

**2012/13 NHS STANDARD CONTRACT
FOR ACUTE, AMBULANCE, COMMUNITY AND MENTAL HEALTH
AND LEARNING DISABILITY SERVICES
(BILATERAL)**

**SECTION B
THE SERVICES**

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SECTION B PART 1 - SERVICE SPECIFICATIONS

Service Specification No.	1.11
Service	Bristol Dementia Wellbeing Service
Commissioner Lead	Emma Moody
Provider Lead	TBC
Period	2014-2019
Date of Review	December 2014

Key Messages:

The Bristol Dementia Wellbeing Service (known as “the Service”) will deliver an integrated person centred Primary Care led model for people with dementia and their family/carers.

At the heart of the Service will be the requirement to focus on the whole family/carers to ensure ongoing wellbeing. This must form the focus for the delivery of the Service, which will be supported by appropriately trained professionals, as well as volunteers, to ensure the right care is delivered at the right time, in the right place.

The Service will understand that co-morbid health conditions are the normality and will provide treatment and support for other mental health conditions as well as working alongside other services that support physical health needs.

1. Population Needs

1.1 Background

The specification is produced as an outcome of the NHS Bristol Modernising Mental Health Project. The overarching outcome of the consultation was for support for people with dementia and their family/carers to be delivered as a separate pathway, taken outside of traditional mental health services and for it to be understood as a long term condition.

This service will support the delivery of the Vision of the Joint Bristol Dementia Strategy 2010-2015, and draws upon current thinking and good practice in the field. It aims to:

- improve the quality of existing services for people with dementia
- invest money into new and existing services to meet the demographic need
- ensure resources are appropriately distributed along the care pathway with increased emphasis on prevention and early intervention
- focus on improving the skills and competencies of all staff who work with people with dementia and their family/carers
- address the specific needs of people with dementia and their family/carers in black and minority ethnic communities and other “equalities” communities
- address the specific needs of people with dementia and a learning difficulty and their family/carers
- consider the need for dementia research when designing services

The Strategy can be found here: www.bristol.nhs.uk/your-health/dementia.aspx

The specification takes account of the three month formal consultation (July to September 2012) and seeks to incorporate the suggested amendments to the model and pathway in light of the feedback, found at: www.bristol.nhs.uk

The Bristol Dementia Wellbeing Service encompasses five stages, a high-level service description is given in section 3.4. The stages are:

Stage 0: Organisational and Service Level Requirements

Stage 1: Assessment

Stage 2: Diagnosis

Stage 3: Supporting Ongoing Wellbeing

Stage 4: Palliative and End of Life Care

National Institute for Health and Clinical Excellence (NICE) Dementia Quality Standards provides clinicians, managers and service users with a description of what a high quality dementia care should look like. The standards describe markers of high quality, cost-effective care that, when delivered collectively should contribute to improving the effectiveness, safety, experience and care for adults with dementia and their family/carers. Each of the ten quality statements have been reviewed and incorporated into the specification, further information can be found at¹:

<http://pathways.nice.org.uk/pathways/dementia#content=view-node%3Anodes-integrated-and-coordinated-care>

1.2 National/Local Context and Evidence Base

Dementia is a syndrome caused by a number of illnesses in which there is a progressive functional decline in memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may also develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering. These cause problems in themselves, complicate care, and can occur at any stage of the illness. Although the risks of developing dementia increase with age, it is not an inevitable part of ageing.²

There are different types of dementia, these include:

- Alzheimer's disease (which accounts for 60% of all cases in people aged over 65)
- Vascular dementia (15–20% of all cases of people aged over 65)
- Dementia with Lewy bodies (15–20% of all cases of people aged over 65)
- Frontotemporal dementia (more common among younger people)

There are over 800,000 people living with dementia in the UK today, a number forecast to rise rapidly as the population ages with around 550,000 people acting as primary carers for people, and this number is expected to almost double within 30 years. Only about 42% of

¹ NICE (2010). Dementia Quality Standards. NICE Implementation Directorate Quality Standards Programme. London: Department of Health.

² Joint Commissioning Panel for Mental Health (2012). Guidance for commissioners of dementia services Volume Two: Practical mental health commission. London: JCP-MH www.jcpmh.info NICE (2010). *Dementia Quality Standards*. NICE Implementation Directorate Quality Standards Programme. London: Department of Health.

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cases of dementia are currently diagnosed³. In the UK, dementia affects²:

- 1 in 6 people aged over 80
- 1 in 25 people aged 70–79
- 1 in 100 people aged 65–69
- 1 in 1400 people aged 40–64

Many cases of dementia may have mixed pathology (for example, Alzheimer's disease and vascular dementia or Alzheimer's disease and Dementia with Lewy bodies). Such cases should be managed according to the condition that is thought to be the predominant cause of dementia.¹

In the UK around 15,000 people aged under 65 years have dementia. This is probably an under-estimate as it is based on referrals to services, and not all people will seek help early in the course of the disease.²

An estimated 15,000 people of all ages from black and minority ethnic groups have dementia, and six per cent of this group will have young onset dementia, compared with two per cent in the wider UK population. People with learning disabilities and Down's Syndrome are at higher risk of dementia. The risk of dementia is higher in the presentation of people with stroke and some other neurological conditions. Between 30% and 70% of people with Parkinson's disease develop dementia, depending on duration of the condition and age.²

Around two thirds of people with dementia live in their own homes and around one third live in care homes. Of the total number of people in care homes, around two thirds are estimated to have dementia³. Between 1998 and 2031, the number of care home places is expected to rise by 63%. Despite around two thirds of people in care homes are estimated as having dementia, in 2008 only 28% of care home places were registered to provide specialist dementia care.⁴

People with the condition are also core users of NHS care, a quarter of hospital beds are occupied with people with dementia over 65 at any one time.³

Dementia is a long-term condition; some people live with it for 10–12 years. On average people live seven years after developing symptoms. This is because many people are not diagnosed until late in their illness.²

The annual costs to the taxpayer of direct health and social care services for people with dementia are around £7.4 billion. The total annual cost per person with dementia in different care settings were estimated as⁵:

- | | |
|--|---------|
| • People in the community with mild dementia | £16,689 |
| • People in the community with moderate dementia | £25,877 |
| • People in the community with severe dementia | £37,473 |
| • People in care homes | £31,296 |

Dementia is a disease that is strongly associated with age and its prevalence is affected by an ageing population; unchecked, this spending pressure on more expensive services is

³ Department of Health (2012). *Prime Minister's challenge on dementia: Delivering major improvements in dementia care and research by 2015*. London: Department of Health.

⁴ Dementia Commissioning Pack (2011). *Service Specification for dementia: better care at home, and in care homes Specialist dementia service*. London: Department of Health.

⁵ Dementia Commissioning Pack (2011). *Case for Change – community-based services for people living with dementia evidences*. London: Department of Health.

likely to rise at an increasingly unsustainable pace. Hospital stays for people aged 60-74 have increased by more than 50% between 1999/2000 and 2009/2010, and hospital stays for people aged 75 and over have increased by 66% in the same period. Identification and diagnosis of dementia often comes late in the illness, when the person needs more expensive care services.

Dementia has been an increasing priority both locally and nationally over the past few years. There is now a wealth of information and evidence to support the delivery of services to enable people to “live well” with dementia.

1.3 Current Key Documents Underpinning the Service Specification Include:

Living Well with Dementia: A National Dementia Strategy, 2009

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058

Quality Outcomes for People with Dementia: Building on the National Dementia Strategy, 2010

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119827

NICE Dementia Quality Standards, 2010

<http://pathways.nice.org.uk/pathways/dementia#content=view-node%3Anodes-integrated-and-coordinated-care>

Dementia: A Public Health Priority, 2012

www.who.int/mental_health/publications/dementia_report_2012/en/index.html

Dementia Commissioning Pack: London: Department of Health 2012

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_127381

Prime Minister's Challenge on Dementia 2012

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_133170

Unlocking Diagnosis: All-Party Parliamentary Group Report, 2012

www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1457

1.4 Local Demographic Information

There are two sets of significantly different projections on the expected prevalence for dementia in Bristol. The first is taken from the 2011 Census data and uses the Bristol population data to understand expected prevalence. The second data set has been provided by Dementia Partnerships South West. This uses the General Practitioner practice lists as the basis for expected prevalence and factors in an adjustment for the number of care homes in the area.

Both sets of data are included below, and it is reasonable to assume that due to the differences between the data sets, there is somewhere between 4,300 and 4,700 people in Bristol, who currently have a form of dementia.

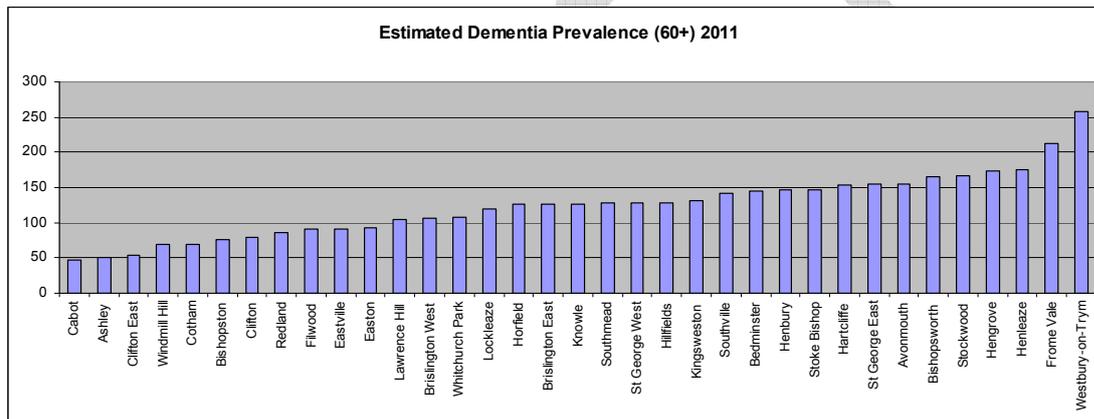
1.4.1 Census Data 2011 Census: Population and Household Estimates for Wards and Output Areas in England and Wales

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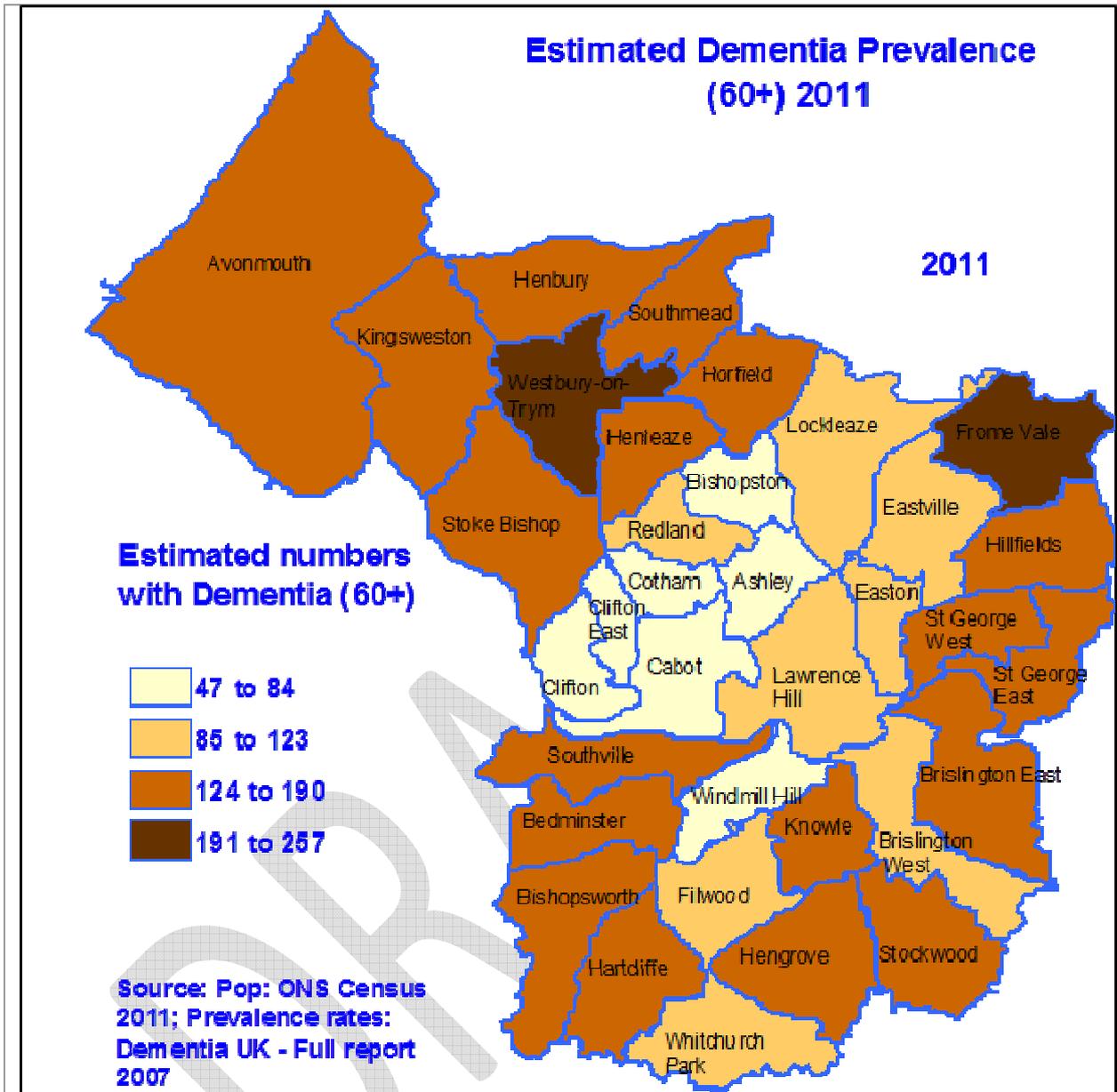
The data below outlines the estimated prevalence of dementia, by City/County boundary and by ward in Bristol.

Estimated Dementia Prevalence in Bristol				
	Estimate d prevalence (All 60+)	% of total popula tion	Males (60+)	Femal es (60+)
Bristol	4334	1.0%	1462	2872
B&NES	2421	1.4%	851	1579
North Somerset	3190	1.6%	1106	2084
South Glos	3023	1.2%	1111	1912
South West	76894	1.5%	27186	49707
England	619380	1.2%	21908	40029
			2	8

Source: 2011 Census



Source: 2011 Census



Source: 2011 Census

1.4.2 Dementia Partnerships South West 2012

This data is taken from the Dementia Partnerships South West Dementia Prevalence Calculator. It takes in to account the number of people on the General Practitioner registers and the number of care home beds in the area, to give an expected prevalence of dementia. The data using this method identifies an expected prevalence that is higher than the data that is based on the Census.

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Estimated number of dementia cases in Bristol 2011/12	Using National Dementia Prevalence Rate (NDPR)	Using Adjusted NDPR (adjusted to weight care home beds)
Living in the community		3,163
Living in residential care		1,370
Total	4,553	4,533
Total Dementia register	2,162	2,162
Diagnosis rate	47.5%	47.7%

Source: Dementia Partnerships South West

	2011/ 12	2012/ 13	2013/ 14	2014/ 15	2015/ 16
Forecast number of cases	4,533	4,643	4,749	4,848	4,946
Diagnosis rate	47.7%	47.7%	47.7%	47.7%	47.7%
Resulting Dementia Register	2,162	2,214	2,265	2,312	2,359

Source: Dementia Partnerships South West

In addition to the above data sets, the table appended in Section 7 illustrates the number of people actually recorded by ward.

2. Scope

2.1 Bristol Vision

The Vision, as stated in the Local Action Plan for Dementia for Bristol (2011-2015), is:

“That all people in Bristol with dementia receive a timely diagnosis, in a place appropriate to their needs, with a range of ongoing support available to them. We expect people with dementia to receive excellent care from diagnosis to end of life, by staff expertly trained in dementia, whether the person is at home, in a care home or in hospital. We expect all family/carers to be properly supported and to have access to a break from the stresses that caring can bring. We expect our services to be joined up and enable people to live well with dementia. Our overarching aim is for Bristol to be a dementia friendly City.”

2.2 Key Principles of Service

The Bristol Dementia Wellbeing Service is supported by key principles, based on current thinking and practice which includes:

- ✓ The person with dementia and family/carers are at the centre of the service and key

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- to making decisions about care
- ✓ Providing a seamless transition between health, social care, voluntary and community sectors⁶ to provide a person centred holistic pathway using a primary care, chronic disease model
 - ✓ A service that recognises that each person is an individual
 - ✓ A service which is provided on the basis of need, not chronological age, that meets the needs of all people, including younger people
 - ✓ A service which can meet the needs of people other co-morbid mental health conditions
 - ✓ A service that enables different elements of the service to be available at different times – from diagnosis as the dementia progresses through to end of life care
 - ✓ Seeing dementia as everybody's business, not just as "health or "social care" issues. Mainstream services and facilities that work towards becoming more inclusive of and accessible to people with dementia and their families, in line with the "Dementia Friendly Communities" national workstream
 - ✓ Care that is actively delivered in collaboration or formal partnership arrangements with other Providers and the Bristol Dementia Health Integration Team (HIT) and should ensure that agencies communicate and work together effectively along the care pathway
 - ✓ A service that affords people a high level of dignity and respect, which is sensitive to their social and cultural background, and which maintains the highest standards of practice
 - ✓ A service where people with dementia are understood as part of wider systems (families, carers, neighbourhoods, communities, friendship groups) and must always be worked with in relation to this key understanding
 - ✓ A service which enables neighbourhoods and communities to be recognised for the important role they have to play in the lives of people with dementia and their families (for example, relationships/friendships, activities, support networks)

2.3 Aims and Objectives

2.3.1 Aim 1: To provide high quality person centred care for people with dementia (and family/carers) who may also have other co-morbid organic or functional mental health and/or physical health conditions, at home, in care homes or other residential settings through:

- ✓ Advice and the delivery of high quality, timely, accurate diagnosis of dementia and other co-morbid mental health conditions
- ✓ An understanding of and sensitivity to the complex presentations of people who have dementia
- ✓ Comprehensive and co-ordinated care services with high quality, cost effective treatments based on the best available evidence
- ✓ A service which is safe for everyone
- ✓ Timely interventions appropriate to people's need, to enable people to remain at home for as long as this is their preferred place of care, aiming to delay admission to care homes
- ✓ A reduction in the number of planned and unplanned admissions to hospital
- ✓ Equality of access and experience for all people who have symptoms or a diagnosis of dementia and their family/carers
- ✓ Providing appropriate support for people with early onset dementia
- ✓ Ensuring people with dementia and family/carers have a strong sense of being in

⁶ Government of South Australia (2009). *South Australia's Dementia Action Plan 2009-2012: facing the challenges together*. Office for the Ageing: Department for Families and Communities.

control of their services

- ✓ A service that is consistent with Social Care Institute for Excellence good practice on caring for people with dementia, in particular good practice around eating well and challenging behaviours

2.3.2 Aim 2: To provide high quality advice and support for other Providers, especially Primary Care, on assessment and management interventions for dementia through:

- ✓ Effective knowledge transfer
- ✓ Development of shared care protocols across organisations
- ✓ Education on good clinical care
- ✓ Contribution to training and organisation service development
- ✓ Providing links and sharing of information, that can support independent living and wellbeing
- ✓ Advice and signposting on other available support

2.3.3 Aim 3: To prevent or minimise the inappropriate use of anti-psychotic medication, including advice on alternative strategies for people with dementia living at home, in care homes or in other residential settings, through:

- ✓ Following the NICE/SCIE guidance on Supporting people with dementia and their family/carers in health and social care (CG42), specifically section 1.7, Interventions for Non-Cognitive Symptoms and Challenging Behaviour in People with Dementia¹
- ✓ Ensuring that people who are prescribed anti-psychotic medication have been fully assessed and are subject to monthly medication reviews
- ✓ Ensuring family/carers are fully involved in the decisions about medication
- ✓ Ensuring there are therapeutic alternatives for people with behaviours that challenge

2.3.4 Aim 4: To promote support and inclusion for people with dementia and family/carers using the Service through:

- ✓ Care orientated to strengths and abilities while attending to difficulties and disabilities to support people with dementia and family/carers
- ✓ Providing access and/or support into purposeful, stimulating and appropriate engagement, activities and connections
- ✓ Promoting people's continued connections with their families, friendships, communities and local neighbourhood
- ✓ Identifying and supporting the cultural and faith groups/spiritual needs of each person
- ✓ Proactively addressing the stigma of dementia and other mental health issues and proactively identifying issues of social isolation
- ✓ A form of expert carer programme for family/carers of people with dementia and uptake that is in line with predicted need, based on the Bristol demographics

2.3.5 Aim 5: To support the development of the workforce and volunteers providing the Service with the right attitudes and skill mix by ensuring that:

- ✓ The provider develops and promotes a culture of continuing learning and improvement throughout the whole Service.
- ✓ Staff receive the training and supervision they need in relation to both current good practices and customer service approaches paying particular attention to the needs of the person with dementia and their family/carers

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- ✓ Workforce capacity and capability are sufficient to deliver the expected outcomes
- ✓ The Provider involves people with dementia and family/carers in the dementia training of staff and volunteers
- ✓ There is a good quality evidence based programme of training for volunteers to promote a sense of empathy with people with dementia and family/carers
- ✓ Staff are familiar with and alert to the benefits of assistive technology and telecare for people with dementia

2.3.6 Aim 6: To promote positive services to people with dementia and family/carers through:

- ✓ Integrated care pathway services and integration across other care Providers where all the component parts are clear and well co-ordinated and used as required through the person's lifetime, including the development of person centred holistic care plans in collaboration/formal partnership arrangements with other Providers
- ✓ Ensuring the service is delivered in a considered and co-ordinated manner
- ✓ Effective systems and processes in place to enable people with dementia and family/carers to have the opportunity to take part in high quality research studies
- ✓ Putting in place procedures, protocols, governance and audit arrangements to support the delivery of good health care
- ✓ Effective communication systems between front-line staff and managers and between members of the staff team providing support to an individual
- ✓ Management and supervision appropriate to the delivery of good quality care
- ✓ Enabling a peer support model of care to be put in place, recognising that the experience of dementia (particularly in the early phases) may mean that the person can actively and valuably contribute to post-diagnostic support (in a paid sessional or voluntary capacity).

2.3.7 Aim 7: To provide a range of agreed consistent, measurable and auditable information, agreed with commissioners, to support the performance management of the Service and give commissioners confidence that the specified service is being provided. As a minimum this performance information will cover:

- ✓ Quality
- ✓ Finance
- ✓ Activity
- ✓ Level of integration with and support of the wider care pathway
- ✓ Person and family/carers reported outcomes

2.3.8 Aim 8: To provide commissioners with confidence that service specifications and operational standards are consistently met. The Provider will ensure the Service is underpinned by the following values:

For people with dementia and their family/carers to:

- ✓ Feel valued and respected
- ✓ Be fully informed and engaged in all aspects of their care
- ✓ Live a normal life as far as possible, be safe and feel secure
- ✓ Be included in local community and activities
- ✓ Not be stigmatised or discriminated against on any grounds
- ✓ Have easy access to up to date and accurate information
- ✓ Have options in the choice of care available locally

Be supported with services that:

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- ✓ Are built around the needs of each individual, their family/carers
- ✓ Promote and enable wellbeing
- ✓ Take into account people's safety

2.4 Inclusion Criteria

The Bristol Dementia Wellbeing Service is designed to meet the needs of people with symptoms or a diagnosis of dementia and will work with them as part of a wider (family) system; it will support their family/carers, whether they are living at home, in care homes or other residential settings. The inclusion criteria include:

- ✓ People presenting with symptoms or a diagnosis of any form of dementia
- ✓ People with suspected or diagnosed dementia, who may/may not have a co-morbid mental health condition
- ✓ People with a learning difficulty and who have suspected dementia or a diagnosis of dementia
- ✓ People who have had a brain injury and previously exhibited symptoms of dementia
- ✓ People who have a GP within the boundary of the NHS Bristol Clinical Commissioning Group
- ✓ All people aged 16 and over if they meet the above criteria

The Service is primarily for people with a diagnosis of dementia and their family/carers however this will not preclude anyone with presenting symptoms of dementia, who does not want to receive a formal diagnosis, from accessing the Service.

2.5 Exclusion Criteria

The following is not the responsibility of this Service:

- ✓ It is not the role of the Bristol Dementia Wellbeing Service to carry out the functions of mainstream hospital or community staff nor to duplicate existing skill provision
- ✓ Whilst it is not the role of the service to directly carry out functions that would normally be understood as those of social care staff, it is recognised that the boundaries are often less than clear and the Service will work closely with Social Care to promote good holistic joint working
- ✓ Whilst it is recognised that people should be generally be supported by the Service that is most appropriate to meet their needs; for example, if the presenting co-morbid mental health condition is more dominant than the dementia, it may be appropriate to refer the person to the Recovery Service or Complex and Chaotic Service, this service will actively work against silo working and will promote inter-agency support and mutual learning and develop clear pathways and protocols to enable smooth transition between pathways

2.6 Equity of Access to Services

The Service must ensure that it is accessible to all, regardless of age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex, sexual orientation and deal sensitively with all people with dementia and family/carers. Policies and practices must be explained in order to actively engage and provide culturally sensitive services to minority groups in the population.

2.7 Geographical Coverage and Boundaries

To access the Service people must be registered with a Bristol General Practitioner. Bristol is divided in to three geographical localities: North and West; Inner City and East, and South. The Service must ensure equity across Bristol's diverse population.

2.8. Referral Sources

All first time referrals must be by the General Practitioner. Once the patient has been accepted by the Service subsequent referrals can be made without the need to go via the General Practitioner who should be informed of the referral by the Provider.

If the person with dementia has already been seen by the Service, a formal referral will not be required, however a request for the Service to actively engage with the person will be accepted from:

- ✓ Self/Family/Carer
- ✓ Crisis Access Points
- ✓ Crisis Service
- ✓ Wellbeing Service (IAPT)
- ✓ Recovery Service
- ✓ Primary Care Staff
- ✓ Acute Trusts Discharge Teams
- ✓ Community Services
- ✓ Social Work Teams
- ✓ Supporting Dementia service
- ✓ Other social care services
- ✓ Intermediate Care Team
- ✓ Safeguarding Team
- ✓ Community Learning Difficulties Team
- ✓ Care Home Providers
- ✓ Third Sector Organisations
- ✓ Community Pharmacy
- ✓ Police
- ✓ Ambulance
- ✓ Fire Brigade

2.9 Interdependencies with Other Services

The Service shall interface with other existing services (listed below) to make and share diagnoses and other relevant services to meet the health and/or social care needs of people with dementia and family/carers. The Service will develop a partnering relationship with:

- ✓ GP Practices
- ✓ Supporting Dementia Service (Bristol City Council), to enable joint working and a shared point of access
- ✓ Other Social Care services
- ✓ Alzheimer's Society

The service will develop working relationships with (not exclusively):

- ✓ GP Practice Staff
- ✓ Recovery Service

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- ✓ In-patient Service
- ✓ Crisis Service
- ✓ Crisis Access Points
- ✓ Wellbeing Services (Improving Access to Psychological Therapies)
- ✓ The Bristol Dementia Health Integration Team
- ✓ Bristol Community Health Integrated Care Teams
- ✓ Social Work Teams
- ✓ Intermediate Care Teams
- ✓ Acute Trusts Discharge Teams
- ✓ Safeguarding Teams
- ✓ Community Learning Difficulties Team
- ✓ Care Home Providers
- ✓ Third Sector Organisations – including Alzheimer’s Society, Carers Support Centre and British Red Cross
- ✓ Community Pharmacy Services
- ✓ Supported housing
- ✓ Drug and Alcohol services
- ✓ Community Pharmacists
- ✓ Emergency Services
- ✓ South West Dementia Strategic Clinical Network
- ✓ The National Institute for Health Research, Clinical, Research Network

3. Applicable Service Standards

3.1. Applicable National Standards e.g. NICE, Royal College

The Provider shall endeavour to comply to the following National Guidance, unless agreed with the Commissioner in advance.

National Memory Service Specification

www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_128877.pdf

NICE Dementia Quality Standards

<http://guidance.nice.org.uk/QS1>

MSNAP Memory Service Accreditation Programme

www.rcpsych.ac.uk

NICE TA217

www.nice.org.uk/nicemedia/live/13419/53728/53728.doc

3.2 Service Accommodation/Buildings

The Provider shall endeavour to:

- ensure that the design of the building is consistent with: **The Dementia Design Checklist, NHS Scotland 2007**
www.dementia.stir.ac.uk/files/DementiaDesignChecklist.pdf
- ensure that care environments are consistent with the principles set out in **Enhancing the Healing Environment, King’s Fund, 2007**
www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-design-dementia

3.3 Applicable Local Documents

The following are local key documents and should be reflected in the Provider's ethos and service model:

Bristol Joint Strategic Needs Assessment

www.bristol.gov.uk/page/joint-strategic-needs-assessment-jsna

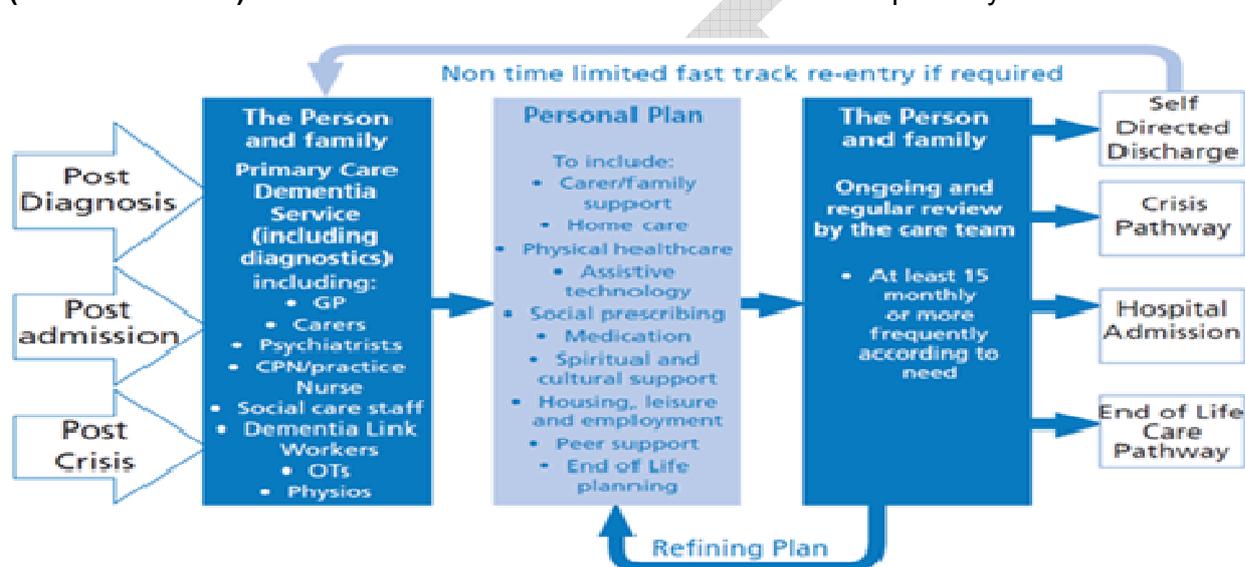
The Joint Bristol Dementia Strategy and the Local Bristol Action Plan (2011-2015)

www.bristol.nhs.uk/your-health/dementia.aspx

The Local Bristol Carers Action Plan

www.bristol.nhs.uk/your-health/carers.aspx

The Bristol Clinical Commissioning Group, Consultation Feedback and Analysis (November 2012) www.bristol.nhs.uk describes the Dementia care pathway as:



3.4 Service Model

In Bristol the General Practitioner is the coordinator of care for people with dementia and their family/carers. The Bristol Dementia Wellbeing Service will work alongside the General Practitioner in primary care, providing specialist advice, ongoing support and specialist interventions. The General Practitioner will be responsible for:

- Raising awareness of dementia (as per the Health Check Local Enhanced Service)
- Case finding for dementia (in line with the Directed Enhanced Service)
- Diagnosing Dementia and providing formal review (including medication) at least every 15 months (as per Local Enhanced Service and QoF)

The Bristol Dementia Wellbeing Service will be based on person centre planning, supporting people with suspected or diagnosed dementia and their family/carers at home, or in a care home, to ensure they maintain independence and a high quality of life where they have chosen to live. The Service will be delivered through a shared care principle with General Practitioners and the Service, providing advice, assessment, treatment and on-going wellbeing support to people with dementia, their family/carers as well as advice, training and education to professionals, to understand and proactively manage their dementia.

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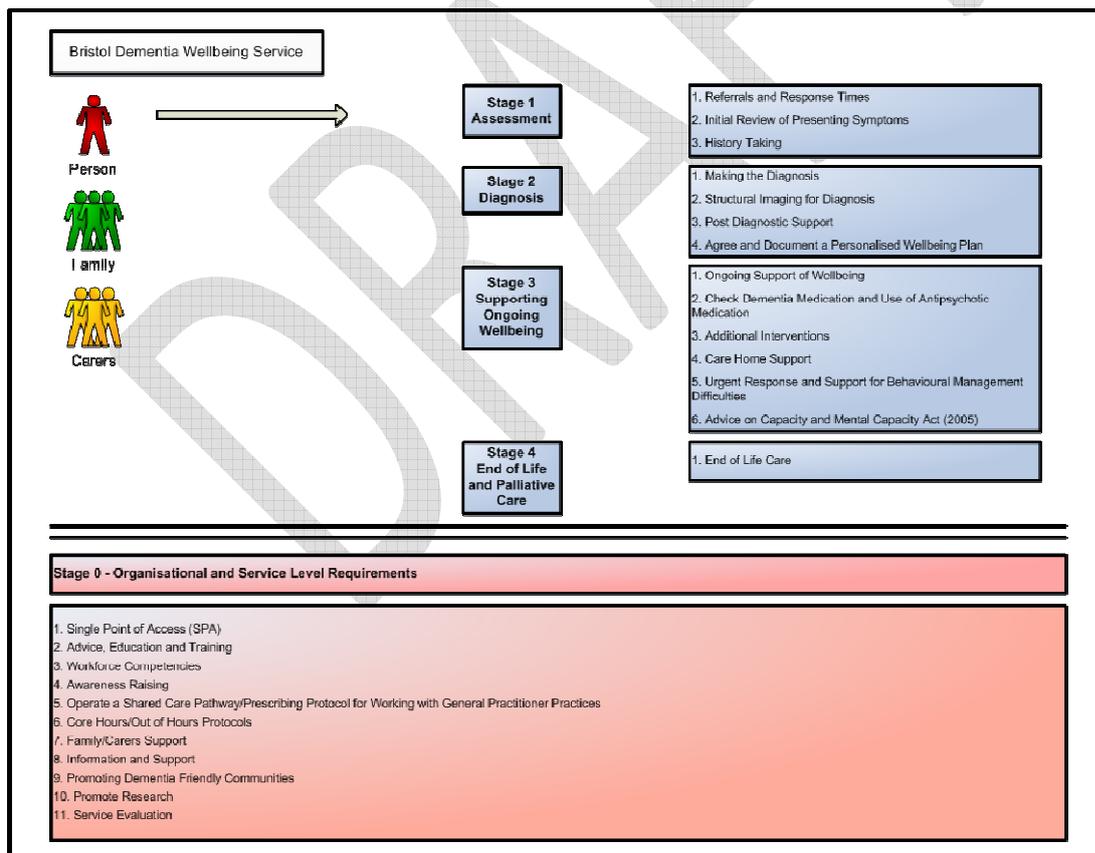
Community/Primary Care based services have the potential to prevent crises and reduce unplanned hospital admissions and delay admission to residential care placements. This Service will support the shift of provision from Secondary Care based services, to a Service based in Primary Care.

The Service will support the person and their family/carers with the dementia as well as any other co-morbid mental health condition that the person presents with.

For the purpose of the specification, the Service is broken down in to five stages, with a number of components for each stage. The following diagram sets out the stages in the Bristol Dementia Wellbeing Service, it should be noted certain elements may take place in parallel rather than in series and not every person with dementia and family/carers will require all components of the service. Stage 0 underpins the whole spectrum of the service and will be required to deliver good quality care; stages 1 to 4 reflect the delivery of the Service.

The Provider shall contribute to establishing procedures, protocols, governance and audit arrangements as well as education and training where needed in order to support a good quality Dementia Wellbeing Service and promote the efficient use of existing resources.

A high-level service description is set out below:



3.4.1 STAGE 0: Organisational and Service Level Requirements

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3.4.1.1 Stage 0: Point 1: Single Point of Access (SPA)

The Service will operate a Single Point of Access (SPA) that will be integrated with Bristol City Council's Supporting Dementia Service. The SPA will be able to initiate first referral to the service, provide advice and support for people who have a diagnosis and family/carers and/or professionals who require information, and fast track people back in to the Service who have not been actively using it. It is important that this component of the Service has a signposting role to help people access other services that will be able to provide support.

3.4.1.2 Stage 0: Point 2: Advice, Education and Training

The following are requirements to fulfil this section of the specification:

- Professionals can access telephone advice from the Service, this will include advice/support for Primary Care to make a diagnosis of dementia and to manage clinical issues
- A named and consistent member of the Service for each GP practice and each care home with nursing in the City. The member of staff will be able to provide easy access to specialist support and advice, they will have a key role in ensuring the Service is embedded within local mainstream services
- "On the job" training and support will be available. This will particularly be required for staff within care homes with nursing
- On-going formal training on dementia will be run for staff in mainstream services, which will be based on a needs analysis of the system
- Staff are able to recognise and deal with safeguarding issues, in-line with Safeguarding Adults policy

3.4.1.3 Stage 0: Point 3: Workforce Competencies

A range of core competencies are required for delivering integrated care of people with dementia and their family/carers at every stage across the pathway. These competencies need to support care including the health and social care of a person with dementia, regardless of the individual or Provider delivering the care. It is acknowledged:

- Core competencies are required to ensure an integrated and seamless workforce, not a workforce artificially split into 'health' and 'social care'⁷

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- Sustained work is needed to embed competencies in the workforce, including voluntary sector and private sector workforces
- Training should enable an understanding of the diversity in dementia, including younger people with dementia, those who have dementia and a learning disability, and those with particular needs from minority backgrounds who may require a more tailored approach

Workforce competencies for every stage of the integrated dementia care pathway, for all staff in health and social care and the third sector should:

- Think “family” at all times in order to provide holistic support
- Promote an information culture
- Communicate effectively with individuals
- Empower family, carers and volunteers to support individuals
- Involve the person with dementia in their own care planning, adhering to the value base of care (identity, dignity, respect, choice, independence, privacy, rights and culture)

The Service will be staffed by an appropriately trained competent workforce with specialist training and able to deliver evidenced based practice¹ sensitively. This will include, but not limited to, the skills of:

- Psychiatry
- Psychology
- Nursing
- Occupational Therapy
- Physiotherapy
- Speech and Language therapy
- Learning Difficulties worker(s)
- Support Workers
- Black Minority and Ethnic worker(s)
- Volunteers

3.4.1.3 Stage 0: Point 4: Awareness Raising

The Service will take a proactive approach, alongside Voluntary sector organisations, in public awareness campaigns of dementia and other co-morbid mental health conditions targeted at different audiences across the whole community to:

- raise the profile of dementia and other co-morbid mental health conditions
- reduce stigma
- promote understanding to Public and Professionals on an on-going basis and during Dementia Week and World Alzheimer’s Day
- promote strategies and lifestyle changes that reduce or delay the onset of dementia
- deliver culturally appropriate dementia awareness and risk reduction awareness programs

3.4.1.4 Stage 0: Point 5: Operate a Shared Care Pathway/Prescribing Protocol for Working with General Practitioner Practices

In Bristol General Practitioners are being supported to undertake a diagnosis of dementia and the initial management in primary care, where this is appropriate. The Provider will

allocate a named appropriately skilled worker to each GP practice to facilitate this. The Provider should ensure that there is a shared care agreement in place for the prescription of cholinesterase inhibitors, as recommended in NICE technology appraisal 217. www.nice.org.uk/nicemedia/live/13419/53728/53728.doc

3.4.1.5 Stage 0: Point 6: Core Hours/Out of Hours Protocols

The Service will run 8am to 8pm; Monday to Friday and 9am to 12pm Saturday. Within these core operating hours the Bristol Dementia Wellbeing Service will operate an effective and timely urgent intervention response.

The Provider will work in collaboration/formal partnership with other services to produce protocols and guidance for crisis responses that occur Out of Hours to ensure there is access to appropriate care. In an extreme case, the Crisis Service (commissioned separately) will provide an out of hours response, in accordance with the specification.

3.4.1.6 Stage 0: Point 7: Family/Carers Support

The Service will be expected to work with family/carers in a variety of ways, including family/carers to be involved:

- input to an individual's wellbeing plan, where this is acceptable to the person with dementia
- in the developments of family/carers support groups
- with organisational service development/improvement activities
- on interview panels for staff recruitment
- in staff training

A key element of Carer's legislation (*Carers Equalities Act 2005*) is that a person identifying themselves as a carer is entitled to a comprehensive assessment of their emotional, psychological and social needs, NICE Dementia Quality Standard (2010), even if the person with dementia does not identify the person as a carer themselves. Therefore, to facilitate the identification, meaningful engagement of and potential support for family/carers, the Service will ensure that:

- people with dementia are invited to bring someone with them to any appointments
- social networks are discussed in any assessment
- all family/carers are offered an opportunity to discuss their role in more detail
- all services will work collaboratively with family/carers providing support advice, on-going assessment and specific family/carers interventions where appropriate (if a family/carer declines an invitation to talk more about their role, then this should be recorded in the appropriate record and a review date set)
- all family/carers identified will be given the initial care plan containing information and advice as an intervention
- all family/carers will be signposted to service that can provide support, this will include access to carers breaks

The commissioners expect that there will be a clear understanding between the Service, family/carers and people with dementia in relation to confidentiality and sharing of information. Family/carers should always be given the opportunity to present their views and their views must be listened to and recorded even if permission is not gained from the person with dementia to relay information back to the family/carers.

3.4.1.7 Stage 0: Point 8: Information and Support

The Provider shall issue and/or signpost to appropriate information, support and follow-up for people with a suspected or confirmed diagnosis of dementia and their family/carers. In sharing information and providing support, the Provider shall ascertain the areas of most interest and relevance to the person with dementia and family/carers and assist them in identifying services and support that are best suited to their needs.

Sharing information shall include, but shall not be limited to:

- guidance on how people with dementia can improve their general health, live positively and maximise their quality of life after diagnosis e.g. using mental exercise, physical activity, dietary advice alongside drug therapy
- medico-legal issues, including driving
- services to support people with dementia and their family/carers from other organisations including peer support services
- services that can advise on welfare benefits
- advice and support on planning for the future, including legal matters associated with loss of capacity, including power of attorney, managing finances and benefits, advance statements, advance decisions to refuse treatment and preferred priorities of care
- services to support people with other health or social care needs
- opportunities for involvement in research studies

Providing support shall include, but shall not be limited to:

- advice and support to manage pharmacological treatment
- support for family/carers of people who have non-cognitive symptoms (e.g. mood disorders, psychotic symptoms and behaviour that challenges)
- assessment of family/carers needs
- support on planning for the future, including legal matters associated with loss of capacity, including power of attorney, managing finances and benefits, advance statements, advance decisions to refuse treatment and preferred priorities of care

All staff will need to have a high level of person centred cultural competency and an understanding of the importance of language access and communication.

Printed information and other formats (audio visual) shall be kept up-to-date and shared with General Practices and other relevant Providers and communities in the language of choice and age appropriate for young carers.

3.4.1.8 Stage 0: Point 9: Promoting Dementia Friendly Communities

The Provider will have a strong role in supporting the development of Bristol as a Dementia Friendly City. The work is at an early point, and the Provider will develop their role as the work takes shape. The Provider will be a member of the Local Dementia Action Alliance.

3.4.1.9 Stage 0: Point 10: Promote Research

The Provider will work collaboratively with the Bristol Dementia Health Integration Team as well as other partners, including NICE as requested by the commissioners to ensure:

- Access to best available evidence

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- Promotion of participation in research

The Provider is required to have systems and processes in place to ensure that people are given the opportunity to take part in high quality research studies⁸; the need for better research was identified as one of three key areas in the Prime Minister's challenge on Dementia (2012)³.

Examples of such systems and processes could include:

- Adopt an 'opt-out' policy in which people with dementia and family/carers are informed that research is a routine part of the philosophy of the Bristol Dementia Wellbeing Service and that they may be contacted about opportunities to join research unless they explicitly request not to be contacted.

AND/OR

- Have a system in place such as a 'consent for approach register' to keep a record of people who are willing to be offered research opportunities, together with relevant demographic details and their diagnosis
- Have job descriptions and plans that make reference to Provider's commitment to promoting peoples recruitment in to research studies and the view that it is a positive intervention
- Inform existing and new employees at induction of the Provider's commitment to contributing to the evidence base, a culture of innovation and improvement, and how employees can contribute
- Ensure access to appropriate research-relevant training
- Facilitate opportunities for people with dementia and family/carers to inform and participate in the research portfolio. For example, research opportunities for people with dementia and family/carers should be clearly presented in clinical areas using posters and leaflets or other media, and in Provider communication strategies

The Provider should understand that research does not only concern medical trials, but can include social and non pharmacological interventions.

The Provider should make a statement on research activities undertaken in their annual Quality Account and should include a statement of the number of people recruited and the number of studies they host.

3.4.1.10 Stage 0: Point 11: Service Evaluation

The Provider is required to perform at least one full evaluation of the service within twelve months of operation, and thereafter at least every 18 months, other monitoring and audit activities may be required more frequently in agreement with the Commissioner.

The full evaluation should use appropriate data to assess whether the Bristol Dementia Wellbeing Service is delivering the objectives as set out in the service specification and is providing value for money while also evaluating the processes involved in running the service. An evaluation plan should be developed in conjunction with the Provider's service delivery plan and clearly state the choice of performance measures that will be collected. This plan should then be agreed with the Commissioner and be funded from the overall value of the contract. The evaluation must be delivered in partnership with an external organisation, to ensure transparency. It is expected the plan will collect a mixture of both quantitative, qualitative and process data (where appropriate), and data might include as a minimum:

- Person with dementia satisfaction interviews (minimum of 30), surveys, complaints

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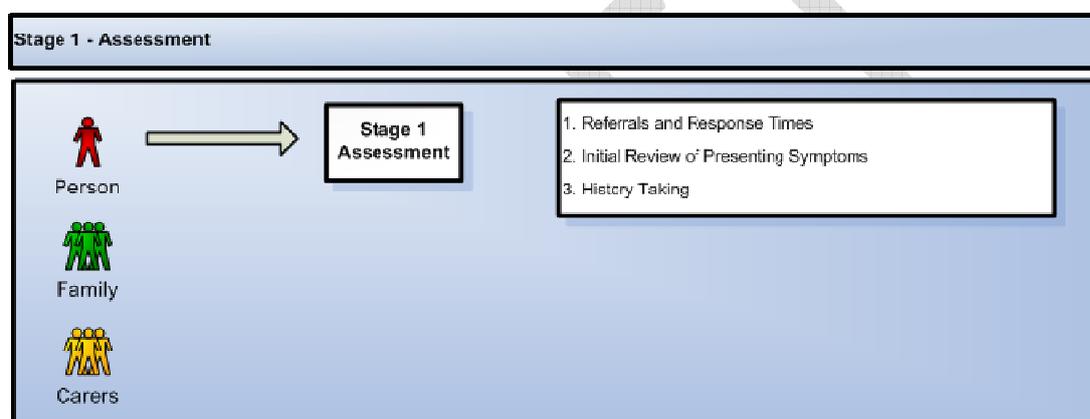
and compliments

- Staff interviews (minimum 20)
- DemQal or other measures appropriate for assessing clinical and cost effectiveness
- Surveys, interviews, focus groups and workshops with stakeholders
- Person reported outcome measures, Quality of Life measures
- Performance measures such as numbers of people accessing the service, referrals, waiting times, demographics, Did Not Attend

The service evaluation is expected to inform the ongoing development of the Service. As a result of the evaluation parts of the Service may cease, change or increase. The Provider is encouraged to constantly reflect best practice in the Service and has the flexibility to try new interventions and to cease out of date ones.

The Service will work closely with external academic bodies, to influence the current curriculum of training and post registration continued professional development, to ensure that the workforce are able to deliver the requirements of the Service.

3.4.2. Stage 1: Assessment



3.4.2.1 Stage 1 Point 1: Referrals and Response Times

The Provider shall respond to all requests relating to adults who meet the eligibility criteria as outlined in section 2.4.

The Provider shall respond to requests and confirm acceptance of referral within [tba] working day(s) of receipt and confirm a date and time to provide advice or support. Where a face-to-face assessment with a person suspected or diagnosed with dementia is required, the Provider will undertake the assessment in the place that is most appropriate for the person, which might be in a clinic, at home or in a care home.

The Provider shall respond to requests for advice by telephone from Primary Care within [tba] working day(s).

Where an urgent response is required, the Provider shall undertake the assessment within the same working day, if within the operating times of the Service, or if appropriate signpost any urgent referrals to the most appropriate service.

3.4.2.2 Stage 1 Point 2: Initial Review of Presenting Symptoms

The Provider shall provide advice and/or support on the initial review of presenting

symptoms, it shall be provided by a suitably qualified and trained professional, who is able to determine whether presenting symptoms or indicators are likely to be those of dementia and/or another mental health problem.

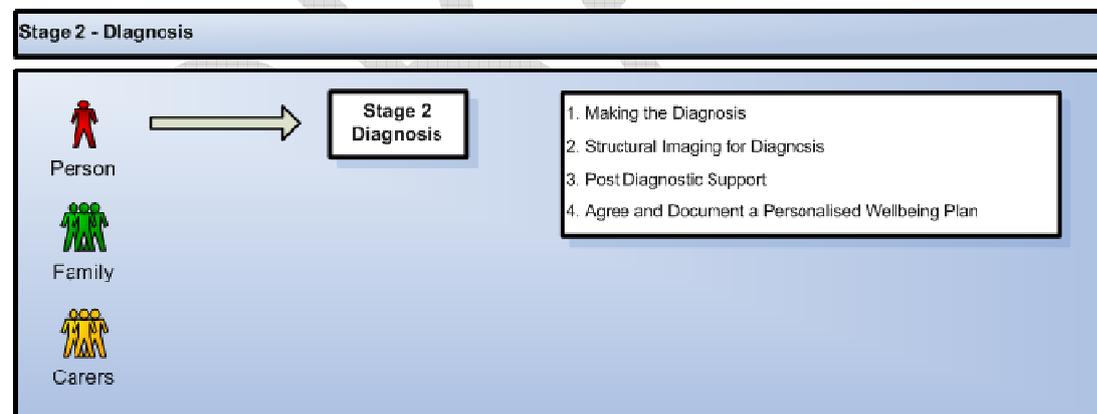
3.4.2.3 Stage 1 Point 3: History Taking

At the date and time agreed with the person who has made the request, the Provider shall advise on or undertake the assessment with the person. History taking shall be undertaken by a suitably qualified and trained professional and shall include, but shall not be limited to:

- a subjective and objective assessment of person's life, social, family and carer history, circumstances and preferences, as well as their physical and mental health needs and current level of functioning and abilities
- assessment of history and impacts of impairments of vision, hearing and mobility
- assessment of history and impacts of impairments of medical co-morbidities and medication
- risk assessment covering all areas appropriate to the individual, e.g. falls, risk to self, childcare or family/carer responsibilities, driving, and financial and legal issues
- family/carer assessment including stress, health and function

From the assessment date, the Provider shall complete the assessment within [tba] working day(s). Upon completion, the Provider shall contact the person and family/carers, with a copy to the General Practitioner, within [tba] working day(s) to organise a time and venue to communicate the outcome; this shall be within [tba] working day(s) of the assessment having been completed. In practice, in most instances the outcome may be shared on the same day as the assessment.

3.4.3. Stage 2: Diagnosis



3.4.3.1 Stage 2 Point 1: Making the Diagnosis

In straightforward cases of Alzheimer's Disease or Vascular Dementia, General Practitioners will be supported (if required) to make a diagnosis of dementia, by an appropriately trained member of the Bristol Dementia Wellbeing Service. The Provider will have an active role in supporting General Practitioners to make a diagnosis, providing timely access to advice and guidance and providing training as appropriate. The Service will put in place a shared care protocol to ensure that this is delivered in a clinically safe and appropriate way.

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A detailed specification for delivering a Memory Service has been written by the Department of Health. The Bristol Dementia Wellbeing Service will encompass aspects of a traditional memory service, and the Provider should work with the Commissioner to ensure that this part of Service meets the appropriate requirements. However, as the Bristol model is moving towards primary care, with General Practitioners taking an active role in diagnosis and management, not all of the standards will be appropriate.

www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_128877.pdf

The Service will undertake the diagnosis of complex dementias, in a clinic based or if appropriate home setting. A diagnosis of dementia and its sub-type shall be made by health care professionals with expertise in differential diagnosis of dementia using international standardised criteria in line with NICE/SCIE Clinical Guideline 42. <http://www.nice.org.uk/nicemedia/pdf/CG042NICEGuideline.pdf> and NICE TA217 <http://www.nice.org.uk/nicemedia/live/13419/53619/53619.pdf>

Diagnoses and subsequent actions fall in to five categories:

Diagnosis	Action
1. No organic or functional mental health problem	Communicated to requesting clinician and General Practitioner
2. Other mental illness (including depression or delirium)	Advice communicated to requesting clinician including the initiation of urgent treatment or referral to other services – General Practitioner informed
3. Dementia (no medication)	Talk through support available via local support organisations or via the community mental health team if needed – General Practitioner informed
4. Dementia (medication)	Talk through available medication and support available via local support organisations and arrange follow-up by community mental health teams if needed – General Practitioner informed
5. Possible dementia	Communicated to requesting clinician and GP with advice refer back to Bristol Dementia Wellbeing Service, if symptoms persist or increase

In some complex presentations (for example in a very young person), the Provider will refer the person to the North Bristol Trust Neurology Service or another appropriate speciality to provide the diagnosis and the Commissioner will be informed.

3.4.3.2 Stage 2 Point 2: Structural Imaging for Diagnosis

Structural imaging should usually be used in the assessment of people with suspected dementia to exclude other cerebral pathologies and to help establish the subtype diagnosis. Magnetic resonance imaging (MRI) is the preferred modality to assist with timely diagnosis and detect subcortical vascular changes, although computed tomography (CT) scanning could be used. Specialist advice should be taken when interpreting scans in people with learning disabilities (NICE¹).

3.4.3.3 Stage 2 Point 3: Post Diagnostic Support

The Provider shall deliver written and verbal information, support and follow-up to people who have had a diagnosis of dementia (no matter where the diagnosis has been made) and their family/carers, with reassurance that empowers the person with dementia and their family/carers¹ to make informed decisions about the management of the condition and their individual wellbeing.

Wherever possible, the Provider shall contact the person or family/carers within [tba] working day(s) of the diagnosis having been made in order to organise a time to discuss the diagnosis with the person and the family/carers together.

The Provider shall support people who have received a diagnosis of dementia and their family/carers in simple, direct language avoiding use of medical jargon and shall communicate in a warm, caring and respectful manner.

The Provider shall ensure that the diagnosis is conveyed to the General Practitioner with the explicit information that the person should be added to the General Practitioner dementia register.

3.4.3.4 Stage 2 Point 4: Agree and Document a Personalised Wellbeing Plan

The Provider shall agree and document a holistic personalised Wellbeing Plan based on the individual's health and social care needs and talk through timely intervention options to empower the person and their family/carers regarding the condition and its management within [tba] working day(s). The Wellbeing Plan should have a focus on maintaining wellbeing, encouraging optimism and focus on positive achievable outcomes. As a minimum the Wellbeing Plan should identify a named care coordinator and identify the contact number and family member/carers who can advocate on behalf of the person with dementia and provide information on:

- physical health including the impact on vision, hearing and mobility
- psychological well-being
- medication
- social care needs
- assistive technology
- activities/occupation
- family/carers needs; caring issues; access to careers assessment
- managing risk and safeguarding
- follow up wellbeing call
- who the person and the family/carer should contact if their needs change
- sources of local information and support

The Provider shall share information about options for care and treatment, including coping methods and strategies and addressing immediate care or support needs.

The Provider shall signpost and provide information to the person and family/carers, as appropriate, about:

- groups run by the Service or other local providers and voluntary organisations
- local care and support services / support groups
- local information sources, including libraries and voluntary organisations such as Alzheimer's Society

Where cognitive enhancing medication is prescribed all healthcare professionals involved should follow the National Guidance. NICE/SCIE Clinical Guideline 42.

<http://www.nice.org.uk/nicemedia/pdf/CG042NICEGuideline.pdf>

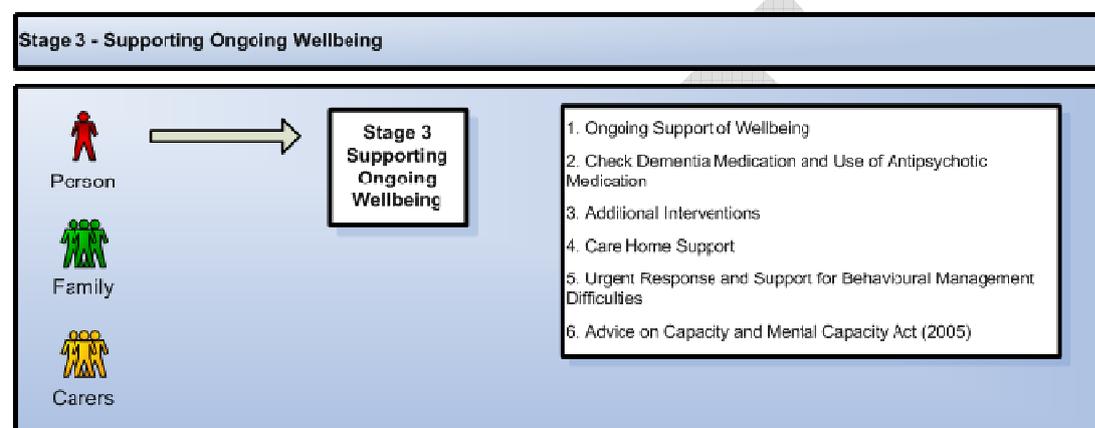
and NICE TA217 <http://www.nice.org.uk/nicemedia/live/13419/53619/53619.pdf>

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The content and number of these post diagnostic sessions will vary according to the person's needs. The Provider shall ensure there is continuing advice and support and that information is available, for example through the Single Point of Access (SPA), local support groups, their General Practitioner and agree regular reviews to ensure on going responsiveness to individual needs which is clearly documented in the personalised Wellbeing Plan.

The Provider should ensure the person with dementia has a copy of "This is Me" from Alzheimer's Society and is encouraged to take this with them if they are ever admitted to hospital or a care home.

3.4.4. Stage 3: Supporting Ongoing Wellbeing



3.4.4.1 Stage 3 Point 1: Ongoing Support of Wellbeing

The Provider will implement a robust service model to support ongoing wellbeing and to provide optimal care after a diagnosis has been made. This will be through a continuous and responsive process of re-evaluation with improved and amended interventions being developed as needs of the person change.

As a minimum the Provider will deliver 6 monthly telephone wellbeing checks to people with a diagnosis of dementia or their identified family/carers, this could be delivered by volunteers. This will provide the opportunity to understand how the person and family/carers are managing and to pre-empt a crisis situation.

The Provider shall also provide timely support and advice to requesting clinicians to help deliver good quality evidence based care to people with dementia and their family/carers and other mental health needs. This support and advice shall include, but not be limited to:

- Updating the Wellbeing Plan (at the 6 monthly telephone wellbeing check)
- Checking medication and advising on appropriate use of alternatives to prescribing antipsychotic drugs
- Managing behavioural and psychological symptoms of dementia
- Therapeutic interventions
- Urgent response and support for crisis events
- Advice on capacity decisions and the Mental Capacity Act (2005)
- Identification of Safeguarding issues, in line with National and Local Guidance

The person with dementia will not be “discharged” from the Service, as dementia is a long term condition; however people will not always be in “active” use of the Service. In addition to the 6 monthly telephone wellbeing check, the Service will provide active interventions as required, which will be triggered by the wellbeing check, the person/family/carers and/or another organisation.

3.4.4.2 Stage 3 Point 2: Check Dementia Medication and Use of Anti-Psychotic Medication

There is a wealth of evidence which states that although there are clinical situations where a time-limited prescription of anti-psychotic medication may be appropriate, anti-psychotic medication is often overprescribed and continued, when alternative approaches may be more beneficial. There is an unambiguous case for a substantial reduction in their use alongside the wider adoption of alternative interventions, which can help to maximise the quality of life for people with dementia and their family/carers.⁹

All people with dementia who are receiving anti-psychotic medication will undergo clinical reviews to ensure that their care is compliant with current best practice and NICE guidelines. The Provider will ensure that alternatives to the person’s prescription have been considered and a shared decision has been agreed regarding their future care.

In cases of poor response, the Provider shall provide recommendations regarding changes to medication prescribed for a mental health need, if safe to do so, and advice on alternative strategies as appropriate.

The Provider shall comply with good practice from available evidence and policy, including:

- ensuring that people prescribed anti-psychotic medication have been fully assessed and are subject of regular monthly medication reviews or more often if appropriate
- ensuring family/carers are fully involved in decisions about medications
- ensuring there are therapeutic alternatives for people with behaviours that challenge

Older people are particularly susceptible to the effects of combinations of medication. The GP alongside the Provider shall check the suitability of medications and their combinations and provide advice on the possible effects, prior to initiation and on an on-going basis as the persons needs dictate. This includes all psychotropic medications (antipsychotic, anti-depressant and mood stabilisers).

3.4.4.3 Stage 3 Point 3: Additional Interventions

The Provider shall provide interventions in line with NICE/SCIE guidelines, which shall include, but not be limited to:

- post diagnostic drop in sessions
- family/carers support group
- therapeutic support including Occupational Therapy, Speech and Language Therapy
- simple assistive technology
- community equipment (accessed via the Integrated Community Equipment Service)
- education sessions in dementia
- psychology support

and signpost/refer on to:

- memory cafes
- peer support groups
- cognitive stimulation therapy
- community hubs
- volunteering opportunities

3.4.4.4 Stage 3 Point 4: Care Home Support

The Service will include liaison provided on an in-reach basis to care homes with nursing, to prevent inappropriate admissions to hospital and/or to provide active intervention at a time of safeguarding. If there is an identified mental health or dementia need of a resident, the Bristol Dementia Wellbeing Service will provide the support regardless of diagnosis.

As well as providing specialist dementia advice the Service is designed to meet some of the specific challenges that exist in care homes due to the large numbers of people with advanced dementia who reside in this setting.

The service will:

- provide education, training and coaching to care home staff to enable them to recognise, prevent and manage challenging behaviours more effectively
- have a particular remit in ensuring that people in care homes are not inappropriately prescribed anti-psychotic medication
- provide specialist input into decision making concerning the initiation, monthly review and cessation of anti-psychotic medication for people with dementia
- focus on making dementia an explicitly owned priority in care homes enabling a minimum standard level of input into care
- prevent escalation of problem behaviours by means of timely intervention
- provide access to specialist advice for problems arising between reviews
- be a source of expertise to draw on, in order to build and maintain a social and therapeutic environment within the care home, that is positive for people with dementia and tailored to their needs

The Service will have a particular remit to support care homes with nursing who are under safeguarding investigation. If a home is under notice, the team will ensure that priority is given to these residents.

3.4.4.5 Stage 3 Point 5: Urgent Response and Support for Behavioural Management Difficulties

The Service should be set up in a way that will enable an “urgent response” during the hours of Service operation, for people with diagnosed/suspected dementia experiencing challenging behaviour. The Service should be able to provide a timely intervention to stabilise a situation. In the case of a family/carers breakdown, the Service will need to work closely with the Supporting Dementia Service, to enable a holistic approach to be taken and to avoid unnecessary admission to hospital.

A full assessment must be offered at an early opportunity to establish the likely factors that may generate, aggravate or improve such behaviour. Individually tailored care plans that help family, carers and/or staff address the behaviour that challenges should be developed, recorded in the notes and reviewed regularly.

It is anticipated that as the Service develops and the Wellbeing Plan and wellbeing checks are being delivered, the requirement for an urgent response will diminish.

If an urgent response is required out of core hours, a response will be required from the Crisis Response Team or the Supporting Dementia Team, depending on the situation. This Service must work closely with the Out of Hours Providers to ensure that there are appropriate plans in place. This will need to include the development of local protocols and guidance.

3.4.4.6 Stage 3 Point 6: Advice on Capacity and Mental Capacity Act (2005)

Treatment and care should take into account person's needs and preferences. People with dementia should have the opportunity to make informed decisions about their care and treatment, in partnership with their care professionals. If people do not have the capacity to make decisions, care professionals should follow the Department of Health's advice on consent and the code of practice that accompanies the Mental Capacity Act.

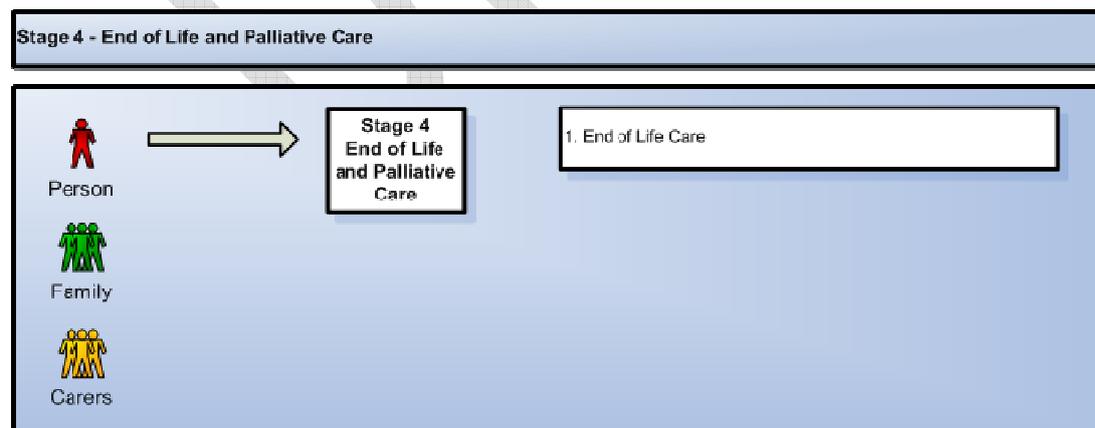
The Provider shall be aware and up to date on advice on capacity decisions and compliance with the Mental Capacity Act (2005). Where appropriate the Provider shall reinforce the message that a diagnosis of dementia does not mean that a person does not have capacity. The Provider should support other non-specialist staff where:

- the level of capacity is genuinely unclear, or
- a significant decision is to be made (e.g. a change in relation to the place of residence)

Where the decision is likely to be in relation to a new place of residence, the Provider shall engage with health and social care professionals, the person with dementia and their family/carers in a timely manner to ensure this is delivered in a coordinated way.

3.4.5. Stage 4: End of Life and Palliative Care

The Service shall have a role in supporting people with dementia and family/carers to make timely end of life care decisions and in the smooth transition to end of life care services.



3.4.5.1 Stage 4 Point 1: End of Life Care

People with dementia who are dying should have the same access to end of life care services as those without dementia. However, treatment decisions differ for people with

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dementia from other people approaching end of life in two ways:

1. The decline in health is less predictable and more variable, making prognosis difficult
2. The deterioration in communication skills prevents people with dementia from expressing their views and wishes later in the disease pathway

The NICE/SCIE Guideline 42 recommends that dementia care should incorporate a palliative care approach from the time of diagnosis until death, aiming to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their choosing, while also supporting family/carers during their bereavement, which may both anticipate and follow death³.

End of life care is normally defined as the care needed during the last year of life. End of life for dementia differs from other long term conditions because of the slow transition, which makes the identification of the time for a transition to end of life difficult.

This Service does not have a specific remit to deliver end of life care. However, there is a key requirement to ensure that the person with dementia and family/carers are equipped with the information to enable them to make well informed decisions. In dementia, end of life care planning should be incorporated early while someone has sufficient mental capacity and where decisions and preferences can be recorded, consistent with principles set out in the Mental Capacity Act, this should consider physical, psychological, social and spiritual needs to maximise the quality of life of the person with dementia and their family/carers. Some benefits include³:

- reducing inequalities and stigma by improving access to information, advice and a range of supportive services
- improving the psychological, physical and spiritual wellbeing of people with dementia and their family/carers through access to an appropriately trained workforce
- improving the quality of care through timely interventions in the right place by a knowledgeable and caring workforce
- increasing choice through advance care planning, advance statements and Advanced Decisions to Refuse Treatment (ADRTs)
- reducing unnecessary hospital admissions by supporting people with dementia to live in a place of their choice for as long as possible
- improving cross boundary and partnership working, improving care coordination, minimising unnecessary duplication and reducing costs
- supporting family/carers and ensuring access to an assessment of need as set out in the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004

The Service will identify a designated end of life champion who will be the point of liaison between the Service and the end of life care pathway leads. The champion will have the ability to cut across pathways sensitively and understand the steps, supporting people by giving practical guidance, advice and signposting to ensure that the needs of people with dementia are being met within the mainstream services.

The Service will develop a close working relationship with existing palliative care services and end of life care services, to ensure that there is a seamless transfer of care at this stage.

4. Key Service Outcomes

4.1 Contract Reporting and Monitoring

The Provider will need to monitor and maintain information on demand and capacity across the Bristol Dementia Wellbeing Service in order to promote effective flow and optimal deployment of resources.

It will also need to establish common requirements across Providers with respect to information sharing to inform whole system governance, collaboration and partnership working.

Contract monitoring meetings for service performance should take place monthly and more frequently if an exception arises such as complaint or adverse incident. The monitoring meeting will discuss activity and outcomes, performance and the Service quality and clinical governance report, including national and local requirements which should be submitted two weeks before the agreed date.

4.2 Outcomes

The ten quality dementia statements, as outlined by NICE-SCIE clinical guideline 42 (CG42), are intended to improve the structure, process and outcomes for health and social care and should inform the basis for audit criteria developed and used locally to improve healthcare.

The Provider will work with the Commissioner to develop and refine the outcomes below:

Outcome area/Statement		Strategic goal for improvement	Key performance indicator	Target
Identification and Diagnosis: <i>I was diagnosed early</i> Linked to: NICE Quality Standards 2, 3: Dementia Strategy Objectives 1,2: <i>I get the treatment and support which are best for my dementia, and my life</i> Linked to: NICE Quality Standards 1, 4, 5, 7, 8: Dementia Strategy Objectives 2, 6, 8, 9, 10, 11, 13, 18:	1	People with dementia diagnosed in a timely way	Increase in the number of people recorded on QOF register with a diagnosis of dementia Proportion of new referrals to memory service that have mild cognitive impairment	5% year on year increase, with maintenance at least 65% [tba]
Appropriate Care and Support: <i>I can enjoy life</i> Linked to: NICE Quality Standards 3, 4: Dementia Strategy Objectives 1, 4, 5, 6: <i>I understand, so I make good decisions and provide for future decision making</i> Linked to: NICE Quality Standards 3, 5: Dementia Strategy Objectives 3, 4,	2	Improved care planning for people with dementia	Patients diagnosed with dementia are offered a personal plan that involves all relevant disciplines and agencies involved in care within 4 [tba] weeks of diagnosis All wellbeing plans include goal setting, crisis contact, what interventions to expect, how to access provider	100% of patients within 4 weeks of diagnosis receive a wellbeing plan 95% of personal plans sent to GP within

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<p>5:</p> <p><i>I am treated with dignity and respect</i> Linked to: NICE Quality Standards 1: Dementia Strategy Objectives 1, 13:</p> <p><i>I feel part of a community and I'm inspired to give something back</i> Linked to: Dementia Strategy Objectives 1, 5, 16:</p> <p><i>I get the treatment and support which are best for my dementia, and my life</i> Linked to: NICE Quality Standards 1, 4, 5, 7, 8: Dementia Strategy Objectives 2, 6, 8, 9, 10, 11, 13,18:</p> <p><i>I know what I can do to help myself and who else can help me</i> Linked to: NICE Quality Standards 1, 3, 4, 5: Dementia Strategy Objectives 3, 4, 5, 6, 13:</p> <p><i>I am confident my end of life wishes will be respected. I can expect a good death</i> Linked to: NICE Quality Standards 5, 9,: Dementia Strategy Objectives 12, 13:</p>			<p>organisations and the offer of end of life planning as appropriate. All wellbeing plans are sent to the GP within [tba] working days</p>	<p>10 working days of completion</p> <p>[tba]% within [tba] days</p>
<p>Appropriate Care and Support:</p> <p><i>Those around me and looking after me are well supported</i> Linked to: NICE Quality Standards 3, 4, 6, 10: Dementia Strategy Objectives 3, 4, 5, 7:</p> <p><i>I understand, so I make good decisions and provide for future decision making</i> Linked to: NICE Quality Standards 3, 5,: Dementia Strategy Objectives 3, 4, 5:</p> <p><i>I am treated with dignity and respect</i> Linked to: NICE Quality Standards 1: Dementia Strategy Objectives 1, 13:</p> <p><i>I get the treatment and support which are best for my dementia, and my life</i> Linked to: NICE Quality Standards 1, 4, 5, 7, 8:</p>	<p>3</p>	<p>Improved information for people with dementia and their carers and family</p>	<p>People with dementia and carers/family are given appropriate information in different formats about dementia and local support services within [tba] weeks of diagnosis</p>	<p>95% satisfaction rate via rolling 6 monthly satisfaction survey</p>

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<p>Dementia Strategy Objectives 2, 6, 8, 9, 10, 11, 13, 18:</p> <p><i>I know what I can do to help myself and who else can help me</i> Linked to: NICE Quality Standards 1, 3, 4, 5: Dementia Strategy Objectives 3, 4, 5, 6, 13:</p>				
<p>Appropriate Care and Support:</p> <p><i>I can enjoy life</i> Linked to: NICE Quality Standards 3, 4: Dementia Strategy Objectives 1, 4, 5, 6:</p> <p><i>I feel part of a community and I'm inspired to give something back</i> Linked to: Dementia Strategy Objectives 1, 5, 16:</p> <p><i>I know what I can do to help myself and who else can help me</i> Linked to: NICE Quality Standards 1, 3, 4, 5: Dementia Strategy Objectives 3, 4, 5, 6, 13:</p>	4	Improved outcomes for people with dementia as a result of wellbeing plan	Achievement of goals on the wellbeing plan	Case note audit [tba]
<p>Appropriate Care and Support:</p> <p><i>I am treated with dignity and respect</i> Linked to: NICE Quality Standards 1: Dementia Strategy Objectives 1, 13:</p> <p><i>I know what I can do to help myself and who else can help me</i> Linked to: NICE Quality Standards 1, 3, 4, 5: Dementia Strategy Objectives 3, 4, 5, 6, 13:</p> <p><i>I am confident my end of life wishes will be respected. I can expect a good death</i> Linked to: NICE Quality Standards 5, 9: Dementia Strategy Objectives 12, 13:</p>	5	Improved ongoing support for people with dementia and their carer and family	<p>People who are not currently "actively engaged" within the service, receive a 6 monthly wellbeing check (3 monthly if the person has no known family/carer)[tba]</p> <p>Proportion of people with dementia whose individual needs are assessed and whose care plan states how those needs will be addressed</p> <p>Proportion of people with dementia with named care coordinator</p> <p>Number of carers assessments for carers of older people as a % of the expected annual incident number of cases of dementia in year</p>	<p>90% achievement</p> <p>Number of contacts and number of active cases</p> <p>NICE Dementia Quality Standards (QS4b)</p> <p>NICE Dementia Quality Standards (QS4b)</p> <p>Provide a baseline of the extent to which carers needs are being assessed</p>
<p>Appropriate Care and Support:</p> <p><i>I understand, so I make good decisions and provide for future decision making</i> Linked to:</p>	6	Improved opportunity for forward planning for patients	Patients diagnosed with dementia are offered the opportunity to setup advanced decisions	Six monthly audit, 95% compliance for offer of support for

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<p>NICE Quality Standards 3, 5: Dementia Strategy Objectives 3, 4, 5:</p> <p><i>I am treated with dignity and respect</i> Linked to: NICE Quality Standards 1: Dementia Strategy Objectives 1, 13:</p> <p><i>I am confident my end of life wishes will be respected. I can expect a good death</i> Linked to: NICE Quality Standards 5, 9: Dementia Strategy Objectives 12, 13:</p>				advanced decisions	
<p>Appropriate Care and Support:</p> <p><i>I know what I can do to help myself and who else can help me</i> Linked to: NICE Quality Standards 1, 3, 4, 5: Dementia Strategy Objectives 3, 4, 5, 6, 13:</p>	7	Reduce the number of crises in the community leading to inappropriate unscheduled care attendance e.g. A&E, walk-in centres and polyclinics	A decrease in the number of patients presenting inappropriately to unscheduled care with a primary diagnosis of dementia	Measure [tba]	
<p>Appropriate Care and Support:</p>	8	Improved support for people caring for people with dementia	All localities have the equivalent of [tba] nurses or other healthcare professional whose objective is to work with and support the carer	[tba]	
<p>Community:</p>	9	Access from GPs to specialist older people's psychiatric liaison services	Presence of older people's psychiatric liaison service. This must include [tba] part-time consultant older people's psychiatrist, junior doctor, two other healthcare professionals and administration support per 100,000 population	[tba]	
<p>Appropriate Care and Support:</p>	10	Improved access to services	Maximum wait time from referral to assessment for any service	[tba] 4 weeks	
<p>Appropriate Care and Support:</p>	11	Improved access to services	Maximum wait time from assessment to diagnosis of dementia	[tba] 4 weeks	
<p>Appropriate Care and Support:</p> <p><i>Those around me and looking after me are well supported</i> Linked to: NICE Quality Standards 3, 4, 6, 10: Dementia Strategy Objectives 3, 4, 5, 7:</p>	12	Carers/family are a partner in care	% of people recorded as having a carer	[tba]	
<p>Appropriate Care and Support:</p> <p><i>Those around me and looking after me are well supported</i> Linked to: NICE Quality Standards 3, 4, 6, 10: Dementia Strategy Objectives 3, 4,</p>	13	Overall experience	Carer satisfaction survey	Person Reported Outcome Measures [tba]	

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<p>5, 7:</p> <p><i>I know what I can do to help myself and who else can help me</i> Linked to: NICE Quality Standards 1, 3, 4, 5: Dementia Strategy Objectives 3, 4, 5, 6, 13:</p>				
<p>Appropriate Care and Support:</p> <p><i>Those around me and looking after me are well supported</i> Linked to: NICE Quality Standards 3, 4, 6, 10: Dementia Strategy Objectives 3, 4, 5, 7:</p> <p><i>I understand, so I make good decisions and provide for future decision making</i> Linked to: NICE Quality Standards 3, 5: Dementia Strategy Objectives 3, 4, 5:</p> <p><i>I can enjoy life</i> Linked to: NICE Quality Standards 3, 4: Dementia Strategy Objectives 1, 4, 5, 6:</p> <p><i>I am treated with dignity and respect</i> Linked to: NICE Quality Standards 1: Dementia Strategy Objectives 1, 13:</p> <p><i>I feel part of a community and I'm inspired to give something back</i> Linked to: Dementia Strategy Objectives 1, 5, 16:</p> <p><i>I know what I can do to help myself and who else can help me</i> Linked to: NICE Quality Standards 1, 3, 4, 5: Dementia Strategy Objectives 3, 4, 5, 6, 13:</p> <p><i>I am confident my end of life wishes will be respected. I can expect a good death</i> Linked to: NICE Quality Standards 5, 9: Dementia Strategy Objectives 12, 13:</p>	<p>1 4</p>	<p>Over all experience</p>	<p>People with dementia report a positive experience with the survey</p>	<p>Person Reported Outcome Measures [tba]</p>
<p>Participation in Research:</p> <p><i>I'm inspired to give something back</i></p> <p><i>I wanted to take part in research and was able to do</i></p>	<p>1 5</p>	<p>Working towards recruiting 10% of people with dementia into research</p>	<p>Adopt an 'opt-out' policy in which service users are informed that research is a routine part of Provider business and that they may be contacted about opportunities to join research unless they explicitly request not to be contacted. Or Have a system in place such as a</p>	<p>Number of people recruited to studies</p> <p>Number of studies actively recruiting and have</p>

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			<p>'consent for approach register' to keep a record of patients who are willing to be offered research opportunities, together with relevant demographic details and their diagnosis</p> <p>Patients/carers are given information on how they can register their interest in joining research studies</p>	<p>recruited on time and to target (this data is available from the National Institute for Health Research)</p> <p>Proportion of people with a diagnosis of dementia on a 'consent for approach register' or similar</p> <p>70% of people with a diagnosis of dementia on a 'consent for approach register' or similar</p>
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4.3 Key Performance Indicators

The Provider will routinely report the following indicators:

- Number of people referred for diagnosis of dementia to Service
- Number of people assessed for a diagnosis of dementia by Service
- Number of people diagnosed with dementia by Service
- Number of people memory nurse supported GP to diagnose in primary care
- Number of people who did not attend diagnostic appointment with reason
- Number of people prescribed ACEI medication
- Breakdown by sex
- Breakdown by age
- Breakdown by ethnicity
- Numbers referred to service by each GP practice
- Numbers referred on to tertiary medical clinic
- Number of people recruited to research studies
- What is being provided to person with dementia and family/carer
- Carers - % of carers assessed/signposted for a break
- Number and names of care homes supported and residents reviewed
- Number of home visits provided in the community by Service
- Number of telephone calls providing advice to professionals
- Number of inappropriate referrals (for example person is not exhibiting symptoms of dementia)
- Routine Staff KPI's [tba]

5. Location of Provider Premises

5.1 Location of Premises

The Provider's Premises will be based in the community close to GP practices, so that a shared care approach can be maximised (space permitting) using a Hub and Spoke Model. [tba]

It will be provided flexibly in locations which are accessible to people across the community. This will include within peoples homes, primary and secondary care settings (including surgeries, health centres) community locations and other suitable settings, which can provide a clinically effective and safe environment.

5.2 Days and Hours of Operation

The core operating hours are anticipated to be:

Monday to Friday	8am to 8pm
Saturday	9am to 12 midday

Appropriate provision should be made to ensure service users and other Providers are signposted to appropriate Out of Hours support.

6. Individual Service User Placement

Not Applicable

7. Supporting Information

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7.1. Estimated Dementia Prevalence in Bristol – by Ward

Estimated Dementia Prevalence in Bristol				
Ward	Estimate d prevalen ce (All 60+)	% of total populati on	Males (60+)	Femal es (60+)
Ashley	51	0.3%	20	31
Avonmouth	155	1.2%	51	104
Bedminster	145	1.2%	49	96
Bishopston	76	0.5%	26	50
Bishopsworth	165	1.4%	58	107
Brislington East	126	1.1%	46	80
Brislington West	106	0.9%	38	68
Cabot	47	0.3%	18	29
Clifton	80	0.7%	27	53
Clifton East	55	0.5%	16	39
Cotham	70	0.6%	19	51
Easton	92	0.7%	31	61
Eastville	91	0.7%	34	58
Filwood	90	0.7%	31	60
Frome Vale	212	1.8%	66	146
Hartcliffe	154	1.3%	54	100
Henbury	146	1.4%	51	95
Hengrove	174	1.5%	58	116
Henleaze	176	1.7%	59	118
Hillfields	129	1.0%	47	81
Horfield	126	1.0%	40	85
Kingsweston	131	1.3%	43	88
Knowle	126	1.1%	41	85
Lawrence Hill	105	0.6%	42	64
Lockleaze	120	1.0%	42	78
Redland	86	0.7%	31	55
St George East	155	1.3%	47	108
St George West	128	1.1%	43	85
Southmead	127	1.1%	45	82
Southville	142	1.1%	41	101
Stockwood	167	1.5%	55	111
Stoke Bishop	146	1.6%	52	94
Westbury-on-Trym	257	2.4%	73	185
Whitchurch Park	109	1.0%	42	66
Windmill Hill	69	0.5%	26	43
Bristol	4334	1.0%	1462	2872

Source: 2011 Census