Joint Health and Social Care Dementia Strategy for Surrey 2022-2027 (DRAFT)

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Foreword

This joint health and social care dementia strategy for Surrey has been refreshed in light of the myriad of strategy that impacts on the wellbeing and independence of people with dementia. The Dementia Strategy Action Board in Surrey, which was formed to implement the previous strategy, agreed it was timely to refresh existing strategies and make one Surrey wide direction of travel, with a clear focus on tackling inequality and making sure no-one is left behind.

This is especially important given the disproportionate impact the Covid-19 pandemic has had on those people with dementia and their carers identified in a report produced by the Alzheimer's Society in 2020.

In this strategy we are pleased to introduce our new and refreshed vision for the Dementia Care pathway, which seeks to improve outcomes for people with dementia and their unpaid carers and families. In this context, we are defining a carer as someone who provides unpaid help and support to a family member, partner, friend or neighbour. Carers include adults, parents or children and young people. They might be adults looking after other adults, parent carers looking after children with a disability and young carers under 18 years of age. Carers may provide emotional as well as physical support, including care for those with mental health concerns and addictions. Without the care they give, those benefiting from their help would find difficulty managing or may be unable to cope.

We wish for all people living with dementia and their unpaid carers to live in dementia friendly communities where they feel empowered and know where to go to seek information, advice and help. In addition, we aspire that people 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.

About the strategy

This strategy sets out the collective ambitions we want to achieve across Surrey to improve the dementia care pathway. In developing this strategy, we have worked with organisations that support people with dementia, their staff, the local voluntary sector and other partners.

The strategy provides the chance to reaffirm our commitment and determination to help people with dementia, and their unpaid carers to continue caring if they are willing and able, and to support their health and wellbeing by achieving outcomes they have identified matter most to them. The feedback from the research completed by Healthwatch Surrey into families, carers and individuals living with dementia was used to shape the strategy. We have listened to people in Surrey who have dementia and their families and carers, to help us understand how Surrey can be a better place to live and how we can deliver better quality services for people

with dementia and their carers. The consultation survey results showed support for the direction of travel in developing services for people with dementia and their carers and families. We have also listened to the views of staff and organisations that care for them.

Our vision

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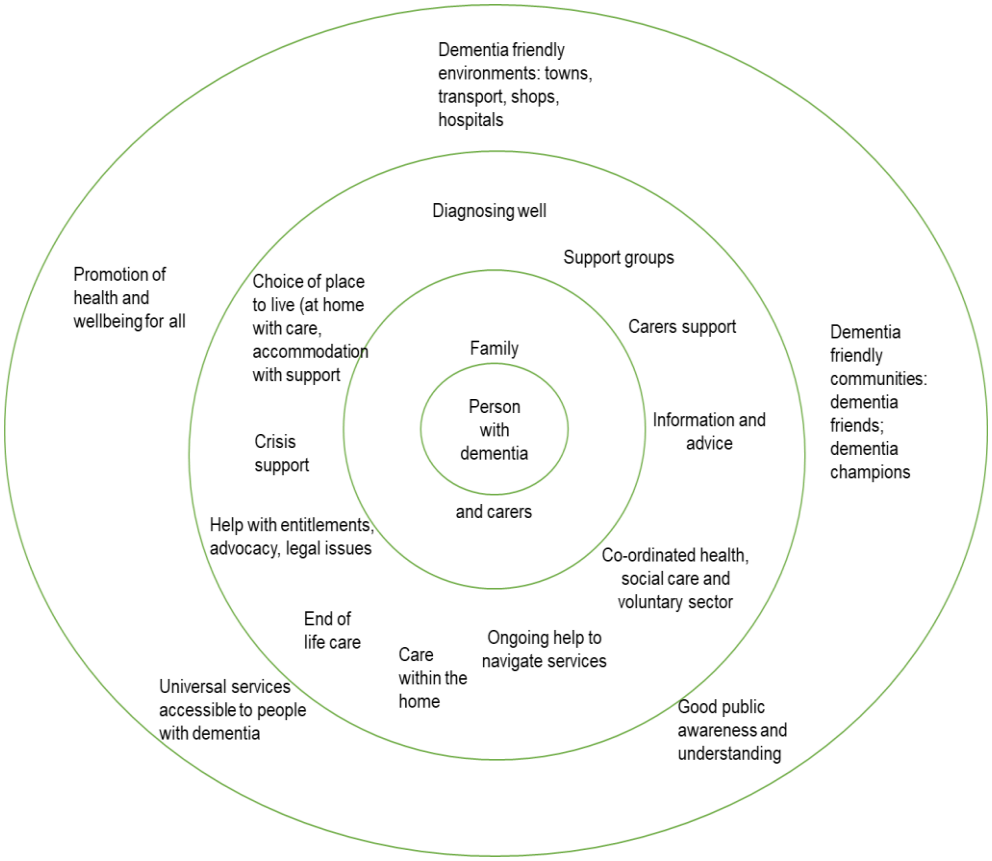
We wish for all people with dementia and their carers to live in dementia friendly communities. They will know where to go to seek information, advice and help. They will have access to the care and support that enables them to live well at home for as long as possible and to die with dignity in their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

Introduction

Surrey County Council and NHS colleagues have worked together with local stakeholders to develop this strategy for people with dementia and their carers. Working in collaboration has enabled us to identify the changes required since the last joint health and adult social care dementia strategy (2017-2021) and set the direction of travel for our services.

This refreshed strategy (2022-2027) recognises the challenges of delivering services at scale (Surrey wide) whilst acknowledging the needs of place-based care in the towns and neighbourhoods in Surrey to ensure people with dementia and their carers receive seamless and localised care. Figure1 demonstrates support and care for a person with dementia and their carer (s).



The direction of the refreshed strategy has been led by the previous strategy and its outcomes. There are a number of national policy statements and pieces of legislation and stakeholder engagement reports that have formed its development including those listed below:

- The Prime Minister's Challenge on Dementia in 2020
- The Care Act 2014
- Dementia 'A state of the nation report on dementia care and support in England
- Alzheimer's Society reports: 'Worst hit – Dementia during coronavirus; Dementia diagnosis to end of life; Ethnic minorities increasing access to diagnosis, Hospital and care homes- increasing access to diagnostics; Report on regional variations and access to diagnostics

Alongside the national direction, local data including the views of local people with dementia and their carers together with staff and organisations involved in their care helped shape the strategy. There is a strong commitment from all members of Surrey's Dementia Action Strategy Board to make positive changes for people with lived experience and their carers.

Currently there are many strategic developments across Surrey that impact on people with dementia and their carers and families, for example:

- Adults Social Care's commissioning strategy for older people

- The joint health and social care carers' strategy
- End of life care strategy
- Local place based integrated partnerships driven frailty and crisis response strategies
- Surrey County Council's accommodation with care and support strategy
- The joint recommissioning of Care within the Home services, between Surrey County Council and NHS continuing healthcare
- New Discharge to Assess arrangements, supporting people leaving hospital and their families/carers

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These are supported nationally by the NHS Long Term Plan (LTP) and the drive for more personalisation for citizens. The LTP has also driven the development of an enhanced contractual relationship between care homes (including care homes for people with a learning disability) with and primary care through a Directly Enhanced Service (DES). This DES provides a strong base to build better support for those with dementias and help to reduce the inequalities they face.

The health and wellbeing strategy for Surrey identifies that dementia is a particular issue in Surrey as people with dementia have a higher number of hospital admissions with longer lengths of stay and higher emergency admissions compared to people the same age without dementia. To meet the health and wellbeing strategy target of reducing emergency admission rates of people with dementia from 3,272 to 2,496 per 100,000 we must do things differently.

Public Health England, Public Health Scotland and the Dementia Statistics hub clearly outline the areas of inequality faced by people with dementia, their carers and families:

- Health inequalities persist into old age and many of the risk factors for dementia are associated with socio-economic inequality such as living in an area of deprivation.
- 67% of people with dementia are women, most likely because women live longer than men.
- Dementia risk increases with age.
- Dementia affects people with a learning disability at a younger age, and people with learning disabilities over 60 are 2 or 3 times more likely to have dementia than the general population.
- The estimated prevalence rates for dementia in the black and ethnic minority (BAME) community are similar to the rest of the population with the exception of early onset (presenting before 65 years) and vascular dementia which have been found to be more prevalent.
- Caring for someone with dementia puts a huge strain on the carer's physical and mental health. It can also strain, at times to breaking point, the relationships with other family members.
- The majority of recipients of unpaid care are older parents or spouses and partners and changes in the make-up of our population indicate that the number of dependent older people in the UK will increase by 113% by 2051.

Carers experience poor physical and mental health, but also have unmet care needs themselves.
- Women are 2.3 times more likely to provide care for someone with dementia for over 5 years.
- 60 -70% of carers for people with dementia are women.
- 63% of carers for people with dementia are retired while 18% are in paid work. 15% of dementia carers say they are not in work because of their caring responsibilities.

There are similar inequalities when looking at preventing dementia:

- Studies with the general population have shown that active treatment of hypertension in middle aged (45–65 years) and older people (aged older than 65 years) without dementia can reduce incidence of dementia
- Research suggests that interventions for other risk factors including more childhood education, exercise, maintaining social engagement, reducing smoking, and management of hearing loss, depression, diabetes, and obesity might have the potential to delay or prevent a third of dementia cases.
- Some of the risk factors highlighted above are more prevalent amongst people from BAME backgrounds, people living in areas of deprivation, people with severe mental illness and people with learning disabilities.

Views of local people and codesign section

During the summer of 2021 Healthwatch Surrey completed a survey and interviewed people with dementia and their carers to find out how the diagnosis and supporting well pathways had worked for them. Some quotes have been added to the body of the strategy to illustrate both good practice and gaps in the support people can access. Below is a list of the three recommendations from the report:

Recommendations

1. Build access to Dementia Navigators (or other professional/managed navigator roles). Ensure adequate resource:

    a. In every locality, iron out postcode lotteries so people in all parts of Surrey have access to a Dementia Navigator when needed

    b. For Dementia Navigators to proactively contact everyone with a diagnosis of dementia on a regular schedule (frequency to be dictated by their individual needs but may be as much as monthly or weekly at times of crisis).

2. Undertake a strategic overview of Support Groups (mapping, funding/stability); build provision in areas with weaker support; help groups become resilient; support dissemination of high-quality information through groups; provide pathways for signposting to groups.

3. Empower Primary Care to signpost effectively by providing primary care networks, GP surgeries and community care with a single point of access to signpost patients to. e.g., local navigator, Dementia Connect.

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Alongside this work conducted by HealthWatch, a substantial amount of feedback was also received as part of the co-production of Surrey County Council's commissioning strategy for older people.

With regards to accommodation with care and support for people with dementia, there was positive feedback about staff within care homes. Some individuals stated that staff have a good understanding of dementia and that it was a good place for people to recover when they needed help.

Ensuring the right home is selected in the first place, one that offers the right training for staff and support for residents, was regularly raised along with other suggested improvements for the sector. These included the need for more specialist care homes, dedicated to those with higher needs or advanced dementia. There was a clear gap identified around dementia support for care homes, training for staff and support from community teams for residents that have high needs.

Other feedback focused on the need for a person-centred approach for everyone, with better communication and more activities to offer a better continuity of care for residents.

During the formal consultation period for this strategy, feedback was sought from a range of different groups and networks such as the Learning Disability Partnership Board, the Adults and Health Select Committee, Dementia Voices and HealthWatch Surrey in addition to individual responses through the Surrey Says website.

The main findings indicated that while all the ambitions laid out in the strategy received more support than dissatisfaction, certain areas or topics of the strategy were felt to need enhancing or were seen as missing altogether.

More emphasis on prevention: Feedback suggested more emphasis was required on prevention and details on what plans will be put in place for communicating with residents to ensure that people are educated at the earliest possible stage about ways to prevent dementia.

Ensure support is visible and easy to access: Of all the ambitions respondents felt least satisfied by the 'supporting well' element. This was reinforced by comments left in other stages of the consultation survey. There is a need to improve the amount of support carers have access to, as well as ensuring they are aware the support exists.

Creating a pathway of treatment and care starting at diagnosis:
Several respondents felt that services lacked a joined-up approach, and this often

left them feeling forgotten or unsupported. Not being given a pathway of care at point of diagnosis led many to fall through the cracks. There should be greater emphasis placed on sharing information between services and ensuring a clear line of accountability.

We received further detail about how to achieve the ambitions identified above. This included: having a strategic approach to support local community groups; having adequately resourced and equitable access to dementia navigator support; making primary care dementia care plans a valuable resource to people with dementia and their carers and having an ambition to 'listen well' across the pathway.

Specific engagement work has also been conducted by Surrey County Council on day opportunities. This survey, enhanced by qualitative interviews conducted by HealthWatch Surrey, highlighted day activity, such as day centres, played a valuable role in supporting people with dementia and their carers. However, there was not an equitable offer across Surrey and transport to the centres could be challenging.

What is clear from both local feedback and the national picture is that a whole system approach to support people with dementia is essential, whether this is supporting care homes and other providers of dementia services or enabling unpaid carers to have a break from caring.

We aim to continue to gather views of local people enabling their input through further co design and co-production. In addition, we have linked up with Alzheimer's Society to establish a local Dementia Voices group that will ensure we understand the views of people with dementia and their carers when implementing service transformation.

Public health data

Data for Surrey Heartlands and Surrey Heath is available on a national level. This data indicates performance on the key indicators for dementia and is summarised in table 1 below.

Indicator	**Surrey Heartlands**	**Surrey Heath**
Estimated dementia diagnosis rate (aged 65 and over)	63.1%, better than England average of 61.9% (as at 31st December 2021)	63.6%, better than England average of 61.9% (NHS Frimley CCG as at December 2021)
Percentage of people with dementia prescribed anti-psychotics in past 6 weeks	9.2%, similar to England average of 9.3% (as at 31st December 2021)	7.8%, better than England average of 9.3%) (NHS Frimley CCG as at 31st December 2021)

Dementia care plan has been reviewed in last 12 months	75.5%, similar to England average	71.6%, lower than England average
Quality rating of residential and nursing care home beds (aged 65 and over)	71.3%, below the England average	78%, better than England average
Dementia rate of emergency admissions	3,248, better than England average	3,788, below the England average
Dementia deaths in usual place of residence	73.1%, better than England average	80.7%, better than England average

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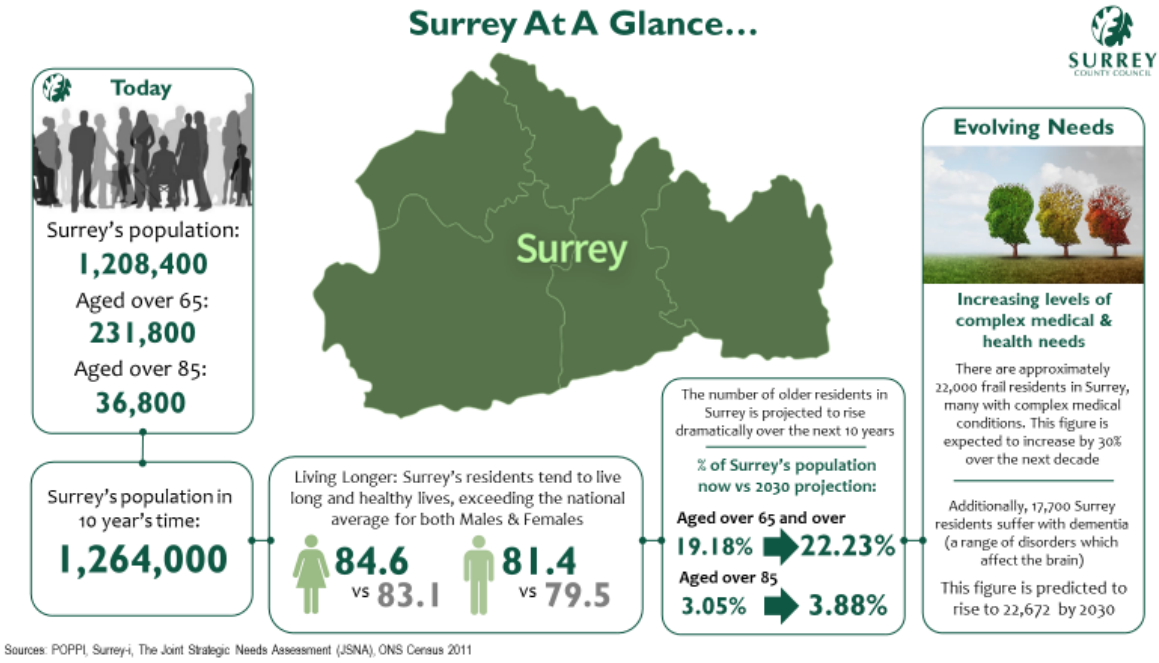
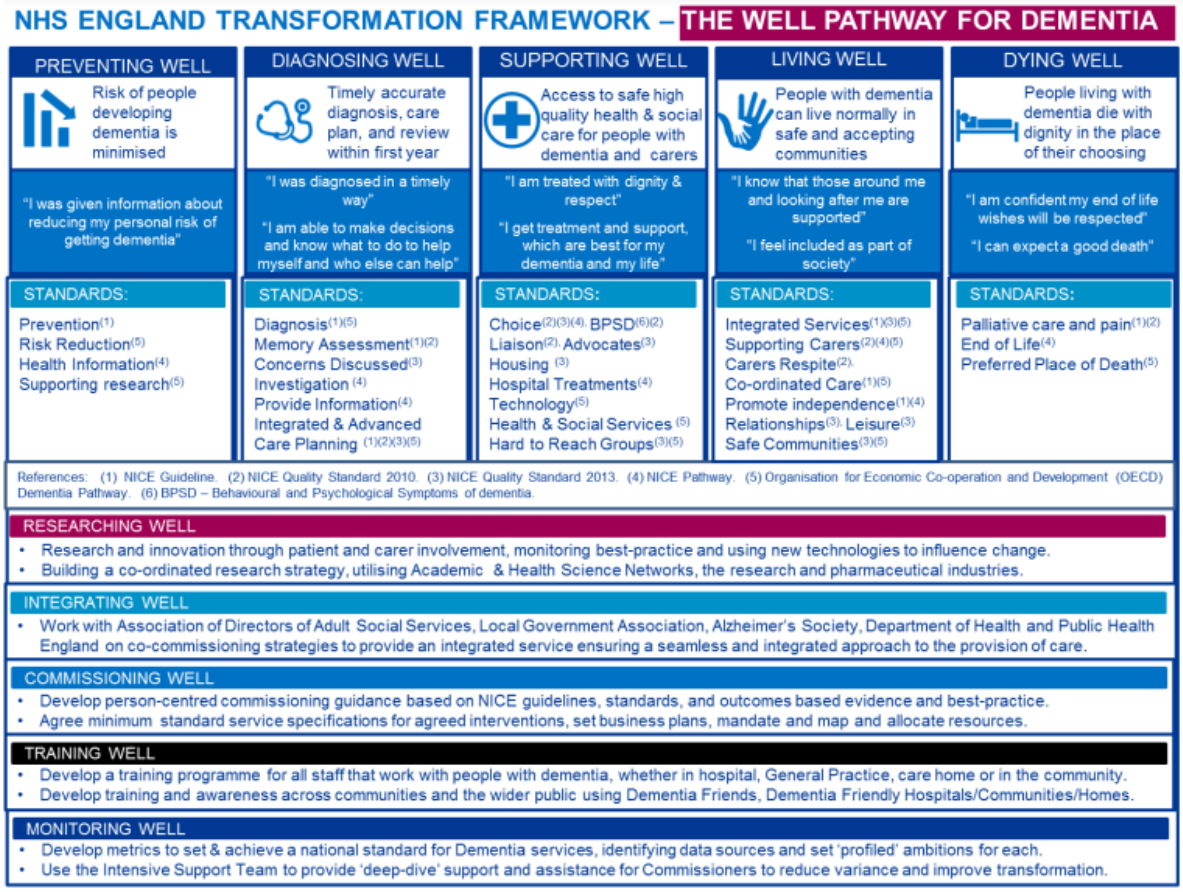
Local Context

Dementia is most common amongst older people and in Surrey it is estimated that between 2020 and 2030 the overall number of people with dementia is forecast to increase by 28%, from 17,700 to 22,672 older people. It is also estimated that there are around 105 people with a learning disability who have dementia.

Most people with dementia will have at least one other condition and this is being identified as part of the developing work on frailty in the different placed based areas. The growing demand for services by people with dementia and their carers means we need to address this challenge with integrated and proactive care for all parts of their journey of care. Figure 2 below shows the demography of older people in Surrey at a glance.



The well pathway for dementia is shown in Figure 3 below.



The outcomes in the well pathway for dementia are illustrated by "I" statements centred on the person with dementia, such as 'I was diagnosed in a timely way'. There are equally important carer centred statements in 'Making it real for carers' which include: having the information I need, when I need it; keeping friends, family and place; my support my own way; feeling in control and safe.

Each section of the well pathway for dementia is expanded on below and describes what we have achieved and what we need to do to improve the pathway for people with dementia and their carers.

Ambitions- Preventing Well

Our aim is to continue to raise public awareness and activities around dementia and the actions people can take to prevent dementia.

What have we done?

- There has been a reduction in smoking prevalence and improved

identification and treatment of hypertension supporting a reduction in dementia prevalence. One You Surrey is Surrey's only specialist stop smoking service, commissioned by Surrey County Council. It has been operational since April 2019 and has helped 3405 smokers to date to achieve a better quality of life. For 2021 through to 2025 One You Surrey has been awarded an additional contract to deliver adult weight management support.

- The increase of resources into Social Prescribing and the provision of Additional Roles Reimbursement Scheme (ARRS) roles in primary care has provided additional support to families reducing social isolation. Surrey has recently won a £500k grant to develop green social prescribing which will further increase resources and coordination in this area.
- The Kent Surrey and Sussex Academic Health Science Network (KSS AHSN) has a number of studies in various stages of set up which may help with prevention: 1. Understanding access to social care for Black and Minority Ethnic (BAME) communities; 2. Co-designing digital 'tracking' tool for people discharged from memory assessment services (MAS) with mild cognitive impairment (MCI)3. PhD looking at outcomes after MCI diagnosis.

What do we need to do?

- Develop and communicate consistent public health messages around how to prevent dementia: new messages focused on encouraging the population to participate in the over 40 health checks to promote healthy lifestyles and encourage a better understanding of healthy eating, drinking and exercise. The health checks could also be used for initial memory and cognitive assessment.
- Prioritise a focus on reducing inequalities: early onset and vascular dementia are more prevalent in people from BAME backgrounds. Currently we do not know if people accessing memory assessment services are proportionate across the demographics of people living in Surrey.
- Ensure we have accessible material for people e.g. Easy Read or a video to enable people to access the information they require.
- Enhance post diagnosis health support for people diagnosed with Mild Cognitive impairment (MCI) and improve pathways and knowledge around when to refer people diagnosed with MCI back to the community mental health team for older people (CMHT-OP) for further assessment.
- Increase early identification of carers of people living with dementia; this should happen at diagnosis (the number of carers of people living with dementia registered with their GP as a carer).
- Ensure we share information on preventing infection /delirium for older people by maintaining adequate fluid and nutrition intake and exercise as part of a healthy lifestyle.

Ambitions- Diagnosing Well

Our aim is for people to have equal access to dementia care; understanding where communities may not be accessing dementia diagnosis and post diagnostic support.

We will address the inequalities and gaps in service with partners to overcome barriers.

What have we done?

- Pre-covid there had been a sustained increase in dementia diagnostic rates (DDR) enabling people with the disease to be signposted to support services and be considered for clinical trials of new treatments. In October 2019 Surrey, for the first time, achieved the 66.7% dementia diagnosis rate target by collaborative working across professionals and disciplines driven by clinical leadership. Unfortunately, the DDR rate fell nationally due to Covid: the current DDR rate for Surrey Heartlands is 63.1% and the national rate is 61.8% against a target of 66.7%. There are two main factors thought to be contributing to the downward fall in DDR:
    1. Covid, as evidenced in the Covid mortality rates disproportionately affected people with dementia. ONS figures show that 27.5% of people who died of Covid had dementia (from 1 March to 30 May 2020). This will have impacted on the existing prevalence calculation and discussions are taking place at a national level as to whether this needs to be readjusted.
    2. There was a reduction in the number of people accessing memory assessment services due to older people staying away from health services/not accessing primary care because of shielding/Covid risk perception and services re-establishing through remote consultations during Covid. Virtual services can be more challenging for those without digital literacy or internet access, as well as cognitive or sensory impairments. In addition, access to MRI scans for accurate diagnosis (ruling out other causes) was delayed and at one point completely suspended due to pressures from Covid.

- We have promoted the FORGET tool in primary care which enables GPs to do a telephone cognitive assessment before referral to Memory Assessment Service (MAS).
- In the restoration and recovery phase the focus is on increasing the memory assessment clinics capacity and, for those who continue to require more stringent social distancing, encouraging virtual assessment where appropriate. To increase capacity, we support the introduction of dementia assessment and diagnosis within our developing integrated hubs utilising the skills of clinicians with a special interest in Dementia. The post diagnostic support will be provided through Admiral Nurses (Guildford & Waverley) /Enhanced Care practitioners (East Surrey) / Dementia Nurse specialist (Northwest Surrey and Mid Surrey) to prevent crisis, reduce emergency acute and psychiatric admissions that have seen recent increase in the placed based areas/localities. These schemes will utilise the additional Dementia diagnosis and post diagnostic resources allocated to Surrey. The roles in each place are slightly different due to different pathways in the placed based areas. Differences between integrated systems will be monitored with actions progressed to improve performance.
- To iron out the postcode lottery of access we have established a pilot to enable the dementia navigator resources to be shared across Surrey on the basis of demand rather than historic funding arrangements. This will enable

the service to meet growing demand with shared capacity across the county. The contract will be monitored to ensure it is able to meet growing demand.

- We have worked closely with the Care Home sector and the Surrey and Borders Partnership Foundation Trust (SABP) care home pathway to ensure dementia diagnosis is completed in a timely manner.
- Our Mental Health Practitioners based in frailty/locality hubs are now included in the Integrated Frailty Multidisciplinary Team meetings to improve diagnosis for this cohort of people.
- We have a Clinical Lead for dementia in Surrey Heartlands who is continuing to work with local practices and secondary care to support an increase in the diagnostic rates. Surrey has had strong engagement and support with the national and regional NHS teams.
- The Surrey wide Dementia Strategy Action Board meets bimonthly, with aim to increase dementia diagnosis rates to pre-covid rates, as well as improving post-diagnostic support for people with dementia and their families
- Young Onset Dementia (YOD) - Surrey and Borders Partnership Foundation Trust (SABP) have established a dedicated young onset diagnosis service, with specialist YOD consultant psychiatrists and clinicians across each area in Surrey. Pre-covid there was a year-on-year increase in referrals, reflecting establishment and promotion of the new service. There was reduction in referrals during covid, reflecting fears about attending for assessments and limitation to services.

Year	**Total referral numbers to young onset dementia services**
2017	194
2018	208
2019	310
2020	131
2021 (to Nov)	206

- SABP also have a learning disability assessment service. Surrey was one of the first areas in the country to begin to develop a database and services for people with Down's syndrome who develop dementia. It has been the focus of the UK's longest running Down's Syndrome and Dementia longitudinal study, which has been running for 20+ years, resulting in a major impact on clinical practice nationally and the development of a range of projects, including development of resources, DVDs and Quality Outcome Measures.

  The team have led the development and publication of national guidance 'Dementia and People with Intellectual Disabilities: Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia published by the BPS (2009, 2015)'. SABP have been operating an assessment, diagnostic and support service for individuals with Down's syndrome since 1999 and have assessed over 500 people to date.

The service currently supports 54 adults with Down's syndrome diagnosed with dementia and a further 32 adults with a learning disability.

- The dementia navigator service has been enhanced with a Dementia Connect model which was rolled out in June 2021. The model includes a keeping in touch contact service for people and their carers following diagnosis, and provides access to the service 7 days a week via telephone and website.
- The current dementia navigator service can support people with dementia, their carers and families both before a formal diagnosis and after. People access this service via the memory assessment services or through linking up with Dementia Connect. The navigator will remain with the individual, their carer and family for as long as is required. The approach is person centred and the pace and frequency of support is determined by the individual, their carers and family.
- Acquired Brain Injury and Alcohol Related Brain Damage: These have previously been identified as gaps within memory assessment services. SABP is working with alcohol and neurological services to implement pathways and protocols between these services and SABP, to close the gap.
- Mental health practitioner pathways in community services - Each Place Based Partnership, apart from East Surrey, has mental health practitioners (MHPs) located within their integrated hubs or community service provider to carry out memory assessment and dementia diagnosis. Work has been completed to implement primary care and secondary care database (EMIS and SystmOne) access for the MHPS.
- MSNAP (Memory Services National Accreditation Programme) - MSNAP Accreditation has been achieved for all CMHT-OPs apart from East Surrey, and North West Surrey is under review. The CMHT-OPs are currently taking part in the National Audit of Dementia memory services with the results due to be published in Feb 2022.
- Dementia Navigators Referrals at Diagnosis- As part of the post diagnosis pathway people are referred to the dementia navigator service. Some of the CMHT-OPs have co-located dementia navigators within the clinics.
- KSS Remote MAS Study -Remote MAS study is just concluding and will be releasing a remote MAS toolkit/patient video. Surrey participated in this study.
- Advice and Guidance e-RS CMHT-OP - Advice and Guidance access through e-RS (electronic referral service) has been launched, for enhanced primary care access to SABP CMHT-OPs. This provides a documented route for primary care to access specialist advice for people with dementia who do not need to be fully assessed by mental health services. This streamlines referral routes for advice and guidance, freeing up capacity in the CMHT-OP for more complex cases. This project is being developed further with a pilot in Mid Surrey to allow care home staff to access a dedicated mental health resource for people with dementia requiring more management support

What did some of you say about the diagnostic pathway?

The following quotes are from people interviewed by Healthwatch and respondents from the consultation survey, which illustrate that there are improvements to be made.

'*Mary's issues were explained as mild cognitive problems. No follow up was given'.*

'It was five weeks after discharge before their GP asked to see them and made the referral to the Older Persons Mental Health Team'.

'A telephone assessment was undertaken in October 2020. This identified "a cognition problem and anxiety". M was referred for a brain scan and commenced on Citalopram. A follow-up telephone appointment (due to covid) in December 2020 resulted in a letter to the GP that states: "Probable Alzheimer's Disease and anxiety". A follow-up post diagnosis phone call in March 2021 (as recorded in a letter to the GP) discharged M back to GP'.

'The family were told that it was vascular dementia, but they were not informed about the type of dementia and how it would affect B'.

'With an ageing population not enough notice is being taken of the rapid deterioration of the older minds and bodies. Plenty of advice for younger people who are stressed but little help or guidance for the elderly. Where do we get help and support?'

'The pathway of care and support should start with the GP and then follow a definitive pathway through diagnosis and appropriate support. In our experience it has been so much more stressful than it needs to be. The support should be offered rather than having to try and access help independently and then potentially missing out on crucial services.'

'Carers' denial needs to be addressed as this will be a barrier to early diagnosis and also may only come to light when the carer reaches crisis.'

'Need to make sure that the needs of people with learning disability and dementia are reflected throughout the strategy'

'Funding for living well to the third sector and travel to venues and back'

What do we need to do?

- We will support the Dementia Connect service which has a keeping in touch contact service for people and their carers following diagnosis, which provides access to the service 7 days a week via telephone and website.
- We will enhance access to Dementia navigators across Surrey to ensure we can meet growing demand.
- Increase access and uptake of baseline assessments for people with Down's Syndrome (DS).
- Mental health practitioner pathways in East Surrey community services work differently to other areas as employed by the Community Trust with no direct supervision from SABP. A new enhanced practitioner role will provide supervision and support with the pathway to improve dementia diagnosis rates in the community and ensure the model is in line with other areas.
- Ensure there is sufficient capacity for imaging capacity for an accurate diagnosis.

Ambitions- Living Well

Our aim is to make sure everyone has the opportunity to live life to the full following diagnosis.

What have we done?

- Mind the Gap: awareness raising with Surrey's South East (SE) Asian population. Provided health & social care professionals with a better understanding on how to attract SE Asian population into local services in order to address low uptake by these communities. The model will be used to further develop links with BAME communities.
- Social prescribing has signposted people to various virtual groups during the pandemic and active groups after lockdown.
- Enhanced Technology Integrated Health Care Monitoring (TIHM) in response to the challenges posed by Covid; the project is now supporting around 650 people with dementia and their carers to manage their physical and mental health and social care needs in the home environment during the pandemic (and continuing to do so) through remote monitoring. The service provides digital access to Surrey Well Being, Surrey Active Portals, Alzheimer's society Dementia Connect service and the Surrey Dementia Roadmap.
- Research conducted into the impact of dementia on those with a learning disability and their carers reported to the dementia strategy board with full support to the Mental Health Partnership Board leading to approval for additional resources to support people with a learning disability.
- Progress on integrated pathways between the acute, community services and primary care. Integrated pathways have been developed in a number of Place Based Partnerships across Surrey. Each Place (except East Surrey) has mental health practitioners in their community services who are clinically supervised by consultants in their community mental health team for older people. Of particular note is the one involving the frailty hubs in North West Surrey. This has addressed a long-standing concern that people were being discharged with uncertain diagnosis status back into the community.
- Both health and social care have continued to support the dementia navigators' contract and implemented the dementia connect model. This vital service continues to support people and their carers after they have been diagnosed with dementia. The board has supported the implementation of change in triage model from an answerphone to a staffed telephone and digital dementia connect service
- Dementia action alliances groups (DAGs). The 25 Surrey DAGs have been transitioned though the ending of the national Alzheimer's society contract which provided them with support and facilitation as well as setting up new groups. We see these groups as vital community assets for the support of people with dementia and their carers and would like to support them into Alzheimer's supported dementia friendly communities. Discussions are ongoing with the voluntary sector to support a Dementia Friendly Co-Ordinator role for Surrey.
- Psychoeducation for carers of people with dementia. CrISP Carer Information and Support Programme (CrISP) training has been funded by the carers workstream and is being rolled out across Surrey through virtual and face to

face courses.
- Young Onset Day Activities. Surrey Heath has implemented a young onset day time activity service facilitated by Younger People with Dementia Berkshire
- Intergenerational Music Project. A Surrey Downs project in care homes linking young people with older people
- Delirium Educational Webinars. SABP hosted webinars for care homes, community staff and primary care to improve delirium identification and management.

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What do we need to do?

- Ensure accessible resources on dementia are available for people with a learning disability
- Focus on establishing Dementia friendly communities (DFC) across all areas of Surrey to provide people with dementia and their carers the support they need living in a supported community. Support the introduction of a Dementia Friendly coordinator/facilitator role to provide strategic support for the local groups and ensure there is a consistent approach to delivering a Surrey wide model whilst removing inequalities of access.
- Ensure there is consistent post-diagnostic support for individuals and their carers and families. This will support the person with dementia and their carer with a better understanding of the disease and how to manage it and consequences of progression and support carers in their caring role.
- Highlight the importance of annual primary care dementia care plan reviews.
- Highlight the TIHM model of support. Consider further roll out of TIHM and related technologies across Surrey for all people and their families with dementias.
- Dementia day support for those with young onset dementia. Individuals and carers of people with young onset dementia may have different peer support needs to those of older age diagnose with dementia and activities are not necessarily suitable e.g., singing songs/talking about things from a different era to their childhood. If appropriately funded, there is scope to expand the Surrey Heath Day time activity model throughout Surrey.
- Young onset dementia accommodation with support offer. People with young onset dementia face inequality across many areas; we need to develop an equitable offer around accommodation with support.

Ambitions- Supporting Well

Our aim is to engage with our communities and faith groups to ensure we reach out to people with dementia and their carers

What have we done?

- Frailty Hubs across Surrey are in development and these have provided much

needed integration across the system.

- End of life and Carers strategies. The development of these strategies has built a common purpose across Surrey which will enable converging approach of support to emerge.
- Dementia Care Plans in primary care. 75.5% of people with dementia in Surrey Heartlands, and 71.6% Surrey Heath, had a dementia care plan review in primary care in 19/20. We aim to improve the value of these plans for people with dementia and their carers.
- Guidance for primary care and carers managing non cognitive symptoms. The guidelines were produced in 2019 and available on Surrey PAD (prescribing advisory database). In 2020 10% of people with dementia in Surrey Heartlands and 9.6% in Surrey Heath were prescribed an antipsychotic medication: this is a similar level to national average. Building on the success of the guidelines, there is now a focus on continued audit of patients with dementia prescribed antipsychotics and plans to relaunch of the guidelines with an educational event.
- Acute hospital admission data. The data shows we do better than the England average for rates of emergency admissions in Surrey Heartlands, but worse in Surrey Heath.
- Community Outreach projects e.g., the Alzheimer's Bus visited Camberly high street and engaged with local people. This supports awareness of services and reducing stigma.
- Development of place based Local dementia partnership board in some of the areas e.g., Surrey Heath, Guildford and Waverley and East Surrey. These Boards bring together local partners to improve communication and awareness of dementia services and increased working relationships to improve care and support for those with dementia and their families/carers.
- Crossroads respite for carers. These are home based breaks funded by Surrey County Council and the NHS providing regular weekly 3.5-hour respite breaks for those who care and aims to make sure the same Carer Support Worker attends each visit.
- Carers prescription offer and Action for Carers. The Q2 2021/22 analysis has shown SABP have made a strong start to the year with carer referrals. We aim for every carer to be aware of the available Surrey wide carer support options.
- Post diagnostic pathway for people with a learning disability. For people with a learning disability there is a robust post diagnostic pathway which continues to offer support to the person, their carers/ staff through to end of life, via a minimum of a 6-month brief review and an annual review, with other interventions including cancer screening programmes available as required.

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What did you say about supporting well?

The HealthWatch report identified that support information was sometimes reported as feeling overwhelming or irrelevant. It also identified that those with rarer dementias and under a neurologist were more likely to be offered research opportunities. A few carers had found their own way to research studies and HealthWatch also interviewed some in the TIHM programme.

‘*A was referred (by a person called Linda) fairly soon after diagnosis to the Elmbridge day centre and the Alzheimer’s Café in Elmbridge’.*

‘She is in the THIM study. She has sensors on the doors and hall, and it reports her temp/pulse/sats/bp daily’.

‘While C was being assessed an Alzheimer's Navigator, came out to see me and said “My job is to look after you, sir”. That was the beginning of a very productive relationship’.

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What do we need to do?

- Improve information. Information has been included on the Surrey Dementia Roadmap and groups have been requested to include information on the Alzheimer’s Society website regarding local resources to ensure people have access to the range of support groups that are available across Surrey. In addition, Dementia Connect has been publicised to primary care with information included on the Surrey Roadmap for Dementia to ensure primary care is aware of the support pathways. Surrey Information point is another useful resource and needs to be highlighted to carers and people with dementia so they can access local information.
- Improve crisis support/expansion of home treatment team. A pilot is being developed in Mid & East Surrey to develop more support for older people in a crisis and prevent hospital admission. Gaps in the care pathway to be identified and rectified, exploring why some carers only present in a crisis. Regular monitoring of the caring situation with access to carers assessments and reviews.
- Improve carers breaks. Home care for people with dementia and equitable offer of day opportunities for people with dementia. Trained and skilled home care staff enable people with dementia to have personalised care and support and give carers a break. Without this, people may not have adequate support to enable them to live at home. Appropriate day opportunities enable people with dementia to have access to meaningful activity and social interaction, whilst also enabling carers breaks.
- Enhance accommodation with care and support for people with dementia. Small scale specialist dementia residential and nursing care is a gap; people with dementia may not receive the high quality and affordable care they require and this is an inequality. People with a learning disability and dementia may not have access to appropriate care if dementia care homes are not skilled in working with people with a learning disability. Conversely, non-specialist dementia care homes may not be able to meet the needs of people with a learning disability if they develop dementia. A person-centred approach should be taken, to allow different options as appropriate e.g., enabling with person with a learning disability to remain in their current home, with extra support if needed.
- Alongside this, we need to have a whole system approach that enables support to wrap around care home residents, with training for staff and support from community teams for residents that have high needs.

- Conduct a strategic review of the support groups across Surrey and invest in local groups to support local communities and further support people with dementia and their carers whilst improving knowledge on advocacy, power of attorney, deprivation of liberties and mental capacity.

Ambitions- Dying well

Our aim is to make sure care is coordinated to enable the person with dementia to live their life as independently as possible until their death. To enable this, we endorse the 6 ambitions from the end-of-life care strategy:

- Everyone is seen as an individual, with care tailored to meet their needs and wishes.
- Everyone has equal access to palliative and end of life care.
- People are made to feel comfortable and their wider wellbeing needs are met.
- Care is coordinated, with different services working together.
- Staff have the skills and knowledge to provide the best care.
- Communities come together to provide help and support.

What have we done?

- The palliative and end of life care and the carers strategies have been published and these areas of work are prioritised in Surrey. The development of these strategies has built a common purpose across Surrey, which will enable converging approaches of support to emerge in the placed based areas.
- People dying in their usual place of residence - Mortality data indicates that in Surrey we have significantly more people with dementia dying in their usual place of residence, and significantly less people with dementia dying in hospital compared to the national average. There are processes in place that enable people to access hospice or home-based care according to their health and personal circumstances.

What do we need to do?

- Ensure supporting conversations about end-of-life planning are considered earlier in the dementia pathway.
- Improve integration of the system to support people with dementia and their carers with clear approaches to coordination of end-of-life care support for all those with dementia and their carers wherever they live across Surrey.
- We need to ensure that individuals have advocates to support them with health and welfare decisions to ensure the wishes of the individual living with dementia are included in care plans.
- Align with planned national GP contract PCN (Primary care network) specifications which will be driving the delivery of anticipatory care and personalised care models for people not in care homes.
- Ensure there is mental health representation in the multidisciplinary team for people in care homes supported by Enhanced Health in Care homes.

Dementia Research:

We have opportunities to develop, support, and implement locally and regionally important research driven activity in our Dementia strategy and practice. Through engagement with regional research organisations, including the Applied Research collaboration and the clinical research network Applied Research Collaboration, the Clinical Research Network, and Dementia collaborations/communities of practice with key stakeholders across the system, we can develop locally important research and evaluation opportunities that benefits our population, improve research capacity in our workforce, and build innovation and evidence into our programmes of work and commissioning decisions.

Some of the research programmes focussed on dementia are listed as follows:

- Time for Dementia
- Problem adaption therapy for depression in dementia,
- Technology Integrated Health monitoring (TIHM)
- Measuring outcomes of people with dementia and their carers
- Patient satisfaction with a remote memory clinic in Covid 19 restrictions
- Supporting independence at home for people with dementia.
- Various PhDs (Transitions in care, MCI, decision making, non- beneficial care)

Next Steps

The proposals co-produced within this document describe how we will:

- Work together
- Develop local services by seeking funding to support the developing programmes
- Measure the impact of our plans on people with dementia and their carers
- Update our key stakeholders on the implementation of this strategy.

The following plan details what we need to deliver and by when to have a positive impact on services for people with dementia and their carers. The plan has been developed by ‘listening well’ to people with dementia, carers and our partners and key stakeholders. We commit to continue to ‘listen well’ as we develop the actions listed below. This high level plan will be turned into a focused delivery plan, where actions and action owners will be outlined, with clear timelines and measures of success identified.

Preventing Well: our aim is to continue to raise public awareness and activities around dementia and the actions people can take to prevent dementia	✓ **By June 2022** we will develop and communicate consistent public health messages around how to prevent dementia. ✓ **By April 2022** we will prioritise a focus on reducing inequalities. ✓ **By April 2022** we will ensure we have accessible material for people e.g., Easy Read or a video to enable people to access the information they require. ✓ **By April 2023** we will enhance post diagnosis health support for people diagnosed with a mild cognitive impairment and working closely with Age UK Surrey. ✓ **By April 2023** we will increase early identification of carers of people living with dementia. ✓ **By June 2022** we will ensure we share information on preventing infection /delirium for older people by maintaining adequate fluid and nutrition intake and exercise as part of a healthy lifestyle.
Diagnosing Well: our aim is for people to have equal access to dementia care; understanding where communities may not be accessing dementia diagnosis and post diagnostic support. We will address the inequalities and gaps in service with partners to overcome barriers	✓ **By March 2022** we will support the Dementia Connect service which has a keeping in touch contact service for people and their carers following diagnosis, which provides access to the service 7 days a week via telephone and website. ✓ **By April 2022** we will increase access and uptake of baseline assessments for people with Down's Syndrome. ✓ **By May 2022** we will make sure dementia navigators are equally available to meet the needs of people across Surrey. The service will be monitored to ensure it is able to manage the predicted growth in activity. ✓ **By June 2022** we will make sure people in East Surrey have access to a new dementia practitioner who will work with others to improve dementia diagnosis rates in the community. ✓ **By June 20203** we will ensure there is sufficient capacity for imaging capacity for an accurate diagnosis.
Living Well: our aim is to make sure everyone has the opportunity to live life to the full following diagnosis	✓ **By June 2022** we will ensure accessible resources on dementia are available for people with a learning disability ✓ **By April 2022** we will have assessed if full roll out of the technology integrated health management system (TIHM) and related

	technologies across Surrey for all people and their families is a viable option. ✓ **By September 2022** we will focus on establishing dementia friendly communities and dementia action groups across all areas of Surrey. ✓ **By September 2022** we will have more robust and consistent post-diagnostic support for individuals and their carers and families and encourage the effective use of care plans in primary care. ✓ **By September 2022** we will highlight the importance of annual primary care dementia care plan reviews. ✓ **By November 2022** we will have a young onset dementia accommodation with support offer. ✓ **By April 2023** we will have more dementia day support for those with young onset dementia.
Supporting Well: our aim is to engage with our communities and faith groups to ensure we reach out to people with dementia and their carers	✓ **By April 2022** include information on the Alzheimer's Society website regarding local resources to ensure people have access to the range of support groups that are available across Surrey. ✓ **By September 2022** have a broader offer of carers breaks available including care within the home to enable people with dementia to have personalised care and support, and appropriate day opportunities to enable people with dementia to have access to meaningful activity and social interaction, and give carers a break. ✓ **By April 2023** we will improve the accommodation with care and support offer to have small scale specialist dementia residential and nursing care available to meet a range of needs. ✓ **By September 2022** we will have a whole system approach that enables community mental health support to wrap around care home residents, with training for staff and support from community teams for residents that have behaviours that challenge. ✓ **By April 2023** we will conduct a strategic review of the support groups across Surrey ✓ **By April 2023** expand crisis support available for people with dementia and their carers and families.

Dying well: our aim is to make sure care is coordinated to enable the person with dementia to live their life as independently as possible until their death. To enable this, we endorse the 6 ambitions from the end-of-life care strategy	✓ **By April 2024** we will encourage conversations about end-of-life planning to be considered earlier in the dementia pathway. ✓ **By April 2022** we will ensure that individuals have advocates to support them with health and welfare decisions to ensure the wishes of the individual living with dementia are included in care plans. ✓ **By June 2022** we will ensure there is mental health representation in the multidisciplinary team for people in care homes supported by the Enhanced Health in Care homes Framework. ✓ **By April 2024** we will align with planned national GP contract PCN (Primary care network) specifications which will be driving the delivery of anticipatory care and personalised care models for people not in care homes. We will ensure the Dementia Navigator services align to the care coordinators and anticipatory care provided by multidisciplinary teams in the new models of care**.** ✓ **By April 2024** we will improve integration of the system to support people with dementia and their carers with clear approaches to coordination of end-of-life care support for all those with dementia and their carers wherever they live across Surrey.
Actions that will help us to achieve delivery of our priority areas	✓ **By April 2022,** a dedicated clinical leadership role is in place to take forward the dementia strategy. ✓ On an ongoing basis, emerging research will be used to inform decision making and new service developments. ✓ On an ongoing basis, we commit to 'listening well' and embedding a person and family centred approach across the pathway ✓ On an ongoing basis, the communications group that considers communication and engagement activity across the Health and Wellbeing Strategy priorities will support us to deliver key information around dementia as needed.

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