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**SURREY**

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Surrey Heartlands Partnership and  
East Surrey Dementia Strategy

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**Our vision for the  
Dementia Care Pathway**

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## Our vision for the Dementia Care Pathway

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We wish for all people living with dementia and their carers to live in dementia friendly communities where they feel empowered and know where to go to seek information, advice and help. That they have access to the care and support that enables them to live well at home for as long as possible and to die with dignity.

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## Introduction

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Surrey County Council and CCG colleagues across Surrey Downs (Mid Surrey), North West Surrey, Guildford & Waverley and East Surrey CCGs, have worked together with local stakeholders and citizens to develop this strategy for people living with dementia and their carers in our area.

This collaborative approach, which is what our citizens expect of us, will be continued and built on in the following ways as the strategy is implemented:

- All new services will be co-produced with citizens, carers and their clinicians.
- The vital role of carers will be acknowledged in all we do.
- We will work closely with all organisations that represent carers locally.
- We will foster collaboration and innovation amongst and between suppliers of services that result in better quality and economies of scale.
- We will build on good local services, people and businesses.
- We will plan at the geographical size that best delivers what our citizens need; be that Surrey-wide, larger or at a smaller scale e.g. districts and boroughs.
- Technology will be at the heart of all we do, it will be used to serve people, to enhance good communication, enable access to information and to support collaboration.









## The existing strategy

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The current Surrey-wide Dementia and Mental Health Strategy is based on three key areas highlighted by the National Dementia Strategy of 2009:

**Improving awareness:** Increased public and professional awareness of dementia and having an informed and effective workforce for people working with dementia.

**Early diagnosis and intervention:** Good quality early diagnosis, and intervention for all; good quality information for those with dementia and their carers, that enables continuity of support and advice.

**Living well with dementia:** Improved quality of care for people with dementia; in home care; respite care/short breaks; intermediate care; general hospitals and care homes.

The current strategy document was reviewed in May 2015. Areas of achievement and potential next steps for consideration for future development were identified.

The current strategy set out to reduce stigma and improve well-being by:

- **Increasing awareness.**  
(Living and supporting well).
- **Providing information on what people can do to help themselves.**  
(Preventing well and supporting well).
- **Improve the quality of people's lives by:**
  - **Providing early diagnosis, treatment and support in the community.**  
(Diagnosing well, living well, supporting well).
  - **Improving the quality and effectiveness of inpatient care in hospital settings.** (Diagnosing well, supporting well, dying well).
  - **Improving the quality of long term care.**  
(Supporting well, dying well).

**The text in brackets shows how the existing strategy links to the key elements in the new strategy.**

## Current services – What we have achieved so far and new ways of working

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The outline of the current services across Surrey Heartlands and East Surrey reflects the achievements of the current strategy.

These include:

- Improved rates of diagnosis.
- Increased access to training through the Dementia Training Consortium, Surrey Skills Academy and Dementia Friendly Surrey.
- A Dementia Navigators service to support people and carers living with dementia.
- Development of dementia friendly communities and action teams.
- Improved access to talking therapies.
- Older Adults Community Mental Health Teams have introduced direct access for GPs to a psychiatrist.
- Surrey County Council is changing the delivery model of day care for people living with dementia and developing a new framework of community opportunities (day care).
- Improved inpatient care in hospitals through enhanced clinical leadership. Hospital Psychiatric Liaison services are now available in all of Surrey's Acute Hospitals.
- Ashford and St Peter's Hospitals NHS Foundation Trust (ASPH) has established a Dementia Strategy in-line with raising awareness for staff and patients in order to improve the quality of care and the environment for people living with dementia who are undergoing treatment in a hospital.
- ASPH have employed an Admiral Nurse who now leads a team of Occupational Therapists focusing on ensuring their dementia strategy is implemented.



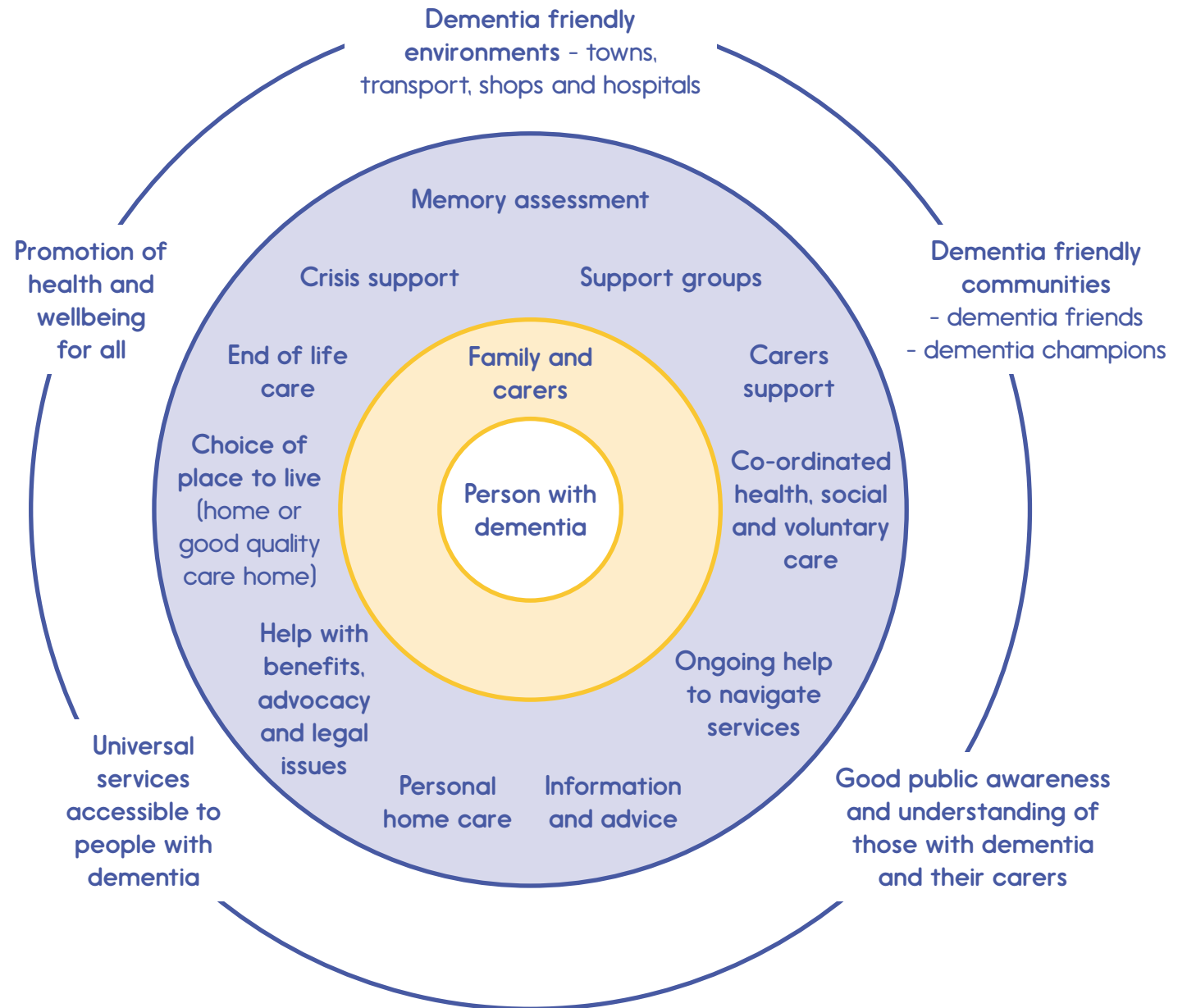
## What we intend to achieve in this new strategy

This new joint health and social care strategy sets out our direction over the next five years, (2017 – 2021).

This strategy recognises the challenges of delivering more localised, seamless services for people with dementia and their carers, in a climate where demands for services are increasing and public funding is decreasing.

For the person with dementia and their carers, this strategy is about a person-centred local community focused response as shown in Figure 1.

Figure 1. Support and care for a person with dementia and their carer(s)





## The national drivers

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**The direction of the new strategy has been guided by the previous strategy and its outcomes. There are also a number of policy statements and pieces of legislation that have informed its development, such as:**

- The Prime Minister's Challenge on Dementia in 2020 ( Feb 2015).
- The Care Act 2014.
- Dementia: 'A state of the nation' report on dementia care and support in England (DOH, 2013).

## Local context

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- Just fewer than 14,000 older people are estimated to have dementia in Surrey. This equates to around 1 in 12 older people (over 65). By 2020 this is predicted to rise to over 17,000 older people.
- It is estimated that there are around 100 people with learning difficulties who have dementia.

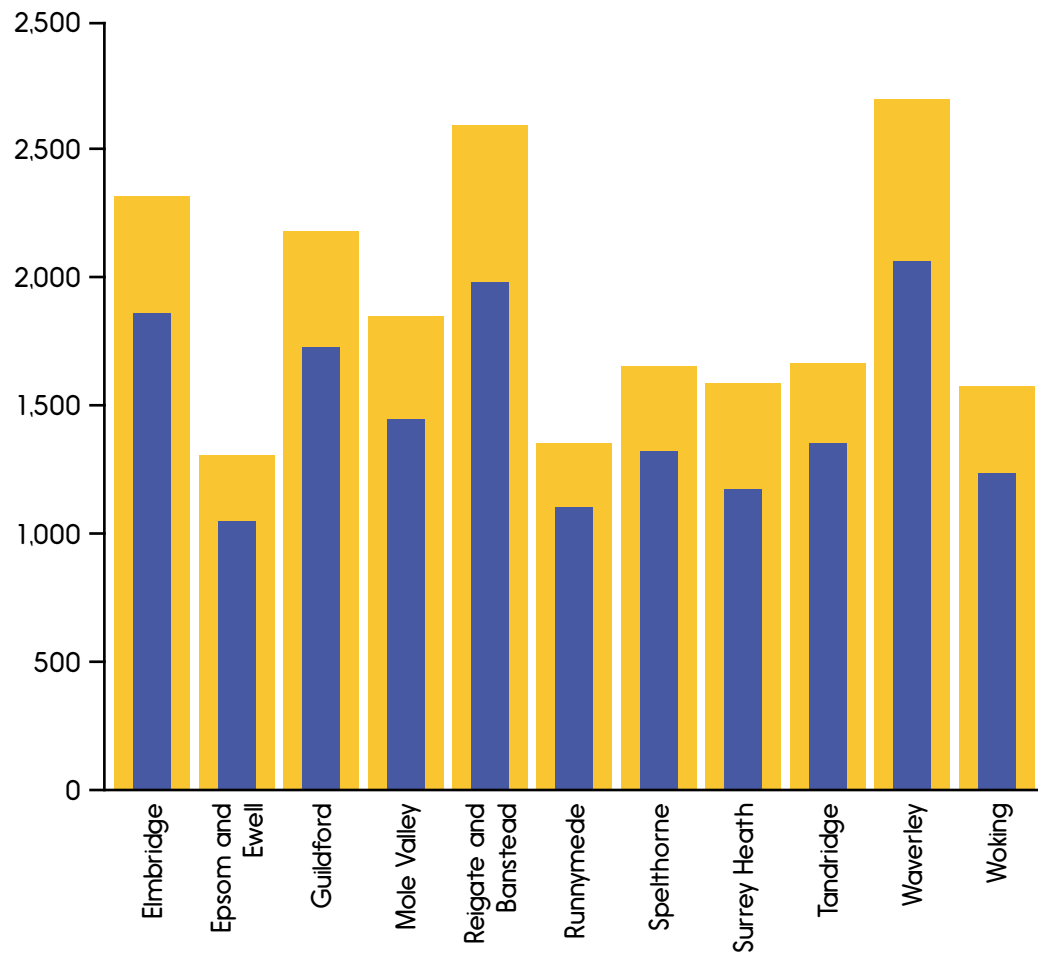
Most people with dementia have at least one other condition. A national study from 2007 showed that 59% of patients with dementia had two or more conditions. When providing care or treatment for someone with dementia, other conditions or illnesses must be taken into account.

The service needs of people with dementia and their carers are predicted to increase greatly over the coming years. Surrey has to be able to meet this rising demand.

Our strategy, in accordance with national guidance and the local context, outlines how we aim to address this challenge.

## Projected population with dementia (Aged 65+) by Borough and District - 2016 and 2025

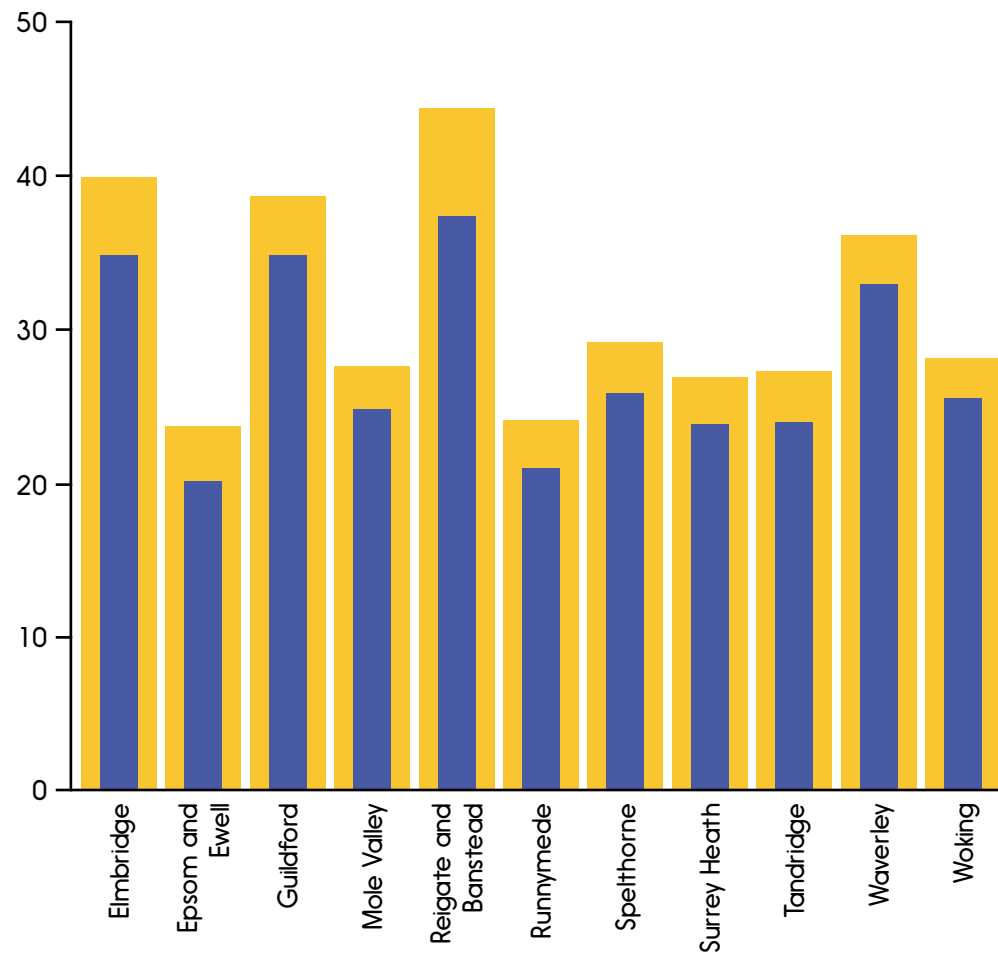
■ 2016  
■ 2025



Source: 2011 Census and population projections (ONS) and dementia prevalence rates

## Projected population with dementia (Aged 30-64) by Borough and District - 2016 and 2025

■ 2016  
■ 2025

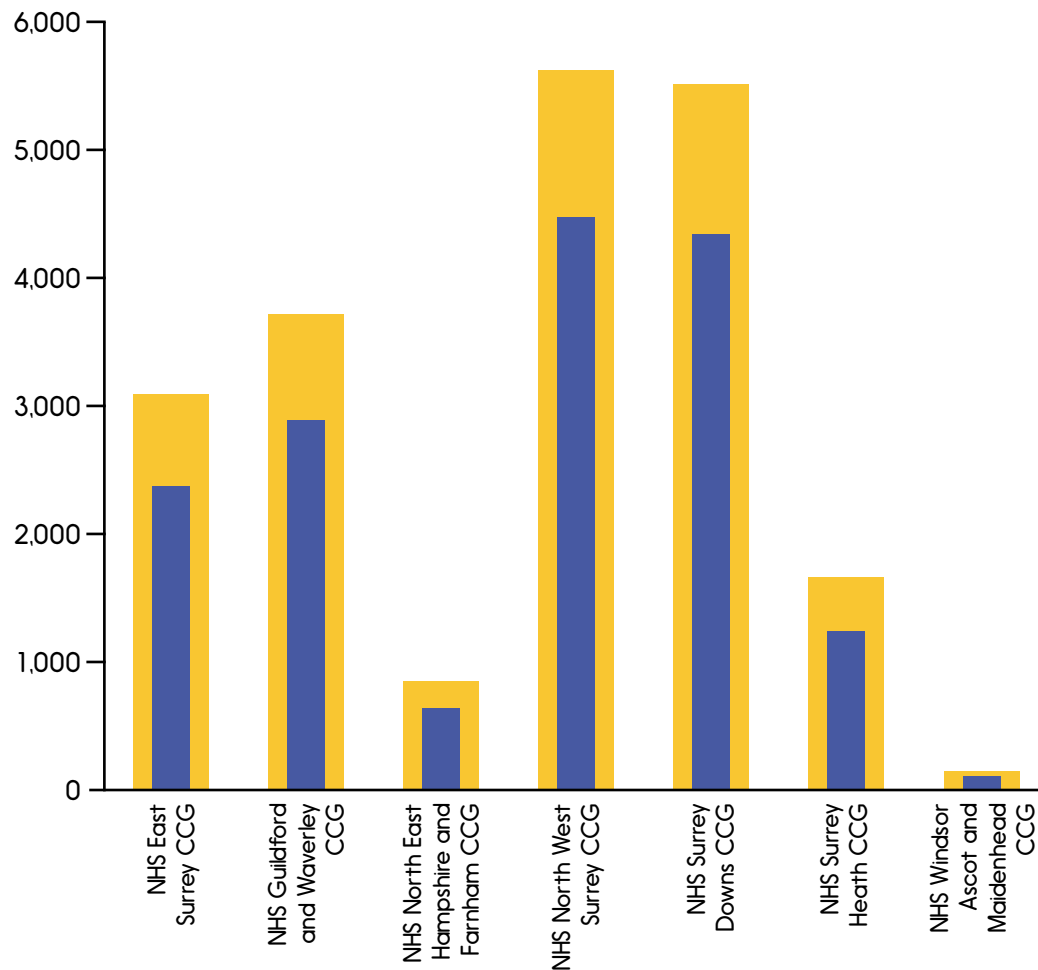


Source: 2011 Census and population projections (ONS) and dementia prevalence rates



## Projected population with dementia (Aged 65+) by CCG - 2016 and 2025

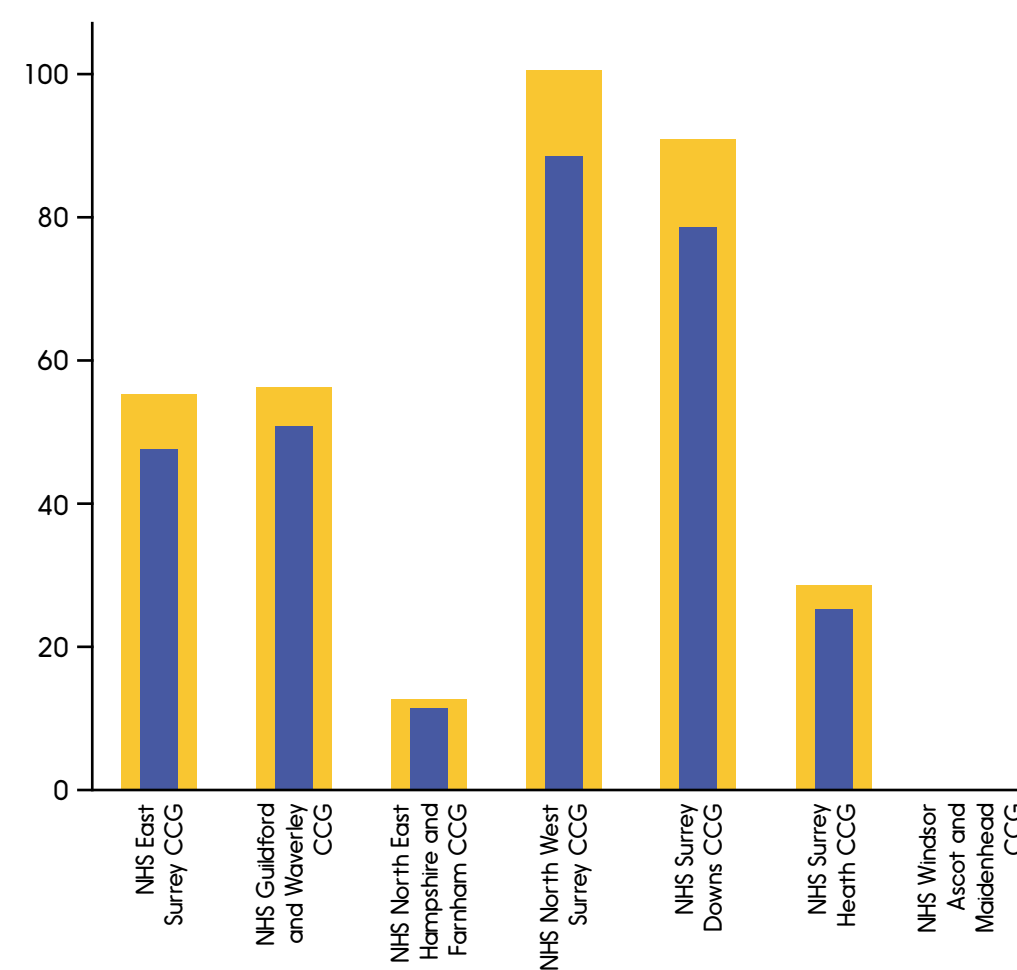
■ 2016  
■ 2025



Source: 2011 Census and population projections (ONS) and dementia prevalence rates

## Projected population with dementia (Aged 30-64) by CCG - 2016 and 2025

■ 2016  
■ 2025



Source: 2011 Census and population projections (ONS) and dementia prevalence rates

## The views of local people and organisations

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We have listened to Surrey Heartlands' people who have dementia and their families and carers, to help us understand how Surrey Heartlands can be a better place to live; and how we can deliver better quality services for people with dementia and their carers. We have also listened to the views of staff and organisations that care for those with dementia.

In 2016 we ran a number of workshops and had many other conversations with our communities and they told us that there were good aspects of health and social care and that community support from the voluntary sector was particularly valued, but they also highlighted challenges that we need to address.

These challenges include:

**1. Improving well-being and awareness** for example by raising public awareness of dementia, and providing education and training to families and carers of people with dementia.

“ Raising awareness of dementia countywide. ”

“ There should be a better recognition that dementia is a family of diseases there is no 'one size fits all'. ”

**2. Timely diagnosis and assessment** by shortening the time between seeing GPs and being assessed by specialists, by involving carers in this process, ensuring people receive a clear diagnosis, with explanations of what to expect next and what support is available.

“ A questionnaire that non-clinical staff e.g. family members can use and score before taking someone to their GP would help. ”

“ GPs need to have training and confidence to diagnose and be open and honest with individuals. ”

**3. Increasing support in the community** by providing up-to date, accessible directories of services, improving linkages and information-sharing between services, and addressing isolation and loneliness.

“ A supportive local community helped my uncle to live alone in his home when his wife died. ”

“ Lack of knowledge amongst clinicians about the community activities available to people - particularly those activities that the borough delivers itself and with partners. ”



**4. High quality long-term, acute and end of life care** by ensuring that staff who are working with patients have the necessary training and understanding to support dementia and other needs. This will enable staff to take a more holistic view (social needs and other aspirations, as well as medical needs).

“ Use Admiral Nurses to provide support through to end of life- take the Macmillan nurse model. ”

“ Ensure people are consulted as to their preferred place of death – advance care plans. Hospices reaching out more into the community. ”

From the engagement exercises we have undertaken there are some populations across our area that we need to focus on to ensure parity and equity of access and provision of services, these include:

- People living alone.
- People diagnosed with early onset dementia.
- People with learning disabilities and Down's Syndrome.
- Black and ethnic minority groups.
- The Gypsy, Roma and Traveller community.
- People with drug and alcohol dependencies.

We will continue to work with a wide range of people in developing plans to put this strategy into action.









# Whole system pathway approach

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Our strategy proposes a whole system care pathway for people with dementia, with four inter-dependent component parts that together describe the journey that individuals and their carers will experience, together with the overarching concept of LIVING WELL within dementia friendly communities.

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Feedback from both carers and people living with dementia tells us that it is a priority for them to have a single framework that encompasses all that is available to people with dementia and their carers; a pathway that follows a life journey. This will make the system easier to understand and navigate; promote consistency and reduce confusion.

“ My husband went through multiple tests back in York before we moved and now that we are down here the GP has referred him to a memory clinic that was back in January and we have not seen anyone yet. I am not sure why we need to do this again. ”

“ I moved my dad from another local authority to Surrey and now we are having difficulty accessing services and knowing where to go. ”



## The living well model

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The five elements of this approach that follow an individual's life journey and maps some of the significant events which are linked to dementia are detailed below.

### A. Living well in dementia friendly communities.

Our overarching aim is for all people and their carers to live well in a dementia friendly community. That they feel safe and accepted in their communities.

The four other elements supporting this overarching aim are:

- B. Preventing well.
- C. Diagnosing well.
- D. Supporting well.
- E. Dying well.

This is detailed in the model opposite, which has been developed from work by NHS England.



## A. Living well in dementia friendly communities

Shaping communities around the views of people with dementia and their carers.

Ensuring early diagnosis, personalised and integrated care is the norm.

Maintaining independence by delivering community based solutions.

Empowering people with dementia and recognising their contribution.

Businesses and services that respond to customers with dementia.

Ensuring that activities include people with dementia.



**B. Preventing well**

**C. Diagnosing well**

**D. Supporting well**

**E. Dying well**





### A. Living well in a dementia friendly community

Two thirds of people with dementia live in their own homes in the community. Some will be in the early stages of their illness, and others near the end of their lives. From the feedback given by individuals and carers, we recognise that the delivery and access to support is crucial for individuals and carers:

“ There is too much information which I don't have time to go through. ”

“ Keep it simple – give people relevant and simple information. ”

It is also important to give people choice and control over decisions about their lives; to remain connected to social networks they enjoyed prior to the onset of dementia. At the heart of this support should be the voice of the individual ensuring flexibility, dignity and respect, empowering them to continue to live meaningful and purposeful lives in their community.

A review of the current strategy and recent feedback highlights that an individual's needs may range from access to universal services such as transport, housing and support to maintain their property and gardens, to help with their physical health including personal care, rehabilitation, reablement and maintaining access to their peer support networks.

“ My dad is not ready to accept going to a day centre with all the 'old people'. How do I know when the right time is to offer him support and what support services are the right ones for him? ”

“ I find the support from my neighbours helps me, they often pop to the shops for me or drive me to the hospital for appointments. ”

“ I want to stay living near my family as they call me every day so I feel confident about living in my flat and going out locally. ”

“ My dad had some help when he came home from hospital, which really helped my mum initially giving her a break and time for settling back home. This really helped us all, it was for a short time, but this gave us time to get some other help arranged on a more permanent basis. ”



Living well requires being supported well and therefore both 'living well in dementia friendly communities' and 'supporting well' are intertwined. The support can be delivered in a variety of ways, through informal support from carers, families, neighbours and the wider community, from paid for care workforce (either domiciliary or care home staff) through to statutory health and social care professionals that interact with the individuals and their families.

The current strategy recognises the important role that volunteers and the wider community projects and groups play in building a sense of community support through the Dementia Friendly Surrey initiative. This new strategy commits to continue to focus on developing local networks of voluntary groups, supporting local people in their communities, promoting Action Alliances and building more localised dementia friendly communities. There is a Surrey-wide benefit to supporting both the practical and emotional needs of individuals living at home. People are often more willing to engage with voluntary and other local informal groups rather than statutory services. The Surrey voluntary sector has close links and networks which are an excellent foundation for future developments.

The current strategy also recognises the important role that the carer provides to people living with dementia. The Care Act 2014, reinforces the need to recognise, assess and offer support to carers as a statutory duty for the Local Authority.

Our current Public Health data indicates that there is a higher incidence of aging carers who may also have increasing needs in their own right. Family members and carers provide the main support to people with dementia living at home. Good community personal support services are beneficial and crucial to ensuring both individuals living with dementia and their carers continue to live a fulfilling and satisfying lifestyle for as long as possible.

We recognise that domiciliary care and care home support is delivered by skilled, trained and compassionate staff and is essential in responding to the changing needs of individuals and their carers throughout their life journey. We will continue to actively engage and support the market development of domiciliary care and care home providers across the Surrey area to ensure excellent standards of care and delivery for people accessing these services.

We recognise that good quality domiciliary care and access to community based opportunities for active engagement can contribute to maintaining a person's independence, reduce social isolation, prevent admission and or delay the permanent admission to care homes and or hospital. We will continue to focus on building those opportunities for developing localised markets and working with providers to continue to deliver this.

## What we want to achieve (our objectives)

### We aim to:

- Build a well-trained, responsive and quality range of care support services from providers who support people living with dementia and their carers. This will enable greater choice and more personalised services from those that deliver the care.
- Build on social prescribing to improve the choice and control people have over their support. Also review how it can be delivered more locally. This is an important method that can often have numerous health benefits both medically and more holistically, by decreasing isolation and increasing social connectedness.

### Support the spread of innovations that:

- Improve options of care and support using technology for people with dementia that enables them to continue to live in their home and community.
- Facilitate the voluntary sector and Dementia Friendly Surrey to influence the support options available locally.
- Improve accessibility and navigation of the complex networks and pathways of support available to individuals and their carers in their community.

We will also provide opportunities to take part in research into dementia to all those with dementia and their carers.







## B. Preventing well

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**This strategy has the aim to continue to raise public awareness and activities around dementia.**

**The strategy acknowledges that:**

- Dementia is not an inevitable consequence of ageing.
- Dementia is a disease – a chronic long-term condition. Its origins are physical. It can affect anyone.
- What's good for your heart is good for your head. Things that you do to keep your heart healthy such as diet and exercise also have the same effect on your brain.
- There are benefits in detecting the disease earlier rather than later. For example, accessing treatments that delay symptoms from getting worse or being able to plan for the future.
- You can still have good quality of life with dementia.
- The actions of families, friends and professionals can improve the quality of life for people with dementia and their carers.
- People diagnosed with dementia can continue to make an important contribution to work, family and their community.

These principles will be used to form the basis of the focus on the prevention of dementia. It will also raise awareness for the population together with the health and social care work force of Surrey Heartlands Partnership and East Surrey.

## Dementia Friendly Surrey

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Since 2013 Surrey County Council has focused on developing a Dementia Friendly Surrey campaign in partnership with the Alzheimer's Society to support Dementia Friendly Surrey.

This programme has involved training local communities to become dementia friendly champions.

Dementia Friendly Surrey community initiatives introduce various wellness activities into communities, to encourage people to reduce the risks of brain decline by giving stimulation to the brain and body as well as reducing social isolation.

Areas that the current strategy identified would need further development are:

- Achieving a Dementia Friendly Surrey – Action Alliances.
- A need to work more collaboratively with Public Health England to explore a more joined up approach and focus on general health and wellbeing for people with a high risk of developing dementia and those currently living with dementia.
- Continue to develop the market to enable person centred choice about support.



## Helping people to self-manage their long term condition

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There is generally a low level of public and non-specialist professional understanding of dementia. The stigma of dementia creates a background where people find it hard to talk about dementia and avoid addressing the possibility that someone is affected. There tends to be a misattribution of symptoms to 'old age', an unwillingness to seek or offer help, and a false view that nothing can be done to assist people with dementia and their carers.

Our current strategy focuses on building dementia friendly communities through raising awareness and training dementia champions amongst both health and social care professionals as well as local volunteers. The recent feedback that we have received from dementia support groups tells us that there is still a need to continue with this. In particular, as well as reducing stigma and improving awareness, we need to dispel some of the myths about dementia. This will encourage communities to become more accepting of dementia. We also need to help people to recognise symptoms so they are able to access diagnostics early.

A dementia friendly community is one where its residents have an awareness and understanding of dementia and how they can be supported and empowered to continue to live a meaningful life in their own home.

This strategy will increase focus on preventative activities and promotion of health and wellbeing. There are factors that can be modified to reduce the risk of developing some types of dementia, particularly vascular dementia. These risk factors include smoking, physical inactivity, high blood pressure and diabetes.

### What we want to achieve (our objectives)

#### We aim to:

- Improve awareness and understanding of dementia by the public and professionals, to reduce stigma and to improve recognition of dementia and the ways to seek help. Achieve a dementia-friendly Surrey Heartlands and East Surrey through working with local communities and organisations, including GP practices.
- Reduce the risk of developing dementia (particularly vascular dementia), promote living a healthy and well life and link this to diabetic care.
- Enable people to be as resilient as possible by promoting good physical and mental health and wellbeing.
- Empower people with dementia and their carers to have a voice and a role in developing support and services that enable them to 'live well'.

## C. Diagnosing well

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The current strategy set out to review the existing pathways and identify gaps and best practice, improve early diagnosis and post diagnostic support. It will also ensure equity for people with young onset dementia and people with learning disabilities, and improve access to training.

Almost 7 out of 10 people with dementia have a formal diagnosis in Surrey Heartlands and East Surrey. A diagnosis is often made at a time of crisis, and may come too late for people with dementia to make choices. Memory services can offer timely diagnosis and management before a crisis has occurred – this can improve quality of life, delay progression of dementia, allow the person and their family to plan for the future, delay unnecessary admission to care homes (for people who want to stay in their own home) and are cost-effective.

Memory services are currently available, but there are groups of people who may not access these in a timely way; such as people under 65, BME communities and those with learning disabilities and Down's syndrome.

We continue to identify a lack of parity for individuals with learning disability and young onset dementia. The route to diagnosis is usually longer for the younger person. 'The needs – young onset dementia' study recently found an average wait of 4.4 years, compared with 2.8 years for older people with dementia. (Baker, C (2013) Young onset dementia: care needs and service provision).

Dementia – in relation to the training required for health and social care professionals and providers who currently support these individuals - require the ability to recognise the need to access diagnostics and support early.

People have told us that they would like a shorter time between referral, diagnosis and ongoing management and support. Meaningful care following a diagnosis of dementia should be coordinated and meet national quality standards.

Across Surrey Heartlands and East Surrey there is a Dementia Navigators Service developed from the current strategy whose purpose is to provide timely and accessible support and sign posting to individuals and their carers post diagnosis.

This type of service enables people to have good quality information, which helps people and their carers to direct their own care. However this service does not often include younger people or those who have a learning disability. The feedback from users of this service is that it can be valuable, but is often hard to predict when and who may need the information.

This strategy aims to encourage work to see how the navigators and others can empower individuals, support them at all stages and make preparations for living with dementia and facing ongoing life events on their journey.

In Surrey Heartlands and East Surrey, Dementia Navigators and Wellbeing Advisors have been shown to be effective in improving the wellbeing and quality of life of people with dementia and their carers.



Feedback from people who have received these services have told us that they have found these services valuable at the beginning of their journey.

“ I have found this group (Dementia Navigators) the most useful – sharing information and knowing where to go otherwise it's so overwhelming. ”

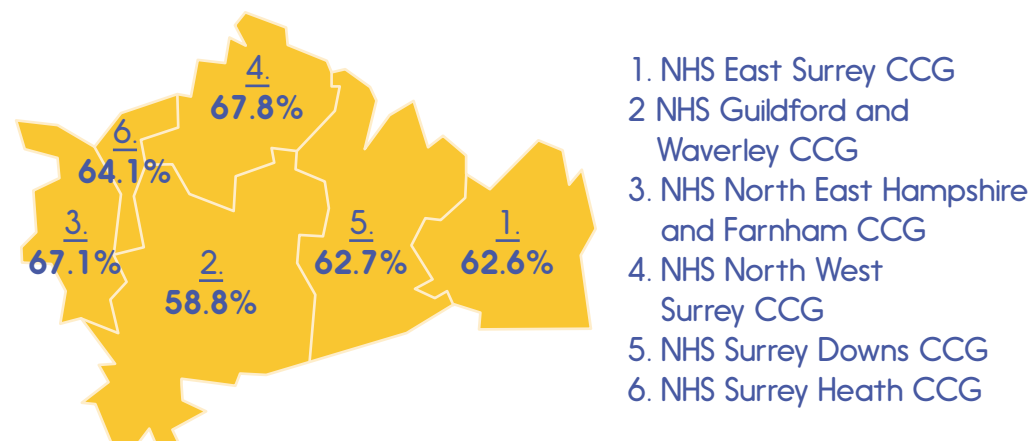
“ People often need to wait for a referral from their GP to a consultant and then memory clinic and then some people are often confused as to why they went to this? ”

“ Diagnosis is not just about having tests. It's the understanding and acceptance of managing the symptoms of the disease. How is this achieved within eight weeks? As this disease is unique, unpredictable and changeable people need degrees of support at various times. How can this be achieved by professionals, support workers etc? ”

Many individuals suffering from vascular dementia have other physical and mental health conditions / diseases and it is important that these people living with dementia have access to ongoing diagnostics and treatment to maintain their health and wellbeing, particularly in relation to other mental health conditions including depression and anxiety. This should be provided by people who understand the complexities of dementia and associated diseases, and we need to ensure that referrals and transitions between organisations and services are seamless and timely to ensure all gaps are bridged clearly.

There are clearly some groups living amongst our communities who are not accessing the support available. We recognise that this may be because they currently do not have a voice to influence the development of dementia care pathway. Our intention therefore would be to focus on some of these groups such as Traveller/ Gypsy communities, BME and others we have identified to help us to influence our future commissioning intentions.

## Dementia diagnosis rates by CCG (March 2016)



Source: Better Care Fund metrics (2013/14-2015/16)

## What we want to achieve (our objectives)

### We aim to:

- Achieve a timely and clear pathway for accessing diagnostics and health services to enable an accurate diagnosis of dementia for people of all ages and backgrounds. For people with dementia and their carers to be supported during this pathway by appropriately trained support staff.
- Diagnose dementia, using a good quality memory service for people of all ages and backgrounds at a place of their choosing.
- Build on the 'navigation pathway' to ensure people with dementia and their carers are able to navigate and understand the range of support available.
- Build a well-trained group of individuals who act as a source of information and can guide and steer individuals and their carers through the network of support as and when they need this during their life journey. Use the information available and facilitate access to this in the format of choice for the individual and their carer.
- Support and encourage the pivotal GP role in diagnosis and support of people with dementia and their carers.
- Work with care homes to ensure they are liaising with each resident's registered GP and that notes are being shared across systems, so that we can ensure patients receive the best care regardless of whether they are living at home or within the care system. Ensure care home staff are trained to use the 'Dear GP' toolkit to identify people with dementia and refer to a GP.







## D. Supporting well

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### **Co-ordinated care**

Co-ordinated care can assist people with dementia to avoid hospitalisation and support people discharged from hospital. In addition, there is good clinical evidence that people with mild to moderate dementia with deteriorating physical health will do well with physical rehabilitation and reablement from intermediate care teams. Health and social care staff should be well trained in understanding how to support people living with dementia. People with severe dementia may need a more specialised service.

### **Primary care**

Primary care teams are a key part of the ongoing coordinated care for people with dementia. GPs play a leading role as part of an existing commitment that, from April 2015, everyone will have access to a named GP with overall responsibility and oversight for their care. This consistent approach is in-line with the feedback from our population that this will help them tell their story only once.

### **Advanced contingency planning**

It is essential that there are robust coordinated services that are equipped to provide rapid support to people and their carers in times of crisis, regardless of the cause. This could be due to the deterioration in their physical health, their mental health and or a change to social circumstances or the needs of their carer. Respite may sometimes be required if a family member/carer is unexpectedly unable to look after their loved one. Advanced decisions and contingency planning will help manage unplanned situations and reduce the risk or need for a 'crisis' or 'urgent' response.

### **Information and training**

People with dementia and their carers need to know how to access information in order to make appropriate contingency plans. Families and carers need to know about common changes, what to do to avoid a crisis, who to contact and the care and support service options available.

Providers need to be able to respond promptly to be able to manage and reduce the risks for individuals facing unexpected situations, to avoid unnecessary hospital or nursing / care home admissions and provide support in the location familiar to those with dementia. Services for people with dementia will need to be aligned with services for other frail people and people with long-term health conditions.

As the disease deteriorates individuals may develop challenging behaviour and psychotic symptoms such as physical or verbal aggression, disorientation, incontinence, or become withdrawn and difficult to engage. The people caring for those with dementia should have an awareness of these issues and how to respond to them, through training staff and carers, or through the use of a specialist service for managing individuals with challenging behaviour.

### **Supporting people in the place they call home**

People across Surrey Heartlands and East Surrey are supported to live in their own homes, sheltered housing, extra care housing, as well as residential and nursing homes. Many of these receive support from care workers with personal and domestic tasks to assist them to continue living well. This strategy recognises that the providers of this support are crucial in continuing to deliver good quality care and we need to continue to foster our relationship and networks with this market through training support to ensure they have a skilled workforce.



## What we want to achieve (our objectives)

### We aim to:

Develop a community dementia service which will:

- Ensure communication and pathways of support overlap and that the transitions between services are robust and clear. To 'plug the gap' and avoid individuals not 'fitting' a pathway. To ensure that the 'journey' for the individual and their carer is seen as a continuum and not a complex stop start pathway shunting between services.
- Improve the co-ordination of care for people with dementia and their carers. In particular the links between dementia care and mental health (including drug and alcohol services), learning disability services and physical health care – as transitions between services are key to good care but is a neglected part of care pathways.
- Ensure equitable and timely access for people with dementia to the full range of universal support services, such as handy person services, transport, housing, falls services, reablement and advocacy support.

### We will also:

- Continue to develop sustainable local peer support and learning networks for the exchange of practical advice and emotional support for people with dementia and their carers, regardless of age, sex, ethnic group or disability.
- Provide 'forums' and opportunities for carers of people with dementia to feedback and actively participate in the development of services to ensure that we understand their needs.
- Provide individuals with a range of support to enable people to live in their own home for as long as long as possible.
- Develop services that work to achieve timely discharge from hospital, reducing hospital length of stay for patients with dementia, increasing the proportion of people able to return to their usual place of residence following hospital treatment.

## E. Dying well

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The aim of good care for people with dementia is to keep people living well, but there will be times when people may deteriorate despite all best efforts, and crises may occur at the end of life. Some people with advanced illness may need to have more intensive support due to an increasing deterioration of both their physical and mental health needs. Careful consideration and communication with both the person and carers will then be focused on supporting the individual as they deteriorate in the location of their choice as much as possible. This may include providing 24 hour support and care.

## End of life care

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Individual areas will have processes in place to ensure that patients can access hospice or home-based care, according to their condition or personal requirements.

It is important to have early conversations with people with dementia and their carers so that they can plan ahead for their future care, which may include palliative, and end of life care.

This reduces the likelihood that difficult and emotional decisions have to be made in crisis, when the wishes of the person with dementia cannot be taken into account.

Planning with the 'whole family' and establishing that individuals have identified advocates to support them with health and welfare decision making is crucial, to ensure that the wishes of the individual living with dementia are reflected in the actions taken.

This approach is also helpful for the patient's relatives as they will be directed to services that can support them once their loved one has passed away, such as bereavement services, as well as the formalities that will need to be carried out.



## What we want to achieve (our objectives)

- Improve the help that people and their carers experience at the end of life. Meeting their needs and keeping them connected to their local community.
- Support care home staff to be skilled in advanced care planning and communicating this with all parties to reduce the risk of avoidable hospital admissions and follow appropriate interventions during end of life.
- Increase the understanding of dementia within hospice settings.
- Raise awareness and training for carers and care workers of how to manage people with challenging behaviour, wherever they live.
- Ensure that every person with dementia, their families and carers are given the opportunity and support to make advanced care plans and have access to advocacy services.
- Engage with the market around managing people living with dementia needing end of life support.
- Ensure that people and their carers are supported in starting those difficult conversations regarding future care plans and preferences for place of death.



## Partnership working

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In order to deliver this joint health and social care dementia strategy we are committed to continue working collaboratively and establishing partnerships with people living with dementia, their carers, voluntary organisations, health and social care workers, domiciliary and care home providers and the wider community.

This document has been created through the active collaboration with:

Citizens with dementia and their carers

Dementia UK

Alzheimer's Society

Surrey and Borders Partnership NHS Foundation Trust

District and Borough Councils:

Woking Borough Council

Elmbridge Borough Council

Spellthorne Borough Council

Runnymede Borough Council

Epsom and Ewell Borough Council

Mole Valley District Council

Reigate and Banstead Borough Council

Tandridge District Council

Guildford Borough Council

Surrey Heath Borough Council

Waverley Borough Council

Surrey County Council

Guildford and Waverley CCG

North West Surrey CCG

Surrey Downs CCG

East Surrey CCG

Ashford and St Peter's Hospitals NHS Foundation Trust

Surrey Carers Association

Sutton Council

GP Clinical Leads

## Next steps

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A detailed set of proposals will be co-produced within Surrey Heartlands and East Surrey to describe how we will:

- Work together.
- Develop local services.
- Fund our joint development intentions.
- Measure the impact of our plans on partners with dementia and their carers.
- Communicate progress and implement the strategy with our community and partners over the next five years and beyond.



## Supporting information [Click blue links to visit. \(Links valid as of December 2017\).](#)

### Increasing diagnosis rates

Some CCGs are engaging with care homes where there may be residents with undiagnosed dementia.

### Quality standards and prevention

The Health and Social Care Act (2012) sets out a responsibility for NICE to develop quality standards and other guidance for health and social care in England. NICE has developed quality and prevention standards to support high quality care for dementia. For further information see:

[nice.org.uk/guidance/qs1](http://nice.org.uk/guidance/qs1)

[nice.org.uk/guidance/qs30](http://nice.org.uk/guidance/qs30)

### The dementia evidence toolkit

The toolkit contains a searchable database of (at the time of writing this) 1,345 research studies, as well as summaries of the main care and treatments: [toolkit.modem-dementia.org.uk](http://toolkit.modem-dementia.org.uk)

### Dementia 2010: the economic burden of dementia and associated research funding in the United Kingdom

This study commissioned by the Alzheimer's Research UK focuses on the costs of dementia (including health and social services, unpaid carers, premature mortality and absence from work) compared with the cost of other medical challenges:

[dementiapartnerships.com/resource/dementia-2010-research-funding](http://dementiapartnerships.com/resource/dementia-2010-research-funding)

### Dementia 2012: A national challenge

This Alzheimer's Society research summarises how well people are living with dementia:

[alzheimers.org.uk/downloads/download/821/alzheimers\\_society\\_dementia\\_2012\\_report](http://alzheimers.org.uk/downloads/download/821/alzheimers_society_dementia_2012_report)

A further survey in 2015 gives an updated picture:

[alzheimers.org.uk/info/20093/reports/253/dementia\\_2015](http://alzheimers.org.uk/info/20093/reports/253/dementia_2015)

### Making it real for people with dementia (2013)

This resource aims to help organisations move towards more personalised and community-based support by providing practical steps to make personalisation a reality:

[thinklocalactpersonal.org.uk/\\_library/MIR\\_dementia\\_FINAL.pdf](http://thinklocalactpersonal.org.uk/_library/MIR_dementia_FINAL.pdf)

### Assistive technology

AT dementia provides information on assistive technology that can help people with dementia live more independently: [atdementia.org.uk](http://atdementia.org.uk)

### Healthwatch

This 2017 briefing summarises feedback to Healthwatch about people's experience of dementia services:

[healthwatch.co.uk/news/what-do-people-think-dementia-services](http://healthwatch.co.uk/news/what-do-people-think-dementia-services)

## References Click blue links to visit. (Links valid as of December 2017).

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