or used as a resource. ... many of those affected by dementia don't know where to go or what is available and they are suffering.
- The joined up approach is so important as many people I come across find the current process bewildering.
- Lack of understanding of the environmental changes that people could readily make.

#### **Memory Assessment Services MAS:**

The service provided by SPFT observed that patients have to be referred to secondary care before a multi-disciplinary approach is implemented.

There are practical problems with the care pathway:

- ➔ Lack of practical support to attend the MAS clinic [except community support];
- ➔ Some patients have not had basic clinical work up before arriving at the MAS clinic.

### Fragmentation in the strategic approach:

There appears to be a fragmentation of the strategic approach with a lack of a truly integrated approach across the care pathway.

- Commissioned services not linked together resulting in greater barriers if [the patient] needs change, as they have to be referred to another service.
- No care pathway to cover needs from initial diagnosis to end of life. Advanced care planning is not being included at every step.

### Dementia Care Advisors:

There were very different perceptions of the effectiveness of dementia advisors. There was a view that there is too much signposting and not enough direct help for carers.

### Social care:

Some commented about areas of insufficient social care provision:

- ➔ Not enough personal assistants being recruited;
- ➔ Lack of respite/activities and services for younger people with dementia;
- ➔ A shortage of affordable day care.

There are transport shortages (especially in rural areas) to get to groups [for carers and cared for]. There are concerns about the forthcoming cuts to social care budgets:

- I am also very concerned by the ongoing budget cuts to adult social care budget in East Sussex which could have an effect on services which help to support people with dementia and their carers and also on the care packages offered through social services and the local authority.

### Community Teams:

Concerns were expressed about people living alone.

- I am worried about the people with dementia that have no carers or family. They used to be picked up by the community mental health teams and worked with to help them to accept services. This no longer happens and they slip through the net. There is nobody to support them with attending appointments etc.

There is the opportunity to ease communication for patients and carers

- ➔ People with dementia and their carers don't have the energy for speaking to several people;
- ➔ Speech And Language Therapy: Lack of this in community teams and in MAS.

### **5.4.3 Opportunities**

#### **Dementia Strategy and Resource allocation**

There needs to be a proper joined up strategy to make sure that everyone has equal access to services.

There will have to be more investment as the needs increase, though there is recognition about resourcing constraints.

- “Each CCG needs to manage within the context of the East Sussex Better Together plans to make services integrated and locally provided but economies of scale need to be considered for specialist services (ie across East Sussex)”.

#### **Care pathway**

There is a view that there needs to be development of services that move across the primary/secondary care boundaries. There is also a view that there needs to be movement of resources/care management from Secondary to Primary Care. There needs to be better integration between different providers. There was an observation/ recognition that a care co-ordinator system that works for children could be adopted for adults too:

- A 'Key Worker' system whereby all agencies work together in the best interests of an individual could be implemented.
- The 'key worker' could be from any organisation. This would be the 'Team around the Adult', similar to what is in practice regarding children.
- Enhancing the co-ordinator role to ensure all agencies are communicated with
- There needs to be a joined up pathway from assessment to support.
- There needs to be a one stop shop for support.

#### **Golden Ticket project**

A number of respondents reported that they liked the Buxted pilot study.

- The Golden Ticket scheme has been great to be part of and it's wonderful to be able to offer people with Dementia and their carers positive support and advice. It's been really nice to see staff members from the CCG, Buxted Medical Practice, Sussex Partnership, MAS and others work together to achieve a positive outcome for patients. It feels as though this is actually something positive that staff WANT to take part in.

#### **Dementia friendly communities**

There are opportunities to develop dementia friendly communities even more to change attitudes, knowledge and give practical advice for the general public.

- Greater effort to work with small scale groups and organisations at local community level to be inclusive of people with dementia.
- Memory cafes also provide the opportunity to build support networks for carers and those diagnosed.
- Help with local training about dementia for business and community groups

There is the recognition of the importance of more practical, hands on support.

- The Primary Care Pilot in Bexhill and Hastings, delivered by the Carers Breaks and Engagement Team in ESCC, is an example of practical hands on support. Opportunity to develop this Pilot to capture good practice links with GPs, MAS, Radiography and Pharmacy.

### Training:

There are opportunities to enhance the training of healthcare professionals, OTs and Social Workers by raising awareness of environmental changes and adaptations that can make a difference in East Sussex.

### Young people with early onset dementia:

There is the potential to offer younger people with early-onset dementia more opportunities and choices e.g. age relevant social activities or stimulating groups etc.

### Personal Assistants [PAs]:

In terms of continuity of care it was suggested it would be helpful if there were more long-term workers for more complex clients. There is the opportunity to identify unmet needs of carers and clients sooner and provide support earlier:

- Identify carers and cared for living with dementia earlier and increase the recruitment drive for PA's through Support with Confidence.

There appears to be a shortage of personal assistants (PAs) that will travel to rural clients

### 5.4.4 Future staffing to support people with dementia

Responses to the question:

**“Within your organisation’s workforce plans, will you have sufficient ‘trained and confident’ staff to provide high quality support to people with dementia and their carers over the next 3-5 years?”**

are identified below by each responding organisation.

## Sussex Partnership foundation Trust [SPFT]:

- Yes providing funding for specialist mental health services is not affected within the local plans. Yes if we are more clear about commissioning intentions so we could plan ahead.

- SPFT have highly trained staff to provide support for people with dementia but there is no longer a specialist community service for [patients with dementia]. Dementia needs to be a specialist service to give the best high quality assessment, treatment and carer support.

- SPFT are aware of the number of employees who are due to retire in the next 3-5 years and are actively working on their succession planning strategy.

- The MSc in Dementia offered through Brighton University has been running for the past 3 years with the first cohort due to complete the course in 2016. In addition, student placements are offered throughout the year to both nursing and allied health professionals. This investment in the workforce of the future frequently leads to interest in working for the Trust on completion of the individual's training.

- The Trust are working with Commissioners to develop a Dementia Intensive Care Unit which is due for completion in 2018. This purpose built enabling environment for people with dementia will be an attractive employment opportunity for staff.

## East Sussex Healthcare Trust [ESHT]:

- There would be sufficient staff only if a whole team were to be embedded - one person cannot consistently achieve this. nb this reply was given in November 2015)

## ESCC Adult Social Care:

- Within the specialist ASC mental health teams there is the [knowledge to provide high quality support to people with dementia] which includes a good understanding of the Mental Capacity Act and Mental Health Act.
- Within generic adult social care teams there is an ongoing training need.
- ESCC have the Care Certificate as the minimum standard- this includes dementia modules. The front line experience provides the opportunity for staff to develop within the role.
- The next 3-5 years will be a challenge with funding cuts, to sustain and develop a dementia skilled and confident workforce resources will need to be increased.

## ESCC Carers Breaks and Engagement Service:

There is staff education and development within this service:

- The service has been providing  
...person centred support for carers and cared for living with dementia.  
...trialling pilot projects to increase the provision of services to this client group, including local Dementia Supper Clubs,  
...healthcare appointment respite provision,  
...[a] primary care pilot project  
...working closely with wellbeing services to refer for tele [health] services and GPS support.
- Staff working with Carers Breaks are supported to be highly trained and confident in providing high quality support to all clients.

## Primary Care Memory Assessment Service [MAS] Education and Development:

The Primary care MAS continues to recruit to the Bradford University post-graduate course and has filled some places in each cohort. There is ongoing assessment of participants learning, nurse training and more nurses have been recruited in the last year. A trained GP has gone on to chair the Dementia Alliance in Bexhill.

## Home Care Company:

Home care providers are training their staff and encouraging families to understand dementia.



- Yes, we are very focused on ensuring that we give our staff the relevant training required and ... will start putting some of our staff on a City and Guilds accredited dementia training course.
- We are also committed to supporting families and have take[n] ....our clients and their families to the organisations that can provide them with support, as well as allowing them access to some of our on line training material. As a dementia champion and member of the Eastbourne Dementia Action Alliance I am also committed to helping spread awareness in the local community as a whole.

## Voluntary Sector

There is learning and development also within the voluntary sector.

- We have extensive training within my organisation for staff and many opportunities for staff to...upskill in order to deliver high quality support to people with dementia and their carers.
- Not in a position to say whether or not we will have enough trained and confident staff over the next 3 to 5 years. I believe that this depends on funding.

## H&R CCG:

- ➔ We continue with basic training, and working with businesses etc through the Dementia Alliance and the Alzheimer's Society to help staff achieve basic skills.
- ➔ We continue to recruit a skill mix of students to the Dementia Care Post Graduate Certificate. I would hope that within 3 years most of the clinicians and their teams will be sufficiently skilled.

## Independent Trainer:

There have been some perceived reductions in training opportunities.

- I am a trainer myself, and can see that there are never enough "trained and confident staff. ESCC used to offer 3 sessions of a two day training course for social workers and assessors, and resource officers. This is down to one course in 2016/17.

## Wealden & Rother District Council:

Wealden and Rother DC have a Dementia Action Alliance action plan, which includes training for all staff, including all of the community and voluntary groups that the council works with and has service level agreements with.

## Rotherfield St.Martin village:

This dementia friendly community are running a Dementia Friendly Initiative across the village and are happy to work with other organisations and groups that need advice.

## Local user views in East Sussex

There is an opportunity to involve the local Healthwatch in capturing user experience further in order to inform strategic planning and patient choice.

## Summary: User and Carer views

- There is limited published evidence about user and carer views of the dementia care pathway.
- There needs to be a local systematic process of capturing user and carer views, especially with regard to the service provided in care homes and acute/community hospitals.
- A short survey of the opinions about strengths, weaknesses, opportunities and threats from a selected group of key local stakeholders was undertaken in the autumn of 2015.
- Communities are becoming more dementia friendly. There are opportunities to develop dementia friendly communities even more, to change attitudes and to give practical advice for the general public. There is a lack of knowledge among patients/carers locally about where to go for advice and what sources of support are available.
- There are differences of approach to the models for the diagnosis and ongoing management of dementia in East Sussex.
- There appears to be fragmentation with a lack of integration across the care pathway. There is a view that there needs to be development of services that move across the primary/secondary care boundaries.
- There are practical problems with the care pathway in terms of attending the clinics and the information provided to the memory assessment clinics beforehand.
- Concerns were expressed about people living alone with dementia.
- There is the opportunity to ease communication for patients and carers with health and social care professionals, to avoid having to repeat their story, with the use of This is Me and Butterfly schemes.
- There is the recognition of the importance of more practical, hands on support for carers.
- There are opportunities to enhance the training of healthcare professionals, OTs and Social Workers by raising awareness of simple environmental changes and adaptations in the home.
- There is the potential to offer younger people with early-onset dementia more opportunities and choices.
- There is the opportunity to identify the unmet needs of carers and clients sooner and provide support earlier.

## Section 6. The Financial Cost of Dementia [National Perspective]

The social and healthcare costs of dementia are set to rise over the coming years as the prevalence increases. This section briefly summarises the evidence about financial costs of caring for people with dementia

### 6.1 Perspectives of costs:

The cost and benefit implications of early diagnosis are different for Government and for society as a whole. [It is important to bear in mind the timescales over which the return on investment is calculated in any health economic analysis.] The **costs to Government** include the provision of early assessment and treatment. These can be set against the potential savings from reduced spending on care homes and acute care.

A substantial number of care home residents are privately funded.<sup>245</sup> Savings can arise from early assessment and treatment for private individuals and their families. Other costs and benefits that may not have a direct impact on Government's finances include effects on quality of life and the impact on carers' time.

Early intervention can reduce institutionalisation by providing in-home support.<sup>246</sup>

*“Early intervention services would be cost-effective, even though there would be a net increase in public expenditure. If they were to reduce care home admissions by 20% the annual cost would, within around six years, be offset by savings to public spending alone.”<sup>247</sup>*

Other studies have shown that the costs of early assessment and treatment are outweighed by later cost savings.<sup>248</sup>

Research undertaken by Kings College London and London School of Economics (2014)<sup>249</sup> has estimated the total **cost of dementia to society** in the UK to the value of £26.2 billion. This includes:

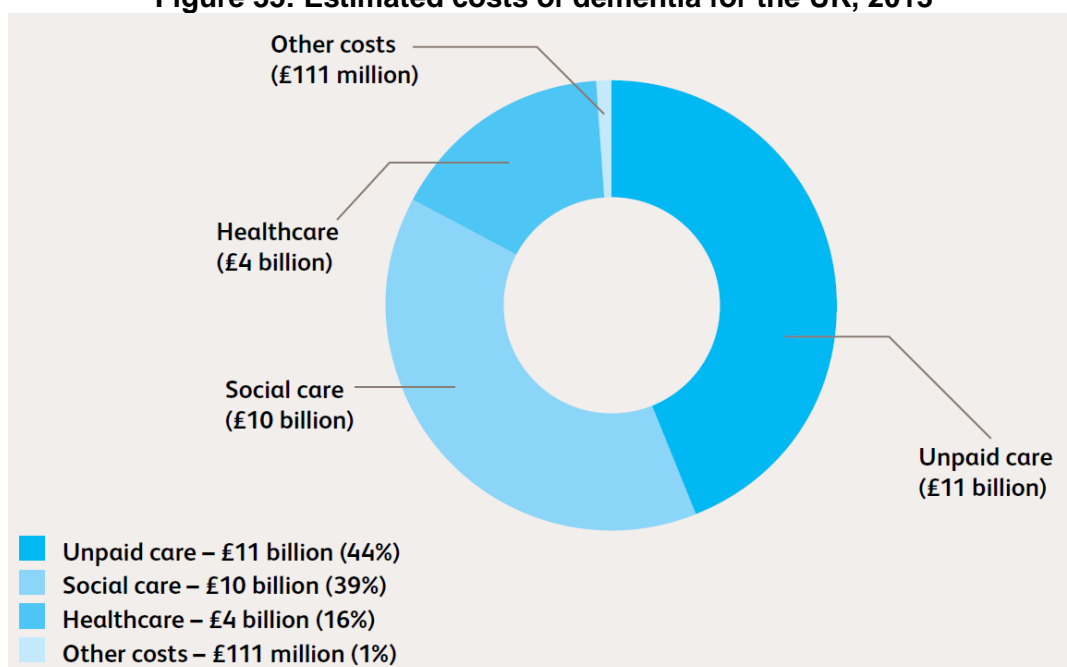
- ➔ Healthcare costs - £4.3 billion
- ➔ Social care costs (publicly and privately funded) - £10.3 billion
- ➔ [£4.5 billion in local authority funded social care plus social care funded by patients and families themselves £5.8 billion]
- ➔ Work of unpaid carers - £11.6 billion
- ➔ Police costs – between £22.1 and £40.3 million
- ➔ Research expenditure - £75 million

A unique feature of dementia is that social costs present a significantly larger burden than health care costs. Individuals with dementia and their families are currently funding two thirds of the resources used in dementia care. The state or public system is not offering people risk protection.

Informal care is not an unending resource. Questions are now being raised about the moral obligations of more distant family members in providing informal care.<sup>250</sup>

Figure 35 provides the estimated breakdown of costs of dementia for the UK, 2013 (Kings College London & London School of Economics, 2014).<sup>249</sup>

**Figure 35: Estimated costs of dementia for the UK, 2013**



The average costs of caring for people with dementia in England are approximately £37k per year for a person in residential care and £29k per year for a person in the community. This cost varies according to severity. For the most complex cases, annual costs of approximately £70k have been reported. These average annual costs by severity and setting are summarised in pounds per person in Table 45, and total annual costs in millions of pounds by severity and setting in Table 46.

**Table 44: The average annual costs of caring for people with dementia by severity and setting (in £, 2012/13 prices)**

	Healthcare	Social care	Unpaid care	Other costs	Total costs
<b>People with dementia living in the community (average cost)</b>					
Mild dementia	2,751	3,121	19,714	137	25,723
Moderate dementia	2,695	7,772	32,237	137	42,841
Severe dementia	11,258	10,321	33,482	136	55,197
All severity levels	3,152	4,054	21,956	137	29,298
(Sector cost as % of total)	(10.8%)	(13.8%)	(74.9%)	(0.5%)	(100%)
<b>People with dementia living in residential care (average cost)</b>					
Mild dementia	4,504	24,737	1,067	136	30,444
Moderate dementia	9,438	25,715	2,901	136	38,190
Severe dementia	8,689	25,874	2,119	136	36,817
All severity levels	8,542	25,610	2,450	136	36,738
(Sector cost as % of total)	(23.3%)	(69.7%)	(6.7%)	(0.4%)	(100%)
<b>All settings (average cost)</b>					
Mild dementia	2,932	5,362	17,781	137	26,212
Moderate dementia	7,837	21,455	9,865	136	39,294
Severe dementia	9,300	22,176	9,575	136	41,187
All severity levels	5,285	12,584	14,237	136	32,242
(Sector cost as % of total)	(16.4%)	(39.0%)	(44.2%)	(0.4%)	(100%)

**Table 45: Total annual cost by severity and setting  
(£ million, 2012/13 prices)**

	Healthcare	Social care	Unpaid care	Other costs	Total costs
<b>People with dementia living in the community (total annual cost)</b>					
Mild dementia	1,120	1,271	8,029	56	10,476
Moderate dementia	168	484	2,007	9	2,667
Severe dementia	267	244	793	3	1,307
All severity levels	1,555	1,999	10,829	67	14,450
(Sector cost as % of total)	(10.8%)	(13.8%)	(74.9%)	(0.5%)	(100%)
<b>People with dementia living in residential care (total annual cost)</b>					
Mild dementia	212	1,165	50	6	1,434
Moderate dementia	1,887	5,142	580	27	7,636
Severe dementia	660	1,964	161	10	2,795
All severity levels	2,759	8,272	791	44	11,866
(Sector cost as % of total)	(23.3%)	(69.7%)	(6.7%)	(0.4%)	(100%)
<b>All settings (total annual cost)</b>					
Mild dementia	1,332	2,436	8,079	62	11,910
Moderate dementia	2,055	5,626	2,587	36	10,303
Severe dementia	926	2,209	954	14	4,102
All severity levels	4,314	10,271	11,620	111	26,316
(Sector cost as % of total)	(16.4%)	(39%)	(44.2%)	(0.4%)	(100%)

### Summary:

- The social and healthcare costs of dementia are set to rise over the coming years as the prevalence of dementia increases.
- It is important to bear in mind the timescales over which the return on investment will be calculated in any health economic analysis of a programme designed to improve the management of dementia.
- The costs of early assessment and treatment are expected to be outweighed by later cost savings.
- The costs to Government include the provision of early assessment and treatment. These can be set against the potential savings from reduced spending on care homes and acute care.
- Early intervention with supported home care can reduce the cost of care home placements.
- The extent of savings depends on the modelling assumptions.
- The average cost per case of a person with dementia increases as the condition becomes more severe. The majority of costs fall on the social and unpaid care sectors.
- Economic models do not fully include the opportunity costs and externally imposed costs to carers.
- There are substantial funding implications to ESCC of implementing the Care Act 2014 and its associated financial pressures in future years.
- Financial abuse of the vulnerable elderly is a growing problem that drains their own assets and ultimately increases the financial burden on society as a whole.

## Section 7. Conclusions

This section summarises priority themes from the JSNA. The gaps/opportunities that have been identified to improve the current position are described with recommendations, please see [Section 8. Recommendations](#). In the current health and social care climate there is much emphasis on sustainability through better community care, living as well as possible with long-term conditions, keeping people out of hospital and reducing length of hospital stays. This focus is particularly relevant when applied to the needs of people with dementia.

### 7.1 Key themes of the JSNA

1. The number of people locally who have dementia, as well as with milder degrees of cognitive impairment, will increase substantially over the next few decades. This is around 57% increase in the number with dementia in the next 15 years, mainly due to a greater number of older people aged 80 and over. As a community we will need adequate resource to deal with this challenge and to provide services more efficiently and sustainably
2. National targets for dementia diagnosis rates have resulted in notable increases in the number of diagnosed cases in each of the three CCGs in East Sussex although there is still room for improvement. Having identified that a person has dementia this must be followed by an equal commitment and support for their post-diagnostic care. This will encourage earlier diagnosis in future and ensure people and their carers live well with dementia.
3. Most of the hidden cost of supporting those with dementia falls on unpaid carers. With more care being provided at home, pressure on carers may increase. We will need to support, advise and empower carers to fulfil their role without a detriment to their own quality of life.
4. Whilst it is important to maintain independence for longer, there needs to be appropriate escalation of care and planning for this when needed. The financial costs of meeting this will fall mainly on adult social care.
5. Dementia services are provided by a range of agencies - acute and primary care, mental health services, social care and third sector. Better cohesion and collaboration is needed via well-coordinated information, advice, advocacy and outreach services.
6. People with dementia and their carers do not always receive equal access to services which support all their other mental and physical health needs
7. There is a need for increased training for paid and unpaid carers, for residential care staff, and health and social care professionals as appropriate to their role.



## 7.2 Gap analysis

For each of the sections of the report gaps and system pressures have been identified. These are identified in Table 48. How these can be addressed is summarised in [Section 8. Recommendations](#).

**Table 46 Gap analysis**

	Gap/Opportunity
<b>Population trends</b>	<ul style="list-style-type: none"> <li>→ Substantial increase in numbers of incident and prevalent cases of dementia is expected</li> <li>→ Active case finding will increase number of new cases identified per year and at an earlier stage of the illness</li> <li>→ Increase in number of carers in population</li> <li>→ Increase in number of people living alone</li> </ul>
<b>Dementia friendly communities</b>	<ul style="list-style-type: none"> <li>→ Opportunity to increase the number of dementia friends and champions across East Sussex</li> <li>→ Limited number of dementia friendly communities currently across East Sussex.</li> <li>→ Opportunity to develop further dementia friendly initiatives in community pharmacies, libraries and transport providers</li> <li>→ Opportunity to create safe havens in communities and adapt for frail elderly</li> <li>→ Limited work in developing a dementia friendly generation</li> <li>→ Opportunity to make greater use of local museums for reminiscence</li> <li>→ Increasing risk of number of drivers on the roads with cognitive impairment</li> <li>→ Financial abuse of the elderly is an ongoing and increasing risk</li> </ul>
<b>Service Planning</b>	<ul style="list-style-type: none"> <li>→ Inequalities in people's ability to fund their own social care</li> <li>→ Limited provision for people with early onset dementia</li> </ul>
<b>Timely diagnosis</b>	<ul style="list-style-type: none"> <li>→ Relatively low diagnosis of expected number of cases</li> <li>→ Unexplained variation in rates of diagnosis between CCGs and by GP practices within CCGs in East Sussex</li> <li>→ Clinician barriers to diagnosis</li> <li>→ Patient/carer barriers to diagnosis</li> </ul>
<b>Information for clients and carers</b>	<ul style="list-style-type: none"> <li>→ Limited awareness of legal advice, financial advice and payment thresholds for social care</li> <li>→ Limited active promotion of voluntary sector support</li> </ul>
<b>Support for carers</b>	<ul style="list-style-type: none"> <li>→ Limited respite care provision</li> <li>→ Opportunity to encourage more workplaces to be carer friendly</li> </ul>
<b>Commissioning dementia care models</b>	<ul style="list-style-type: none"> <li>→ Uneven primary care service delivery</li> <li>→ Variation in diagnosis and ongoing management</li> </ul>
<b>Reducing dementia inequalities</b>	<ul style="list-style-type: none"> <li>→ Variation in dementia care provided, levels of community support and access to services</li> </ul>
<b>People with protected characteristics</b>	<ul style="list-style-type: none"> <li>→ No accurate figures for current numbers of LGBT groups with dementia or as carers</li> <li>→ Limited provision for and increased life expectancy of people in learning disability groups</li> </ul>

<b>Risk factors</b>	<ul style="list-style-type: none"> <li>→ Unequal distribution of CVD risk in population</li> <li>→ No estimate of distribution of CVD risk in ethnic minority groups</li> <li>→ Under diagnosis of diabetes</li> <li>→ Undiagnosed hypertension</li> <li>→ Further opportunities to reduce alcohol consumption and other risk factors predisposing to dementia</li> </ul>
<b>Primary and community care</b>	<ul style="list-style-type: none"> <li>→ Opportunity to improve communication and clarify referral pathways i.e if a health or social care professional in any part of the system suspects memory loss, or the need for more support, they can refer or signpost to the correct service</li> <li>→ Under performing practices on the QoF indicator for a patient with dementia to receive an annual review of their care</li> <li>→ Opportunity to optimise the management of co-morbid conditions</li> <li>→ Ongoing risk of persons going missing</li> <li>→ Mismatch of supply and expressed demand for community services</li> <li>→ Opportunity to pick up previously unidentified case by ambulance service and refer to community services</li> </ul>
<b>Memory Assessment Services MAS</b>	<ul style="list-style-type: none"> <li>→ Demand for clinic appointments exceeds supply.</li> <li>→ Waiting time for an initial MAS assessment exceeds 6 weeks</li> <li>→ Variation in referral rates to memory assessment clinics and proportion diagnosed with dementia</li> <li>→ Poor quality information in some referrals</li> <li>→ Opportunity to strengthen follow up of some people who do not attend memory clinics</li> </ul>
<b>Secondary healthcare</b>	<ul style="list-style-type: none"> <li>→ Opportunity to optimise admission process</li> <li>→ Under-utilisation of current secondary care beds</li> <li>→ No community follow up (for some people) after a new diagnosis of dementia in acute trust</li> <li>→ Delayed discharges to community</li> <li>→ Opportunity to promote further Dementia Friendly environments in health and social care sector</li> <li>→ Opportunity to improve personal care in hospitals</li> <li>→ Butterfly [dementia patient] awareness scheme partially implemented to date</li> </ul>
<b>Social care</b>	<ul style="list-style-type: none"> <li>→ No free dementia support service for crisis situations in community</li> <li>→ No fully implemented joint health and social care assessment process</li> <li>→ Post-diagnosis social and health care are not yet fully co-ordinated</li> <li>→ No accessible information in ASC ESCC about patient numbers with dementia</li> </ul>
<b>Housing</b>	<ul style="list-style-type: none"> <li>→ Unmet need for advice about environmental adaptations</li> <li>→ Limited provision of suitable housing in the community</li> </ul>
<b>Care homes</b>	<ul style="list-style-type: none"> <li>→ Limited information about quality of care provided in care homes.</li> <li>→ Care homes recently closed from failed CQC inspections.</li> <li>→ Insufficient EMI care capacity available in system.</li> </ul>
<b>End of Life Care</b>	<ul style="list-style-type: none"> <li>→ Advanced Care Planning not systematically implemented</li> </ul>

<b>Medicines management</b>	<ul style="list-style-type: none"> <li>→ No recent anti-psychotic drug prescribing audit</li> <li>→ Ongoing issues with poor adherence to drug regimes</li> <li>→ Opportunity to optimise medicines on discharge from hospital</li> <li>→ Opportunities to improve medicines use in care homes</li> </ul>
<b>Workforce development</b>	<ul style="list-style-type: none"> <li>→ Limited Mental Capacity Act awareness</li> <li>→ Limited Primary care staff uptake of dementia training</li> <li>→ Home care providers dementia knowledge base unknown</li> </ul>
<b>Stakeholder consultation</b>	<ul style="list-style-type: none"> <li>→ Limited use of voluntary sector expertise</li> <li>→ Opportunity to develop the Personal Assistant role further</li> </ul>
<b>User views</b>	<ul style="list-style-type: none"> <li>→ No systematic process to capture user views about the care received in NHs &amp; RHs and in acute/community hospitals to inform commissioning</li> </ul>
<b>Assistive technology</b>	<ul style="list-style-type: none"> <li>→ Opportunity for more assistive technology packages to be implemented locally</li> <li>→ Ensuring health and social care staff fully understand the potential of assistive technology and how to access this</li> </ul>

## Section 8. Recommendations

### STRATEGIC RECOMMENDATIONS

#### RECOMMENDATIONS FOR COMMISSIONERS

Information for people and their carers	1: East Sussex County Council and Clinical Commissioning Groups will wish to ensure that people with dementia and carers who <i>self-fund</i> are able to access the same high quality information and advice as those who are eligible for support from the Adult Social Care department.	Consider need for further development
Support for people with dementia and their carers	<p>1: Commissioners will wish to obtain regular information about how well clients known to ASC and GP practices are being supported.</p> <ul style="list-style-type: none"> <li>Commissioners will wish to work with primary care and other appropriate agencies to increase the proportion that have care plans in place and ensure that these are being reviewed at least annually.</li> </ul> <p>2: ESCC will wish to continue to set a good example of being a dementia and carer friendly employer.</p> <ul style="list-style-type: none"> <li>ESCC, in collaboration with the third sector, will wish to continue influencing local employers to be carer friendly.</li> </ul>	<p>Consider need for further development</p> <p>Consider need for further development</p>
Making East Sussex dementia friendly	<p>1: All pharmacies, libraries and transport providers should be encouraged to become Dementia Friendly.</p> <p>2: When promoting Dementia Friendly Communities this should extend to non-geographical communities as well [for example, faith groups].</p> <p>3: East Sussex County Council may wish to encourage dementia awareness in schools and explore the opportunity of identifying a local school to be a dementia champion.</p> <p>4: East Sussex County Council may wish to continue actively supporting the Community Safety Partnership and trading standards to reduce abuse of vulnerable elderly people.</p> <p>5: Clinical Commissioning Groups/ESCC may wish to consider encouraging more drivers to access the Experienced Driver Assessment scheme.</p>	<p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p>
Planning services	<p>1: East Sussex County Council and Clinical Commissioning Groups will wish to ensure that services are needs-led and person centred.</p> <p>2: East Sussex County Council and Clinical Commissioning Groups should ensure access to age appropriate services for people with early onset dementia.</p> <p>3: East Sussex County Council will wish to continue to</p>	<p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need</p>

	<p>commission respite which is flexible, offers choice, and includes expansion of domiciliary respite.</p> <p><b>4:</b> East Sussex County Council and Clinical Commissioning Groups may wish to continue commissioning activity-based groups for people with dementia focusing on wellbeing and quality of life: e.g. singing, music and arts-based therapies which are dementia friendly.</p> <p><b>5:</b> ESCC and CCGs will wish to continue commissioning appropriate levels of diagnostic activity and post-diagnosis support in the light of the increasing ageing population.</p> <p><b>6:</b> Clinical Commissioning Groups and mental health providers will wish to consider evidence obtained from the experience of the primary care Memory Assessment Service [MAS] in EHS and H&amp;R CCGs, the SPFT provided Memory Assessment Service [MAS], the Golden Ticket Pilot, the ESCC Carers Break and Engagement Service and the ESCC Carers Breaks Primary Care Pilot when planning future services.</p> <p><b>7:</b> Commissioners will wish to promote access to interventions recommended in NICE guidance such as Cognitive Stimulation Therapy for all East Sussex residents with dementia.</p> <p><b>8:</b> Commissioners will wish to ensure that people with dementia can access falls prevention interventions and services which promote recovery.</p>	<p>for further development</p> <p>Consider need for further development</p> <p>In progress</p> <p>In progress</p> <p>Implementation agreed</p> <p>Consider need for further development</p>
<b>Reducing inequalities</b>	<p><b>1:</b> Access to, and resources for, developing dementia friendly community programmes should be fair and equitable.</p> <p><b>2:</b> East Sussex County Council, Clinical Commissioning Groups, providers and voluntary organisations may wish to utilise the dementia prevalence map and the older people living in deprivation map when planning health, social care and transport services.</p>	<p>Consider need for further development</p> <p>Consider need for further development</p>
<b>People with protected characteristics</b>	<p><b>1:</b> Commissioners and providers will wish to ensure that current and future services are accessible to service users and their carers of different ethnic groups, religions and lesbian, gay, bisexual and transgender, and traveller communities.</p> <p><b>2:</b> Commissioners and providers should collect information about users, in accordance with the Equality Act 2010, to ensure services are equitable.</p>	<p>Consider need for further development</p> <p>In progress</p>
<b>Risk factors</b>	<p><b>1.</b> Health and social care commissioners will wish to encourage effective public health interventions at County, CCG and GP practice level to reduce all factors which increase cardiovascular risk.</p> <p><b>2.</b> ESCC and CCGs will wish to collaborate with PHE in national healthy lifestyle campaigns to raise awareness of actions the public can take to reduce their risk of dementia.</p>	<p>In progress</p> <p>In progress</p>

	<p><b>3.</b> As employers, ESCC and CCGs should include dementia risk reduction as part of the Workplace Wellbeing Charter.</p> <p><b>4.</b> East Sussex County Council, Clinical Commissioning Groups, providers and voluntary organisations will wish to continue working together with local representative groups of people to help their understanding of the increased risk of dementia.</p>	<p>In progress</p> <p>In progress</p>
<b>Timely diagnosis</b>	<b>1:</b> Clinical Commissioning Groups should assist GP practices to standardise dementia coding and undertake coding audits where this has not already taken place.	In progress
<b>Primary and community care</b>	<p><b>1.</b> Commissioners and all providers throughout the dementia pathway should work together to develop clear, jointly-agreed referral pathways.</p> <p><b>2.</b> Health services and adult social care may wish to develop their work with Sussex Police to identify people at increased risk of going missing and intervene early within integrated pathways.</p> <p><b>3.</b> ESCC may wish to consider auditing how well the currently commissioned services [supply] meet expressed demand at each level of the care needs pyramid.</p> <p><b>4:</b> CCGs may wish to explore opportunities to extend the management of people with dementia patients within practices.</p> <p><b>5:</b> CCGs should aim to reduce unexplained variation in QoF dementia indicators for annual reviews and baseline tests.</p>	<p>In progress</p> <p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p> <p>In progress</p>
<b>Memory Assessment Service</b>	<p><b>1.</b> Commissioners may wish to consider how the safety net system for DNAs to memory clinics can be strengthened further.</p> <p><b>2.</b> CCGs may wish to consider working towards meeting nationally identified waiting time recommendations of six weeks for first appointment at Memory Assessment Services.</p> <p><b>3.</b> CCGs should continue regular feedback to practices of their relative performance in terms of number of referrals and diagnoses, and also explain the variation in referral practice taking into account demographic and statistical variables.</p>	<p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p>
<b>Secondary Care</b>	<p><b>1:</b> The findings of the CCG review of dementia acute assessment beds in SPFT, and the commissioning of a community-based crisis service, with step-up and step-down bed provision, should continue to be implemented.</p> <p>In particular, the use of any newly-commissioned beds from SPFT in the community should be evaluated regularly, with bed utilisation data validated regularly to ensure they are meeting need and are value for money.</p> <p><b>2:</b> ESCC [and CCGs] should continue to review the</p>	<p>In progress</p> <p>Consider need</p>

	<p>process for timely and safe discharges back to the community.</p> <p><b>3:</b> Acute and community hospitals will wish to continue to adopt the King's Fund principles of Enhancing the Healing Environment [EHE] for all wards looking after people with dementia, and specific areas should be available within A&amp;E departments and acute assessment units.</p> <p><b>4:</b> Acute and community hospitals should continue to improve personal care in hospital e.g. encourage all areas to take up the Butterfly Scheme and evaluate the scheme to assess its impact.</p> <p><b>5:</b> Acute and community hospitals may wish to develop further opportunities for activity/stimulation in in-patient areas in acute and community hospitals. Hospitals may wish to explore the use of volunteer and lay dementia champions.</p> <p><b>6:</b> CCGs may wish to consider a local CQIN which may include proactively encouraging more family members to stay with their relatives with dementia in hospital if they wish.</p>	<p>for further development</p> <p>In progress</p> <p>In progress</p> <p>In progress</p> <p>In progress</p>
<b>Integration</b>	<p><b>1:</b> ESCC should continue to work in partnership with CCGs towards integrated, joint, health and social care personal budgets based upon integrated personalised care plans.</p> <p><b>2:</b> ESCC [and CCGs] should continue to develop integrated discharge planning, single assessments and care plans, and integrated community support teams.</p>	<p>In progress</p> <p>In progress</p>
<b>Social care and housing</b>	<p><b>1:</b> East Sussex County Council and CCGs may wish to consider commissioning a comprehensive, flexible, Dementia Support Service and crisis team.</p> <p><b>2:</b> The Local Authority and all three CCGs may wish to consider the guidance in the Joint Declaration from the Department of Health about the development of a local joint action plan.</p> <p><b>3:</b> Information about how to modify/adapt housing should be given to all people with dementia and their carers as part of a holistic advice and information service.</p> <p><b>4:</b> Clinical Commissioning Groups and East Sussex County Council may wish to recognise the benefits of the existing Dementia Extra Care Housing Schemes and support the roll out of new schemes.</p> <p><b>5:</b> ESCC may wish to consider further working with District and Borough councils to meet the needs of people with dementia in proposed new housing developments.</p>	<p>In progress</p> <p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p>
<b>Assistive technology</b>	<p><b>1:</b> ESCC and CCGs will wish to promote the use of telecare and telehealth, where appropriate, and ensure that the workforce has appropriate levels of knowledge and understanding about its application.</p> <p><b>2:</b> ESCC will wish to continue implementing the currently</p>	<p>Consider need for further development</p>



	<p>available assistive technology and to work in partnership with local businesses to develop innovation in its application.</p> <p><b>3:</b> ESCC may wish to promote the Assistive Technology Charter and on-line information resources.</p>	<p>In progress</p> <p>In progress</p>
<b>Care homes</b>	<p><b>1:</b> ESCC may wish to encourage the development of nursing home [NH] provision, especially EMI homes, as part of its market management.</p> <p><b>2.</b> Care homes in East Sussex should be encouraged to sign the Dementia Pledge and encourage their workforce to take on dementia leadership roles.</p> <p><b>3.</b> Commissioners [ESCC and CCGs] and supporting organisations may wish to continue focusing on improving the culture and leadership in a greater number of care homes that have residents with dementia.</p> <p><b>4.</b> Care homes should be encouraged to reach out in their community to de-stigmatise dementia, improve the image of care homes and help make East Sussex a dementia friendly county.</p> <p><b>5.</b> Care homes may wish to work in collaboration with appropriate health and social care practitioners in the identification of people who are, or have been, exhibiting symptoms and signs of dementia.</p> <p><b>6.</b> Commissioners should ensure appropriate services are in place for the diagnosis of dementia in care homes.</p>	<p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p>
<b>End of Life Care</b>	<p><b>1.</b> HWLH CCG may wish to consider the recommendations of the end of life care report, when published, and ESHT will wish to implement the recommendations of their CQC report.</p> <p><b>2.</b> Commissioners and providers should work together to help more people with dementia die in their place of choice. This could partly be achieved by ensuring that every patient with a diagnosis of dementia has an advanced care plan [ACP]</p> <p><b>3.</b> Advanced Care Planning should be undertaken at the earliest possible opportunity before mental capacity has declined.</p>	<p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p>
<b>Medicines management</b>	<p><b>1:</b> Commissioners should receive regular reports from the new Medicines Optimisation in Care Homes service, when this is introduced.</p>	<p>In progress</p>
<b>Workforce education and development</b>	<p><b>1:</b> ESCC should continue to provide Dementia training for the wider workforce in East Sussex, including bespoke courses targeted at organisations with a specific identified need.</p> <p><b>2.</b> ESCC and CCGs should continue to:</p> <ul style="list-style-type: none"> <li>develop training based on nationally recognised criteria for knowledge and competence, where possible relating to qualifications</li> </ul>	<p>Consider need for further development</p> <p>In progress</p>

	<ul style="list-style-type: none"> <li>• promote Skills for Care Common Core Principles for Dementia, and Skills for Health.</li> <li>• make full use of the Social Care Institute for Excellence dementia gateway learning resources.</li> </ul> <p>3. All training providers should consider how best to work together and pool resources under the umbrella of ESBT to ensure best value and consistency.</p> <p>4. Providers should ensure that staff receive appropriate training and consider models of value-based recruitment.</p> <ul style="list-style-type: none"> <li>• Providers, especially acute hospitals, community healthcare, care homes and domiciliary care organisations, should include essential dementia knowledge and skills in their job specifications when recruiting care staff.</li> </ul> <p>5. All organisations should ensure that staff are sufficiently knowledgeable about the Mental Capacity Act (2005), including the Deprivation of Liberty safeguarding system, and the Mental Health Act (1983 amended 2007).</p> <p>6. CCGs should actively promote uptake of dementia e-learning for NHS staff.</p> <p>7. CCGs may consider obtaining assurance that GP practices are meeting CQC standards with regard to dementia training of their staff.</p> <p>8. CCGs should ensure that general dental practitioners and practice staff are included in dementia training, and extend this to other allied health professionals.</p> <p>9. ESCC should adopt home care staff training standards in service specifications for commissioned services, when these have been developed.</p> <p>10. Future training programmes should consider including people with lived experience of dementia.</p>	<p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p> <p>New scheme</p> <p>Consider need for further development</p> <p>Consider need for further development</p>
Service user views	2: ESCC and CCGs may wish to build upon existing collaboration with the CQC to develop a deeper understanding of service quality in each locality.	In progress
Local research	<p>1: Commissioners should encourage full involvement in research and development of new approaches for dementia care in collaboration with relevant academic institutions.</p> <p>2: Commissioners will wish to consider the findings of the formal evaluation of the Golden Ticket project when available.</p> <p>3: CCGs may wish to consider introducing a dementia risk prediction algorithm in primary care.</p> <p>4: ESCC and CCGs may wish to work in collaboration with BSMS to develop new ways of evaluating and quantifying carers' quality of life.</p>	<p>In progress</p> <p>In progress</p> <p>Consider need for further development</p> <p>Consider need for further development</p>

	<b>5:</b> Commissioners will wish to consider the findings of the evaluation of the study of MRI in the primary care-led MAS when available.	<b>In progress</b>
	<b>6:</b> H&R and EHS CCG may wish to undertake a study of post-diagnosis support, subject to funding.	<b>In progress</b>

# OPERATIONAL RECOMMENDATIONS

## RECOMMENDATIONS FOR PROVIDERS

<b>Support for people with dementia and their carers</b>	<p><b>1:</b> ESCC may wish to facilitate developing the skills of local people who can then undertake the role of a Personal Assistant to support people with dementia.</p> <p><b>2:</b> Providers of carers training may wish to encourage more carers to take up the offer of carers training at appropriate times during the dementia journey. E.G. CRISP programme.</p> <p><b>3:</b> Providers of health and social care will wish to encourage more carers to have a carer's assessment.</p> <p><b>4:</b> Providers of health and social care may wish to ensure that every person living with dementia has a personalised care plan in relation to their needs, including an escalation plan and a named key worker, signed by their GP and reviewed annually.</p>	<p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p>
<b>Making East Sussex dementia friendly</b>	<p><b>1:</b> ESCC, District and Borough Councils should continue to support the role of Dementia Action Alliances in promoting communities to become more dementia friendly, introducing opportunities for social prescribing and promoting dementia friendly businesses, recognised by the British Standards Institute [BSI] specification.</p> <p><b>2:</b> ESCC may wish to facilitate public library reminiscence projects for people with dementia, working with the voluntary sector.</p> <ul style="list-style-type: none"> <li>District and Borough Councils may wish to encourage the roll out of local museum projects.</li> </ul> <p><b>3:</b> ESCC may wish to continue encouraging dementia friends and champions training for ESCC employed staff, and in partner organisations.</p>	<p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p>
<b>Risk factors</b>	<p><b>1:</b> ESCC Public health should evaluate the dementia component of NHS Health Checks and enhance the NHS Health Check training package locally.</p> <p>Public health may also wish to:</p> <p><b>2:</b> Encourage Dementia Champions to promote risk reduction messages.</p> <p><b>3:</b> Promote risk reduction messages locally through the PHE's One You Campaign.</p> <p><b>4:</b> Undertake a health equity audit of dementia risk reduction.</p> <p><b>5:</b> Include dementia risk reduction in the prevention of diabetes, CVD and blood pressure programmes.</p>	<p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p> <p>Consider need for further development</p>
<b>Primary and</b>	<p><b>1:</b> GPs may wish to continue to support the development</p>	<p>In progress</p>

<b>community care</b>	<p>of personalised care plans.</p> <p><b>2:</b> GPs may wish to continue to manage co-morbidity in the context of managing dementia as a long term condition.</p>	In progress
<b>Memory Assessment Service</b>	<p><b>1:</b> Commissioners and providers of memory assessment services will wish to continue working to improve the quality of referral information from GP practices as a way of increasing clinic capacity and reducing delays in diagnosis.</p> <p><b>2:</b> Patients who do not attend [DNA] should be referred to a support agency for further engagement.</p>	<p>In progress</p> <p>Consider need for further development</p>
<b>Secondary Care</b>	<p><b>1:</b> People with dementia admitted to an acute hospital as an emergency should receive a comprehensive, multi-disciplinary team review, including social work and consultant involvement <i>within 24 hours</i>.</p> <p><b>2:</b> Every effort should be made to ensure that the patient goes to the right ward first time.</p> <p><b>3:</b> All patients with dementia should have their hydration, nutritional and communication needs assessed and immediate action taken where appropriate.</p> <p><b>4:</b> The agreed dementia care pathway within each acute trust should be followed by all clinical specialties.</p> <p><b>5:</b> ESHT will wish to report the findings of the 2016 national dementia audit to the commissioners when completed.</p>	<p>In progress</p> <p>In progress</p> <p>In progress</p> <p>In progress</p> <p>In progress</p>
<b>Social care and housing</b>	<p><b>1:</b> ESCC and CCGs will wish to continue working towards a joint health and social care assessment process.</p>	In progress
<b>Assistive technology</b>	<p><b>1:</b> ESCC will wish to continue encouraging the use of telemedicine or telecare on a case-by-case basis, as part of care assessments.</p>	In progress
<b>Home care</b>	<p><b>1:</b> Providers of home care will wish to ensure their staff receive adequate dementia training and information, especially in relation to managing difficult behaviour and about Advanced Care Planning.</p> <p><b>2:</b> Providers of home carers will wish to make every effort to ensure consistency of staff.</p>	<p>Consider need for further development</p> <p>Consider need for further development</p>
<b>Care homes</b>	<p><b>1:</b> ESCC will wish to ensure the findings of recent CQC inspections are urgently addressed by providers as part of the ongoing assurance process.</p> <p><b>2:</b> Multi-disciplinary team protocols should be used within care homes to ensure regular GP involvement, as well as involvement of other health and social care staff.</p> <p><b>3:</b> There should be ongoing efforts, as part of care home CQC inspections, to optimise the living environment in the care home sector.</p>	<p>Urgent action needed</p> <p>Consider need for further development</p> <p>Consider need for further development</p>
<b>Medicines management</b>	<p><b>1:</b> Acute hospitals should ensure that discharge letters of people with dementia accurately reflect medications on discharge and explain reasons for medication changes.</p> <p><b>2:</b> CCGs will wish to encourage GPs to refer more people with dementia and carers to their local Medicines Use Review service.</p>	<p>In progress</p> <p>In progress</p>





## Section 9. Appendices

### Appendix 1: 'Six Paths to a Good Life with Dementia'.

#### #1 Respecting identity: 'It's not one size fits all'

Seeing people as distinct individuals is central to having a good life with dementia. This means a genuine and determined desire to treat and respect those with dementia as unique and valuable.

- How do we reduce fear so people feel less pressure to self-identify as 'having dementia'?
- How do we overcome the dementia label, and the stereotypes, bad habits and compromises that flow from it?
- How do we design services that allow people's individual identities to flourish and grow?

#### #2 Embracing now: 'It's a moment-living life'

The gradual disappearance of memory brings about a strong desire to focus on the thing that is being lost. While support with 'remembering' can be hugely valuable to people with dementia, this should be balanced with the importance of experiences in the here and now.

- How do we empower people with dementia to make their own choices about whether to 'consume' memories or not?
- What more can we do to enable people to 'live in the moment'?
- What are the implications of focusing more on what people with dementia can do, rather than what they can't?

#### #3 Sustaining relationships: 'You don't always need words'

Dementia brings out different aspects of relationships. Some are beautiful, but others are tainted by prejudice, preconception and impatience. For those with dementia to thrive, sustaining meaningful relationships is essential – and that responsibility extends throughout society.

- How can we allow people with dementia to lead fulfilling social lives, on their own terms and without stigma?
- How do we create conditions that enable the meaningful continuation of important relationships?
- What can we do to normalise dementia, and ensure people do not feel ghettoised?

#### #4 Valuing contrast: 'Good days and bad days'

Happiness is complicated – a roller-coaster of highs and lows, of being able to express ourselves freely and gain contentment in whatever we choose. But this nuanced reality can be absent, or difficult to achieve, for those living with dementia.

- How do we assess what makes someone with dementia happy?
- How can we overcome the determination to eliminate unhappiness from the lives of people with dementia?
- How do we design care environments which allow people with dementia to experience and express a full range of emotions?

#### #5 Supporting agency: 'What's there to worry about?'

Letting a person with dementia take risks is hard to square with our desire to keep vulnerable people safe. But if the knowledge of certain death brings a sense of freedom and thirst for life, then to enable a good life we need to be clearer about what it is we are protecting people from.

- How can we promote spontaneity, choice and risk as assets in a life with dementia?
- How do we design dementia services to ensure we do not restrict individuals' freedoms by limiting them to our desired routines?
- What role can technology play in providing reassurances to carers about individuals' safety?

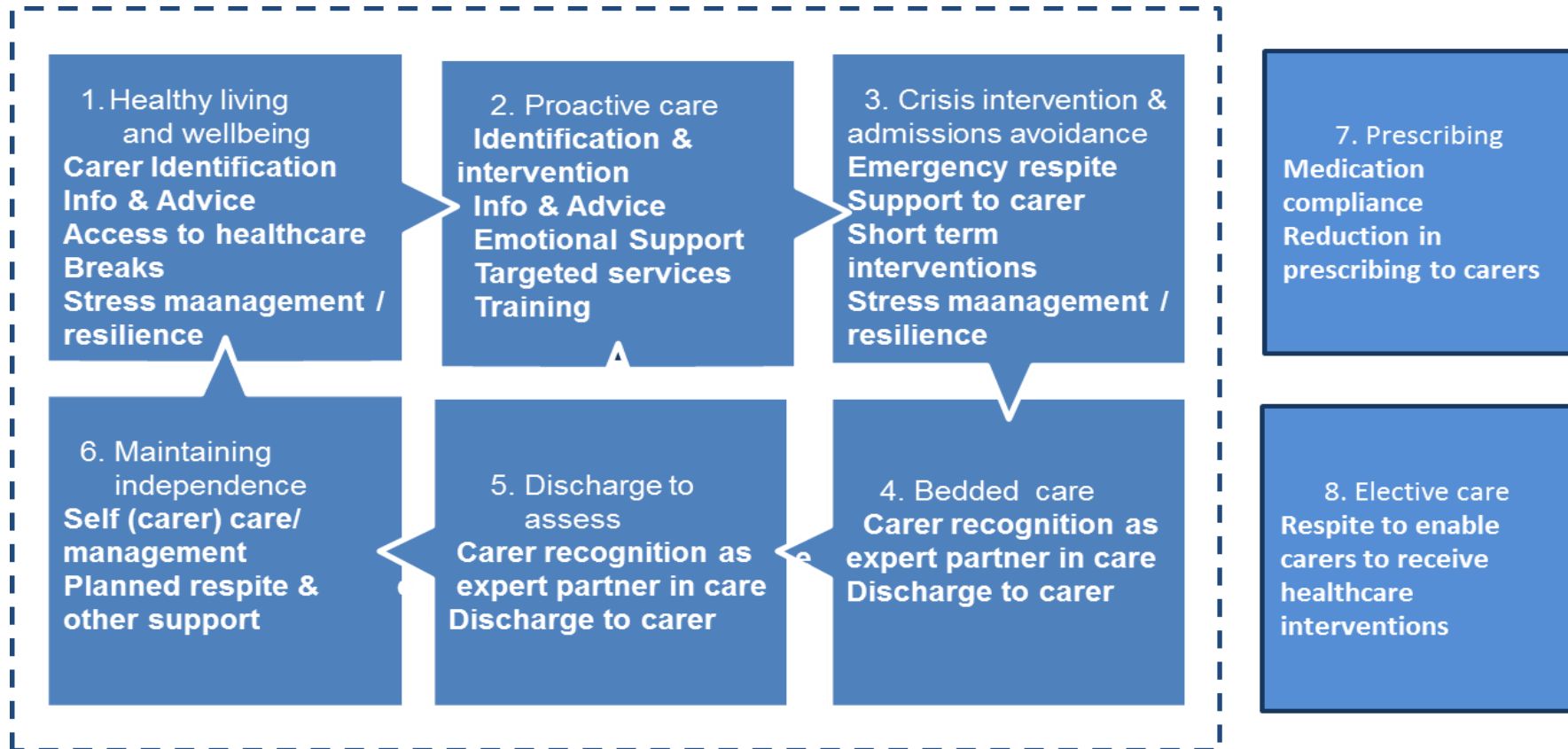
#### #6 Maintaining health: 'My priority in life'

Dementia is a serious condition which requires specialist treatment. But that focus can cause unintended disregard for other parts of an individual's health which, if neglected, may become a source of needless suffering, or limit opportunities to live well.

- How do we design services that have the flexibility to address every aspect of a person's good health, regardless of their dementia?
- What more can be done to enable people with dementia to communicate their feelings in relation to health and wellbeing?



## Appendix 2 ESBT Six Box Model



## Appendix 3 Commissioned services to support people with dementia and their carers by CCG in East Sussex:

	HWLH	EHS	H&R
<b>Memory Assessment Service</b>	<ul style="list-style-type: none"> <li>• Provided by SPFT in a Secondary Care Environment &amp; currently piloting a multi-disciplinary team approach to diagnosis in the community</li> </ul>	<ul style="list-style-type: none"> <li>• Provided by ICC [a federation of GPs] in a Primary Care Environment</li> </ul>	<ul style="list-style-type: none"> <li>• Provided by ICC [a federation of GPs] in a Primary Care Environment</li> </ul>
<b>Primary Care</b>	<ul style="list-style-type: none"> <li>• Piloting the 'GT' model promoting integrated post diagnostic support for people with dementia and their carers</li> <li>• Direct referral to Community Support Workers providing short term interventions for people with dementia and those that care for them</li> </ul>	<ul style="list-style-type: none"> <li>• Direct referral to Dementia Advisors and Community Support Workers providing short term interventions for people with dementia and those that care for them.</li> </ul>	<ul style="list-style-type: none"> <li>• Direct referral to Dementia Advisors</li> <li>• Piloting the use of named Community Support Workers aligned with practices [Bexhill] to provide additional support to Primary Care in their management of patients with dementia</li> </ul>
	<ul style="list-style-type: none"> <li>• Developing ongoing support program with voluntary agencies to link in with GT model</li> <li>• GP Leadership Programme (Dementia)</li> </ul>	<ul style="list-style-type: none"> <li>• GPs with Special Interest (Dementia)</li> <li>• <i>Practice Nurses in GP surgeries are taking on support and information roles.</i></li> </ul>	<ul style="list-style-type: none"> <li>• GPs with Special Interest (Dementia)</li> <li>• <i>Practice Nurses in GP surgeries are taking on support and information roles.</i></li> </ul>
<b>Secondary/Acute Services</b>	<ul style="list-style-type: none"> <li>• Dedicated Dementia Lead and 3 day Dementia Champions Programme in place across both hospital sites.</li> </ul>	<ul style="list-style-type: none"> <li>• Dedicated Dementia Care Lead and Multi-disciplinary / organisational 6 day Dementia Care Champions Programme in place across both hospital and community sites. <i>Staff can choose to apply and submit for academic accreditation at Levels 4 -7.</i></li> </ul>	<ul style="list-style-type: none"> <li>• Dedicated Dementia Lead and Dementia Champions Programme in place across both hospital sites.</li> </ul>
	<ul style="list-style-type: none"> <li>• Business case submitted to provide dedicated dementia nursing team.</li> </ul>	<ul style="list-style-type: none"> <li>• Business case submitted to provide dedicated dementia nursing team.</li> </ul>	<ul style="list-style-type: none"> <li>• Business case submitted to provide dedicated dementia nursing team.</li> </ul>
	<ul style="list-style-type: none"> <li>• Older Peoples Mental Health Liaison Service</li> </ul>	<ul style="list-style-type: none"> <li>• Older Peoples Mental Health Liaison Service</li> </ul>	<ul style="list-style-type: none"> <li>• Older Peoples Mental Health Liaison Service</li> </ul>
	<ul style="list-style-type: none"> <li>• National Butterfly Scheme in place</li> <li>• Dementia CQUIN in place</li> </ul>	<ul style="list-style-type: none"> <li>• National Butterfly Scheme in place</li> <li>• Dementia CQUIN in place</li> </ul>	<ul style="list-style-type: none"> <li>• National Butterfly Scheme in place</li> <li>• Dementia CQUIN in place</li> </ul>

	<ul style="list-style-type: none"> <li>• Ongoing scoping of development of Dementia Shared Care Ward</li> </ul>	<ul style="list-style-type: none"> <li>• Ongoing scoping of development of Dementia Shared Care Ward</li> </ul>	<ul style="list-style-type: none"> <li>• Ongoing scoping of development of Dementia Shared Care Ward</li> </ul>
	<ul style="list-style-type: none"> <li>• SPFT Care Home In-reach Team (Practice Development approach to improving care)</li> </ul>	<ul style="list-style-type: none"> <li>• SPFT Care Home In-reach Team (Practice Development approach to improving care)</li> </ul>	<ul style="list-style-type: none"> <li>• SPFT Care Home In-reach Team (Practice Development approach to improving care)</li> </ul>
	<ul style="list-style-type: none"> <li>• Dementia Care Inpatient Beds (Beechwood ward Uckfield/St.Gabriels ward Conquest) SPFT</li> </ul>	<ul style="list-style-type: none"> <li>• Dementia Care Inpatient Beds (Beechwood ward Uckfield/St.Gabriels ward Conquest) SPFT</li> </ul>	<ul style="list-style-type: none"> <li>• Dementia Care Inpatient Beds (Beechwood ward Uckfield/St.Gabriels ward Conquest) SPFT</li> </ul>
	<ul style="list-style-type: none"> <li>• Secondary Care (Living Well with Dementia Teams)</li> </ul>	<ul style="list-style-type: none"> <li>• Secondary Care (Living Well with Dementia Teams)</li> </ul>	<ul style="list-style-type: none"> <li>• Secondary Care (Living Well with Dementia Teams)</li> </ul>
		<ul style="list-style-type: none"> <li>• <i>MDT Pre-assessment of people with complex needs prior to elective admission</i></li> </ul>	
<b>Adult Social Care</b>	<ul style="list-style-type: none"> <li>• Carers Table 37 P.139</li> </ul>	<ul style="list-style-type: none"> <li>• Intermediate Care [IC] Milton Grange;</li> <li>• IC in Hampden Park; IC in Hailsham</li> <li>• Carers Table 37 P.139</li> </ul>	<ul style="list-style-type: none"> <li>• Primary care pilot carers project Bexhill.</li> <li>• Carers Table 37 P.139</li> </ul>
<b>Voluntary and Community Services Sector (including Carers Services)</b>	<ul style="list-style-type: none"> <li>• Alz Soc Dementia Advisors Service</li> <li>• Alz Soc Dementia Support Worker Service</li> <li>• Alz Soc Befriending Service</li> <li>• Alz Soc CRISP 1&amp;2 Courses</li> <li>• Alz Soc Early Onset Club</li> <li>• Alz Soc Singing for the Brain</li> </ul>	<ul style="list-style-type: none"> <li>• Alz Soc Dementia Advisors Service</li> <li>• Alz Soc Dementia Support Worker Service</li> <li>• Alz Soc Befriending Service</li> <li>• Alz Soc CRISP 1&amp;2 Courses</li> <li>• Alz Soc Early Onset Club</li> <li>• Alz Soc Singing for the Brain</li> <li>• Developing programme of CST courses for the newly diagnosed</li> <li>• <i>Dementia Action Alliances Eastbourne, Bexhill, Hastings</i></li> <li>• <i>Numerous charitable and self-help groups.</i></li> </ul>	<ul style="list-style-type: none"> <li>• Alz Soc Dementia Advisors Service</li> <li>• Alz Soc Dementia Support Worker Service</li> <li>• Alz Soc Befriending Service</li> <li>• Alz Soc CRISP 1&amp;2 Courses</li> <li>• Alz Soc Early Onset Club</li> <li>• Alz Soc Singing for the Brain</li> <li>• Developing programme of CST courses for the newly diagnosed</li> </ul>

## Appendix 4: Learning Outcomes for Dementia Education Programme: Sussex Community Trust (SCT)

### One Day Programme:

The one day programme is an opportunity to learn more about the syndrome 'dementia' and how it impacts on a person who has this diagnosis. The day is focused around communication and helping you to feel more confident supporting the person in your own role. You will learn about issues that are pertinent to living with dementia, including the importance of person centred approaches.

The day is delivered by SCT's specialist dementia nurses, practice development colleagues and a consultant trainer specialising in dementia care. The programme has been designed for nursing and allied health professions staff working in areas where they have frequent contact with people living with dementia and their carer's. By the end of the one day programme participants will have key learning outcomes (in line with Tier 2 Dementia Education), including:

### **Behaviour & different realities / Communication:**

- ➔ Describe the potential effects that the symptoms of a dementia can impact on how the person might behave in situations, their relationships and activities and how can affect their well being
- ➔ Identify key ways to respond to a person living with dementia who is distressed and articulate ways to approach their needs to reduce the risk a situation escalating

### **Assessment and recognising need:**

- ➔ Articulate the reasons why people living with dementia are more at risk of poorer health outcomes and ultimately reduced wellbeing and physical health
- ➔ Demonstrate knowledge of how to support the person with nutritional needs and personal care
- ➔ Describe why people living with dementia may have the reduced ability to communicate if experiencing physical illness, pain and mental distress

### **Understand the lived experience of dementia:**

- ➔ Explain how the effects of how a diagnosis of dementia may lead to the need for additional support or environmental adjustment to maintain active engagement in community life and valued activities
- ➔ Describe why the impact of environmental challenges can result in frustration and distress
- ➔ Identify the importance of activity and occupation for people living with dementia and how this can be incorporated in practice that will support their end of life care

### **Delirium:**

- ➔ Describe what delirium is, its prevalence and impact on a person living with dementia. Identify the differences between a dementia process, depression and delirium

### **Half Day Programme:**

A session designed to help increase awareness of the needs of a person living with dementia and to gain an understanding of how best to help and respond to them. This session is suitable for Trust staff working across all divisions and specialities. As the elder

population grows the person living with dementia will be accessing many of our services and it is the responsibility of everyone to ensure they have an awareness of how to adjust and respond to the person's needs.

## Key Learning Outcomes (In line with Tier 1 Dementia Awareness Level Training)

By the end of the half day programme participants will be able to:

- ➔ **Knowledge of the condition:** Describe the types of dementia and differences between a dementia, delirium and depression etc.
- ➔ **Awareness:** Demonstrate the ability to recognize the common signs and symptoms of a diagnosis of dementia, recognizing that needs are not being met when a person behaves in a way that is challenging and be more aware of a possible dementia process happening. Demonstrate improved confidence in supporting people with dementia.
- ➔ **Communications:** Demonstrate increased awareness of communication skills, listening skills and appropriate language
- ➔ **Person centred care:** Describe the key points of how person centered approaches underpin dementia care
- ➔ **Signposting:** Articulate how to access local community services that can provide information and support for people living with dementia and their families and carers.

## Appendix 5 ESHT Education delivery in line with HEE programme for dementia

### Tier 1

- An overview of dementia with an awareness of different sub types, presentation, disease process and manifestations e.g delirium.
- Person centred care and the impact on the person living with dementia and that of their family members.
- Information on tools and resources that can support people e.g. This is Me (Life History documents)
- Effective communication strategies and tools are introduced and discussed.
- The Butterfly Scheme implementation

Sessions may delivered by ESHT Dementia Care Lead or Support Workers

### Tier 2 - Half day – Building on Tier 1

Outcomes

- To provide an overview of the symptoms of dementia and the effects it may have on the person in healthcare settings.
- Helpful strategies and practical approaches to improve quality of care

Delivered by SPFT Mental Health staff

### Tier 3 - 6 DAY PROGRAMME for Dementia Care Champions

Key Learning Outcomes (in line with Tier 3 Dementia Education)

The programme consists of 6 days spaced out over 9-10 months. The 6 days are organised as workshops and cover a specific numbers of themes and topics in dementia care. There is a supporting workbook to accompany each day. In between each day champions will be offered a series of different work based or practical work place learning activities to carry out with others. It is these activities that will help prepare and gently start you and your team members on the journey to more person-centred dementia care.

The programme will offer champions the following learning opportunities:

- a peer group to discuss what's happening with dementia care in your work places: what's working and not working and an opportunity to learn from each other
- a planned programme of learning that will equip you with what you need to know about dementia care in order to be a dementia care champion and help others to change their practice
- opportunities to learn and practice skills for caring more compassionately with people who are living with dementia
- core practice develop skills to enable you to be more successful in facilitating others to become more dementia care friendly
- the opportunity to seek academic accreditation for your learning *IF* you wish
- an interesting and fun learning experience
- access to learning resources and programme facilitators for clinical supervision

Delivered by the Trust Dementia Care Lead and supported by people with dementia and their carers, as well as other professionals and specialists.

## Glossary of Terms

**ACER** Addenbrookes Cognitive Evaluation-Revised Cognitive Functioning Tool

**AChE** Acetyl Choline Esterase Inhibitors

**A&E** Accident and Emergency Department

**ACP** Advance Care Planning

**ASC** Adult Social Care

**BME** Black and Minority Ethnic Groups

**BPSD** Behavioural and Psychological Symptoms in Dementia

**BSUH** Brighton and Sussex University Hospitals

**CAB** Citizens Advice Bureau

**CCG** Clinical Commissioning Group

**CFAS** Cognitive Function and Ageing Study

**CG** Clinical Guideline

**CMHT** Community Mental Health Team

**CrISP** Carer Information and Support Programme (Alzheimer's Society)

**CQC** Care Quality Commission

**CQUIN** Commissioning for Quality and Innovation (payment)

**CSW** Carers Support Worker

**CVD** Cardio vascular disease

**CVS** Community and Voluntary Sector

**DES** Directly Enhanced Service

**DH** Department of Health

**DNA** Did Not Attend

**DoLS** Deprivation of Liberty Safeguards

**EoLC** End of Life Care

**ESCC** East Sussex County Council

**ESHT** East Sussex Healthcare Trust

**GHS** General Household Survey

**GP** General Practitioner

**GPS** Global Positioning System

**GPwSI** GP with a Special Interest

**ILAT** Integrated Locality Assessment Team

**IRR** Incidence Rate Ratio

**KPI** Key Performance Indicators

**LCS** Locally Commissioned Service

**LGBT** Lesbian, Gay and Bisexual, Transgender

**LOS** Average Length of Stay

**LPA** Lasting Power of Attorney

**MAR** Medication Administration Record

**MAS** Memory Assessment Service

**MCI** Mild Cognitive Impairment

**MDT** Multidisciplinary Team

**MH** Mental Health

**MRC** Medical Research Council

**MRI** Magnetic Resonance Imaging

**MUR** Medicines Use Review

**NICE** National Institute for Health and Care Excellence

**NIHR** National Institute for Health Research

**NMS** New Medicines Service

**ONS** Office for National Statistics

**OPMH** Older peoples' mental health

**OT** Occupational Therapist

**PALS** Patient Advisory Liaison Service

**PM** Prime Minister

**PPC** Preferred Priorities for Care

**PRH** Princess Royal Hospital

**PUFA** Poly Unsaturated Fatty Acid

**QALY** quality Adjusted Life Year

**QOF** Quality and Outcomes Framework

**RCT** Randomised Controlled Trial

**RMN** Registered Mental Nurse

**RSCH** Royal Sussex County Hospital

**SPFT** Sussex Partnership NHS Foundation Trust

**SCIE** Social Care Institute for Excellence

**WHO** World Health Organisation





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