London Borough of Richmond upon Thames

JOINT DEMENTIA STRATEGY 2016-2021

Preventing Well

Diagnosing Well

Living Well

Supporting Well

Dying Well

LONDON BOROUGH OF RICHMOND UPON THAMES

NHS Richmond Clinical Commissioning Group

Contents

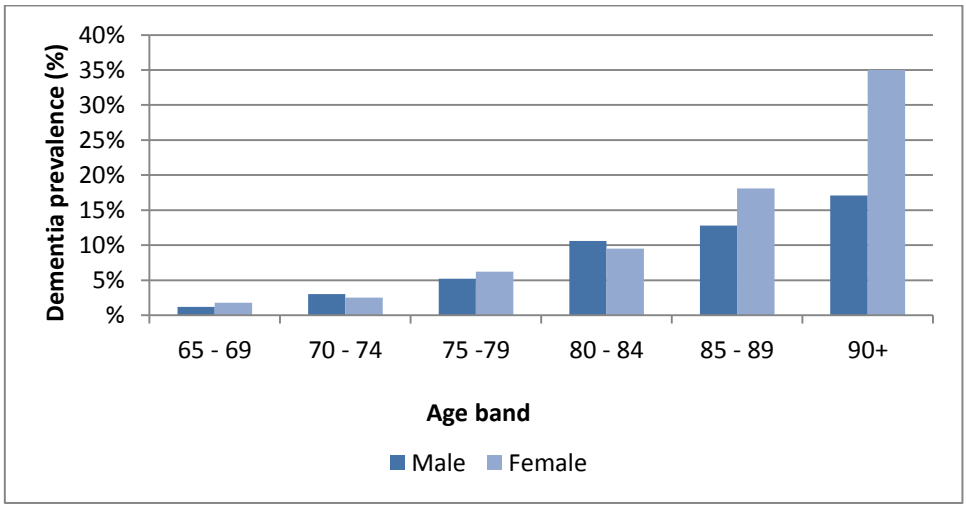
INTRODUCTION

What is dementia?

Dementia is an umbrella term for a range of progressive disorders affecting the brain, the most common of which are Alzheimer's disease and vascular dementia. It is more common in those over 65 years of age, but can occur in younger people. Dementia results in a progressive decline in multiple areas of function, including memory, reasoning, communication skills and the skills needed to carry out daily activities. Some people may also develop behavioural and psychological symptoms such as depression, psychosis, aggression, and eating problems, which can challenge the skills and capacity of carers and services. The impact of dementia on an individual and their family may be compounded by personal circumstances such as changes in financial status and accommodation, or bereavement. There is no cure for dementia, but people can live with it for many years after diagnosis. Recent evidence is emerging that healthy lifestyles such as avoidance of tobacco, alcohol, poor diet and physical inactivity can reduce the risk of dementia.

Nationally, there are currently estimated to be 622,000 cases of dementia in those over 65 years of age[1]. Prevalence of dementia increases with increasing age (Figure 1). More women than men are diagnosed with dementia each year and it has become the leading cause of death among women in the UK[2].

Figure 1: Estimated dementia prevalence in the UK (per cent) by age band



[1] NHS England, Letter from Dr Dan Harwood - London Dementia SCN Clinical Director 2015
[2] Alzheimer's society report March 2015

Why do we need a Joint Strategy?

National context

Action on dementia has been building nationally for the last five years. In 2009 the Department of Health published an ambitious national dementia strategy[3] which detailed 17 objectives that, when implemented locally, would result in significant improvements in the quality of services and the understanding of dementia in the UK. In 2010, the Dementia Action Alliance was set up "to bring about radical changes in the way society responds to dementia"[4]. A National Dementia Declaration was developed, containing "I statements" that set out what is important to people with dementia[5]:

- *I have personal choice and control over the decisions that affect me.*
- *I know that services are designed around me, my needs and my carer's needs.*
- *I have support that helps me live my life.*
- *I have the knowledge to get what I need.*
- *I live in an enabling and supportive environment where I feel valued and understood.*
- *I have a sense of belonging and of being a valued part of family, community and civic life.*
- *I am confident my end of life wishes will be respected. I can expect a good death.*
- *I know that there is research going on which will deliver a better life for people with dementia, and I know how I can contribute to it*

To drive quality improvements in dementia services, the National Institute for Health and Care Excellence (NICE) issued quality standards for dementia (2010) and for living well with dementia (2013), which give statements on best practice for service provision. The NICE guidelines on dementia, first published in 2006, will be updated for publication in September 2017 due to a number of new research findings.

In March 2012 the Prime Minister launched a national challenge to fight dementia, which has led to unprecedented action across the country. More people have now received a diagnosis of dementia than ever before, over 1 million people have been trained to be dementia friends to raise awareness

[3] Living well with dementia https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf
[4] http://www.dementiaaction.org.uk/
[5] http://www.dementiaaction.org.uk/nationaldementiadeclaration

in local communities, over 400,000 NHS staff and over 100,000 social care staff have been trained in better supporting people with dementia, and there has been a significant increase in research spending[6]. Building on this, a new Prime Minister's challenge was launched with the aspiration that, by 2020, England will be the best country in the world for dementia care and support, and for people with dementia, their carers and families to live, and the best place in the world to undertake research into dementia and other neurodegenerative diseases[4].

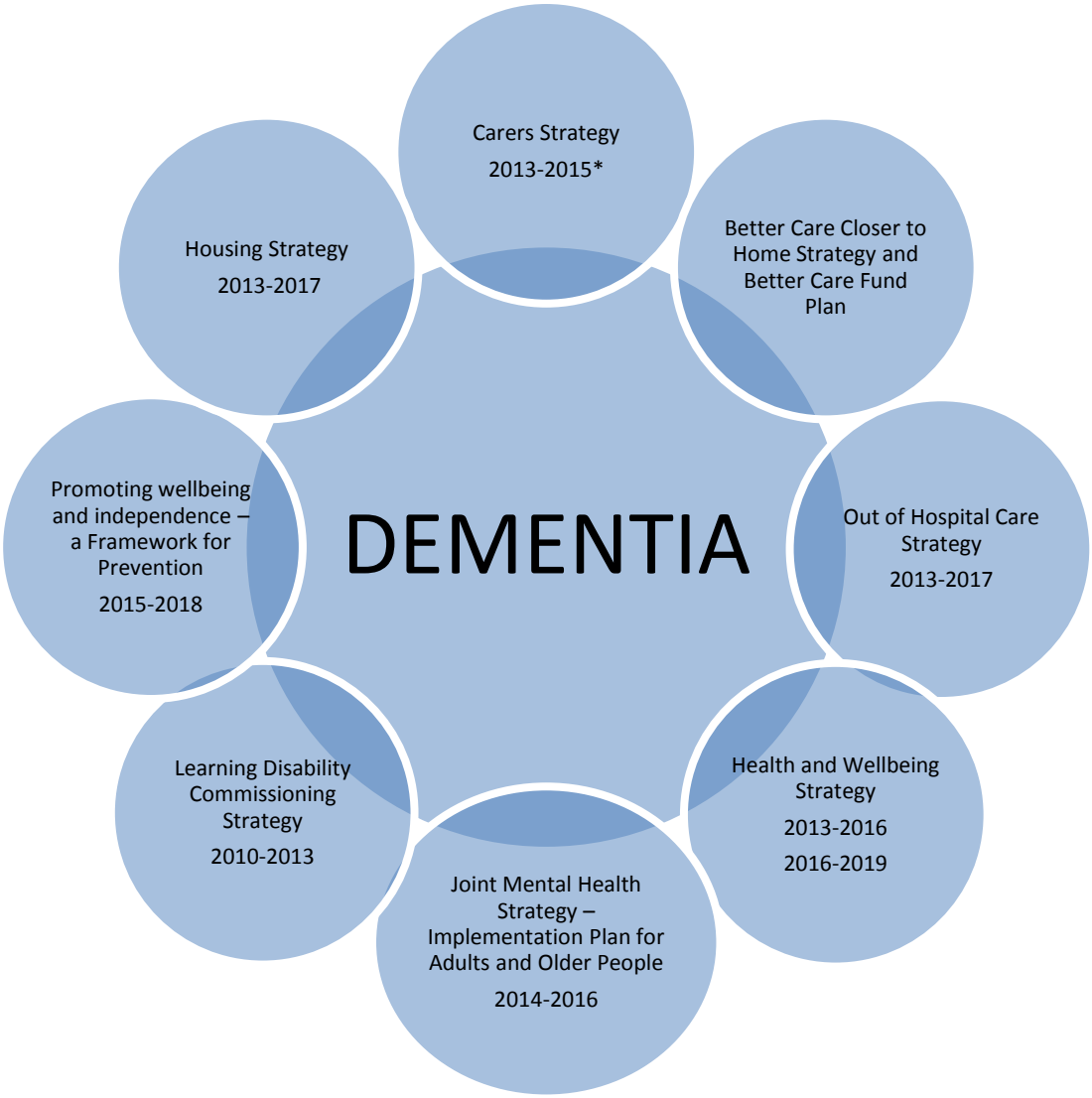
Local strategic and commissioning context

Richmond has invested significantly over the last few years in health and social care services in both the statutory and voluntary sectors for people with dementia and their carers. This Joint Strategy will capture this existing framework of comprehensive service provision in one place, and demonstrate the choice and range of services available to those with dementia and their carers in Richmond. This consolidation will also highlight where there is more to do to enable those with dementia in Richmond to live well and be supported appropriately.

A number of strategies have been developed in Richmond in recent years that focus on issues relevant to dementia (Figure 2). However, delivery of services for people with dementia and their carers is dependent on an integrated approach to commissioning health and social care services across the care pathway. This Joint Strategy will bring relevant elements from these strategies together to set out how health and social care services for people with dementia and their carers will develop over the next five years.

[6] Prime Ministers Challenge on Dementia https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020

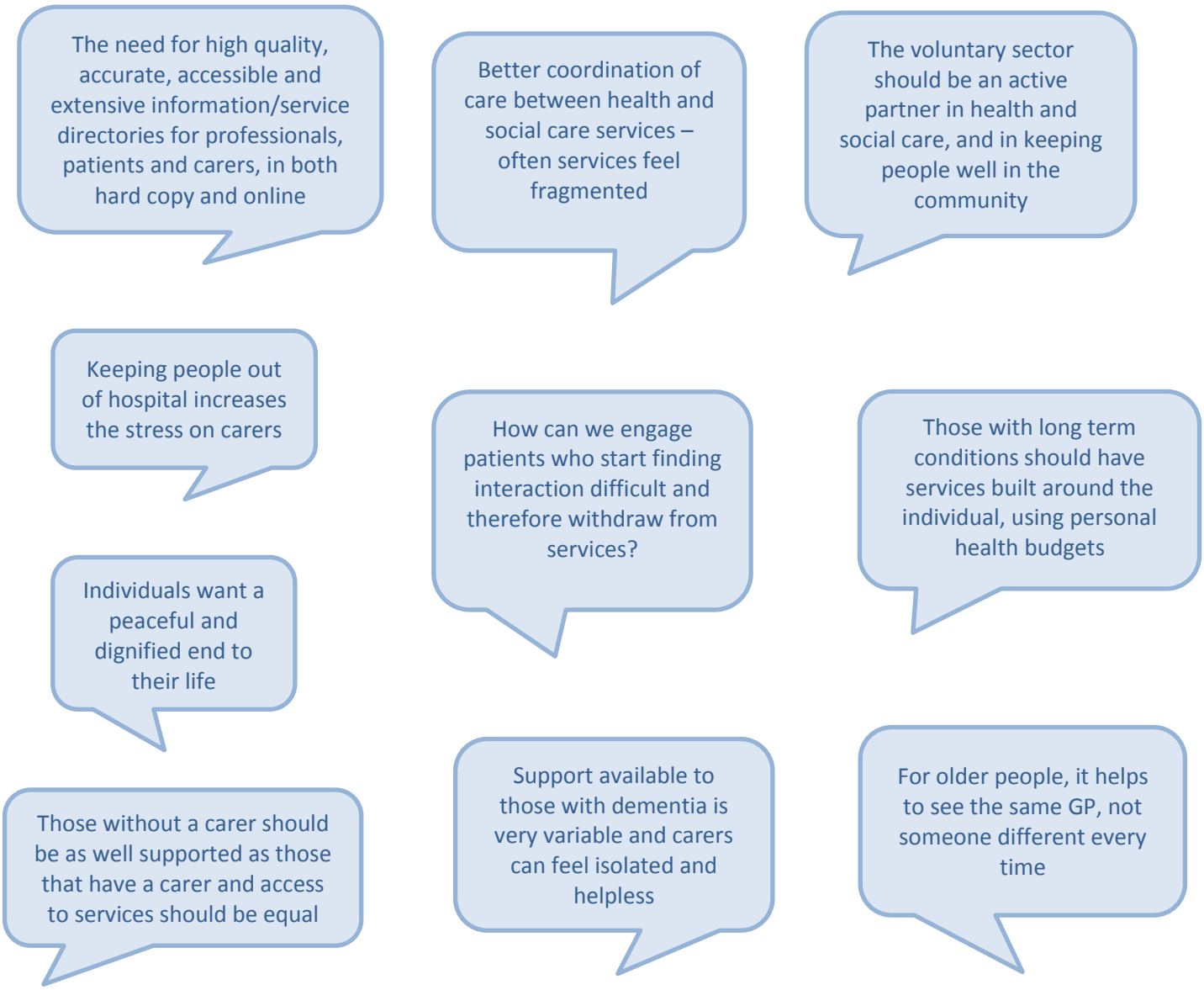
Figure 2: Current and recent Richmond health and social care strategies relevant to dementia



*The Carers Strategy will be refreshed and published in 2016

Local views on dementia services

Views on dementia services from local residents and carers have been collected through a number of engagement events by the CCG for ongoing work streams[7]. The main themes from this local engagement in relation to dementia are set out below and have informed the development of the Strategy.



[7] Engagement events reviewed were:

- Better Care Closer to Home: Richmond Out of Hospital Care Strategy - Engagement Report 2013
- Inpatient mental health services in south west London consultation Event, hosted by Friend of Barnes Hospital – December 2014
- SWL CCGs: Inpatient Mental Health Services in South West London, Consultation Report – February 2015
- Outcomes That Matter: Community Mental Health in Richmond - April 2015
- Help us build a new NHS in south west London: Public and local stakeholder deliberative engagement events - September 2015

Dementia in Richmond over the next five years

In Richmond, as of January 2016, 1947 people over 65 years of age were estimated to be living with dementia[8]. This estimate excludes people with young-onset dementia. 1,319 people of all ages have received a confirmed diagnosis of dementia and it is estimated that a further 745 have not been formally diagnosed or have not yet presented to services.

The prevalence of dementia is increasing nationally. In Richmond, the number of people aged over 65 living with dementia is expected to rise to 2235 by 2021 – a 15% increase over the next 5 years – and to 2561 by 2025 – a 32% increase over the next 10 years. Table 1 gives a breakdown of the increase over the next five years for men and women in Richmond.

Table 1: Estimated number of people living with dementia in Richmond, aged 65+, 2016-2021

Year	Men	Women
2016	668	1,337
2017	682	1,358
2018	687	1,394
2019	725	1,434
2020	746	1,435
2021	767	1,468

Given this estimated rise in the prevalence of dementia over the next five years, this Joint Strategy provides an opportunity to analyse how current services in Richmond will meet this future demand.

[8] NHS England, Letter to CCG Clinical Leaders, Dementia Diagnosis Rates (unpublished)

Scope and purpose

This Joint Dementia Strategy sets out our five year vision for people with dementia and their carers in the London Borough of Richmond upon Thames. It will look at all aspects of dementia care and services, from prevention to end of life care, to ensure that:

- opportunities to prevent certain forms of dementia are maximised;
- community understanding of dementia is improved;
- the Local Authority and Clinical Commissioning Group (CCG) are prepared for the future needs of people with dementia;
- Richmond becomes a dementia friendly community that enables people with dementia to stay living independently in the community for longer;
- carers of people with dementia are given the support they need;
- people with dementia are able to live well in Richmond.

The framework for this Joint Strategy has been taken from the NHS England Dementia Pathway Transformation Framework. There are five elements to the Framework:

- ***Preventing well*** *– the risk of people developing dementia is minimised;*
- ***Diagnosing well*** *– timely diagnosis, integrated care plan and review within the first year;*
- ***Living well*** *– people with dementia can live normally in safe and accepting communities;*
- ***Supporting well*** *– access to safe high quality health and social care for people with dementia and carers;*
- ***Dying well*** *– people living with dementia die with dignity in the place of their choosing.*

The primary audience for this Joint Strategy is the commissioners of health and social care services in Richmond, but it will also be of interest to people with dementia and their carers, and to service providers.

Austerity

The Local Authority and CCG are operating within the context of significant budget pressures due to central government reductions or restrictions, combined with increased demand for local services. Central government funding restrictions are expected to continue for the foreseeable future, as part of the Government's strategy to reduce the national deficit.

No additional financial resources have been identified to implement this strategy. We will be seeking to implement the strategy within, and through the redistribution of, existing resources.

Engagement [and Consultation[9]]

A Joint Dementia Strategy Steering Group was formed to guide development of the strategy and oversee delivery. The membership of the group[10] comprised representatives from Health Watch, Richmond Council for Voluntary Service, the Local Authority, Richmond Clinical Commissioning Group, and a number of dementia carers. The Steering Group met monthly during the first half of 2016.

The team carried out extensive stakeholder engagement with the statutory and voluntary sectors in Richmond to discuss the current services for those with dementia and their carers, and to investigate what the future could and should look like.

Awareness of the Strategy was raised at a number of groups and events including the Richmond Dementia Action Alliance, the Community Involvement Group and the Older People's Mental Health Steering Group. Members were invited to contact the team with any input they felt was useful, or if they had any questions or comments. As a result of this engagement, a number of meetings were set up with interested stakeholders to hear their views.

[9] This section will be updated once the public consultation is complete
[10] See Appendix 1

PREVENTING WELL

The risk of people developing dementia is minimised

What is happening in Richmond to prevent dementia?

Richmond Local Authority (LA) and CCG are committed to prevention of long term conditions as set out in the Care Act (2014), which emphasises the importance of a shift in service provision towards preventative services, with the aim of preventing, reducing and delaying the need for care. The LA and CCG recently published "Promoting wellbeing and independence – a Framework for Prevention 2015-2018"[11] and are committed to working in partnership to deliver this strategic framework to improve the health and well-being of Richmond's population and to support people to remain independent. The four priorities for this strategic framework were identified as:

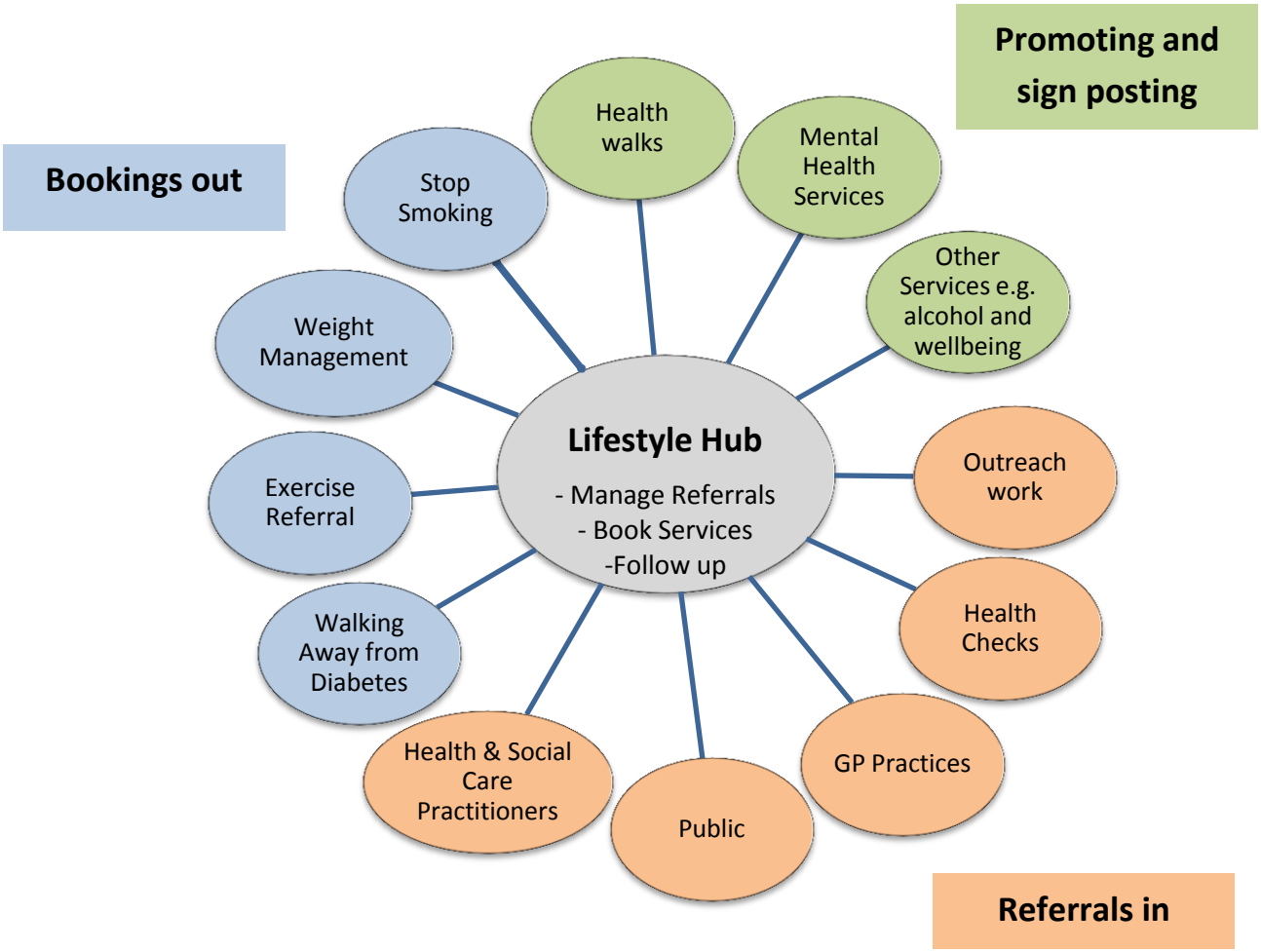
- **Priority 1:** Making health and wellbeing everyone's business
- **Priority 2:** Creating healthy communities – harnessing local community assets to support people and their carers
- **Priority 3:** Re-shaping healthy lifestyles services and embedding self-care
- **Priority 4:** Reducing and delaying demand for care – promoting a recovery focussed model across health and social care pathways

More information on this Strategic Framework and its implementation can be found here.

Research on dementia has indicated that some types of dementia have the same risk factors as cardiovascular disease and stroke, for example smoking, lack of regular physical exercise and excessive alcohol consumption[12]. In Richmond, a new service model for lifestyle prevention services, Live Well Stay Well, has been commissioned since September 2015. Live Well Stay Well is a health hub with five key prevention services – NHS Health Checks, weight management, exercise referral, walking away from diabetes, and healthy walks.

[11] http://www.richmond.gov.uk/framework_for_prevention_2015-18.pdf
[12] PHE: Health matters: midlife approaches to reduce dementia risk https://www.gov.uk/government/publications/health-matters-midlife-approaches-to-reduce-dementia-risk/health-matters-midlife-approaches-to-reduce-dementia-risk

Figure 4 – Live Well Stay Well service model



This service model has increased the capacity of frontline lifestyle services and additionally targets outreach delivery to identify high risk populations. The focus of these services is to reduce long term conditions, including dementia.

The NHS Health Checks programme is aimed at everyone between 40 and 74 years of age who has not been previously diagnosed with heart disease, hypertension, stroke, diabetes or kidney disease. As well as testing for these conditions, the programme includes a dementia element for those over 65 years, with information provided and referral to the memory clinic if needed. In Richmond, the programme is being delivered by 27 general practices, 2 pharmacies and via a community outreach provider, and reached its invitation target last year. More than 6000 health checks were completed, with an uptake rate of 53%. The programme has been successful in detecting more than 500 cases of cardiovascular disease and referring a similar number to lifestyle services. Richmond's success story has been published on the NHS Health Checks website and in an international journal.

What do we want to achieve in the next five years for the prevention of dementia?

1. We will ensure that the objectives in the Framework for Prevention are implemented and monitored, and that prevention is embedded in all our services
2. We will improve awareness of "What's good for your heart is good for your head" through all our public health prevention services
3. We will support national dementia prevention initiatives as set out in the Prime Minister's Challenge on Dementia 2020 and the NHS 5 year Forward Plan, for example a national healthy ageing campaign
4. We will work to achieve the national uptake target of 65% for invitations to NHS Health Checks; this will be achieved via better targeting of invitations, community outreach, opportunistic checks within our services and engaging GP practices
5. We will work towards the implementation of the recommendations in the 2015 NICE guidance on "Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset"

DIAGNOSING WELL

Timely diagnosis, integrated care plan and review within first year

What is happening in Richmond to diagnose dementia?

Diagnosis, memory assessment and investigation

There is a clear diagnostic pathway for dementia in Richmond. All Richmond residents and those registered with a Richmond GP have good access to memory clinic services provided by South West London St George's that specialise in the diagnosis and initial management of dementia. The memory clinic accepts referrals from Richmond GPs, the Hounslow and Richmond Community Healthcare dementia clinical specialists and hospitals. Those referred into the service are seen within 2 weeks for an initial assessment[13], and most will have a CT scan as part of the investigations to confirm diagnosis and type of dementia. A confirmed diagnosis is given within 8-10 weeks[11]. Carers are encouraged to attend the memory clinic and to be a part of the diagnosis.

Some referrals are made to the memory clinic services provided by the West London Mental Health NHS Trust, usually due to geographical proximity. A small proportion of diagnoses occur in secondary care and in the community, and, where appropriate, patients are referred back to their GP for management.

A new tool for diagnosing dementia in care home residents was recently piloted in two care homes in Richmond. The Dementia Assessment Referral, or DeAR-GP, tool is used by care workers to identify care home residents with suspected dementia and refer them to their GP for further assessment[14]. The tool was found to be effective and efficient, and over 87% (20 out of 23) of the care home residents reviewed using the tool were either diagnosed with dementia or referred for further assessment. The Alzheimer's Society estimates that up to 80% of residents in care homes have dementia or severe memory problems[15].

[13] Information provided by SWL St Georges NHS Trust by email, March 2013
[14] http://www.hin-southlondon.org/news/DeAR-GP%20tool%20report%20published
[15] Alzheimer's Society, 2013

In 2012, 46% of those estimated to have dementia had been diagnosed in Richmond. Since then, there has been a huge drive to improve diagnosis rates. Educational events have been held with GPs and other frontline healthcare staff to raise awareness, and significant work has been done in partnership with GP practices to improve the coding of dementia cases. As of January 2016, the diagnosis rate for Richmond was 65.5% - a substantial improvement. However, as of January 2016, there is still work to do to reach the national diagnosis rate of 67.2%[16].

Provide information

When individuals receive their diagnosis at the memory clinic, they and their carer are provided with both verbal and written information about their condition and any possible treatment. All newly diagnosed individuals are referred to the Dementia Care Advisor, provided by the Alzheimer's Society, who sits within the memory clinic and acts as an information navigator following diagnosis. Those diagnosed at the memory clinic and their carers have access to the Dementia Care Advisor on an ongoing basis to aid them in accessing services in the area, and local GPs can also refer individuals diagnosed elsewhere to that service. The memory clinic psychological services also provide support group work following initial diagnosis.

A dementia services guide for Richmond is available for those who have been diagnosed, available in both hard copy and online[17]. Richmond residents now also have access to two newly commissioned websites that provide information on local services and give residents the opportunity to choose the services most suited to their needs:

- **Careplace**[18] is a recently launched online care directory that captures information on all health and social care services in a number of London boroughs, including Richmond. Users can access descriptions and contact details of all dementia-related services in Richmond via a quick search for keywords such as 'dementia' or 'carers';
- **Quickheart**[19] is a new website for Richmond residents, provided by Richmond Local Authority, which contains information and advice on general health and social care issues, as well as specific diseases such as dementia.

[16] NHS England, Letter to CCG Clinical Leaders, Dementia Diagnosis Rates (unpublished)
[17] http://www.richmond.gov.uk/your_guide_to_dementia_services_2014.pdf
[18] https://www.careplace.org.uk/ - Richmond-specific information on the website is provided by the London Borough of Richmond upon Thames
[19] Quickheart will launch in May 2016

A Carer Information and Support Programme (CrISP1), run by the Alzheimer's Society, is also available to Richmond residents via the Carers' Hub[20]. These sessions are for the family and friends of someone who has recently received a diagnosis of dementia and aim to improve quality of life for both the person diagnosed and their carers. Topics covered include understanding dementia, legal and money matters, providing support and care and coping day to day.

Care plan

Initial management of newly diagnosed individuals is provided by the memory clinic. Follow-up care is transferred back to the GP once the individual's condition is stable and their medication regime is well established. This leads to a more holistic service experience with the GP responsible for their ongoing personalised care plan, which is reviewed at least annually. In Richmond in 2014/15, 75% of people with dementia had had a face-to-face care review in the previous 12 months, a similar proportion to both the national (77%) and London figures (78%)[21]. GPs have recently received dementia education and training to keep their skills and knowledge up-to-date. Individuals have ongoing access to memory clinic services, for example the consultant psychiatrist, where necessary, through their GP.

[20] http://www.richmondcarers.org/
[21] HSCIC QOF 2014-15 http://www.hscic.gov.uk/article/2021/Website-Search?productid=19196&q=quality+outcome+framework+2014%2f15&sort=Relevance&size=10&page=1&area=both#top

What do we want to achieve in the next five years for the diagnosis of dementia?

Diagnosis, memory assessment and investigation

1. We will keep up the momentum in improving diagnosis rates and strive to achieve and maintain the national ambition of two thirds diagnosed
2. We will ensure that all GP practices are correctly coding dementia diagnoses through use of the dementia toolkit
3. We will investigate what role the dementia clinical advisers at Hounslow and Richmond Community Healthcare can play in continuing to improve dementia diagnosis in the borough, by working with GPs and raising awareness in their service
4. We will ensure that all those resident in Richmond or who are registered with a Richmond GP have ongoing access to the memory clinic service of their choice
5. We will work with our memory clinic services to improve the efficiency of diagnosis
6. We will investigate what professional support is available to individuals following their initial assessment at the memory clinic, prior to confirmed diagnosis
7. We will continue to monitor the capacity of our memory clinic services to deal with the increasing number of dementia patients in the borough in the next 5 years and feed this into our commissioning plans
8. We will work with our GP practices towards the implementation of the recommendations from NICE on the diagnosis and management of those with mild cognitive impairment[22]
9. We will work with our memory clinic services and all GP practices to roll out best practice for immediate post diagnosis support, as set out in the recent guidelines from the Living Well with Dementia Working Group of the London Dementia Strategic Clinical Network[23]
10. We will work with our local care homes to implement the Dementia Assessment Referral Tool (DeAR-GP) to identify dementia in care home residents

[22] NICE guidance on dementia 2009
[23] Immediate post diagnosis support guidelines - Living Well with Dementia working group, London Dementia Strategic Clinical Network, Sept 2015

Provide information

11. We will ensure that all those diagnosed with dementia who are resident in Richmond or are registered with a Richmond GP have ongoing access to dementia care advice, so that they can access up-to-date information on services for those with dementia and their carers
12. We will work with GP practices to make sure that details for accessing dementia care advice are provided to patients at their annual review, so that those who do not feel the need to engage with services straightaway have the opportunity to do so later on if they wish
13. We will work with our memory clinic services to ensure that the patient's GP is copied into the patient's information letter
14. We will update the dementia services guide for Richmond and ensure that it is provided in hard copy or e-copy as preferred at the time of diagnosis
15. We will ensure that information on dementia on the Richmond Local Authority website (www.richmond.gov.uk) is easy to navigate and up to date, with a link to NHS Choices, Quickheart and Careplace

Care plan

16. We will ensure that all those diagnosed with dementia have access to a named GP with overall responsibility and oversight for their care, as set out in the Prime Minister's Challenge on Dementia 2020[24]
17. We will commit to the proposed National Declaration on post-diagnostic dementia care and support
18. We will work with GP practices to ensure that all those diagnosed with dementia are invited to an annual review to discuss their care

[24] https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020

LIVING WELL

People with dementia can live normally in safe and accepting communities

What is happening in Richmond to enable those with dementia to live well?

Supporting carers and respite

Richmond recognises and values the role of carers and their central role in maintaining the health and wellbeing of the people for whom they care. The Richmond Carers Strategy 2013-15 set out the borough's vision for carers to be able to achieve their full potential, live their lives with confidence and resilience and access quality services that promote independence and deliver value for money. Considerable progress has been made against the aims of the Strategy. Evaluation of this, and consultation with service users, is being carried out to inform the shape and direction of the refreshed strategy which will be published in 2016, and will reflect the commitment that Richmond has to supporting carers.

We know that, in England, 39% of carers spend 100 or more hours each week looking after, or caring for, a person with dementia and over half have been in their caring role for more than five years[25]. This can put a considerable physical and mental strain on the carer. In addition, 1 in 4 carers have a long-standing illness, 1 in 5 have a physical impairment or disability[26]. Richmond provides a carers' assessment service for all carers, including those who care for people with dementia[27]. The assessment builds a picture of the physical, emotional and practical impact on the life of a carer, and ensures that their needs are recognised. Information on the amount of support they are providing, their health and wellbeing, relationships, housing/accommodation, and work and learning is collected; this is used to work out what help and support they may need now and in the future. Richmond publishes a Carers Directory[28] on the Council website that contains comprehensive information and contact details for organisations which provide support and services to carers.

[25] Focus on dementia – HSCIC, 19 January 2016
[26] Personal Social Services Survey of Adult Carers in England, 2014-15
[27] http://www.richmond.gov.uk/carers_assessments
[28] http://www.richmond.gov.uk/carers_directory.pdf

Richmond commissions the Carers Hub Service[29], a universal information and advice service providing emotional support, financial and debt advice, short breaks and leisure programmes, a Young Carers' service, training for carers, opportunities for carer engagement, carer awareness training for professionals and strategic leadership, as well as linking to support for healthy lifestyles and psychological wellbeing. The service is provided by Richmond Carers Centre in partnership with 8 other local organisations[30], for example, Richmond AID who provide advice on eligibility for state and local benefits. An example of a dementia-specific service provided by the Carers Hub is The Caring Café where people with dementia, their families and friends, can meet for a coffee or lunch to share experiences and spend time together. Support Workers from the partnership organisations are on hand to provide guidance and information.

Richmond has a number of support services for people with dementia and their carers, which provide a change of scene for the person with dementia, and allows their carer to have a break from caring to carry out their normal activities, for example;

- Homelink day respite care[31] offers support and day care for people with dementia two days each week via a nurse-led day respite centre;
- The Woodville Centre is a specialist day centre in Richmond borough designed to support individuals who need specialist care and offer respite to their carers. The Centre provides a therapeutic, stimulating, safe and friendly environment for people with dementia and others to spend the day. An innovative range of activities and facilities are available, including arts and crafts, bingo, music, Singing for the Brain and reminiscence. These activities, focussing on sensory stimulation, are delivered both individually and in groups to encourage social interaction and relationship building.

In Richmond, short term respite is provided by Shared Lives Dementia[32], a registered care service which offers care placements to people experiencing dementia in a different setting from where they usually live. Short-term respite placements are arranged in the homes of Shared Lives Carers who have been assessed, trained and approved to look after someone experiencing dementia.

[29] www.richmondchs.org
[30] Addiction Support and Care Agency (ASCA), Alzheimer's Society, Crossroads Care, Ethnic Minorities Advocacy Group (EMAG), Grace Debt Advice, Homelink, Integrated Neurological Services, Richmond Homes and Lifestyle Trust
[31] http://www.homelinkdaycare.co.uk/
[32] Shared Lives Dementia http://www.richmond.gov.uk/home/services/adult_social_care/residential_care_options/shared_lives/shared_lives_dementia.htm

Feedback from residents suggests that accessing longer term respite care, and accessing respite care at short notice, is a challenge in Richmond; we recognise this and will explore ways to improve this.

Richmond has a large number of self-funders of care compared to both London and nationally. Many services are open to self-funders, including Shared Lives Dementia and the Woodville Centre.

However, despite these services in Richmond, only 30% of all adult carers in 2014/15 had as much social contact as they would like; this fell from 39% in 2012/13 and is lower than London (36%) and England (39%)[33]. Although not dementia specific, this suggests that the services available to carers in Richmond may not be reaching all those that need them.

Relationships

Forming and maintaining relationships is key to living well with dementia. Evidence from a national survey highlighted the impact of loneliness and social isolation on people living with dementia, particularly for those living alone. Nearly two-thirds of people with dementia surveyed said they felt anxious or depressed, and of those living alone, nearly two-thirds reported feeling lonely[34]. In Richmond, approximately 20% of people with dementia (around 400 individuals) currently live alone[35].

Peer support groups can provide an important opportunity to speak to other people in a similar situation and provide social interaction. Peer support groups have also been shown to return a social value greater than the investment made[36]. In Richmond, there are a number of formal and informal peer support groups for people with dementia. Other groups, for example the FiSH Retro Café in Mortlake, and the Alzheimer's Society supper club, also provide events for those with dementia and their carers to enjoy themselves, while meeting others and forming relationships.

[33] LBRuT Public Health Outcomes Framework update, February 2016
http://www.datarich.info/jsna/newsflashes20160217
[34] Alzheimer's Society (2013). Dementia: The hidden voice of loneliness. Alzheimer's Society.
www.alzheimers.org.uk/dementia2013
[35] Based on England level estimates of the proportion of people with dementia who live alone
[36] http://www.hin-southlondon.org/resources/sroidementiapeersupport

Richmond commissions a tailored peer support service for those with young onset dementia from the Alzheimer's Society. This service has supported 30 individuals with young onset dementia during 2015/16, providing a weekly space to meet and discuss their diagnosis and any issues they are facing. This model has been used as an example of best practice in South London[37].

Richmond is committed to combatting loneliness and isolation in the borough. Frontline service staff are trained to recognise loneliness and isolation when they make contact with members of the public and can refer individuals to the Richmond Community Independent Living Service (CILS).

CILS delivers services which help individuals to:

- make a positive contribution to their local community;
- reduce social isolation; and
- improve their wellbeing either through delaying deterioration and dependency or aiding recovery.

Services are designed to deliver a network of informal support services, including advice, befriending and respite from a variety of statutory and voluntary organisations, including MIND, Age UK and the Alzheimer's Society.

Arts, Culture, Leisure

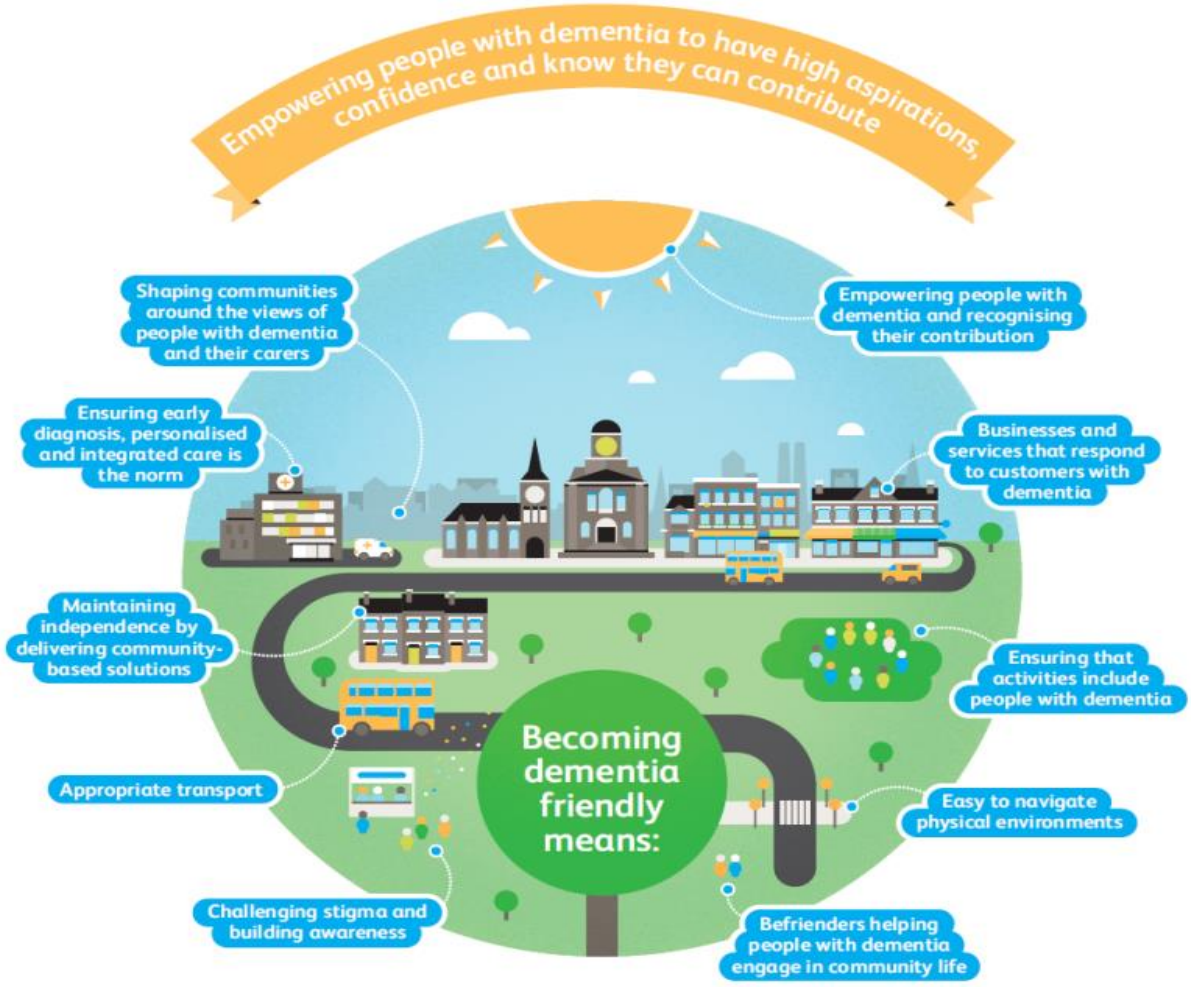
Many cultural and leisure organisations in Richmond provide dementia friendly activities for people with dementia and their carers. Some examples include Talk and Draw at Orleans House Gallery, dementia-friendly sensory sessions at Hampton Court Palace, Share a Book Group held by the Alzheimer's Society, Strawberry Hill House Gardening Club, and dementia health walks at Kew Gardens. Richmond's Cultural Partnership Strategy 2015-19 provides more information on the borough's cultural goals for the next few years[38].

[37] http://www.hin-southlondon.org/system/resources/resources/000/000/095/original/HIN_Interactive_Toolkit_September_15_LIVE.pdf
[38] http://www.richmond.gov.uk/cultural_partnership_strategy_2015_to_2019.pdf

Promote independence and safe communities

Richmond is committed to creating a dementia-friendly community in the borough to enable those with dementia, and their carers, to maintain and develop their involvement in, and contribution to, their community.

Figure 5 – Becoming Dementia friendly means…



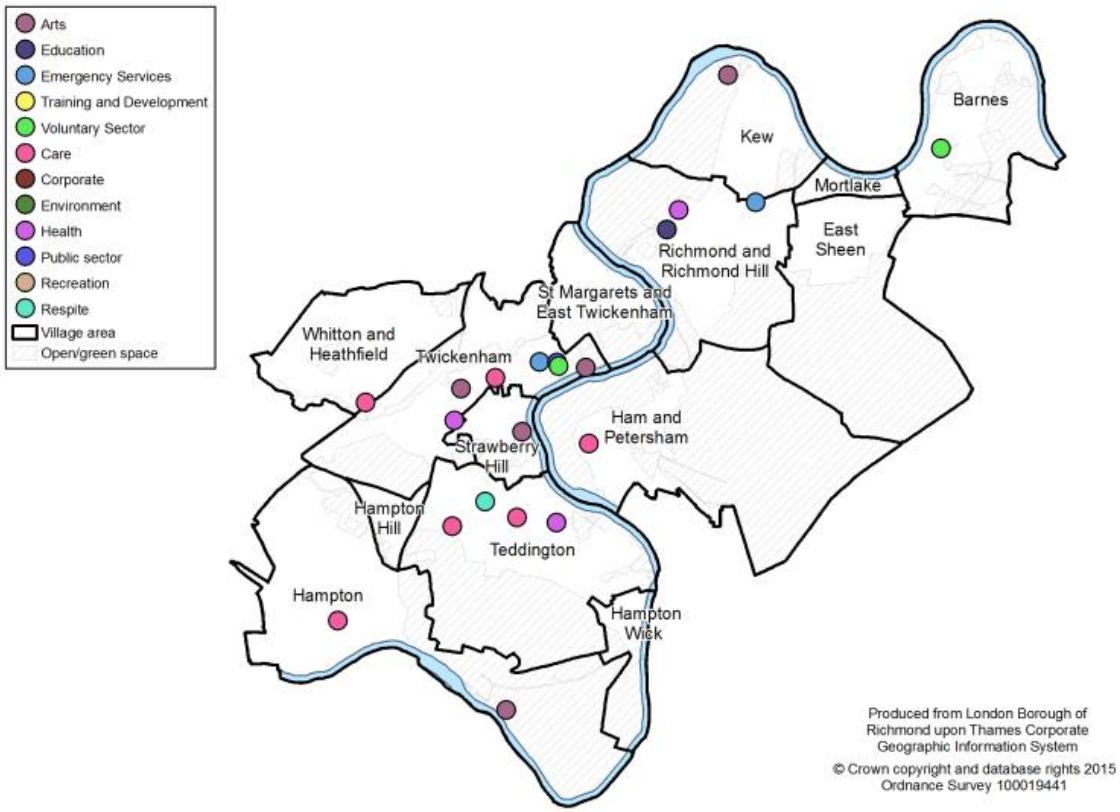
Richmond's Dementia Action Alliance[39] (RDAA) was launched in March 2014 to help local businesses and organisations to become dementia-friendly. As of March 2016, the Richmond DAA has grown to 68 members with a diverse membership including voluntary organisations and community centres,

39 http://www.dementiaaction.org.uk/local_alliances/4742_london_borough_of_richmond_upon_thames_dementia_action_alliance

representation from the public sector, private companies and community interest groups, GP surgeries and hospitals, emergency services, and representation from the arts and heritage sector (Figure 6). Within the membership there are organisations specialising in areas such as cancer, learning disabilities, young onset dementia and BME communities. Meetings are held quarterly and are themed, with significant time for networking to enable sharing of information and partnerships to form.

The Alzheimer's Society's Dementia Friends programme aims to challenge people's perceptions of dementia and transform the way the nation thinks, acts and talks about the condition. Richmond has a rapidly growing network of Dementia Friends – as of January 2016 there were 2,918 Dementia Friends in Richmond, and 84 Dementia Champions – who are helping to create a safer community for those with dementia.

Figure 6 – Richmond Dementia Action Alliance organisations (as at September 2015)



The Richmond Village Planning initiative[40] gives the opportunity for local residents to shape their local area, particularly focusing on planning and maintaining local character. For this, the Council has worked with residents to define 14 natural communities ("Villages"). Using the Village Planning infrastructure, and working with the RDAA, the Council is developing and piloting the Dementia Friendly Villages initiative. This aims to tap in to community networks to help localise the reach of the RDAA and better target local businesses such as those situated along a high street, or those that offer services to a local community and the places accessed by local residents. The Council's Community Links team is a key partner in delivery and accessing local knowledge. Barnes has been identified as the first pilot and local groups, Barnes Community Association and FiSH Neighbourhood Care Scheme are teaming-up with the Council and RDAA to identify and engage local organisations. The Council is working to roll out a similar approach in Hampton Hill by linking in with the Village Planning process as it takes place.

Richmond Parks Team is also working towards establishing Dementia Friendly Parks in the borough and has undertaken work to define what it means for a park to be Dementia Friendly. Parks and other public spaces can contain barriers to those with dementia who wish to use them, for example:

- physical barriers (e.g. steps, slopes, lack of benches)
- conceptual barriers (e.g. fear for personal safety)
- organisational barriers (e.g. lack of information, lack of transport) barriers

As part of the Dementia Friendly Villages initiative, the team is working with Friends of Barnes Village Green to pilot the borough's first Dementia Friendly Park in Barnes. This has included changes to signage, benches and destinations within the green area as well as increased understanding and awareness of dementia through Dementia Friends sessions.

The Metropolitan Police in Richmond became members of the RDAA in 2014, demonstrating their commitment to helping to create a dementia friendly borough. They have pledged to create Dementia Champions within their organisation to provide Dementia Friends sessions to their workforce. Improving awareness of dementia within the police force in Richmond will enable them to communicate with, and support, those with dementia who come into contact with the police.

[40] http://www.richmond.gov.uk/village_plans

What do we want to achieve in the next five years to enable those with dementia to live well?

Supporting carers, respite

1. We will continue to provide a comprehensive assessment service to the carers of those with dementia, and will monitor the number of carers assessments being carried out for carers of people with dementia
2. We will continue to provide support services, and short term respite services, for those with dementia that enable their carers to have a break from caring
3. We will consider ways to improve access to longer term respite care
4. We will explore ways to improve access to respite care at short notice
5. We will work to raise awareness of the range of services available to carers of people with dementia in the borough
6. We will support the implementation of the refresh of the Richmond Carers' Strategy

Relationships

7. We will continue to work with the voluntary sector to ensure that people with dementia and their carers have access to the peer support networks that they need

Arts, Culture, Leisure

8. We will continue to work with institutions and businesses in Richmond to provide a wide range of dementia-friendly arts, cultural and leisure activities to people with dementia and their carers, which are accessible and sustainable
9. Where needed and where possible, we will work with voluntary and community organisations to provide transportation to and from these activities

Promote independence and safe communities

10. We will continue to work towards the creation of a dementia friendly community where people with dementia feel safe, can maintain their independence for as long as possible and can contribute to community life
11. We will continue to increase the number of Dementia Friends and Dementia Champions across the borough, particularly within our Dementia Friendly Village areas
12. Through the Richmond Dementia Action Alliance, we will engage with high street businesses, schools, churches and faith groups, community groups, pharmacies and GP surgeries to increase dementia awareness

SUPPORTING WELL

Access to safe, high quality health and social care for people with dementia and their carers

What is happening in Richmond to enable those with dementia to be supported well?

Health and social care services

Richmond is committed to ensuring that people with dementia have access to high quality services that help maintain their physical and mental health and wellbeing. Most people with dementia will be living with another medical condition or disability as well as dementia – a recent national survey by the Alzheimer's Society found this was the case for 72% of respondents[41]. Local analysis shows around 50% of people with dementia in Richmond have three or more other chronic conditions, including depression, diabetes, heart disease and respiratory conditions[42]. In addition, 45% of people living with dementia in Richmond will be in the moderate to severe stages of the disease[43] where the need for services is higher than the earlier stages.

Richmond provides a wide range of health and social care services to people with dementia. Integration of these services is key to providing a holistic package of care based on need and to enable people with dementia and their carers to navigate the system. Richmond LA, CCG and Health and Wellbeing Board are committed to the integration of services, and Richmond's Health and Wellbeing Strategy 2013-16[44] focussed on this issue. This led to the establishment of the Joint Collaborative Commissioning Team for Health and Social Care in Richmond and the joint commissioning of integrated services such as the Community Independent Living Service and the Carers' Hub service.

Most people with dementia in Richmond will be referred into health and social care services by their GP, based on their individual need. Individuals can also self-refer for social care services via the Adult

[41] Dementia 2014: Opportunity for Change, Alzheimer's Society, September 2014
[42] Richmond HNA http://www.datarich.info/jsna/health-conditions/dementia#
[43] NHS England and NHS South of England, 2012
[44] http://www.richmond.gov.uk/health_and_wellbeing_strategy_april_13.pdf

Access Team[45]. Hounslow and Richmond Community Healthcare has recently appointed two Dementia Clinical Specialists who work across the borough with those with dementia and their carers to help them access the services that they need, reduce unnecessary hospital admissions and assist in care planning. They also work across the statutory and voluntary sectors to improve diagnosis rates, case find and promote a person-centred care approach[46] to dementia, namely:

- Valuing people with dementia and those who care for them
- Treating people as individuals; appreciating that all people have a unique history and personality
- Looking at the world from the perspective of the person and listening to their voice
- Recognising that all human life is grounded in relationships and that people need to live in a social environment, which supports their wellbeing

In Richmond we have worked hard to build a greater understanding of dementia amongst all health and social care staff across the borough. A consolidated programme of dementia awareness training was rolled out in 2014-15, with all staff receiving basic training and specialist providers, for example managers of residential nursing or day centres, receiving enhanced training. Providers also committed to working to NICE dementia quality standards and many individuals have signed up to become Dementia Friends.

Choice

People with dementia in Richmond have access to a comprehensive range of health and social care services that they can access depending on their needs. These services are set out in detail in the comprehensive Dementia Care Guide for frontline practitioners[47], an online resource that is updated every 6 months and enables health and social care staff to offer a choice of services to people with dementia.

Richmond is leading the way on the Self-Directed Support agenda with nearly all users of Adult Services having Personal Budgets. The use of Personal Budgets for care facilitates choice as they allow people to manage their care in a way that suits them.

[45] https://www.richmond.gov.uk/adult_access_team
[46] Commitment to the care of people with dementia in hospital settings - Royal College of Nursing https://www2.rcn.org.uk/__data/assets/pdf_file/0011/480269/004235.pdf
[47] http://www.richmond.gov.uk/dementia_care_guide_for_front_line_practitioners.pdf

Richmond residents have also had the opportunity to participate in research on interventions for dementia, for example the Valuing Active Life in Dementia (VALID) study[48] which is evaluating community occupational therapy for people with dementia and their family carers.

Hospital treatments

We recognise that hospitalisation should be the last resort for a person with dementia, as it can be a deeply distressing experience due to the unfamiliar environment. In addition, people admitted to hospital who also have dementia stay in hospital for longer, are more likely to be readmitted and more likely to die than people without dementia who are admitted for the same reason[49].

However, nationally there has been a 48% rise in emergency admissions for people with dementia since 2008/9[50] and in Richmond, hospital admission rates for people with dementia are higher than those seen in England as a whole[51]. However, our overall emergency hospital admission rate is among the lowest in the country.

In Richmond, we have a number of services in place that aim to keep people with dementia out of hospital where possible. In particular, the Richmond Response and Rehabilitation Team (RRRT) provides an urgent care assessment, observation and support for people whose health needs would otherwise lead to a hospital admission and works to get people with dementia out of hospital as quickly as possible. A pilot project has also recently been funded to reduce hospital admissions of people with dementia from care homes with a nurse liaison officer providing support and training to staff on symptom recognition, practical skills, condition planning and providing a rapid response service to avoid unnecessary transfer to hospital.

All our local hospitals have prioritised work on dementia in recent years. Kingston Hospital launched a Dementia Strategy in 2014[52], and is working towards delivery of its strategic priorities which include positive relationships of care, involved and supported carers, active days and calm nights for all and creating a dementia friendly environment. West Middlesex University Hospital opened a new

[48] https://www.ucl.ac.uk/valid
[49] Care Quality Commission, Care update, Care Quality Commission, March 2013
[50] LBRuT 2015, Dementia and admission to acute general hospitals in an emergency http://www.datarich.info/jsna/newsflash20150813
[51] Richmond HNA http://www.datarich.info/jsna/health-conditions/dementia#
[52] https://www.kingstonhospital.nhs.uk/media/64128/dementia-strategy-2014-17.pdf

dementia friendly ward in 2014 and has developed a comprehensive dementia pathway for patients. Staff at Teddington Memorial Hospital, which provides rehabilitation, palliative and continuing care, have been trained to recognise the signs of dementia and to provide dementia friendly care, and the wards are being refurbished to be dementia friendly.

Liaison

A strong body of research indicates that liaison psychiatry not only improves the quality of care for patients over 65 years of age but can significantly reduce discharges to institutional care and health costs overall[53]. All Richmond residents have access to a psychiatric liaison service at Kingston and West Middlesex hospitals. The service provides specialist dementia advice, liaison and training to all wards and the emergency departments; can make referrals to the memory clinic service; and liaises with GPs and other services during discharge planning.

Behavioural and psychological symptoms of dementia

People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are referred to the Richmond Community Mental Health Team (CMHT) for assessment. The Richmond CMHT comprises psychiatrists, community psychiatric nurses, community support workers, occupational therapists, psychologists, speech and language therapists and dieticians, offering outreach, day centre assessment, intensive home treatment and in patient care if necessary. This multidisciplinary team has a number of programmes in place to help people with dementia that are having difficulty, including the Crisis Resolution and Home Treatment Service and the Community Mental Health Recovery Service.

Advocates

In Richmond, people with dementia, with the involvement of their carers, are able to access independent mental capacity advocate and independent mental health advocate services through Knowledge Advocacy Guidance[54]. The aim of the IMCA service is to provide safeguards for people who lack the capacity to make certain important decisions at the time a decision needs to be made, and who have no appropriate family or friends to consult. A person has a legal right to an IMHA if they are detained under the Mental Health Act 1983 (as amended 2007) or where particular

[53] Richmond CCG 2 Year Operational Plan 2014-2016
[54] http://www.kagadvocacy.org.uk/

neurological treatments are proposed. The role of the IMHA is to represent the person on their care, detention and treatment.

Housing

Nationally, around one third of people with dementia are estimated to live in residential care settings and almost two-thirds in private households in the community[55]. In Richmond, this equates to around 1300 people with dementia living in the community and around 650 people with dementia in care homes. A YouGov poll for the Alzheimer's Society in 2014[56] found that 85% of people would want to stay at home for as long as possible if diagnosed with dementia rather than go into a care or nursing home. Enabling people to live as independently as possible at home is therefore an important aim for our dementia services. In order to support this, people with dementia in Richmond are able to access a range of housing options:

Support at Home

Richmond upon Thames is an area with high home ownership with 76.5% people owning their own homes[57]. Given that the majority of people with dementia live at home, considerable numbers of people with dementia will be being cared for in their own home by a mixture of informal and formal care.

Richmond has recently commissioned a new Help to Live at Home service which will start in July 2016. Help to Live at Home will be a holistic service which will empower people to live independent lives near the people and places that are important to them and will support people to recover their independence after a health or personal crisis. The service will be person-centred, giving the service user a real say in their care and providing the outcomes that are important to them, for example, provision of care at a particular time to suit that individual. This service also aims to reduce unplanned hospital admission, reduce the number of residential or nursing placements and improve the quality, and increase the diversity, of local services.

Other services available to people who wish to remain at home include:

- **Equipment service** which provides a range of specialist equipment to assist people with dementia to live safely at home. This may include the provision of equipment such as grab rails, stair lifts and ramps, and major adaptations such as extensions, and level access showers.

[55] Prime Minister's Challenge 2020
[56] https://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=2065
[57] Extra Care Housing Evidence Base Richmond upon Thames 2015

- **Home maintenance service** which carries out small repairs and minor adaptations, home security measures that prevent burglaries and maintain independent living, facilitating hospital discharge, and fire safety checks, alarm and smoke detector installation.
- **Assistive technology** which can be fitted to monitor activity and call for help in emergency situations. People with dementia are one of the targeted groups for promotion of these types of interventions[58], including telehealth systems, to enable them to continue living at home safely and independently.

Extra Care Housing

Extra Care housing has been shown to meet the needs of and provide a good quality of life for many people with dementia, enabling them to live in a community and retaining their independence for as long as possible. There are two schemes in Richmond upon Thames (Dean Road, Hampton and Sandown Court, Twickenham) providing a total of 67 self-contained one or two-bedroomed flats.

Richmond Council recognises the benefits of Extra Care housing for those living with dementia which is reflected in the Housing Strategy 2013-2017[59]. As the Council had already developed additional units of accommodation, the strategy focus is to make best use of existing supported housing stock if this is feasible. A secondary aim of the strategy is to ensure issues around dementia and housing are considered over the lifetime of the strategy which would be achieved as follows:

- The Council will work with Metropolitan, and South West London and St George's Mental Health Trust Rehabilitation Team to better identify and assess individuals able to move into alternative housing arrangements. Previously, individuals have spent in excess of five years and, in some instances, ten years in supported housing options. The optimum time for many is two years. New clients will be made aware that supported housing is a temporary housing solution to support them in gaining the skills to live independently.
- Housing Services will work with community mental health teams to inform them of the various housing options available for people who move on from supported housing which may include a housing association tenancy or private rented property.
- During the lifetime of the strategy Council staff will work with Registered Providers to ensure they consider the potential for specialist dementia provision and dementia friendly specifications in the development of any new Extra Care schemes.

[58] Better Care Closer to Home Richmond Out of Hospital Strategy 2014-17
[59] Richmond upon Thames Housing Strategy 2013-17

There is an estimated need for at least an additional 81 extra care units in the borough[60] and this will direct activities towards the achievement of further units.

Residential Care

There are 26 care homes in the borough of Richmond, all of which are required to comply with CQC Regulations and meet the needs of people with dementia in a safe and appropriate environment. Whilst there has been a downward trend in admissions since 2007, admissions to Elderly Mentally Ill (EMI) beds (which are often used for people with dementia) have remained fairly constant[48].

The Council and the CCG are aware that the provision of EMI beds in the borough is not meeting demand and are initiating a review of provision, and considering strategic solutions to the issue.

Technology

Richmond provides a range of assistive technology and telecare to people with dementia[61], to enable them to continue living at home safely and independently. People with dementia can have a system of alarms, sensors and other equipment fitted in their home, which monitors activity over time and will raise a call for help in emergency situations such as falls, fire, floor or lack of movement in the home. Help is on hand 24 hours a day, 365 days a year. Reminder equipment is also available, for example for medication.

[60] Extra Care Housing Evidence Base Richmond upon Thames 2015
[61] http://www.richmond.gov.uk/dementia_gadgets

What do we want to achieve in the next five years to enable those with dementia to be supported well?

Health and social care services

1. We will continue to provide a comprehensive health and social care service to people with dementia and their carers
2. We will work towards provision of health and social care services that are timely, flexible and meets the particular needs of the individual
3. We will investigate holding a dementia specific session of the Richmond Health and Social Care Coproduction Group (Richmond's service user and carer engagement group)
4. We will work with GP practices to ensure they know how to access health and social care services for people with dementia under their care
5. We will continue to raise awareness of the dementia care pathway, and the choice of services on offer, with people with dementia and their carers
6. We will continue to raise awareness of the Hounslow and Richmond Community Healthcare dementia clinical advisers
7. We will work towards implementation of the new NICE guidance on "Older people with social care needs and multiple long-term conditions"
8. We will ensure that future training of staff in health and social care services follows the Dementia Core Skills Education and Training Framework[62]
9. We will work with voluntary and community organisations to identify funds available and explore the provision of new services in the borough to support those with dementia and their carers

[62] http://www.skillsforhealth.org.uk/services/item/176-dementia-core-skills-education-and-training-framework

Hospital treatments

10. We will keep working with GPs, community services and local hospitals to ensure people with dementia can access urgent care in the community and avoid unnecessary hospital admissions
11. When people with dementia have been admitted to hospital, we will continue to provide services that get them out of hospital as quickly as possible and back to their familiar environment. We will work with our community and hospital-based liaison services to ensure they are working together effectively to achieve this

Technology

12. We will ensure that Richmond residents have access to assistive technologies and telecare to enable them to remain safely in their own homes

Housing

13. We will work towards ensuring that people with dementia in Richmond have access to housing that meets their specific needs
14. We will monitor the need for dementia beds in our care homes and ensure that any increased need is met
15. We will work towards implementing the 2015 NICE guidance on home care[63]
16. We will work with our local care homes to ensure they are following NICE quality standard 50: Mental wellbeing of older people in care homes (2013)
17. We will roll out the new Open Dementia e-learning programme to all residential care providers from September 2016[64]

[63] https://www.nice.org.uk/guidance/ng21
[64] http://www.scie.org.uk/dementia/open-dementia-e-learning-programme/

DYING WELL

People living with dementia die with dignity in the place of their choosing

What is happening in Richmond to enable those with dementia to die well?

Research suggests that people with neurological conditions, with dementia as the underlying cause, are more likely to die in a care home than at home or in a hospice[65] and Richmond data supports this – in 2013, 47% of people with dementia over 65 years died in a care home, 39% died in hospital and 12% died at home[66].

A survey[67] carried out for Sue Ryder found the top four priorities for people at the end of life were:

- being pain free;
- surrounded by loved ones;
- having dignity and privacy; and
- being in familiar surroundings

Richmond published a three year End of Life Care Strategy in 2010 which focussed on care planning, having difficult conversations early, and improved coordination of end of life care. A training programme was developed and delivered to care home and community providers to improve their skills and confidence in identifying those in the last year of life. GPs were given training to enable them to have difficult conservations around diagnosis and dying. A two year programme was recently commissioned to identify the 1% of patients in their last year of life, and ensure advanced care plans were drawn up to document the wishes of the patient. Work has also been ongoing with the Richmond GP Alliance to facilitate access to patient records out-of-hours.

Deaths in hospital have reduced year on year since the implementation of the End of Life Care Strategy, with the proportion of people dying in their usual place of residence increasing from 33.6%

[65] Sleeman KE, Ho YK, Verne J, Glickman M, Silber E, Gao W, Higginson IJ; GUIDE_Care Project, Place of Death
[66] HSCIC QOF 2014-15 http://www.hscic.gov.uk/article/2021/Website-Search?productid=19196&q=quality+outcome+framework+2014%2f15&sort=Relevance&size=10&page=1&area=both#top
[67] Sue Ryder, A time and a place: what people want at the end of life 2013

in 2010/11 to over 40% in 2014/15. A high proportion of terminal admissions (49%) are for those aged 85 years and above, compared with the England average (38%)[68].

As part of their role, the HRCH dementia clinical specialists have been raising awareness with healthcare providers about dementia-specific issues in relation to end of life care. These include issues with pain recognition and nutrition.

Richmond has extended palliative care beyond cancer, and services are provided by Princess Alice Hospice and Royal Trinity Hospice in the borough. The commissioned services are available to all those registered with a Richmond GP and include both inpatient services and community matrons who provide care in the individual's own home or normal place of residence. Richmond also commissions a bereavement support service[69] for all Richmond residents.

[68] Richmond Clinical Commissioning Group Commissioning Intentions 2016/2017
[69] http://www.cruse.org.uk/richmond

What do we want to achieve in the next five years to enable those with dementia to die well?

1. We will work on the development of a comprehensive older person's care record, similar to the Kingston Care Passport, which will be a live electronic patient record that can be shared and updated by all care agencies and care workers involved in a patient's care
2. We will continue to support those caring for someone with dementia at the end of their life
3. Following the end of life, we will support carers appropriately through a transition period
4. We will raise awareness of our commissioned bereavement support service
5. We will encourage nursing and care homes to achieve Gold Standard Framework accreditation around end of life care to support people to die in a place of their choosing. Research has shown that, following GSF accreditation, care homes have reduced hospital-based deaths by two thirds[70]
6. We will investigate how the principles of 'compassionate communities' can be integrated with our approach to Dementia Friendly Villages
7. We will review the Public Health Approaches to End of Life Care toolkit published by Public Health England and the National Centre for Palliative Care
8. We will work with providers to explore the 'right to stay' for relatives when a person with dementia is nearing the end of their life, either in hospital or in the care home
9. We are committed to refreshing the End of Life Care Strategy in the near future

[70] GSF CentreRound 10-13 2013-14 Accreditation care homes evaluations

CONSIDERATION OF PARTICULAR GROUPS

The Equality Act 2010 makes it unlawful to discriminate against people with a protected characteristic[71]. To examine the potential impact of the Joint Dementia Strategy on those with protected characteristics, we carried out an Equality Impact and Needs Analysis (EINA). The main findings of the EINA indicate that the greatest benefits will be derived by targeting information and services to women with dementia, black and minority ethnic communities, those with learning disabilities, those with young onset dementia and those with a low socio-economic position.

We will work towards advancing equality in all Richmond's dementia services

One issue identified in the EINA was the lack of data on the protected characteristics and dementia both nationally and locally.

We will work with local providers of dementia services to collect information on the protected characteristics of service users

Black, Asian and minority ethnic communities

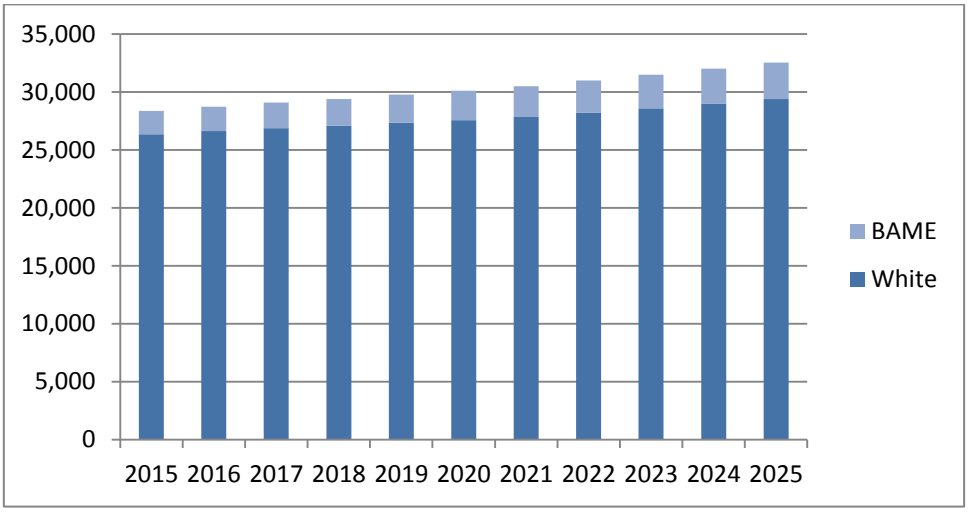
Nationally, there is growing evidence that certain Black, Asian and minority ethnic (BME) communities have a higher prevalence of dementia than white communities. In addition, the BME population is ageing and this will lead to a predicted seven fold increase in dementia cases in England and Wales in these ethnic groups in the next forty years[72]. This is in contrast to a predicted two fold increase in white communities in England and Wales in the same time period.

Like London, Richmond is a multicultural community, with 15% of the population identifying as being from BME groups and this is expected to rise to 17% by 2025. Figure 3 demonstrates the projected increase in the population of over 65s from BME communities – by 2025, 10% of over 65s in Richmond will be from BME communities.

[71] The protected characteristics are gender (sex), age, sexual orientation, marriage and civil partnership, disability, race/ethnicity, pregnancy and maternity, gender reassignment, religion including belief and non-belief

[72] APPG on Dementia – Dementia does not discriminate July 2013

Figure 3: Projected population aged over 65 years by ethnicity in Richmond



Awareness of dementia is lower in BME communities, and ethnicity can be a significant factor in the extent to which dementia is understood or acknowledged, or in people's willingness to seek help. In some languages there is no word for dementia, or the word used has a strong association with mental problems that carry stigma. People with dementia from BME communities are therefore at risk of late diagnosis, and of not accessing services that would help at an earlier stage. Health system issues related to ethnicity, such as reduced access and psychiatric misdiagnosis, will also have a role to play in under-diagnosis within certain ethnic groups.

It has also been observed that people with dementia who do not have English as their first language often lose the ability to speak or understand English as their disease progresses, and instead revert to their mother tongue. This has implications for services and residential settings as individuals will feel isolated and may not have their needs met if they are not able to communicate or be understood.

Caring arrangements may also vary across ethnic groups, and this needs to be taken into consideration when identifying and providing services to those with dementia and their carers. There may be family and community pressure for an individual to continue caring for someone alone, even when the burden of caring is considerable, although some community attitudes are thought to be changing.

Recent research by the local branch of the Alzheimer's Society indicates that many of the issues facing those with dementia in BME communities nationally exist here in Richmond. In order to start to address these issues, and to engage with these communities, the Alzheimer's Society held 21

information and awareness dementia sessions for a variety of BME groups in Richmond during 2014/15, speaking to over 400 individuals. They also signed up more than 65 Dementia Friends through these sessions.

We will continue to raise awareness of dementia and available services in local BME communities, and work towards configuring those services to meet the needs of those from BME communities

Learning disabilities

People with a learning disability are more vulnerable to developing dementia than the general population, and the prevalence of dementia is higher in those with a learning or developmental disability than in those without. People with a learning disability are more likely to develop the condition at a younger age, for example, one in three people with Down's Syndrome will develop dementia in their 50s, and the likelihood increases with age.

It is estimated that 3,621 adults with a learning disability live in Richmond. Learning disability services in Richmond currently serve 12 individuals with a diagnosis of dementia[73]. The local provider of healthcare to those who have a learning disability in Richmond delivers a comprehensive dementia care pathway which provides specialist assessment, support and training from diagnosis to end of life. Once a referral is made, a full assessment is carried out by a range of health specialists in the learning disability health and psychology services. If a diagnosis is confirmed, the individual is assigned a dementia case coordinator to oversee their care, and multidisciplinary reviews are held at least annually, involving the individual, their family and/or carer and the health and social care team. An environmental assessment is completed to assess the suitability of their current placement, make their living environment more dementia friendly and anticipate future support and placement needs. Post-diagnostic support is offered to the individual and their peers/friends/partner, and family members and carers are offered training tailored to the clinical needs of the individual. End of Life Care Planning is also carried out, including consideration of advance statements, capacity and consent issues and links with palliative care services. The local provider also works to raise awareness of dementia in those with learning disabilities in the community, with families and carers, and with other relevant provider organisations.

[73] Personal communication, March 2016

We will ensure that a comprehensive dementia assessment and management service will be provided to those with learning disabilities. We will investigate opportunities to raise awareness of dementia and learning disabilities in Richmond amongst our local GPs, provider organisations and voluntary services

Young-onset dementia

There are estimated to be at least 42,000 people with young-onset dementia (those with onset before age 65) in the UK – 1 in 20 of all those with dementia. In Richmond, it is estimated that there are 117 individuals with young-onset dementia, and this is expected to rise to 145 individuals by 2025[74].

A diagnosis of young onset dementia can be devastating and can have severe emotional and psychological consequences. As this disease has been considered 'rare', there has been a chronic lack of appropriate services for those with young onset dementia, leading to social isolation for this group and their families. Services for dementia need to reflect the needs of those with young onset dementia. Issues around loss of work, fiscal impact and effects on children and families need to be considered. People within this group are usually determined to continue with 'normal life' as long as possible and require a dementia friendly world of work, leisure, commerce and community if this is going to be possible.

In 2013, Richmond CCG identified a gap in the provision of support to those with young-onset dementia, their family and carers, in Richmond. In 2014 a weekly peer support group was commissioned through the Alzheimer's Society, based on the needs of this group, and this has been running successfully since then with over 40 individuals supported. A social meet up for carers and family members is held quarterly and the group is exploring setting up a social space for individuals to meet and self-direct social games. Where individuals would prefer one-to-one support, this has also been offered where possible.

We will ensure that support to those with young-onset dementia, based on their identified needs, is provided in the future

[74] 2014 Alzheimer's Society study

IMPLEMENTATION PLAN

The South West London 5 Year Strategic Plan[75], published in June 2014, sets out a 10 Point Plan that is intended for commissioners of dementia services to use to inform their action plans and future commissioning intentions. The ten points relate to commissioning services for those individuals who have already received a diagnosis of dementia. The principles draw together best practice and the latest guidance to promote the improvement of locally, and regionally, provided services.

1. *Dementia services should be person-centred, needs-focussed and integrated*
2. *The Better Care Fund should be used to jointly commission dementia services.*
3. *The commissioning and provision of dementia services should be 'ageless' taking into account other co-morbidities and enabling independence.*
4. *The commissioning and provision of services to those with dementia should be flexible and responsive, including in times of crisis or where specialist care is required.*
5. *A single point of access to services and a dementia care coordinator is a way of achieving seamless care for people with dementia and provides support for their carers.*
6. *Improvements in dementia care must also improve care in hospital, including for those receiving a diagnosis in hospital.*
7. *The dissemination of existing good working practices in south west London is key to improving dementia services.*
8. *Multidisciplinary case management is a good way to ensure integrated working.*
9. *Commissioners should use local and national examples of best practice to design innovative and improved services that will fit their locality and ensure that communities are dementia-friendly.*
10. *The creation of dementia-friendly communities involves engaging not only with health and social care providers, but also wider community stakeholders.*

[75] http://www.swlccgs.nhs.uk/wp-content/uploads/2014/06/SWL-5-year-strategic-plan.pdf

The objectives from this Joint Strategy will feed into a comprehensive Joint Dementia Strategy Action Plan based around the above principles in the 10 Point Plan. Implementation of the Action Plan will be overseen and delivered by the Richmond Collaborative Commissioning Team. An annual review of progress made against the Joint Dementia Strategy Action Plan will be carried out and published.

APPENDIX 1

Membership of the Dementia Strategy Steering Group

Anna Raleigh (Chair)	**LBRuT, Public Health Consultant**
Luis Agüera	Carer
Pauline C	Carer
Janet Cole	LBRuT, Early Intervention/Prevention Manager
Margaret Dangoor	Carer
Charlotte Flynn	LBRuT, Public Health Specialty Registrar (Lead author of the Joint Strategy)
Aileen Jackson	RCCT, Commissioning Manager (left November 2015)
Dr Stavroula Lees	RCCG, Clinical Lead for Mental Health
Bruno Meekings	RCVS, Community Involvement Coordinator
Caroline O'Neill	RCCG, Engagement
Jackie Phillips	RCCT, Interim Commissioning Manager (joined January 2016)
Kathy Sheldon	Richmond Healthwatch
Hilary Shenken (Minutes)	RCCG

In attendance

Melanie Cressey	RCCT, Partnerships Coordinator
Marianne Devereux	RCCG, Qualities & Engagement
Catherine Stelling	LBRuT, Public Health

Key

LBRuT	London Borough of Richmond upon Thames
RCCG	Richmond Clinical Commissioning Group
RCCT	Richmond Collaborative Commissioning Team
RCVS	Richmond Council for Voluntary Service

APPENDIX 2

LONDON BOROUGH OF RICHMOND UPON THAMES

Dementia Equality Impact and Needs Analysis (EINA) 2015/16

Dementia Equality Impact and Needs Analysis (EINA)

Directorate:	Adult Community Services
Service Area:	Public Health, Health Care and Social Care
Name of service/ function/ policy/ being assessed:	Joint Dementia Strategy
Officers leading on assessment:	Charlotte Flynn
Other staff involved:	Anna Raleigh, Rachel Kidd, Steven Bow, Aileen Jackson (now left the CCG)

SUMMARY OF THE KEY FINDINGS

The Equality Act 2010 makes it unlawful to discriminate against people with a protected characteristic. To examine the potential impact of the Joint Dementia Strategy on those with protected characteristics, we carried out an Equality Impact and Needs Analysis (EINA). The main findings of the EINA indicate that the greatest benefits will be derived by targeting information and services to **women with dementia, black and minority ethnic communities, those with learning disabilities, those with young onset dementia** and **those with a low socio-economic position**.

A short summary of the findings related to the protected characteristics which have implications for the Joint Dementia Strategy is given below:

- Age – dementia prevalence increases with age, with the proportion of people with dementia doubling for every five year age group. As the population ages, the numbers of those with dementia will also increase – in Richmond it is predicted that the number of dementia cases will increase by over 30% by 2025. Services need to be able to continue to provide quality care to all despite this increase.

  In addition, the needs of those with young onset dementia must to be met. 1 in 20 of those with dementia are less than 65 years of age. Nationally, provision of appropriate services for these individuals has historically been poor leading to social isolation for them and their families.

  Age is also key to dementia prevention initiatives. Taking steps to reduce risk in mid-life will reduce the likelihood of developing dementia in later life.

- Disability – dementia is one of the major causes of disability in the elderly, but timely diagnosis can provide early access for individuals and their carers to support and services that can help to manage the condition and maintain and prolong independence as long as possible.

  People with dementia often have multiple long term conditions and can demonstrate challenging behaviour, increasing their disability.

  Having a learning disability increases the likelihood of developing dementia; in particular there is a higher prevalence of Alzheimer's disease in those with Down's syndrome.

- Gender – dementia has become the leading cause of death among women in the UK. Women are also far more likely to become carers of those with dementia than men.

- Gender reassignment – research suggests that memory loss associated with dementia can affect an individual's ability to remember that they have reassigned their gender, and that health and social care staff can misinterpret a person's efforts to reassign their gender as 'confusion'.

- Marriage and civil partnership – it is important that health and social care services are aware of and respectful of the legal equivalence of marriage and civil partnership when dealing with individuals with dementia, their partners and families.

- Race/ethnicity – there is growing evidence that certain black and minority ethnic (BME) communities have a higher prevalence of dementia than white communities. In addition, the BME population is ageing, and this will lead to a predicted seven fold increase in dementia cases in the next forty years. Awareness of dementia in BME communities is low and this needs to be addressed to avoid late diagnosis. There are also a number of actual and perceived barriers to healthcare within BME communities that lead to a lack of engagement with available services. 14% of the population in Richmond is from a BME community.

- Religion and belief including non-belief – care provided should respect the religious and other beliefs of those with dementia. Religious organisations may be able to provide a link between individuals and health and social care services, so should be engaged in the borough's action on dementia.

- Sexual orientation – older lesbian, gay and bisexual (LGB) individuals are more likely to live alone, be single and have no children to call upon in times of need, so may have more social care needs. However, fear of cultural stereotypes and discriminatory attitudes can prevent LGB individuals from accessing the services and care that they need.

- Socio-economic position – populations with a low socio-economic position have increased prevalence of Alzheimer's disease.

Consideration of equality issues with regards to carers was carried out in the EINA for the Richmond Carers Strategy, which is being developed in tandem with the Joint Dementia Strategy.

This EINA has highlighted a number of population groups that require attention, information and specialist services with regards to dementia. The needs of these groups, and the actions that can be taken to improve care, will be included in the development of the Joint Dementia Strategy. Gaps in data that have been identified will be investigated and prioritised, to enable a fuller picture of the protected characteristics of those with dementia in Richmond to be realised.

1. BACKGROUND

The London Borough of Richmond Upon Thames and Richmond CCG are developing a Joint Dementia Strategy which sets out the five year vision for people with dementia and their carers in Richmond. It will look at all aspects of dementia care and services, from prevention to end of life care, to ensure that:

- opportunities to prevent certain forms of dementia are maximised;
- community understanding of dementia is improved;
- the Council and Clinical Commissioning Group (CCG) are prepared for the future needs of people with dementia;
- Richmond becomes a dementia friendly community that enables people with dementia to stay living independently in the community for longer;
- carers of people with dementia are given the support they need;
- people with dementia are able to live well in Richmond.

The Joint Strategy builds on an existing framework of service provision in Richmond, where significant investment in services for people with dementia and their carers has occurred over the last few years. However, it is recognised that there is more to do to make Richmond a positive place to live with a dementia diagnosis, and to plan for the future when the numbers of people with dementia in Richmond will increase. The framework for the Joint Strategy has been taken from the NHS England Dementia Pathway Transformation Framework, which is based on the Organisation for Economic Co-operation and Development's dementia pathway. There are five elements to the Framework:

- Preventing well – the risk of people developing dementia is minimised;
- Diagnosing well – timely diagnosis, integrated care plan and review within the first year;
- Living well – people with dementia can live normally in safe and accepting communities;
- Supporting well – access to safe high quality health and social care for people with dementia and carers;
- Dying well – people living with dementia die with dignity in the place of their choosing.

The intended audience for the Joint Strategy is commissioners of health and social care services, but it will also be of interest to service providers, people with dementia and their carers.

2. WHY THIS EINA NEEDS TO BE UNDERTAKEN

People in all population groups should have access to an appropriate range of services that support people with dementia and their carers, whether they are living at home, living in a care or nursing home or receiving care in a general hospital. Such services should be flexible, ranging from early intervention to specialist home care services, and responsive to the personal needs and preferences of each individual. Services should be accessible to people living alone or with carers, people who pay for their care privately, through personal budgets, or through Local Authority arranged services, and should be tailored to take account of the needs of

specific groups whose needs are different from the majority population.

A successful outcome from the implementation of the Joint Dementia Strategy would be improvements in services for all people with dementia across the whole of Richmond.
The EINA will inform the development of the Joint Dementia Strategy and will be an integral part of the needs analysis at the start of any related dementia and older person's services commissioning process.

3. SCREENING FOR RELEVANCE

The screening for relevance exercise is included at the end of the document (Appendix 1).

4. INFORMATION SOURCES

Information source	***Description and outline of the information source***
https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy	National Dementia Strategy
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168222/dh_094054.pdf	National Dementia Strategy EINA
http://www.dementiaaction.org.uk/nationaldementiadeclaration	National Dementia declaration
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf	Prime Ministers challenge on dementia 2020
http://dementiapathfinders.org/approaching_an_unthinkable_future_lr.pdf	An unthinkable future: understanding the support needs of young onset dementia
https://www.gov.uk/government/publications/dementia-prevalence-in-groups-by-protected-characteristics	Prevalence of dementia in population groups by protected characteristics – a systematic review of the literature – Public Health England
https://www.richmond.gov.uk/jsna	Joint strategic needs analysis (JSNA) for Richmond
http://www.datarich.info/	Data Rich - population forecast for Richmond
http://www.raceequalityfoundation.org.uk/resources/downloads/dementia-black-and-minority-ethnic-communities	BME Communities and Dementia – Race Equality Foundation
http://dementiavoices.org.uk/wp-content/uploads/2015/03/Over-the-Rainbow-LGBTDementia-Report.pdf	Over the Rainbow LGTB Dementia summary report - DEEP

Information source	*Description and outline of the information source*
http://www.scie-socialcareonline.org.uk/the-dementia-challenge-for-lgbt-communities-a-paper-based-on-a-roundtable-discussion-2-december-2014/r/a11G000000A3HSWIA3	The dementia challenge for LGTB communities. National Care forum discussion paper
http://www.healthylives.stonewall.org.uk/includes/documents/cm_docs/SOGIAG/DH_078356%20brief%204.pdf	Older lesbian, gay and bisexual (LGB) people – Department of Health and Stonewall
http://www.alzheimersresearchuk.org/wp-content/uploads/2015/03/Women-and-Dementia-A-Marginalised-Majority1.pdf	Women and dementia 'A Marginalised Majority' – Alzheimer's Research UK
https://www.jrf.org.uk/report/dementia-through-eyes-women	Dementia through the eyes of women
https://www.nice.org.uk/guidance/QS30/documents/supporting-people-to-live-well-with-dementia-qs-equality-analysis-32	Equality analysis – Supporting people to live well with dementia - NICE
http://dementiapartnerships.com/wp-content/uploads/sites/2/PHE-Dementia-Equity-Event-Summary.pdf	Equality and health inequality in dementia – Public Health England
https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1857	Dementia does not discriminate – House of Commons All Party Parliamentary Group on Dementia

5. ANALYSING IMPACT, NEEDS AND EFFECTS

Protected Group	Estimated impact	Findings
Age	**High**	**National information/data** Dementia prevalence increases steadily with age, with the proportion of people with dementia doubling for every five year age group. As the population of the UK ages and lives longer, so the number of people with dementia will rise. Predictions indicate that there will be 1 million people with dementia in the UK by 2025. One of the misapprehensions of both the public and professionals alike has been that dementia is a normal part of the aging process, and simply a consequence of getting old. However, dementia is not an inevitable consequence of the ageing process, and nationally dementia awareness is improving. However, this historic lack of understanding and

		awareness has resulted in fear of those with dementia, which leads to stigma and social isolation. Although dementia is primarily an illness associated with older people, there are also a significant number of people, currently around 15,000 nationally, who develop dementia much earlier in life. This is termed young onset dementia. A diagnosis of young onset dementia can be devastating, and can have severe emotional and psychological consequences. As this disease has been considered 'rare', there has been a chronic lack of appropriate services for those with young onset dementia, leading to social isolation for this group and their families. Services for dementia need to reflect the needs of those with young onset dementia. People within this group are usually determined to continue with 'normal life' as long as possible and require a dementia friendly world of work, leisure, commerce and community if this is going to be possible. Age is also key to dementia prevention initiatives. Taking steps to reduce risk in mid-life will reduce the likelihood of developing dementia in later life. **Richmond information/data** Richmond borough has the highest proportion of people over 75 and living alone in London and this will rise in future. It is estimated that there are 1947 people with dementia in Richmond currently, and that this will rise to 2561 by 2025. Services need to be able to absorb this user increase and continue to provide quality care to all with dementia in Richmond. There are estimated to be 117 people with young onset dementia in Richmond currently, and this is projected to increase to 145 by 2025. Services need to take account of the particular needs of younger people with dementia and their family carers, which might include issues around childcare, employment and peer support.
Disability	**High**	**National information/data** Surveys show that dementia is one of the major causes of disability in the elderly, affecting personal care, everyday cognitive activities, and social behaviour. Timely diagnosis and better quality of care can make a major contribution to the postponement of disability and the prolonging of independence. Services also need to be aware of and responsive to

		the disability that dementia can cause in those who suffer from it. The majority of people with dementia have one or more comorbidities or long term conditions which may be disabling themselves, or may exacerbate the disabling effects of dementia. This complicates the care that people with dementia require. People with a learning disability are more vulnerable to developing dementia than the general population, and the prevalence of dementia is higher in those with a learning or developmental disability than in those without. People with a learning disability also usually develop the condition at a younger age, for example one in three people with Down's syndrome will develop dementia in their 50s. Carers of those with dementia can often have disabilities of their own and, nationally, 84% of carers report health problems 'related to caring'. 94% of carers say that caring has affected their mental health. **Richmond information/data** 21,447 (11%) people in Richmond report that they have some form of disability or health problem that affects their day-to-day activities. 50% of Richmond residents with dementia also have three or more chronic conditions, including depression, diabetes and heart disease. It is estimated that 3,621adults with a learning disability live in Richmond. Learning disability services in Richmond currently serve 13 individuals with a diagnosis of dementia.
Gender (Sex)	**High**	**National information/data** In March 2015, Alzheimer's Research UK reported that dementia has become the leading cause of death among women in the UK, and women are more likely than men to have dementia in their lifetimes. There is also evidence that there is resistance to talking about dementia as a women's issue, and that women's experiences are missing from research. In addition, women are far more likely to end up as carers of those with dementia than men. Women are also more likely to reduce their hours or stop working to care for someone with dementia, and some feel penalised at work for taking on care responsibilities.

		Service provision needs to reflect the needs, skills and attributes of women with dementia, female carers and the female care workforce. **Richmond information/data** Local estimates are that in 2015 there were 621 men and 1,321 women aged over 65 with dementia in the borough. Census 2011 data shows that 59% of the 15,725 people in Richmond who provide unpaid care are female (9,262) and 41% are male (6,463).
Gender reassignment	**Medium**	**National information/data** There is very little national data published. The few published reports discuss the issue of the impact of memory loss on a person's ability to remember that they have reassigned their gender, and the misinterpretation by health and social care staff that a person is 'cross dressing' because they are confused. Person Centred planning has a key role in ensuring needs and wishes are met. **Richmond data** There are no reliable or definitive figures available locally or nationally on the size of the transgender population, but it is estimated that roughly 0.6% to 1% of the population are transgender (which includes those who experience some level of gender discomfort but do not wish to reassign their gender). Between 8 and 20 per 100,000 have gender dysphoria (distress at mismatch between gender identity and biological sex). Based on these figures it is estimated that there are between 1,148 and 1,914 transgender people, and between 16 and 39 people with gender dysphoria, living in Richmond Borough.
Marriage and civil partnership (only in relation to first part of the duty: eliminate discrimination and harassment)	**Low**	There is limited evidence available on the particular health and social care needs of people in terms of marriage and civil partnership. However, it is important that health and social care services are aware of and respectful of the legal equivalence of marriage and civil partnership when dealing with individuals, their partners and families.

Pregnancy and maternity		N/A
Race/ethnicity	**High**	**National information/data:** People from all races and ethnic groups are affected by dementia. However, there has been a lack of data on the prevalence of dementia in different ethnic groups, but studies are beginning to report a higher prevalence of dementia in some black and minority ethnic (BME) groups compared to Caucasians. For example, a study in a small area of London found a larger prevalence in people of black-Caribbean ethnicity, and this remained after controlling for socio-economic position. It is known that some preventable risk factors for dementia, particularly vascular dementia, are more prevalent in BME communities. The BME population in the UK has traditionally had a younger demographic than the majority white population. However, this is changing and a growing proportion of the BME population is now aged over 65. As prevalence of dementia increases with increasing age, it is likely that an increasing number of people from BME communities will develop dementia. Current estimates suggest there are nearly 25,000 people with dementia from BME communities in England and Wales and that this number is expected to grow to nearly 50,000 by 2026 and over 172,000 people by 2051. This is nearly a seven fold increase in 40 years, compared to a two fold increase across the UK population as a whole in the same time period. Awareness of dementia is lower in BME communities, and a Dementia UK report noted that ethnicity can be a significant factor in the extent to which dementia is understood or acknowledged, or in people's willingness to seek help. In some languages there is no word for dementia, or the word used has a strong association with mental problems that carry stigma. People with dementia from BME communities are therefore at risk of late diagnosis, and of not accessing services that would help at an earlier stage. The APPG on Dementia established that there is an 'urgent need' to increase awareness of dementia among BME communities. Health system issues related to ethnicity, for example reduced access, will also have a role to play in under-diagnosis within certain ethnic groups. People may be

		reluctant to use services that are not culturally sensitive, or not available in suitable languages. Professional training should enable an understanding of the differing needs of people from BME backgrounds. Local information campaigns should also be targeted at those communities where there is currently a lower level of awareness of dementia. It has also been observed that people with dementia who do not have English as their first language often lose the ability to speak or understand English as their disease progresses, and instead revert to their mother tongue. This has implications for services and residential settings as individuals will feel isolated and not have their needs met if they are not able to communicate or be understood. Research has also shown that black and minority ethnic people with dementia may be at particular risk of misdiagnosis, and of being labelled as 'mentally ill'. Diagnostic and screening services need to be aware of this issue and ensure discrimination does not occur. Caring arrangements may also vary across ethnic groups, and this needs to be taken into consideration when identifying and providing services to those with dementia and their carers. There may be family and community pressure for an individual to continue caring for someone alone, even when the burden of caring is considerable, although some community attitudes are thought to be changing. **Richmond data:** Like London, Richmond is a multicultural community, with 15% of the population identifying as from Black, Asian and minority ethnic groups (BME) and this is expected to increase to 17% by 2025. Recent research by the local branch of the Alzheimer's Society indicates that many of the issues facing those with dementia in BME communities nationally exist here in Richmond.
Religion and belief including non-belief	**Medium**	**National information/data:** There are no data on whether religion and belief change the prevalence of dementia or affect the course of the disease in any way. However, care provided for people with dementia should respect religious and other beliefs, as religion may play an important part in the lives of

<table>
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<td>people with dementia. For example, care homes should ensure that those who wish to keep religious observance are able to do so.

People may be reluctant to use services that do not meet their religious needs, for example services that only open at certain times that conflict with religious observance.

In addition, religious organisations may be able to provide a link between individuals and health and social care services, for example in reaching carers who do not use any voluntary sector services.

Richmond data: The population of Richmond is predominantly Christian (55%) or without a religion (28.45%). Residents stated their religion in the 2011 Census and the table below indicates the numbers of those who follow each of the major religions in the UK.

<table>
<tr><th>Stated religion (Census 2011)</th><th>Number of Richmond residents</th></tr>
<tr><td>Christian</td><td>103319</td></tr>
<tr><td>Buddhist</td><td>1577</td></tr>
<tr><td>Hindu</td><td>3051</td></tr>
<tr><td>Jewish</td><td>1409</td></tr>
<tr><td>Muslim</td><td>6128</td></tr>
<tr><td>Sikh</td><td>1581</td></tr>
</table>
</td>
</tr>
<tr>
<td>Sexual orientation</td>
<td>Medium</td>
<td>National information/data:
Older people are overwhelmingly perceived to be heterosexual; consequently, older lesbian, gay, bisexual and transgender (LGBT) people have often been invisible in service provision for older people.

Older LGBT people are more likely to live alone, be single and have no children to call upon in times of need, so older LGBT people with dementia may have greater health and social care needs than their heterosexual contemporaries.

There is a lack of formal research on LGBT communities and dementia. However, reports that draw on interviews and discussions with LGBT carers and people with dementia highlight a number of issues. In some settings there has been a lack of recognition of LGBT relationships, and a</td>
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		failure to accept same sex partners, for example exclusion of a partner by a care home. In addition, research shows that LGBT people are often unwilling to declare their sexuality on admission to residential care due to fear of discriminatory attitudes, and this may apply to other health services and settings. LGBT people with dementia may forget their identity, or come out to family and friends despite a lifetime of keeping their identity secret. This can damage relationships at a time when they are needed most. There are also a range of cultural stereotypes and assumptions that are associated with LGBT individuals and communities, and this is a concern to LGBT people when accessing carer and other services. **Richmond data:** A conservative estimate of the number of lesbian, gay, bisexual and transgender people in Richmond is 9500 (5% of total population). Therefore, assuming the incidence of dementia is equal across populations, there will currently be about 100 people with dementia from the LGBT community in Richmond.

Characteristic	Estimated impact	Findings
Socio-economic position	**High**	There is an increased prevalence of Alzheimer's disease in populations with a low socio-economic position. Socio-economic position is a predictor for dementia rates, and is routinely controlled for in statistical analyses. In addition, rural living, especially in early life, is associated with increased risk of dementia. However, the mechanism for this is not clear.
Carers	**High**	There are around 540,000 carers of people with dementia in England. It is estimated that one in three people will care for a person with dementia in their lifetime. Locally, 8.5% of all residents are carers and with the ageing population this is likely to increase. The carer population is also ageing.

		Carers are more likely to be women, and are more likely to report health problems compared to those not providing care. Consideration of equality issues with regards to carers will be carried out in the Richmond Carers Strategy EINA, which is being developed in tandem with this document.

6. DATA GAPS

Gaps in data	***Action to deal with this***
There appears to be a local gap in data regarding the protected characteristics of people with dementia. Clarity is needed about what data Richmond commissioned dementia services collect on service users and whether it includes information on protected characteristics.	All specific dementia commissioned services are required to collate this information. More work is needed to identify whether this information is being collated or not. All Richmond CCG and LA older age services should record dementia specific data alongside the protected characteristics information. This action will be included in the Joint Dementia Strategy action plan.
Specific research is needed to understand the prevalence of dementia in those from BME communities and the reasons behind this in the UK.	This is a national issue.
There is a lack of formal research on LGB communities and dementia	This is a national issue.
There are no reliable or definitive figures available locally or nationally on the size of the transgender population	This is a national issue.
There is a lack of awareness amongst BME communities about dementia both locally and nationally	Awareness raising about dementia amongst BME communities to be included in the Joint Dementia Strategy action plan.
Clarity is needed about what information local learning disability services hold on those with dementia	More work needed by Dementia Strategy project group and Learning Disabilities commissioners.
There is a possible lack of data from service users, stakeholders and customers on dementia services in Richmond and their impact on the protected characteristics	More work needed by Dementia Strategy project group – existing engagement information to be interrogated.
Clarity is needed about what information available from local services on those with young onset dementia	More work needed by Dementia Strategy project group
We need to identify ways to advance equality in all Richmond dementia	To be included in the Joint Dementia Strategy

services once we have a fuller picture	

7. CONSULTATION

Colleagues from the CCG and Council (Public Health) have provided a range of information and advice about dementia and protected characteristics which have been used to shape the EINA. An early draft of the EINA was taken to the Richmond CCG Community Involvement Group (CIG) in November 2015, which includes a wide range of statutory and voluntary organisations, and who gave very useful feedback and additional references to be considered.

A final draft of the EINA was considered by the Dementia Strategy Steering Group in January 2016, and a number of additional points were added as a result of their discussions.

The EINA is also scheduled to be reviewed by the:

- CCG Quality and Safety Committee
- ACS Directorate Equalities Board

The EINA will continue to be a working document and will evolve with the development of the Strategy over the coming months.

8. ACTION PLANNING

Issue identified	Planned action	Lead officer	Completion Date
There appears to be a local gap in data regarding the protected characteristics of people with dementia. Clarity is needed about what data Richmond commissioned dementia services collect on service users and whether it includes information on protected characteristics.	Identify what information Richmond commissioned dementia services are collecting on the protected characteristics.	JCC/PH	March 2016
	Include an action in the Joint Dementia Strategy action plan for all Richmond CCG and LA older age services to record dementia specific data alongside the protected characteristics information.	JCC/PH	June 2016
There is a lack of awareness amongst BME communities about dementia and available	Include an action in the Joint Dementia Strategy action plan to continue awareness	JCC/PH	June 2016

services both locally and nationally.	raising about dementia and available services amongst BME communities in Richmond.		
Services may not be configured for BME community users	Include an action in the Joint Dementia Strategy action plan on configuring services for BME community users.	JCC/PH	June 2016
Clarity is needed about what information local learning disability services hold on those with dementia	Identify what information local learning disabilities services hold on those with dementia.	JCC/PH	March 2016
There is a possible lack of data from service users, stakeholders and customers on dementia services in Richmond and their impact on the protected characteristics	Interrogate existing engagement information for service user and stakeholder feedback.	JCC/PH	March 2016
Clarity is needed about what information is available from local services on those with young onset dementia	Liaise with Alzheimer's Society and GP lead.	JCC/PH	March 2016
We need to identify ways to advance equality in all Richmond dementia services once we have a fuller picture	Include equality actions in the Joint Dementia Strategy and its action plan.	JCC/PH	June 2016

9. MONITORING AND REVIEW

The completion of the actions in this EINA will be monitored through RP3 updates in alignment with ACS EINA protocol. All actions will be incorporated into the development of the strategy and into the Joint Dementia Strategy action plan.

10. PUBLICATION

Approved by	Departmental Equalities Board
Date of approval	16.03.16
Date of publication	

Appendix 1 – Screening for relevance exercise

Public Sector Equality Duty 2011: Initial Screening for Equality Relevance and Impact

Name of Directorate Contact	**Adult and Community Services**		
	Charlotte Flynn **Anna Raleigh**	**Telephone** **E-mail**	**020 8891 7253** **charlotte.flynn@richmond.gov.uk** **anna.raleigh@richmond.gov.uk**

Service/ Function	**Are the areas listed below relevant to your service/ function? Please answer H, M or L for 'High' Medium or Low' or state if there is NO information.**											
	Age	Sex	Race	Disab'	Re&B	GeR	P&M	M&CP	SO	Eliminating discrimination, harassment or victimisation	Advancing equality of opportunity between different groups	Fostering good relations
Joint Dementia Strategy	H	H	H	H	M	M	L	L	M	M	H	M

Legend			
Age	**Age**	**Sex**	**Sex**
Race	**Race**	**Disab'**	**Disability**
Re&B	**Religion and Belief**	**SO**	**Sexual orientation**
GeR	**Gender re-assignment**	**P&M**	**Pregnancy and maternity**
M&CP	**Marriage and civil partnership**		