

**Joint Dementia Strategy 2016-2021  
Consultation and Engagement Report**

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# Introduction

This report presents an overview of the method and findings of engagement and consultation undertaken during the development of the Joint Dementia Strategy 2016-21.

If you have any further comments or questions about the Joint Dementia Strategy, please contact [publichealth@richmond.gov.uk](mailto:publichealth@richmond.gov.uk)

## 

## About the strategy

The Joint Dementia Strategy 2016-21 is owned by the London Borough of Richmond upon Thames and the Richmond Clinical Commissioning Group (CCG), and sets out their five year vision for people with dementia and their carers in the London Borough of Richmond upon Thames. It looks 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 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 captures the existing framework of services provision in one place to demonstrate the choice and range of services available to those with dementia and their carers and brings together relevant elements of different strategies to show how it will develop over the next five years. This consolidation will highlight where there is more to do to enable those with dementia in Richmond to live well and be supported appropriately.

The framework of the Joint Strategy is modelled on the NHS England Dementia Pathway Transformation Framework, and focuses on the five main areas of;

* 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.

These five areas, with the addition of a chapter on particular groups, make up the chapters of the Joint Strategy. At the end of each chapter are a number of joint objectives that the Council and CCG want to achieve over the next five years for dementia services.

## Strategy development

A Dementia Strategy Steering Group was formed to oversee development of the Joint Strategy, and included members from the CCG, Council, voluntary sector, Healthwatch and unpaid carers for people with dementia. A comprehensive review of recent national guidance on good practice was completed, and mapping of existing service provision undertaken. Given that services for those with dementia are commissioned across a number of health and social care service areas, Council and CCG strategies with relevance to dementia were also reviewed and cross-referenced. A number of engagement meetings and events were held to discuss the chapters and the objectives for the next five years (see section on Engagement for more details).

An Equalities Impact and Needs Assessment (EINA) was undertaken to assess the impact of dementia on groups with protected characteristics.

# Engagement

The Joint Strategy was drafted with input from across the Council and CCG. The Dementia Strategy Steering Group met on a monthly basis to review the proposed content of the Joint Strategy, discuss the chapters and the objectives for the next five years. A number of engagement activities were undertaken to gather views from other external stakeholders, such as the voluntary sector, dementia service providers and carers, prior to formal consultation. Partnerships and engagement included:

* CCG GP leads for dementia and learning disabilities;
* Council and CCG commissioners for learning disabilities, adult services, end of life care, older people, mental health;
* CCG Older People’s Mental Health Steering Group;
* Members of the Council’s Housing Team;
* Members of the Council’s Arts and Culture team;
* Your Healthcare;
* South West London St George’s Mental Health Trust;
* Richmond Council of Voluntary Services;
* Embracing Age;
* Alzheimer’s Society;
* Richmond Dementia Action Alliance.

The draft EINA was considered by the CCG’s Community Involvement Group, who provided a number of useful references and clarifications. The Dementia Strategy Steering Group also reviewed the draft EINA prior to its approval by CCG and Council bodies.

# Consultation

The formal consultation on the draft Joint Strategy was hosted on the Council’s consultation webpages for six weeks, from Monday 11th April – Friday 20th May 2016. The format and content of the consultation questionnaire was drafted in partnership with the Council’s Community Engagement Team. The questionnaire aimed to capture views on the draft Joint Dementia Strategy within the following areas:

* How far stakeholders agreed with the purpose of the Joint Strategy;
* How far stakeholders agreed with the direction of travel outlined in the five main chapters (preventing well, diagnosing well, living well, supporting well, dying well)
* Whether stakeholders were aware of any other dementia services that were not mentioned in the five main chapters of the Joint Strategy;
* Which objectives stakeholders would prioritise as their ‘top three’ for each of the five main chapters;
* Whether the Joint Strategy had captured all relevant issues facing particular groups; and
* Any other comments.

### Consultation distribution and promotion

Information about the consultation was distributed widely as follows:

* Circulation through council and CCG mailing lists, including voluntary sector organisations, Patient Participation Groups, membership of the Community Involvement Group, membership of the Older People’s Mental Health Steering Group, Learning Disabilities Partnership Board, and the Dementia Action Alliance;
* Circulation through the Hounslow and Richmond Community Health Care mailing lists and social media;
* Circulation to local care home providers;
* Circulation through GP, CCG, and council staff newsletters;
* Inclusion in the RCVS Voluntary sectors news bulletin;
* Inclusion in the Healthwatch news bulletin.

The consultation was promoted through a joint Council and CCG press release and on their social media accounts.

### Consultation engagement events

Members of the Dementia Strategy Steering Group held discussions on the Joint Dementia Strategy with local stakeholders, service users and volunteers at the following meetings or venues:

* Ethnic Minorities Advocacy Group Older People’s Group
* Health and Social Care Co-production Group
* Richmond Carer’s Centre
* Richmond Dementia Action Alliance

# Results

### Number of responses

Twenty two consultation responses were received online or as paper-copy questionnaires as part of the formal consultation. One written response was received by email, and a number of comments were gathered through attendance at stakeholder groups or meetings. The majority of respondents specified that they were completing the survey on behalf of an organisation or as a local resident. For more detailed demographics of respondents see [Appendix 1](#_Appendix_1_–Demographic).

|  |  |
| --- | --- |
| Response | Number |
| As an organisation | 10 |
| As a local resident | 9 |
| As a carer, or former carer, of someone with dementia | 4 |
| As a user of dementia services | 0 |
| Other | 2 |
| Not answered | 1 |
| *In what capacity are you completing this survey? (tick all that apply)* | |

### 

### Purpose of the Joint Strategy

Respondents were asked whether the draft Joint Strategy achieved the following purpose:

* 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.

21 respondents gave an answer to whether they agreed or disagreed with this purpose, of which 15 strongly agreed and 6 agreed. There were some additional comments on the purpose; these are summarised in [Appendix 3](#_Appendix_3_-).

### What we are trying to achieve

Respondents were asked whether they agreed or disagreed with what the Council and CCG are trying to achieve over the next five years in each of the five main Strategy chapters; preventing well, diagnosing well, living well, supporting well, and dying well. Almost all respondents either strongly agreed or agreed with what we are trying to achieve over the next five years in each area.

There were a number of comments for each section and these are summarised in [Appendix 3](#_Appendix_3_-).

### Additional services

The majority of respondents said that they were not aware of any additional services that were not mentioned in the draft Joint Strategy. Thirteen respondents identified additional services and where these services are relevant to the Joint Strategy, they will be included in the final strategy document.

### 

### Prioritisation of objectives

The five main chapters included a number of objectives that the Council and CCG aim to achieve in the next five years to improve services for those with dementia and their carers. Respondents were asked to prioritise their top three objectives for each chapter. Members of the Dementia Action Alliance were also asked to prioritise their top three objectives during a session of their 2016 AGM in April.

A summary of the prioritisation of objectives is included in [Appendix 2](#_Appendix_2-_Prioritisation) – this is an amalgamation of the prioritisation of consultation respondents and members of the Dementia Action Alliance. This prioritisation will be used to inform the action plan for the final Joint Strategy.

### Consideration of particular groups

The final chapter of the draft Joint Strategy considered the particular issues of three groups identified as high priority through the EINA; those from black and ethnic minority (BME) groups, those with learning disabilities, and those with young onset dementia. The majority of respondents either felt that the Joint Strategy captured the key issues relating to these groups or did not know.

Six respondents felt that there were other particular groups that should be considered as part of the Joint Strategy – their comments are summarised in [Appendix 3](#_Appendix_3_-).

### Further comments

Respondents were asked to leave any other comments relating to the draft Joint Strategy. Twelve respondents commented – these are summarised in [Appendix 3](#_Appendix_3_-).

### Engagement events

Members of the Dementia Strategy Steering Group held discussions on the Joint Dementia Strategy at a number of local meetings. Key findings are summarised in [Appendix 3](#_Appendix_3_-).

# Action taken

Comments collected through the consultation questionnaire and feedback from individuals and groups outlined in this report have been used to inform the development of the final Joint Dementia Strategy.

Some respondents felt that the strategy was too long meaning it was not a very public-friendly document, and that there were too many objectives. Whilst it is agreed that the Joint Dementia Strategy is quite long, value was seen in bringing together all priorities and actions around dementia in one place as the relevant services are currently delivered across a number of teams and organisations. However, action will be taken to streamline the number of objectives – more strategic objectives will remain part of the Strategy whilst underlying actions will be incorporated into the subsequent action plan. It was also agreed that an overall Executive Summary would be published that highlight the strategic direction.

Some changes were made to the Joint Strategy as a result of new research, guidance or policy that was published during consultation. In addition, some information was clarified following additional engagement with commissioners and service providers. The following broad changes were made as a result of consultation responses:

* We clarified that GPs are able to make a diagnosis themselves where appropriate, without referral to the memory clinic, in cases of advanced dementia;
* Inpatient diagnosis in hospitals was identified as a gap in services during consultation, information has been added to the strategy and a new objective included to investigate this issue;
* The London Strategic Clinical Network published new guidance on post diagnostic support planning and care during the consultation period, so the Strategy has been updated to reflect this guidance and the forthcoming metrics for CCGs in this area, including a new objective;
* Clarification on the access to neurologists for those with rarer forms of dementia was included;
* Clarification of the wording around the reach of Richmond’s carer services was included;
* Addition of a new strategic objective about supporting those with dementia to remain at home where it is safe for them to do so and the best place for them to be;
* A new objective was included to encourage our local care and nursing homes to ensure quality of life at the end of life, and to share good practice in end of life dementia care.

# Appendix 1 – Respondent demographics

**In what capacity are you completing this survey?**

|  |  |
| --- | --- |
| Response | Number |
| As an organisation | 10 |
| As a local resident | 9 |
| As a carer, or former carer, of someone with dementia | 4 |
| As a user of dementia services | 0 |
| Other | 2 |
| Not answered | 1 |
| *Tick all that apply* | |

Organisations included health care services, statutory and voluntary sector organisations and the church.

**Gender**

|  |  |
| --- | --- |
| Response | Number |
| Male | 3 |
| Female | 16 |
| Other | 0 |
| Not answered | 3 |

**Age**

|  |  |
| --- | --- |
| Response | Number |
| Under 18 | 0 |
| 18-24 | 1 |
| 25-34 | 2 |
| 35-44 | 1 |
| 45-54 | 5 |
| 55-64 | 6 |
| 65-74 | 1 |
| 75+ | 3 |
| Not answered | 3 |

**Do you consider yourself to have a disability?**

|  |  |
| --- | --- |
| Response | Number |
| Yes | 1 |
| No | 17 |
| Not answered | 4 |

**Ethnic group**

|  |  |
| --- | --- |
| Response | Number |
| White | 17 |
| Mixed/ multiple ethnic group | 0 |
| Asian or Asian British | 1 |
| Black/African/Caribbean/Black British | 1 |
| Other | 0 |
| No answered | 3 |

# Appendix 2- Prioritisation of objectives

|  |  |
| --- | --- |
| **Objective** | **Number** |
| **PREVENTING WELL** |  |
| We will ensure that the objectives in the Framework for Prevention are implemented and monitored, and that prevention is embedded in all our services | 16 |
| We will improve awareness of “What’s good for your heart is good for your head” through all our public health prevention services | 13 |
| 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 | 14 |
| 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 | 20 |
| 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” | 16 |
| **DIAGNOSING WELL** |  |
| We will keep up the momentum in improving diagnosis rates and strive to achieve and maintain the national ambition of two thirds diagnosed | 5 |
| We will ensure that all GP practices are correctly coding dementia diagnoses through use of the dementia toolkit | 6 |
| 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 | 3 |
| 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 | 4 |
| We will work with our memory clinic services to improve the efficiency of diagnosis | 5 |
| 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 | 3 |
| 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 | 6 |
| 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 | 7 |
| We will work with our local care homes to implement the Dementia Assessment Referral Tool (DeAR-GP) to identify dementia in care home residents | 8 |
| 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 | 7 |
| 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 | 5 |
| We will work with our memory clinic services to ensure that the patient’s GP is copied into the patient’s information letter | 0 |
| 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 | 2 |
| 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 | 4 |
| 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 | 7 |
| We will commit to the proposed National Declaration on post-diagnostic dementia care and support | 5 |
| We will work with GP practices to ensure that all those diagnosed with dementia are invited to an annual review to discuss their care | 7 |
| **LIVING WELL** |  |
| 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 | 13 |
| 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 | 11 |
| We will consider ways to improve access to longer term respite care | 3 |
| We will explore ways to improve access to respite care at short notice | 7 |
| We will work to raise awareness of the range of services available to carers of people with dementia in the borough | 8 |
| We will support the implementation of the refresh of the Richmond Carers’ Strategy | 8 |
| 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 | 11 |
| 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 | 8 |
| Where needed and where possible, we will work with voluntary and community organisations to provide transportation to and from these activities | 7 |
| 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 | 13 |
| We will continue to increase the number of Dementia Friends and Dementia Champions across the borough, particularly within our Dementia Friendly Village areas | 2 |
| 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 | 2 |
| **SUPPORTING WELL** |  |
| We will continue to provide a comprehensive health and social care service to people with dementia and their carers | 13 |
| We will work towards provision of health and social care services that are timely, flexible and meets the particular needs of the individual | 16 |
| 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) | 2 |
| 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 | 14 |
| 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 | 5 |
| We will continue to raise awareness of the Hounslow and Richmond Community Healthcare dementia clinical advisers | 0 |
| We will work towards implementation of the new NICE guidance on “Older people with social care needs and multiple long-term conditions” | 1 |
| We will ensure that future training of staff in health and social care services follows the Dementia Core Skills Education and Training Framework | 6 |
| 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 | 9 |
| 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 | 9 |
| 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 | 2 |
| We will ensure that Richmond residents have access to assistive technologies and telecare to enable them to remain safely in their own homes | 6 |
| We will work towards ensuring that people with dementia in Richmond have access to housing that meets their specific needs | 3 |
| We will monitor the need for dementia beds in our care homes and ensure that any increased need is met | 2 |
| We will work towards implementing the 2015 NICE guidance on home care | 1 |
| 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) | 2 |
| We will roll out the new Open Dementia e-learning programme to all residential care providers from September 2016 | 1 |
| **DYING WELL** |  |
| 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 | 17 |
| We will continue to support those caring for someone with dementia at the end of their life | 14 |
| Following the end of life, we will support carers appropriately through a transition period | 11 |
| We will raise awareness of our commissioned bereavement support service | 3 |
| 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 | 17 |
| We will investigate how the principles of ‘compassionate communities’ can be integrated with our approach to Dementia Friendly Villages | 5 |
| 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 | 2 |
| 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 | 13 |
| We are committed to refreshing the End of Life Care Strategy in the near future | 2 |

# Appendix 3 - Summary of detailed feedback from the consultation

| **Source/ Section** | **Summarised comment (that required a response)** | **Response / action** |
| --- | --- | --- |
| Purpose | Some respondents were concerned about the difficulty of delivering the strategy in a time of reduced budgets and austerity. It was felt there was a lack of detail about costings and a request to ensure services are adequately funded. | Despite these times of austerity, Richmond is committed to providing sustainable services for those with dementia across the health and social care spectrum.  Providing details of costings is difficult as those with dementia utilise services across a variety of service and budget areas, as this Strategy demonstrates. |
| Purpose | A comment emphasised the importance of training and education in the workforce for changing attitudes and supporting a holistic approach, as tackling the stigma and making dementia more universally understood can result in huge changes in attitudes and promoting ‘living well’. | We have invested in training and education of the health and social care workforce in Richmond and will continue to do so, as outlined in the strategy. In Richmond we are working hard to promote an inclusive community for those with Dementia, as outlined in the ‘Living Well’ section. |
| Purpose | Although the strategy recognises the need to support people who have no carers, one comment suggested the approach to achieving this is not adequately covered | The strategy highlights the role of CILS for those who live alone; a service which helps them to make a positive contribution to their local community and reduces social isolation. Those who live alone can access dementia services through the dementia navigator at the memory clinic and through the GP who will see the person with dementia on at least an annual basis. |
| Prevent well- additional services | CILS signposting and the encouragement of healthy living as services to ‘prevent well’ were missing. | CILS is covered in the living well section but we recognise the contribution of the service in preventing dementia in so far that it promotes social connectivity. |
| Prevent well- additional services | When asked if there were any other services to prevent well, one comment mentioned adequate home care and support services that can help with issues like gaining power of attorney. Also important is the impact of local social networks which needs higher prioritisation / recognition. | These issues are covered in the ‘Living well’ and ‘Supporting well’ chapters. |
| Prevent well- what we are trying to achieve | Concern was raised about the difficulty of seeing the same GP for people with dementia, and whether GPs are committed to the strategy. | There has been significant engagement with lead GPs in the CCG Governing Body in the development of the strategy. The increased diagnosis rate reflects GP awareness and engagement but we acknowledge more can be done and outline objectives for this in the strategy. We will be highlighting the strategy to GPs when it is published. |
| Prevent well- what we are trying to achieve | A respondent supported the inclusion of national initiatives for dementia prevention. However, they felt recent reports indicate that NHS Health Checks are not resource effective. | We are aware of current research regarding NHS Health Checks. In Richmond we will target health check invitations to those most at risk and hard to reach groups in order to maximise effectiveness. |
| Prevent well- what we are trying to achieve | One comment agreed with the need for self-care and health promotion and would like to know more about the ‘recovery based approach’ in relation to dementia care. | Richmond is currently working to implement Outcomes Based Commissioning which focusses on commissioning services that maximise outcomes for patients. Dementia commissioning is part of the ‘frail elderly’ pathway. |
| Preventing well- what we are trying to achieve | One person felt that too much emphasis is placed on prevention and that there is little proven impact of this. | The strategy considers the whole dementia pathway, from pre-dementia to end of life, and all stages are equally considered. In terms of the impact of prevention, recent research has shown that a large proportion of dementia is vascular and therefore the evidence for the prevention of dementia is strong. |
| Diagnosing well- additional services | When asked about additional services to help ‘diagnose well’, one person felt the voluntary group field workers feedback is not formalised and that the field workers see dementia developing before the GP or healthcare professionals. | We recognise the valuable engagement that voluntary sector field workers have with our older population in Richmond. It is vital that all workers encourage their clients to access their GP as soon as possible, if dementia is suspected. |
| Diagnosing well- additional services | Teddington Memorial hospital and diagnosis in acute hospitals is not mentioned as services to ‘diagnose well’ | Diagnosis in secondary care has been added to the strategy. |
| Diagnosing well- additional services | In relation to diagnosing, one person felt that there is nothing in the strategy about addressing the fear of dementia and reluctance to be diagnosed. | This is a key objective of initiatives such as Dementia Friendly Villages and the Dementia Action Alliance, which aim to address the stigma about dementia and promote understanding. This is included in the Living Well chapter. |
| Diagnosing well- additional services | There is no mention of the role of neurologists for diagnosing early onset and rare forms of dementia. One person felt their role is particularly valuable. | This has been added to the strategy. |
| Diagnosing well- what we are trying to achieve | It was felt that setting some objectives and monitoring them clearly would be helpful, as not all strategies are always achieved. | The strategy aims to set a direction for dementia services in Richmond, as well setting out all existing services in one place. An action plan will follow the publication of the final strategy and be implementation of the plan will be overseen by the Older People’s Mental Health Steering Group. |
| Diagnosing well- what we are trying to achieve | One person felt that the strategy ignored the role of the voluntary sector and the role they play in informing people what to do if they are worried about dementia, signposting, supporting and destigmatizing the disease. | We recognise the valuable engagement that voluntary sector field workers have with our older population in Richmond. It is vital that all workers encourage their clients to access their GP as soon as possible, if dementia is suspected. |
| Diagnosing well- what we are trying to achieve | One comment said that the information about the link between learning disabilities and dementia is incorrect as the significant increase in risk only relates to those with Down Syndrome. | According to the Alzheimer’s Society there is an increased risk for all those with learning disabilities - about 1 in 5 people with a learning disability who are over the age of 65 will develop dementia compared to about 1 in 14 in the general population. Those with Down’s syndrome are more likely to develop dementia at a younger age – a third of people with Down’s syndrome develop dementia in their 50s. |
| Diagnosing well- what we are trying to achieve | Some pathways need improving, such as ensuring diagnosis in acute hospitals is followed up by primary care, and that information about diagnosis and care plans can be more freely shared.  It should be noted that delays in the pathways can result in disengagement as patient readiness for a diagnosis can be an issue. Another comment felt that more should be done to address reluctance. | We have added an objective to the strategy to address diagnosis in secondary care. In addition, there is currently a requirement for hospitals to take action towards becoming ‘dementia friendly’.  Nationally, there is new guidance about post-diagnostic care and support plans for those with dementia, and we will be implementing this in Richmond.  We are working hard to increase dementia awareness in Richmond, including promotion of Dementia Friendly Village and the Richmond Dementia Action Alliance to help destigmatise the disease and help those with dementia to live well. |
| Living well- additional services | When asked about additional services for ‘living well’ one person mentioned that the Dementia Advisor services embedded in the memory clinic and the Dementia Support service which offers one-to-one support are not mentioned. | The role of dementia advisor at the memory clinic, and the valuable work that they do to help those who are newly diagnosed navigate dementia services on an ongoing basis, is outlined in the ‘Diagnosing well’ section. |
| Living well- what we are trying to achieve | A need for a commitment to longer-term respite care was mentioned, and it was felt that improving access was meaningless without this | Longer term respite care is available in Richmond via personal budgets or for self-funders. |
| Living well- what we are trying to achieve | It was felt that people needed more than just peer support networks, such as one to one support for people living with dementia and their carers to learn how to live with the disease independently | There are a number of services for those with dementia and their carers in Richmond to help them live independently as long as it is safe to do so. These services can be accessed via the GP or the dementia advisor at the memory clinic. |
| Living well- what we are trying to achieve | Training offers huge potential to develop up to date and positive practice. A different, positive approach to dementia care is needed, recognising the strengths, assets, interests of the individual and carer. There is a huge range of support in the community and it is important to maximise/ facilitate uptake. | Richmond is currently working to implement Outcomes Based Commissioning which focusses on commissioning services that maximise outcomes for patients. Dementia commissioning is part of the ‘frail elderly’ pathway. |
| Living well- what we are trying to achieve | One respondent felt that a simple document that helps people understand a typical pathway/ journey would be useful. | There is no typical pathway through dementia services as it depends very much on individual circumstances. Dementia Advisors, however, provide personalised navigation, as outline in the ‘Diagnosing Well’ section. |
| Living well- what we are trying to achieve | The strategy mentions dementia friendly activities, such as arts and heritage; one person noted that transport must be included. | We recognise that transport is very important to the successful delivery of dementia friendly activities; where needed and where possible, we will work with voluntary and community organisations to provide transportation to and from these activities |
| Supporting well- additional services | One person felt that the statement on page 34 about the number of beds not meeting demand is an issue to be addressed. | This has been addressed in the objectives of the supporting well section. |
| Supporting well- additional services | In supporting well, it was felt that services to assist people in managing money are important and are not sufficiently recognised in the strategy. | Richmond provide services to help carers and service-users manage financial decisions and this is included in the Living Well chapter. |
| Supporting well- additional services | The support offered by the Integrated Neurological Service (INS) is not mentioned; one person described this support as ‘life changing’. | The INS deliver valuable services to those with neurological conditions and their carers in Richmond; however they do not provide services to those with dementia, unless an individual develops dementia as a result of their neurological condition. It was therefore felt that their work does not fall within the scope of the Strategy |
| Supporting well- what we are trying to achieve | One respondent felt that there is a need to look at the needs of service users with dual diagnosis, such as learning disabilities and dementia. | Richmond has a comprehensive service for those with learning disabilities who develop dementia and this is covered in the ‘consideration of particular groups’ section. |
| Supporting well- what we are trying to achieve | One response felt that more efficient integration of care should be a key focus of the strategy, such as community health care professionals contributing to care planning meetings. | Nationally, there is new guidance about post-diagnostic care and support plans for those with dementia, and we will be implementing this in Richmond. |
| Supporting well- what we are trying to achieve | A respondent felt that the statement about having ‘housing to meet specific needs’ does not adequately reflect to the need to support people to stay in their own homes. One person was concerned that there should be emphasis on support to live at home when other family members may disagree and prefer residential care. | We have a new objective to the strategy to reflect our commitment to supporting Richmond residents to remain at home where it is safe for them to do so and the best place for them to be. |
| Supporting well- what we are trying to achieve  Key issues for people with early onset dementia | A respondent felt that there is a need for more services tailored towards the needs for young people who develop dementia. They often consider local services inappropriate to their needs and become isolated. E.g. having driving licence revoked but not eligible for dial-a-ride on age. | We recognise this need, however there is difficulty in providing services for a small number of individuals within one borough. We will be investigating the possibility of provision of services across a number of boroughs. |
| Dying well- additional services | The Princess Alice Hospice was highlighted as an additional service is supporting people to ‘die well’. | The role of hospices in the provision of palliative care are included in the Strategy. |
| Dying well- additional services | Community matrons and district nurses were highlighted as an additional service is supporting people to ‘die well’. | We recognise the pivotal role they play in enabling dementia patients to die in their place of choice |
| Dying well- additional services | Regarding the questionnaire format, it was felt that the request to prioritise initiatives does not make clear whether objectives that are not chosen will be deprioritised. | The purpose of the prioritisation was to help us better understand the views of residents and stakeholders, rather than to look to remove any objectives from the strategy. Those with a higher prioritisation may be actioned first, dependant on available resources. |
| Key issues for BME groups | The following actions were recommended for supporting people with Dementia from BME groups:   * Train relevant staff in cultural sensitivities and requirements, and ensure dementia services are culturally sensitive * Match health professionals for certain ethnic groups – e.g. speak the language * Develop a dementia awareness programme to reach BME communities. E.g. partner with places of worship to reduce the stigma   It was felt that raising awareness was a key priority. | We will be investigating configuring dementia services for service-users from BME communities in Richmond and will take these recommendations into account. |
| Key issues for people with learning disabilities | Accommodation is a major factor for people with learning disabilities and dementia. | Richmond has a comprehensive service for those with learning disabilities who develop dementia and this is covered in the ‘consideration of particular groups’ section, this includes provision of accommodation. |
| Key issues for learning disabilities | Regarding issues for people with learning disabilities who have dementia and those who develop early onset dementia, it was felt the key issues were captured but that it does not cover how they will be met or achieved. | We have included overarching objectives for both of these areas. Richmond has a comprehensive service for those with learning disabilities who develop dementia. With regards to young onset dementia there is difficulty in providing services for a small number of individuals within one borough. We will be investigating the possibility of provision of services across a number of boroughs. |
| Key issues for early onset | One respondent felt there is currently not enough funding for those with early onset dementia. For example, there should be volunteering for those who need to give up their job. Dementia placements appear to start from the age of 55 years, and therefore an age appropriate resource is needed for respite.  More clarity is needed on how services will be differentiated for those with early onset dementia, e.g. those with family care responsibilities or those who work | There is no age limit for accessing respite via Shared Lives Dementia. With regards to funding, there is difficulty in providing services for a small number of individuals within one borough. We will be investigating the possibility of provision of services across a number of boroughs. |
| Another groups that should be considered | LGBT groups were suggested as another particular group to be considered in the strategy. | For the purposes of the strategy, the protected characteristics identified as ‘high impact’ were covered in the strategy document- all other protected characteristics were considered within the Equalities Impact Needs Assessment (EINA). You can view this at; <http://www.richmond.gov.uk/acs_eina_reports> |
| Another groups that should be considered | When asked which other groups should be considered, one person felt more could be done to address that women are disproportionately affected by dementia. | Although this is an important point, it is not clear what could be done to address this issue specifically, apart from raising awareness. Current services cater to all patients, regardless of sex. |
| Another groups that should be considered | When asked which other groups should be considered, dementia awareness in schools was suggested, to help children understand relatives who might have the condition. | The Dementia Action Alliance works with organisations across the borough to raise awareness and take action to become ‘more dementia friendly’. Schools are one of the key target groups for the alliance, and this suggestion has been fed back. |
| Another groups that should be considered | People who do not have friends or family carers or who live alone were suggested as another particular group to be considered in the strategy. | The strategy highlights the role of CILS for those who live alone; a service which helps them to make a positive contribution to their local community and reduces social isolation. Those who live alone can access dementia services through the dementia navigator at the memory clinic and through the GP who will see the person with dementia on at least an annual basis. |
| Any other comments | Some comments suggested that the strategy was too long and not layman friendly. | Whilst it is agreed that the Joint Dementia Strategy is quite long, value was seen in bringing together information about services in to one place as the relevant services are currently delivered across a number of teams and organisations. A summary document will be produced which highlights the main objectives over the next five years. |
| Any other comments | In gathering views about the strategy/services, one person felt that an expert user panel where people with dementia are supported to express their own views is needed. | There is an objective within the supporting well section regarding this – holding a dementia specific session of the Richmond Health and Social Care Coproduction Group (Richmond’s service user and carer engagement group). |
| Email response | One person was concerned by the definition of dementia, as it risks people who hallucinate or hear voices being misdiagnosed. The person felt that there is an overprescribing of anti-depressants and anti-psychosis drugs for those diagnosed with dementia. | There is a robust diagnostic process in place for dementia, including a CT scan in most cases, which minimises the risk of misdiagnosis.  With regards to anti-psychotic drugs, there has been a move nationally to reduce the prescription of unnecessary antipsychotic medication to those with dementia. An example of research to facilitate this is: <https://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=1238> |
| Group engagement- Richmond Carers Centre | The importance of information guides for carers and dementia services in printed and online versions was mentioned, however these are not regularly updated  The centre felt it would be useful to have information about the diagnosis process and memory clinic to help those who are unsure about getting a referral. | We recognise this issue, and have included three objectives about the provision of up to date information to those with dementia and their carers in the ‘Diagnosing Well’ section. We will be including an action in the action plan to ask the memory clinic to provide some information about the diagnostic process. GPs will be able to give this to their patients who are unsure about their referrals. |
| Group engagement- Ethnic Minorities Advocacy Group Elders Group | A key finding from the meeting was that members were keen to learn how to prevent or delay dementia, for example activities in social settings to help keep the brain and body exercised. They welcomed the suggestion of having a Dementia Friends session with the group. A few had experience of dementia due to a friend or neighbour | We have liaised with EMAG to organise a Dementia Friends session with the Elders Group which will include information on prevention. |
| Group engagement- Richmond Dementia Action Alliance | A workshop was held with RDAA, in which a range of comments were gathered from stakeholders. A range of themes were identified including:   * Grouping objectives in the strategy * The importance of quality of life at the end of life * More work needed on dementia diagnosis and care in care homes | We have streamlined the objectives in the strategy, and have included a new objective about the importance of quality of life at the end of life. Diagnosis of dementia is a major focus of Richmond’s dementia services and we will be working to improve diagnosis in care homes. |
| Group engagement- Health and Social Care coproduction group | Concerns were raised about the quality of home care services; carers do not always maintain a routine which is important for people with dementia. They should be better trained in dementia specific issues.  The group felt carers should be considered equal partners in care. They need yearly assessments and services as well. | Richmond were aware of these issues and have procured home care services from a new provider from July 2016.  All carers are offered a carers assessment and this can be reviewed when circumstances change. Richmond provides many services to carers which are outlined in the Strategy and in the new Carers Strategy which will be published in 2016. |