

# Table of Contents

# Age Well

Table of Contents	2
COVID-19 Impact on the JSNA Report	5
1. Introduction and Overview	6
2. Demography	6
2.1 Demand on Social Care and Health Services	7
2.2 Decline Following Hospital Admission	8
2.3 Social Isolation	8
3. Life Expectancy and Healthy Life Expectancy at 65 Years	9
3.1 Life Expectancy at 65 Years	9
Males	9
Females	10
3.2 Healthy Life Expectancy at 65 Years	11
Males	11
Females	12
3.3 Inequalities in Life Expectancy at 65 Years	13
Males	13
Females	14
3.4 Ward-level Life Expectancy at 65 Years	15
4. Main Causes of Morbidity and Mortality	16
4.1 Morbidity in Older Adults	17
4.2 Mortality in Older Adults	18
Mortality Risk Factors	18
Mortality Rates by Cause	19
Excess Winter Deaths	23
5. Falls, Frailty and Mobility	24
5.1 Falls	30
At-Risk Groups	31
Hospital Admissions as a Result of a Fall	31
Hip Fractures	35
Current Services on Offer	36
Evidence-based Interventions	36
5.2 Common Mental Disorders	39
5.3 Care and Support Services for Older People	39
5.4 Interventions aimed at Improving Mobility in Older People	42
5.5 Data Sources	42

6. Adult Social Care Outcomes	43
6.1 Reablement Following Hospital Discharge	43
6.2 Social Isolation	46
7. Vaccinations	48
7.1 Seasonal Flu Vaccine	48
7.2 Pneumococcal Polysaccharide Vaccine	49
7.3 Shingles Vaccine	50
8. Dementia Prevention and Care	51
8.1 Dementia Definition	51
8.2 Causes of Dementia	52
8.3 Dementia Prevalence	53
8.4 Emergency Admissions for Dementia	56
8.5 Mortality from Dementia	57
8.6 National Policy Context for Dementia	59
8.7 Local Policy Context for Dementia	60
8.8 The Financial Cost of Dementia to the UK	62
8.9 Dementia in Richmond?	63
8.10 Risk of Developing Dementia	63
Non-modifiable Risk Factors for Dementia	64
Modifiable risk factors for dementia	64
8.11 Evidence-based Interventions	67
Preventing Dementia	67
Diagnosing Dementia	68
Support After a Diagnosis of Dementia	68
Enabling a Fulfilling Life with Dementia	69
Ensuring Dignity and Comfort for Those Dying with Dementia	72
Community and Stakeholder Views on Dementia	73
8.12 Level of Need in The Richmond population	74
Prevalence	74
Early Onset Dementia	74
Dementia and Ethnicity	74
Dementia in Relation to Co-morbidities	75
Geographic Variation	75
Residential Status of Dementia Patients	76
Emergency Admissions	77
Use of Antipsychotic Drugs in Dementia Patients	79
Future Projections in People Living with Dementia and Need for Social Car	
Unpaid Caring for People with Dementia	80

Limitations to the Dementia Data/Information	80
Dementia Within the Landscape of COVID 19	80
Current Dementia Services on Offer in Richmond?	82
Improvement Opportunities in Dementia Prevention and Care	89
9. End of Life Care	93
9.1 The Overview of End of Life Care	93
9.2 Definitions and Scope of End of Life Care	94
9.3 National Policy Context for End of Life Care	95
9.4 Local Policy Context for End of Life Care	96
9.5 End of Life Care in Richmond	96
9.6 Equity in End of Life Care	97
9.7 The Level of Need for End of Life Care	98
Death Rates	98
Place of Death	98
Hospital Admissions at The End of Life	101
Permanent Admissions to Residential and Nursing Care Homes	103
9.8 Care Home and Nursing Care Beds Capacity	104
9.9 Limitations to The Data and Information on End of Life Care	106
9.10 Causes of Unmet Need	107
Choice of Place of Death	107
Sharing Data	107
Specific Groups and Health Inequalities	107
9.11 Evidence-based Interventions	110
Bibliography	113
Acronyms	117
Acknowledgments	119

# COVID-19 Impact on the JSNA Report

The COVID-19 pandemic in 2020 has had multiple and wide ranging impacts on the population. It has increased and expanded the role of both statutory and voluntary sector organisations, and other community led services. The pandemic has created a whole new set of challenges for carers, hospitals, GPs and care homes, leaving in its wake health and social care service backlogs, establishment and management of a new and significant vaccination programme. The impacts span the life course and wide-ranging issues from political, economic, social, technology, lifestyle and health.

The pandemic has highlighted more starkly, issues such as health and social inequalities and deprivation, anxiety and mental ill-health, and many others. The JSNA health outcomes and wider determinants data presented in this JSNA generally predate the pandemic and could be expected to deteriorate in areas such as life expectancy, mortality and morbidity rates. Mortality from COVID-19 has had an unequal impact on different population sub-groups and exacerbated health inequalities; however, this will not be fully reflected in this JSNA as the data is not yet available at a local level.

It remains important to monitor pre-Covid time trends to understand the baseline from which to measure the local effects of Covid on key statistics. The Protect Well chapter has more detailed COVID-19 health outcomes and impact. It is expected that the first post-COVID information will be available in the next 12 months as we continue to monitor the available information.

# 1. Introduction and Overview

This JSNA chapter provides a high-level summary on the older population of Richmond, and some of the factors affecting their health, wellbeing, and social care needs. Meeting the needs of an ageing population has considerable consequences for planning health and social care services and therefore this JSNA will be used to agree key priorities to improve the health and wellbeing of our older people, balancing the challenge of increasing need and the increasing cost of meeting that need within current budget levels.

For the purpose of this JSNA chapter, the term 'older people' has been defined as those over the age of 65 years. In some sections, data relating to a lower group has been included, for example, such as reference to early onset dementia. The report is organised under the following broad theme headings: Falls and Frailty, Safeguarding in the Elderly, End of Life Care and Dementia, and draws upon evidence from a range of sources. Wherever possible the data has been split further by age as the 'older' (aged over 75 years or 85 years+), will have more pressing and complex needs than the younger cohort.

The population is ageing with a large cohort of people now reaching their later years. This increased demand is set to continue as the population is living longer, yet many of these years are lived in poorer health, which may lead to difficulties with mobility and completing activities and daily living (ADL). Without capacity building, systems may be unable to meet the demand for high quality care services, both in the community and in accommodation settings. Nonetheless, adopting preventative approaches and supporting health and wellbeing at a younger age may reduce, delay or prevent the need for costly social care provisions. The national prevention agenda can provide residents with the tools required to live healthily and independently in the community for as long as possible. Ultimately by tackling wellbeing earlier in the life course, the outcomes for older people can be significantly improved and the most vulnerable people in society will continue to have access to high quality services.

# 2. Demography

For latest Demographic information please go to the population explorer on <u>DataRich</u>. In Richmond in 2021 16.2% (n=32,403) of the total population is 65 years +old. The proportion of older adults in the borough is higher than the London average (12.3%) with all 65+ age groups making up a larger population proportion than in London (**Figure 1**).

Population Pyramid: Richmond vs. London 90+ 85-89 80-84 Richmond Males Richmond Females London 75-79 70-74 65-69 0.0 2.0 1.5 1.0 0.5 0.5 1.0 1.5 2.0 % of total population

Figure 1: Residents aged 65+ as proportion of total population - comparison with London, 2021

Source: @GLA 2018-based population projections @Greater London Authority 2021

In line with the national picture, the number of older people in Richmond is projected to increase, many of whom will live with age-related needs that will make them more vulnerable to experiencing difficulties with mobility and personal care.

In the next 20 years the numbers and proportion of older people within the population is predicted to increase substantially, from 32,403 (16.2% of population in 2021) to 45,784 (22.0% of population in 2041)<sup>1</sup>.

### 2.1 Demand on Social Care and Health Services

The current use of social care support highlights the prevalence and complexity of need within the population.

With an ageing population, demand on social care services is expected to increase as people are more likely to require health and care support later in life. While life expectancy is higher than the national average, the healthy life expectancy remains lower than actual life expectancy in Richmond. This means that demand on services is expected to rise as more people are living longer in poorer health.

The current use of social care support also reveals the prevalence and complexity of need within the population. In Richmond, 1,784 people received support from Adult Social Care Services within the community or accommodation-based services in 2018-19 (refer to level of need section for more detail). This included 328.1 per 100,000 permanent admissions to care homes of people aged 65 years

<sup>&</sup>lt;sup>1</sup> Wandsworth Accommodation-Based Care Commissioning Statement 2018-19, Commissioning Programme and Business Intelligence, September 2 020.

and over in 2018/19², indicating the demand for more intensive support for people with the highest level of need. The loss of independence due to difficulties with mobility and personal care, can be lifealtering and damaging to the physical and mental wellbeing of older people and therefore is a key priority within Richmond.

### 2.2 Decline Following Hospital Admission

Older people are more susceptible to dramatic decline after a minor incident or illness. Of A&E attendances and 'long lengths of stay' in hospital, a large proportion are attributable to older people.

In Richmond, there were 18,425 non-elective admissions to hospital in 2018-19 (all ages)<sup>3</sup>. Any hospital stays, unexpected or planned, can have a significant impact on the individual. This is particularly true for older people who are more susceptible to hospital acquired infections, mental decline, increased frailty, loss of independence and muscle deterioration. For example, for a person aged 80 years and over, every ten days in hospital is equivalent to ten years of muscle deterioration<sup>4</sup>. A study also found that 30% to 60% of older people experience functional decline following discharge from hospital, which increases the risk of readmission, social care support and mortality<sup>5</sup>. In order to keep older people in good health for as long as possible, preventative services are essential for the avoidance of hospital admissions, costly both for the person and overall system.

### 2.3 Social Isolation

Social isolation, common amongst older people, can have a negative impact on both physical and mental health. The National Institute of Ageing research shows that social isolation is an associated risk factor for heart disease, cognitive decline and high blood pressure<sup>6</sup>. It is also thought that common mental health conditions, including depression and anxiety, are also caused by social isolation<sup>7</sup>. Sadly, older people are especially susceptible to becoming isolated due to the death of people with whom they have close relationships, a loss of income, or difficulties with mobility. Ultimately, isolation amongst older people gradually worsens as their confidence lessens. Age UK estimates that at least 1.4 million older people in the UK are chronically lonely<sup>8</sup>. 3.6 million older people consider that the

<sup>&</sup>lt;sup>2</sup> Permanent admissions to residential and nursing care homes per 100,00 aged 65+', Public Health Profiles, 2019, [website]. Available at:

https://fingertips.phe.org.uk/search/PERMANENT%20ADMISSIONS%20TO%20CARE%20HOMES#page/3/gid/1/pat/6/par/E12000007/ati/102/are/E09000026/iid/1194/age/27/sex/4.

<sup>&</sup>lt;sup>3</sup> Better Care Fund Performance Dashboard, Department of Adult Social Services, 2018-19.

<sup>&</sup>lt;sup>4</sup> '10 days in a hospital bed leads to 10 years' worth of lost muscle mass in people over age 80', British Geriatrics Society, [website], 2018. Available at: <a href="https://www.bgs.org.uk/blog/10-days-in-a-hospital-bed-leads-to-10-years%E2%80%99-worth-of-lost-muscle-mass-in-people-over-age-80">https://www.bgs.org.uk/blog/10-days-in-a-hospital-bed-leads-to-10-years%E2%80%99-worth-of-lost-muscle-mass-in-people-over-age-80</a>.

<sup>&</sup>lt;sup>5</sup> Hoogerduijn J et al., The prediction of functional decline in older hospitalised patients, Age and Ageing, 2012. Available at: https://academic.oup.com/ageing/article/41/3/381/32060.

<sup>&</sup>lt;sup>6</sup> 'Social Isolation, Ioneliness in older people pose health risks', National Institute on Ageing, 2019. Available at: <a href="https://www.nia.nih.gov/news/social-isolation-loneliness-older-people-pose-health-risks">https://www.nia.nih.gov/news/social-isolation-loneliness-older-people-pose-health-risks</a>.

<sup>&</sup>lt;sup>7</sup> 'Social Isolation, Ioneliness in older people pose health risks', National Institute on Ageing, 2019. Available at: <a href="https://www.nia.nih.gov/news/social-isolation-loneliness-older-people-pose-health-risks">https://www.nia.nih.gov/news/social-isolation-loneliness-older-people-pose-health-risks</a>.

<sup>&</sup>lt;sup>8</sup> All the Lonely People: Loneliness in later life', Age UK, 2018. Available at: <a href="https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-priefings/loneliness/loneliness-report final 2409.pdf">https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-priefings/loneliness/loneliness-report final 2409.pdf</a>.

television is their main form of company<sup>9</sup> and 1 in 3 people aged 75 years and over say that their loneliness is out of control<sup>10</sup>.

In South West London, it is estimated that 39% of older people say that they are sometimes lonely (12,384 individuals) and 9% are chronically lonely (2,858)<sup>1112</sup>. Within Richmond, the areas that have the highest risk of loneliness in people aged 65 years and over are Hampton, Ham, areas around Twickenham and South Richmond<sup>13</sup>. By using data from the 2011 census, it is estimated that 12% of households in Richmond are pensioners living alone<sup>14</sup>. Although living alone does entail that someone is socially isolated, it can lead to a greater vulnerability, particularly if they are living alone due to the death of a spouse or relationship breakdown.

From respondents to the Adult Social Care Outcomes Framework, only 47.9% of social care users aged 65 years and older in Richmond reported having as much social contact as they would have like. However, this is higher than both the London average for all ages and the national average for people aged 65 years and over<sup>15</sup>. Overall, the data highlights the issue of social isolation in Richmond as despite generally better outcomes than inner London boroughs, many older people in Richmond suffer from isolation.

# 3. Life Expectancy and Healthy Life Expectancy at 65 Years

Life expectancy at 65 is an estimate of the average number of years at age 65 years a person would survive if he or she experienced the age-specific mortality rates for that area and time period throughout his or her life after that age.

### 3.1 Life Expectancy at 65 Years

### **Males**

In 2017-19 Richmond's male life expectancy at the age of 65 was 20.6 years (6th highest in London, **Figure 2**), which was 8.3% higher than the England average and 4.3% higher than London average. The

<sup>&</sup>lt;sup>9</sup> Loneliness in Later Life; Age UK, 2015. Available at: <a href="https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/health-wellbeing/rb">https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/health-wellbeing/rb</a> june15 lonelines in later life evidence review.pdf

<sup>&</sup>lt;sup>10</sup> Combatting loneliness one conversation at a time, Jo Cox Commission, 2017.

<sup>&</sup>lt;sup>11</sup> 'Safeguarding the Convoy: A call to action from the Campaign to End Loneliness', Oxfordshire Age UK, 2011.

<sup>&</sup>lt;sup>12</sup> Harris et al, Predictors of depressive symptoms in older people: a survey of two general practice populations, *Age and Ageing*, 2003.

<sup>&</sup>lt;sup>13</sup> 'Risk of Loneliness in England 2016 Maps', Age UK, 2016, Available at: <a href="http://data.ageuk.org.uk/loneliness-maps/england-2016/">http://data.ageuk.org.uk/loneliness-maps/england-2016/</a>

<sup>&</sup>lt;sup>14</sup> London Borough of Richmond upon Thames Census Borough Profile, 2013. Available at: https://www.richmond.gov.uk/media/14639/census borough profile 2013.pdf

<sup>&</sup>lt;sup>15</sup> LG Inform, Proportion of people who use services who reported that they had as much social contact as they would like in Richmond upon Thames, 2019. Available at: <a href="https://lginform.local.gov.uk/reports/lgastandard?mod-metric=10676&mod-area=E09000027&mod-group=AllBoroughInRegion\_London&mod-type=namedComparisonGroup">https://lginform.local.gov.uk/reports/lgastandard?mod-metric=10676&mod-area=E09000027&mod-group=AllBoroughInRegion\_London&mod-type=namedComparisonGroup</a>

latest Borough figure was also 19.1% higher from year 2001–03, in comparison with a 16.6% increase in England's rate in the equivalent time period (**Figure 3**).

Life expectancy at 65, 2017 - 19 (Males) Life expectancy (Years) 20 England London 10 5 Harrow Barnet Brent Ealing Merton Bexley Kensington and Chelsea Camden Enfield Hillingdon **Richmond** Kingston Waltham Forest Croydon Wandsworth Tower Hamlets Hounslow Hammersmith and Fulham Havering Westminster Redbridge Bromley Sutton Haringey Hackney Newham Islington Greenwich Lambeth Southwark \_ewisham Barking and Dagenham

Figure 2: Male life expectancy at 65 years by local authority, 2017-19

Source: PHE Public Health Outcomes Framework

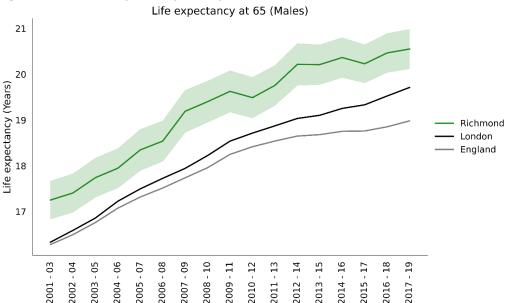


Figure 3: Male life expectancy at 65 years, 2001–2019

### **Females**

Richmond's latest female life expectancy at 65 was 23.6 (5th highest in London, **Figure 4**), which was 10.5% higher than the England average and 5.6% higher than London average. The latest Borough figure was also 18.4% higher from year 2001–03, in comparison with a 10.9% increase in England's rate in the equivalent time period (**Figure 5**).

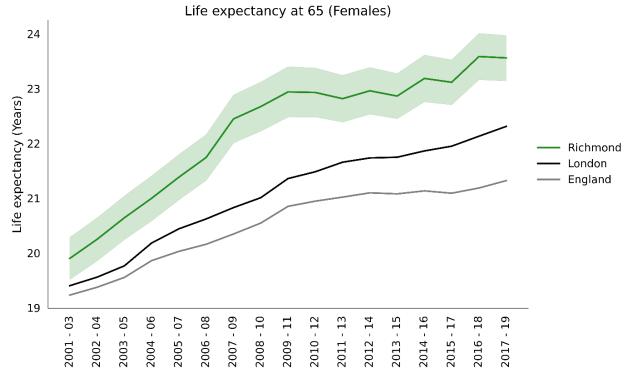
<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values Source: PHE <u>Public Health Outcomes Framework</u>

Life expectancy at 65, 2017 - 19 (Females) Life expectancy (Years) 20 15 England London 10 5 0 Lambeth Hackney Islington Tower Hamlets Ealing Harrow Barnet Brent Merton Kensington and Chelsea Sutton Bexley Westminster Richmond Southwark Haringey Redbridge Kingston Waltham Forest Enfield Hammersmith and Fulham Wandsworth Hounslow Croydon -ewisham Hillingdon Havering Newham Greenwich Barking and Dagenham Bromley

Figure 4: Female life expectancy at 65 years by local authority, 2017-19

Source: PHE <u>Public Health Outcomes Framework</u>

Figure 5: Female life expectancy at 65 years, 2001–2019



<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values Source: PHE <u>Public Health Outcomes Framework</u>

### 3.2 Healthy Life Expectancy at 65 Years

### **Males**

In 2017–19, Richmond's healthy life expectancy for males was 13.8 years, which is the 2nd highest rate in London (Figure 6), 30.9% higher than the England average and 42.4% higher than the London

average. The latest Borough figure for 2017–19 was also 19.0% higher than in 2009–11, in comparison with a 6.2% increase in England's rate in the equivalent time period (**Figure 7**).

Healthy life expectancy at 65, 2017 - 19 (Males) Tite expectancy (Years) 12.5 10.0 7.5 5.0 2.5 England London 0.0 Kingston Hounslow Havering Islington Haringey Merton Barnet Ealing Redbridge Tower Hamlets Kensington and Chelsea Sutton Hammersmith and Fulham **Waltham Forest** Westminster Croydon -ewisham Bexley Barking and Dagenham Lambeth Harrow Southwark Wandsworth Hillingdon Newham Bromley

Figure 6: Male healthy life expectancy at 65 years by local authority, 2017-19

Source: PHE Public Health Outcomes Framework

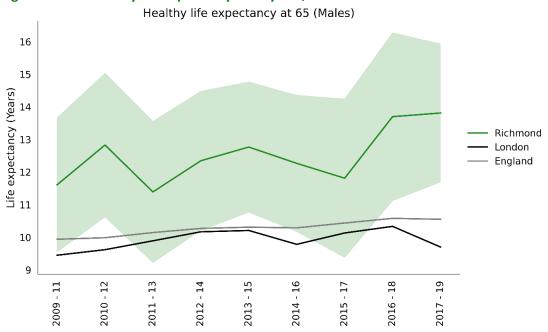


Figure 7: Male healthy life expectancy at 65 years, 2009–2019

### **Females**

Richmond's latest female healthy life expectancy at 65 was 11.0 years, which is the 12th highest rate in London (Figure 8), 0.7% lower than the England average and 5.6% higher than the London average. The latest Borough figure for 2017–19 was also 12.1% lower than in 2009–11, in comparison with a 4.1% increase in England's rate in the equivalent time period (Figure 9).

<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values Source: PHE <u>Public Health Outcomes Framework</u>

Healthy life expectancy at 65, 2017 - 19 (Females) Life expectancy (Years) 15 England London 5 Havering Greenwich Barnet Merton Enfield Hammersmith and Fulham Bexley Kensington and Chelsea Waltham Forest Redbridge Lewisham Richmond Croydon Hounslow Ealing Camden Harrow Islington Bromley **Nandsworth** Southwark Haringey Sutton Westminster Hillingdon Barking and Dagenham Lambeth **Tower Hamlets** 

Figure 8: Female healthy life expectancy at 65 years by local authority, 2017-19

Source: PHE <u>Public Health Outcomes Framework</u>

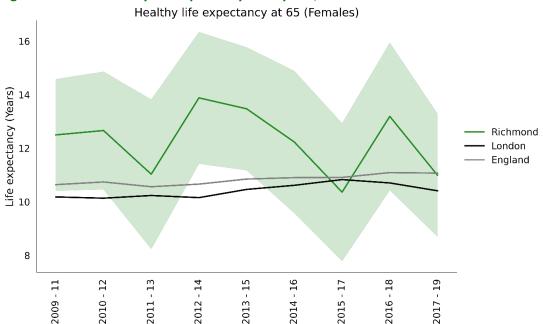


Figure 9: Female healthy life expectancy at 65 years, 2009-2019

## 3.3 Inequalities in Life Expectancy at 65 Years

### **Males**

Richmond's latest inequality in male life expectancy at 65 years was 3.8 (10th lowest value in London, **Figure 10**), which was 22.4% lower than the England average and 15.6% lower than London average. The latest Borough figure was also 2.7% higher from year 2010–12, in comparison with a 6.5% increase in England's rate in the equivalent time period (**Figure 11**).

<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values Source: PHE <u>Public Health Outcomes Framework</u>

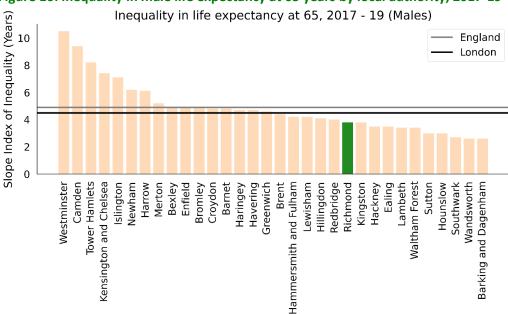


Figure 10: Inequality in male life expectancy at 65 years by local authority, 2017-19

Source: PHE Public Health Outcomes Framework

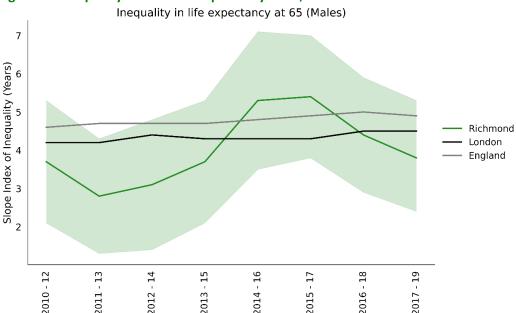


Figure 11: Inequality in male life expectancy at 65, 2010–2019

#### **Females**

Richmond's latest inequality in female life expectancy at 65 years was 0.0 years (lowest in London, **Figure 12**). The latest Borough figure has decreased substantially from year 2010–12, in comparison with a 17.5% increase in England's rate in the equivalent time period (**Figure 13**).

<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values Source: PHE <u>Public Health Outcomes Framework</u>

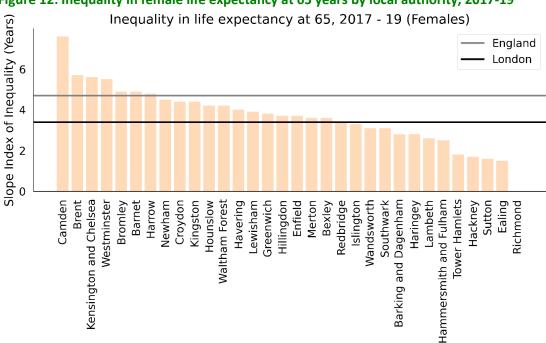


Figure 12: Inequality in female life expectancy at 65 years by local authority, 2017-19

Source: PHE Public Health Outcomes Framework

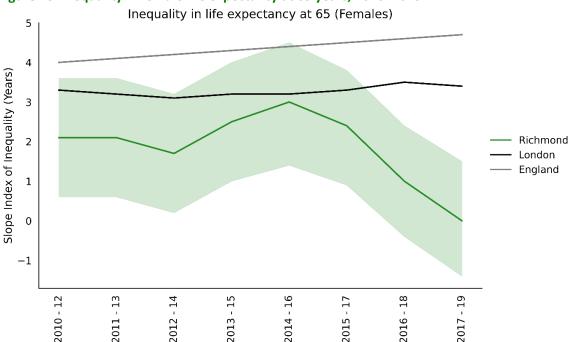


Figure 13: Inequality in female life expectancy at 65 years, 2010–2019

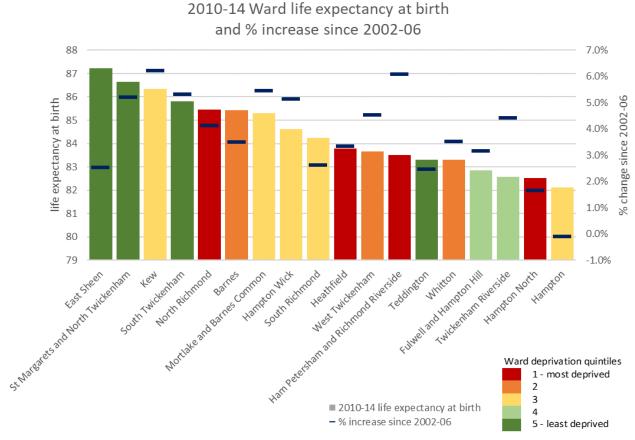
### 3.4 Ward-level Life Expectancy at 65 Years

The latest (2010-14) Ward-level life expectancy at 65 years and percentage increases in life expectancy since baseline of 2002-06 are presented in **Figure 14**. Life expectancy was the highest in two Wards from the least deprived quintile (East Sheen and St Margarets). However, the relationship between

<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values Source: PHE Public Health Outcomes Framework

deprivation and life expectancy at Ward-level is not too obvious, with the most deprived Wards having, typically, average life expectancy. Interestingly, there was a substantial variation in relative gains in life expectancy at Ward-level. Hampton was the only Ward with a slight decrease in life expectancy from baseline (-0.1%: from 82.2 in 2002-06 to 82.1 9 in 2010-14). The highest gains in life expectancy of over 6% were recorded in Kew and Richmond Riverside.

Figure 14: Ward-level life expectancy at 65 in 2010-14 with percentage increases since 2002-06 by Ward deprivation quintile



Source: London DataStore: Life Expectancy at Birth and Age 65 by Ward and London Wards Indices of Deprivation

# 4. Main Causes of Morbidity and Mortality

The Global Burden of Disease (GBD¹6 provides modelled estimates of the burden of poor health and disability. The burden of disease analysis is a way to compare the impact of different diseases, conditions or injuries in a population and break it down by age group. The only age group for older adults that is available in the GBD toolkits is 70 years and over. The impact of disease on Richmond older adults can be divided into morbidity (living with a disease) and mortality (dying from a disease).

<sup>&</sup>lt;sup>16</sup> Global Burden of Disease. 2019

### 4.1 Morbidity in Older Adults

The GBD also provides modelled estimates of the burden that can be attributed to a number of risk factors. It uses years lived with disability (YLD) to attribute the burden of morbidity.

YLD is a measure of morbidity that combines the prevalence of each disease with a rating of the severity of its symptoms (excluding death itself), to give an overall measure of the loss of quality of life.

Age related hearing loss, diabetes, chronic obstructive pulmonary disorder (COPD), followed by lower back pain and vision loss were the most common causes of YLD in Richmond. These five conditions were responsible for 37% of all years of life in disability in residents aged 70+. For London males diabetes was causing the most YLD.

For females aged 70+ the top five causes for Richmond were hearing loss, lower back pain, diabetes, followed by vision loss and COPD: all responsible for 36% of all YLD. The top causes for London females were different: the order of top causes is different to Richmond, with lower back pain causing the largest number of YLD and falls replacing vision loss in the list of top 5 causes of disability (**Table 1**).

Table 1: Top 5 conditions responsible for highest number of years of life lived with disability at age 70+ in Richmond and London, 2019

Top 5 conditions accounting for greatest burden of disease (YLD rate per 100k, % of total YLD)										
	Males and females aged 70+									
Sex	Area name	1st	2nd	3rd	4th	5th				
Males	Richmond	Age-related hearing loss (2679, 9.99%)	Diabetes (2240, 8.35%)	COPD (1733, 6.56%)	Low back pain (1721, 6.44%)	Blindness and vision loss (1652, 6.17%)				
	London	Diabetes (2782, 10.4%)	Age-related hearing loss (2178, 7.9%)	COPD (1992, 7.6%)	Low back pain (1886, 7.0%)	Falls (1332, 5.3%)				
Females	Richmond	Age-related hearing loss (2654, 8.8%)	Low back pain (2346, 8.1%)	Diabetes (1971, 6.8%)	Blindness and vision loss (1883, 6.5%)	COPD (1697, 5.9%)				
	London	Low back pain (2780, 9.7%)	Diabetes (2384, 8.3%)	Age-related hearing loss (2279, 7.9%)	Falls (1882, 6.9%)	COPD (1726, 6.1%)				

Key:

Non-communicable diseases

Injuries

Source: Global Burden of Disease. 2019

### 4.2 Mortality in Older Adults

In 2019, ischaemic heart disease was the leading cause of death in males aged over 70 years, followed by lower respiratory infections and COPD. Lung cancer was 5<sup>th</sup> most common cause in London, in Richmond, it was prostate cancer (6.8% of all deaths).

In females aged over 70 years, ischaemic heart disease, Alzheimer's disease and lower respiratory infections were the leading causes of death in Richmond and in London. However, Alzheimer's disease was the 2nd most frequent cause of deaths in Richmond, for London it was the 3rd most common cause of mortality **Table 2**.

Table 2: Top 5 causes of mortality in males and females aged 70 and over, 2019

	Top 5 causes of death, 2019							
	Males and females aged 70+ (death rate per 100k, % of total YLD)							
	1st	2nd	3rd	4th	5th			
Richmond Males	Ischaemic heart disease (673, 15.1%)	Lower respiratory infections (375, 8.4%)	COPD (319, 7.1%)	Alzheimer's disease (318, 7.1%)	Prostate cancer (306, 6.8%)			
London Males	Ischaemic heart disease (912, 16.6%)	COPD (453, 8.2%)	Lower respiratory infections (444, 8.1%)	Stroke (384, 7.0%)	Lung cancer (362, 6.6%)			
Richmond Females	Ischaemic heart disease (602, 12.7%)	Alzheimer's disease (521, 11.0%)	Lower respiratory infections (459, 9.7%)	Stroke (394, 8.3%)	COPD (297, 6.3%)			
London Females	Ischaemic heart disease (664, 13.4%)	Lower respiratory infections (475, 9.6%)	Alzheimer's disease (473, 9.5%)	Stroke (447, 9.0%)	COPD (343, 6.9%)			

Key:

Non-communicable diseases

Communicable, maternal, neonatal, and nutritional diseases

Source: Global Burden of Disease. 2019

### **Mortality Risk Factors**

Causes of death in the population are influenced by a broad range of factors. Using the Global Burden of Disease, certain risk factors for disease can be ranked based on the proportion of deaths. Risk factors are divided into three main groups: behavioural, metabolic and environmental (Figure 15).

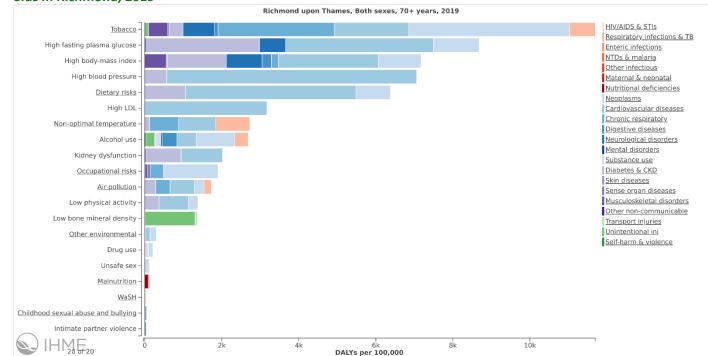


Figure 15: Attribution of deaths to risk factors broken down by broad cause of death in over 70 year olds in Richmond, 2019

Source: Global Burden of Disease. 2019

The risk factors accounting for the highest proportion of deaths among those aged over 70 years was tobacco, high fasting plasma glucose, high body-mass index and blood pressure. Smoking accounted for deaths from five major causes: neoplasms, chronic respiratory diseases, cardiovascular diseases, respiratory diseases, and respiratory infections.

High fasting plasma glucose accounted for deaths from two main causes, cardiovascular diseases (heart disease and stroke), and diabetes and kidney diseases. High body mass index contributed to cardiovascular, cancer, diabetes and kidney diseases. Dietary risks in this age group contributed to deaths predominantly from cardiovascular disease.

### **Mortality Rates by Cause**

Richmond's latest (2017-19) cardiovascular mortality rate of people aged 65+ was 842.9/100,000 population (n=816, 4th lowest rate in London, **Figure 16**), which was 19.3% lower than the England average and 15.2% lower than London average. The latest Borough figure was also 48.4% lower from year 2001–03, in comparison with a 49.4% decrease in England's rate in the equivalent time period (**Figure 17**). The rate of decrease in Richmond's rate has stalled since 2014-16.

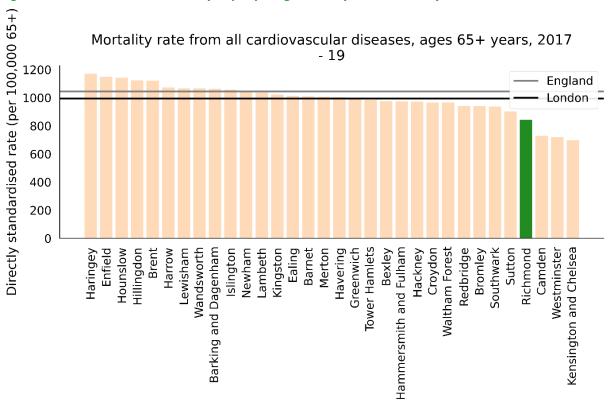
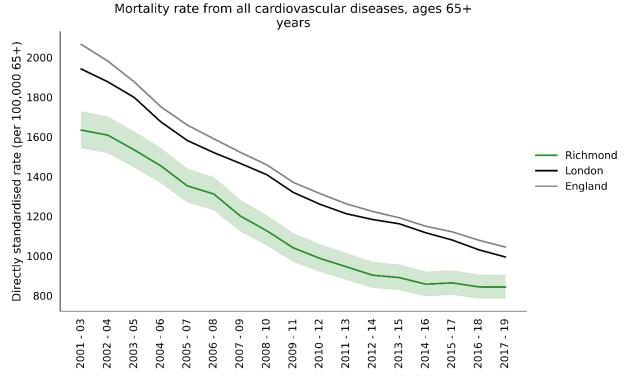


Figure 16: Cardiovascular mortality in people aged 65+ by local authority, 2017-19

Source: PHE Public Health Profiles

Figure 17: Cardiovascular mortality in people aged 65+, 2001–2019



<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values Source: PHE, <u>Public Health Profiles</u>

Richmond's latest (2017-19) respiratory mortality rate of people aged 65+ was 420.1 (n=405, 5th lowest rate in London, **Figure 18**), which was 31.8% lower than the England average and 23.0% lower than London average. The latest Borough figure was also 48.8% lower from year 2001–03, in comparison with a 23.0% decrease in England's rate in the equivalent time period (**Figure 19**).

Directly standardised rate (per 100,000 65+) Mortality rate from respiratory disease, ages 65+ years, 2017 - 19 England 800 London 600 400 200 Hillingdon Sutton Islington **Tower Hamlets** Newham Ealing Enfield Haringey Brent Kensington and Chelsea Barking and Dagenham Merton Waltham Forest Bexley Southwark Hammersmith and Fulham Kingston Redbridge Wandsworth Barnet Richmond Camden Harrow Westminster Lewisham Havering Hounslow Greenwich Croydon Hackney \_ambeth Bromley

Figure 18: Respiratory mortality in people aged 65+ by local authority, 2017-19

Source: PHE Public Health Profiles

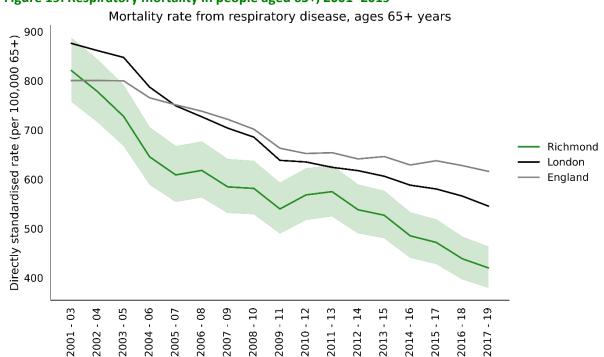


Figure 19: Respiratory mortality in people aged 65+, 2001–2019

Source: PHE, Public Health Profiles

<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values

Richmond's latest (2017-19) cancer mortality rate of people aged 65+ was 890.0 (n=828, 7th lowest rate in London, **Figure 20**), which was 17.2% lower than the England average and 8.2% lower than London average. The latest Borough figure was also 21.5% lower from year 2001–03, in comparison with a 12.3% decrease in England's rate in the equivalent time period (**Figure 21**).

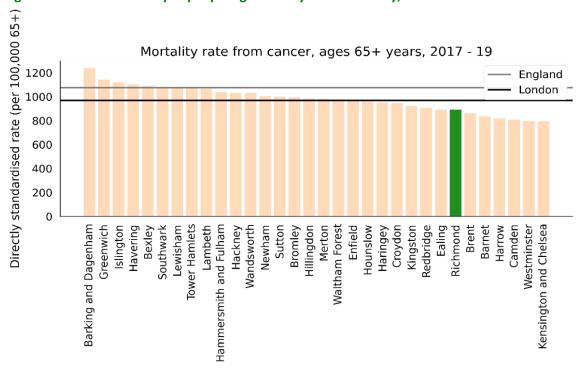


Figure 20: Cancer mortality in people aged 65+ by local authority, 2017-19

Source: PHE Public Health Profiles

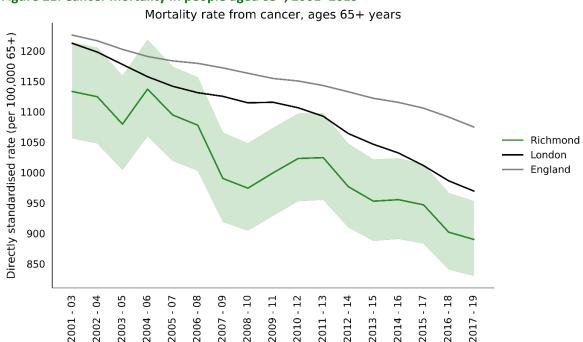


Figure 21: Cancer mortality in people aged 65+, 2001–2019

<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values Source: PHE, <u>Public Health Profiles</u>

#### **Excess Winter Deaths**

The number of excess winter deaths is linked to the outside temperature and the underlying level of disease in the population as well as other factors, such as how well equipped people and their environments are to cope with the drop in temperature.

Richmond's latest excess winter deaths of people aged 85 years and over was 7.0% (n=12, 6th lowest rate in London, **Figure 22**), which was 61.3% lower than the England average and 58.8% lower than London average. The latest Borough figure was also 60.1% lower from year Aug 2001–Jul 2002, in comparison with a 27.8% decrease in England's rate in the equivalent time period (**Figure 23**).

Excess winter deaths index (age 85+), Aug 2018 - Jul 2019 England 30 London Ratio (%) 10 0 Harrow Sutton Bexley Kensington and Chelsea Southwark Merton **Tower Hamlets** Barking and Dagenham Hammersmith and Fulham Brent Haringey Redbridge **Waltham Forest** Wandsworth Hillingdon Ealing Havering Kingstor Croydon Enfield Lambeth Hounslow Barnet Hackney Newham Westminster Richmond Greenwich

Figure 22: Excess winter deaths of people aged 85+ by local authority, Aug 2018-Jul 2019

Source: PHE <u>Public Health Profiles</u>

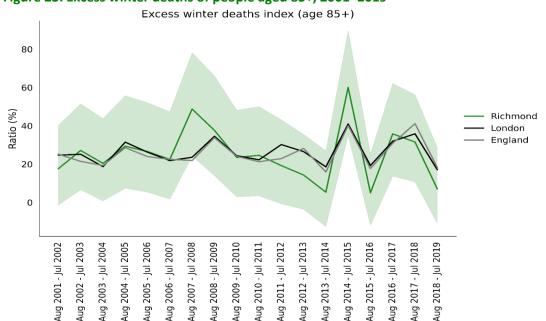


Figure 23: Excess winter deaths of people aged 85+, 2001–2019

Source: PHE, <u>Public Health Profiles</u>

<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values

# 5. Falls, Frailty and Mobility

Ageing, as a 'slowing down' process<sup>17</sup>, can turn simple activities into barriers that prevent a person from living healthily and safely in the community. As people age, it is likely that they will experience some degree of difficulty with activities of daily living (ADL) including:

- Mobility the capability to move independently or with assistive devices around an environment<sup>18</sup>. Having difficulties with one or more mobility tasks classifies as having issues with mobility. Tasks may include getting up and down the stairs, walking down the road, and moving around the house<sup>19</sup>.
- Personal care the completion of tasks to maintain personal hygiene, such as washing, toileting and administering medicines.
- Domestic care the activities to maintain a healthy living environment, including cooking meals and cleaning.

Due to the sequence of escalation, some older people may struggle to cope with domestic tasks yet are still able to be independent with their personal care. However, all the above can be exacerbated by issues with frailty. Frailty is a state of low energy, slower walking speeds, and poor strength<sup>20</sup>. It is not an inevitable consequence of the ageing process, however prevalence rates for frailty do increase with age (**Figure 24**). Women are also more likely to be affected by frailty in comparison to men. The severity of frailty has also been found to increase dramatically in the year prior to death<sup>21</sup>.

The ageing process presents a variety of challenges for older people including frailty, illnesses and agerelated conditions, such as dementia. As a result, some older people may have needs that require support from social care services, as they are unable to cope with basic self-care tasks.

The impact of ageing and loss of independence not only has a detrimental impact on a person's life but also places strain on the overall health and social care system due to the need for costly and intensive support services. These services are underpinned by the statutory obligations outlined in the Care Act 2014. It places a duty on local authorities to promote person-centred care that acknowledges the physical, mental and emotional well-being of the person. The aim is to achieve this through strengths-based and preventative care and support services.

This is because many age-related conditions that exacerbate mobility and personal care issues can be reduced, delayed or prevented by early lifestyle adjustments and interventions. Ultimately, by acknowledging the future impact of an ageing population today will help to create sustainable systems that promote the best outcomes for older people and their communities.

<sup>&</sup>lt;sup>17</sup> Jaul E and Barron J, Age-Related Diseases and Clinical and Public Health Implications for the 85 Years Olds and Over Population, Front Public Health, Vol. 5, 2017. Available at:

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5732407/.

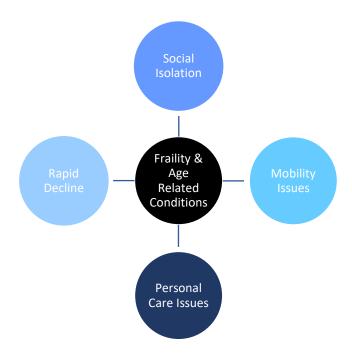
<sup>&</sup>lt;sup>18</sup> Webber S et al., Mobility in Older Adults: A Comprehensive Framework, The Gerontologist, Vol.50, No.4, 2010. Available at: <a href="https://academic.oup.com/gerontologist/article/50/4/443/743504">https://academic.oup.com/gerontologist/article/50/4/443/743504</a>.

<sup>&</sup>lt;sup>19</sup>Mobility, Projecting Older People Population Information System, [website], 2018. Available at: https://www.poppi.org.uk/index.php?pageNo=342&sc=1&loc=8640&np=1.

<sup>&</sup>lt;sup>20</sup> Frailty: what's it all about?, British Geriatrics Society, 2018. Available at: https://www.bgs.org.uk/resources/frailty-what%E2%80%99s-it-all-about.

<sup>&</sup>lt;sup>21</sup> Steptoe A et al., Cohort Profile: The English Longitudinal Study of Ageing', International Journal of Epidemiology, Vol.42, No.6, 2013. Available at: <a href="https://academic.oup.com/ije/article/42/6/1640/735886">https://academic.oup.com/ije/article/42/6/1640/735886</a>.

Figure 24: Diagram demonstrating the issues caused by frailty and age-related conditions



Older people may also lose confidence in their ability to complete activities of daily living (ADL) or may become fearful of leaving their home due to decline in their physical or mental health. Identifying issues with mobility and personal care generally occurs after a sudden incident, where a person presents to health and social care services in crisis.

The likelihood of experiencing issues with mobility, personal care and frailty increase with age, with the greatest prevalence amongst people aged 85 years and over. They are also most likely to experience rapid decline in their independence. There are several causes of mobility and personal care issues, including:

- Sensory Impairments: In Richmond, 2,778 older people are estimated to have a moderate or severe visual impairment and a further 928 people are predicted to have a registrable eye condition<sup>22</sup>. This can have a severe and sudden impact on a person's ability to get around and complete ADL.
- Unhealthy Lifestyles: As a person ages the barriers to maintain an active lifestyle become more challenging, such as pre-frailty and a loss of confidence. Being overweight and or inactive can cause that additional challenge on top of the general ageing process that prevent an older person from being independent. A person is classified as obese if they have a BMI of 30 or above. In Richmond, it is estimated that in 2020 there are 9,685 people aged 65 and year who have a BMI of 30 or more<sup>23</sup>.

<sup>&</sup>lt;sup>22</sup> Population by Age, Projecting older People Population Information System, 2018. Available

at: https://www.poppi.org.uk/index.php?pageNo=341&areaID=8640&loc=8640

<sup>&</sup>lt;sup>23</sup> Obesity in Richmond upon Thames, Projecting Older People Population Information System, 2018, Available at: https://www.poppi.org.uk/index.php?pageNo=343&sc=1&loc=8359&np=1.

- **Frailty**: The national prevalence rates are estimated to be at 6.5% for those aged 60-79 years; 30% for those aged 80-89 years and 65% for those aged 90 and over<sup>24</sup>. Frailty can cause a loss of confidence and reduce physical ability to complete ADL.
- Falls: Falls can cause irreversible deterioration in the person's ability to live independently. An older person may experience numerous less serious falls, before a major falls or accident resulting in significant deterioration. In Richmond in 2018-19, there were 845 per 100,000 emergency admissions due to falls in those aged 65 and over<sup>25</sup>, which has been increasing steadily since 2016-17<sup>26</sup>. The recovery period for older people can be prolonged and exacerbated by other predictive factors. Please see the falls chapter for further detail.
- Mental Health: Common mental health conditions are different to cognitive disease, such as dementia. Mental health conditions are common amongst the whole population, yet for older people their symptoms may be exacerbated by their reduced ability to be independent. For example, a sudden lifestyle change, or incident can lead to depression from feelings of isolation and frustration, which in turn can trigger more serious mental health symptoms. According to Age UK, almost half of those aged 55 years and over have reported suffering with depression, of which 21% reported symptoms worsening with age. Events later in life, such as the death of a spouse, may trigger serious mental illness. Mental health issues are still stigmatised in the wider community and many older people feel unable to voice their feelings in comparison to younger people<sup>27</sup>.

Examining the number of people living with these related conditions adds to the overall picture of need and the possible future demand on services. However, issues with mobility and personal care are multifaceted, whereby they are both the result of and cause of other age-related conditions. Any condition that has a significant impact can be referred to as life limiting. Currently 40% of older people in Richmond are estimated to live with a life limiting condition that affects their daily life either a little or a lot<sup>28</sup>. From the 2011 census data, it has been predicted that the proportion of older people is predicted to increase with the largest increase in those aged 85 years and over.

### Figures from Table 3 indicate:

 people aged 85 years and over are most likely to require social care support and are the fastest growing age group

<sup>&</sup>lt;sup>24</sup> Gale C et al., Prevalence of frailty and disability: findings from the English Longitudinal Study of Ageing, Age and Ageing, Vol.44, No. 1, 2015. Available at: <a href="https://academic.oup.com/ageing/article/44/1/162/2812359">https://academic.oup.com/ageing/article/44/1/162/2812359</a>.

<sup>25</sup> 'Emergency hospital admissions due to falls in people aged 65 and over'. Public Health Profiles, 2019.

<sup>&</sup>lt;sup>25</sup> 'Emergency hospital admissions due to falls in people aged 65 and over', Public Health Profiles, 2019. Available at:

 $<sup>\</sup>frac{\text{https://fingertips.phe.org.uk/search/falls\#page/3/gid/1/pat/6/par/E12000007/ati/102/are/E09000026/iid/224}{01/age/27/sex/4}$ 

<sup>&</sup>lt;sup>26</sup> 'Emergency hospital admissions due to falls in people aged 65 and over Richmond upon Thames', Public Health Profiles, 2019. Available

 $at: \underline{https://fingertips.phe.org.uk/search/falls\#page/4/gid/1/pat/6/par/E12000007/ati/102/are/E09000027/iid/22401/age/27/sex/4/cid/4/page-options/car-do-0.}$ 

<sup>&</sup>lt;sup>27</sup> Half of adults aged 55 and over have experience mental health problems', *Age UK*, 6<sup>th</sup> October 2017. Available at: <a href="https://www.ageuk.org.uk/latest-news/articles/2017/october/half-aged-55-have-had-mental-health-problems/">https://www.ageuk.org.uk/latest-news/articles/2017/october/half-aged-55-have-had-mental-health-problems/</a>.

<sup>&</sup>lt;sup>28</sup> Life Limiting Conditions in Richmond upon Thames, Projecting Older People Population Information System, 2018. Available at: <a href="https://www.poppi.org.uk/index.php?pageNo=343&sc=1&loc=8359&np=1">https://www.poppi.org.uk/index.php?pageNo=343&sc=1&loc=8359&np=1</a>.

- by 2050, there is predicted to be a significant increase in people living with conditions that limit them 'a little' and 'a lot'. Mobility issues are also predicted to increase dramatically
- it is important to note that one person could live with mobility, frailty and a life limiting condition
- life-limiting conditions could have significant impact on mobility and increase frailty; the combination of which could lead a person to require intensive social care support.

Table 3: Estimated prevalence of life-limiting conditions and ageing population in Richmond, 2020 – 2050

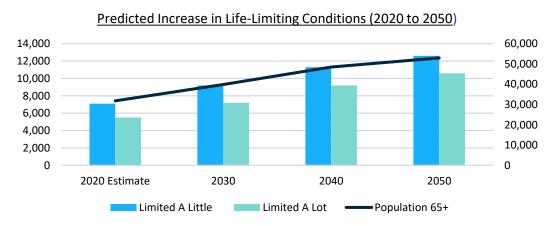
Older People Population Increase							
Age Group	2020	2050	2020–2050 % increase				
65-74 years	17,293	19,937	23,060	23,087	25%		
75-84 years	9,954	13,630	16,126	18,267	46%		
85+	4,507	6,381	9,333	11,675	61%		

Ageing Population	Percentage Increase from 2020								
Need	2020 Actual	2030	2030 2030 % 2040 2040 % 2050						
			increase		increase		increase		
Limited A Little	7,100	9,200	29.6%	11,300	59%	12,600	77%		
Limited A Lot	5,500	7,200	31%	9,200	67%	10,600	93%		
Mobility issues	5,900	7,800	32.2%	9,900	68%	11,400	93%		

Source: Projecting Older People Population Information System

**Figure 25** below illustrates the increasing level of need in the population of people aged 65 years and over.

Figure 25: Predicted increases in population size and in population living with limiting conditions<sup>29</sup>
Source: <u>Projecting Older People Population Information System</u>

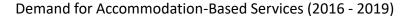


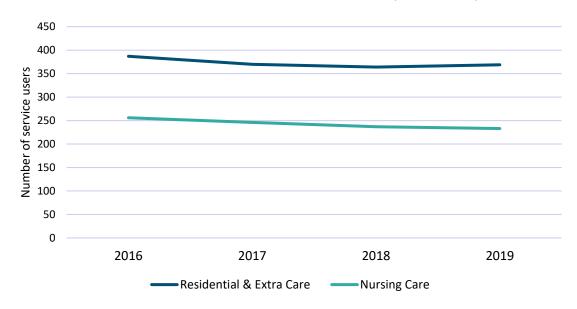
<sup>&</sup>lt;sup>29</sup> Population by Age, Projecting older People Population Information System, 2018. Available at: <a href="https://www.poppi.org.uk/index.php?pageNo=341&areaID=8640&loc=8640">https://www.poppi.org.uk/index.php?pageNo=341&areaID=8640&loc=8640</a>.

**Figure 26** illustrates recent demand for residential and nursing care, which has marginally declined over the past four years. This may be linked to the Council's focus on community-based interventions to help people remain at home for as long as possible.

Figure 26: Demand for social care services in Richmond, 2016–2019

Source: Richmond Adult Social Care





In 2018-19, there were there were 1,784 services users, of whom 833 people received community-based services including homecare, day care, and services received via a direct payment, and 605 people who received accommodation-based care as indicated in **Table 4** below.

Table 4: Service users in Richmond, 2018/19 with forecasts for 2030 30

	2018/19	2030	
	65+	65+	
Community Based Services *	833	1121	
Direct Payments	250	336	
Home Care	571	768	
Day Care	109	147	
Accommodation Based Services	605	740	
Extra Care	50	62	
Residential Care	322	393	
Nursing Care	233	285	

\*Community based services as shown above exclude respite provision, outreach and equipment Source: Richmond Adult Social Care

The estimated increases by 2030 are based upon the estimated population increase in older people with high enough needs that they require social care support (data taken prior to the Covid-19 pandemic). In line with this, the number of service users across all services is predicted to increase over the next ten years.

<sup>30</sup> Richmond Accommodation-Based Care Commissioning Statement 2018-19, Commissioning Programme and Business Intelligence, September 2020.

The numbers demonstrate that as far as possible people will be supported to live independently in the community for as long as possible. Home Care is a favoured support option for older people, as they can remain living in their own home and supports the building of resilience. To help recovery following hospital admission, some people will be offered a reablement package of care. A person will receive a short-term care package that focuses on regaining the person's independence through a goal centred approach. In 2018-19, 92% of people were still at home 91 days after discharge from hospital into rehabilitation services. This is similar to the rest of London and England<sup>31</sup>. Direct Payments are another method that allows the service user greater choices and control. Service users are given a budget from which they can arrange their own services. For example, they may employ their own personal assistant or arrange day activities or homecare.

In terms of accommodation-based services, there is likely to be an increase across most accommodation care categories with a shift towards independent living options such as extra care which is being promoted as an alternative to residential care. Needs analysis and demand modelling based on a combination of population projections and service use reveals the need to develop:

- Residential Care: an increase of approximately 150 units by 2035
- Extra Care: it is predicted that 50 to 70 additional residential units required<sup>32</sup>
- Nursing Care: it is estimated that a further 80-90 additional placements with the focus on dementia provision will be necessary by 2035, at an average of 5 to 6 additional units per vear<sup>33</sup>.

Table 5 shows the estimated population size of different ethnicities in the over 65 population in Richmond and the number of people utilising council provided services by ethnicity. In Richmond, the three largest ethnic groups within the over 65 years population are White at 92%, followed by 6% Asian or Asian British, and 1% Other Ethnic Group. By comparing attendance in services with the overall population percentage it can be identified that there is a lower number of Asian or Asian British people living in accommodation-based services. One possible explanation could relate to differences in culture, whereby Asian families are more likely to look after older family members in their own homes. However, the reasons behind this should be explored further given the diversity within the Borough. Age UK has also found that services for older people can fail to engage older people from a Black, Asian, Minority Ethnic background<sup>34</sup>. For example, some older people may not be proficient in the English language and can only converse in their first language. This presents a barrier to attending services that are designed for English speakers and only have English speaking staff. From the data above we cannot currently discern the reasons for or between the active choice not to engage with services and services that are inaccessible to all, particularly for minority groups.

However, it is critical to note that the data is on Council provided services only, which reflects a different demographic of need in comparison to the wider older population.

Other older people may organise their own support and services, more likely to be affluent White populations, which is not reflected in the table.

<sup>31</sup> Percentage of people aged 65 and over who were still at home 91 days after discharge from hospital', Public Health Profiles, 2018-19. Available at:

 $<sup>\</sup>underline{https://fingertips.phe.org.uk/search/91\%20days\#page/3/gid/1/pat/6/par/E12000007/ati/102/are/E09000026/iid/90584/age/27/sex/4.}$ 

<sup>&</sup>lt;sup>32</sup> Richmond Accommodation-Based Care Commissioning Statement 2018-19, Commissioning Programme and Business Intelligence, September 2020.

<sup>33</sup> Ibid.

<sup>34 &#</sup>x27;Connecting with culture to reduce loneliness amongst ethnic minority communities', Age UK, 2018. Available at: https://www.ageuk.org.uk/our-impact/policy-research/loneliness-research-and-resources/connecting-cultured-to-reduce-loneliness/.

Table 5: Council arranged service users by ethnicity in Richmond, 2018/19

Service Attendance of people aged 65+ by Ethnicity 2018/19									
	Population	%*	Community	%**	Accommodation	%**			
White	29,056	92%	655	90%	540	95%			
Asian or Asian British	1,785	6%	37	5%	8	1%			
Other Ethnic Groups	403	1%	17	2%	11	2%			
Mixed	286	1%	1	0%	0	0%			
Black or Black British	217	1%	17	2%	7	1%			

<sup>\*</sup>Percentage of the overall 65 plus population.

Source: Richmond Adult Social Care

### 5.1 Falls

A fall is defined as an event which causes a person to, unintentionally, rest on the ground or lower level, and is not a result of a major intrinsic event or overwhelming hazard<sup>35</sup>.

The Public Health Outcomes Framework reported that in 2017 to 2018 there were around 220,160 emergency hospital admissions related to falls among patients aged 65 years and over, with around 146,665 (66.6%) of these patients aged 80 and over<sup>36 37</sup>.

The likelihood and severity of injury resulting from a fall is related to bone health. People with low bone mineral density are more likely to experience a fracture following a fall. One of the main reasons why people have low bone mineral density is osteoporosis. In the UK, over 3 million people in the UK have osteoporosis and they are at much greater risk of fragility fractures.

The human cost of falling includes distress, pain, injury, loss of confidence, loss of independence and mortality. Falling also affects the family members and carers.

Financially, unaddressed fall hazards in the home are estimated to cost the NHS in England £435 million. The total annual cost of fragility fractures to the UK has been estimated at £4.4 billion which includes £1.1 billion for social care; hip fractures account for around £2 billion of this sum. Short and long-term outlooks for patients are generally poor following a hip fracture, with an increased one-year mortality of between 18% and 33%, and negative effects on daily living activities such as shopping and walking<sup>38</sup>.

<sup>\*\*</sup>Percentage of the ethnic group attending community or accommodation services

<sup>35</sup>https://www.gov.uk/government/publications/falls-applying-all-our-health/falls-applying-all-our-health

<sup>&</sup>lt;sup>36</sup>https://fingertips.phe.org.uk/profile/public-health-outcomes-

framework/data#page/3/gid/1000042/pat/6/par/E12000007/ati/102/are/E09000032/iid/22401/age/27/sex/4

<sup>&</sup>lt;sup>37</sup>https://fingertips.phe.org.uk/profile/public-health-outcomes-

<sup>&</sup>lt;sup>38</sup>https://www.gov.uk/government/publications/falls-applying-all-our-health/falls-applying-all-our-health

### **At-Risk Groups**

As people get older, they are more likely to fall. Furthermore, falls can become recurrent and result in injuries including head injuries and hip fractures.

Falls and fall-related injuries are a common and serious problem for older people. People aged 65 years and older have the highest risk of falling, with 30% of people older than 65 years, and 50% of people older than 80 years falling at least once a year<sup>39</sup>.

Amongst older people living in the community, 5% of those who fall in a given year will end up with fractures and hospitalisation. One in two women and one in five men in the UK will experience a fracture after the age of  $50^{40}$ .

The causes of having a fall are often multifactorial and occur due to the presence of risk factors. Risk factors for falls include, but are not limited to, a history of falls, muscle weakness, poor balance, visual impairment, polypharmacy, environmental hazards, and a number of specific conditions<sup>41</sup>.

### Hospital Admissions as a Result of a Fall

Falls are the largest cause of emergency hospital admissions for people aged 65 years +, and substantially impact on long term health outcomes of older adults, often resulting in people moving from their own home to long-term nursing or residential care.

Richmond's latest rate of emergency admission due to falls in people aged 65 years + was 2,567 per 100,000 population (n=825, 5th highest rate in London, Figure 27), which was 15.5% higher than the England average and 15.9% higher than London average. The latest Borough figure was also 35.6% higher from year 2010/11, in comparison with a 4.5% increase in England's rate in the equivalent time period. Richmond's rate has been steadily decreasing between 2012 and 2016; in 2017/18 it increased substantially and remains significantly higher than the averages for London and England ever since (Figure 28).

<sup>39</sup> https://www.nice.org.uk/guidance/cg161/chapter/Introduction

<sup>40</sup> https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2017/03/falls-fracture.pdf

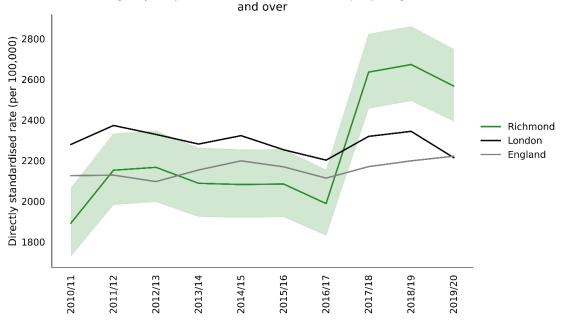
<sup>&</sup>lt;sup>41</sup> https://www.gov.uk/government/publications/falls-applying-all-our-health/falls-applying-all-our-health

Directly standardised rate (per 100,000) Emergency hospital admissions due to falls in people aged 65 and over, 2019/20 England 3000 London 2500 2000 1500 1000 500 0 Islington Ealing Merton Richmond Wandsworth **Tower Hamlets** Hammersmith and Fulham Camden Barnet Brent Kensington and Chelsea Enfield Redbridge Barking and Dagenham Harrow Southwark Croydon Greenwich Haringey Newham Waltham Forest Hounslow Kingston Hackney Lambeth \_ewisham Hillingdon Bromley Bexley Westminster

Figure 27: Emergency hospitalisations following falls in people aged 65 years + by local authority, 2019/20

Source: PHE Public Health Profiles

Figure 28: Emergency hospitalisations following falls in people aged 65+, 2010–2020 Emergency hospital admissions due to falls in people aged 65

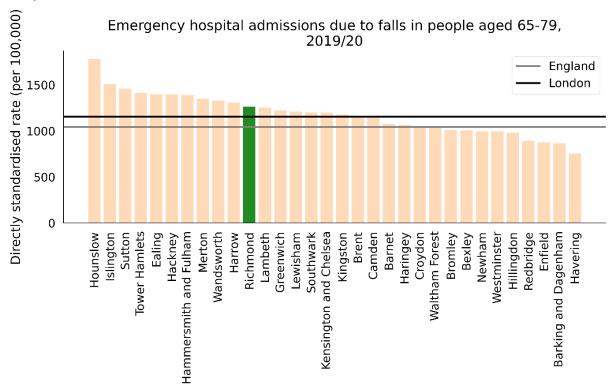


<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values Source: PHE <u>Public Health Profiles</u>

The rate of hospitalisation following a fall in people aged 65-79 years remains above the England and London average rates showing some signs of improvement in 2019/20. Richmond's latest rate was 1262.3 (n=280, 11th highest rate in London, **Figure 29**), which was 21.2% higher than the England average and 9.3% higher than London average. The latest Borough figure was also 34.2% higher from

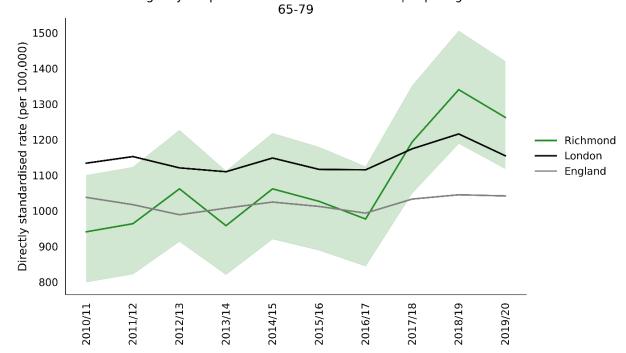
year 2010/11, in comparison with a 0.4% increase in England's rate in the equivalent time period (Figure 30).

Figure 29: Emergency hospitalisations following falls in people aged 65-79 years by local authority, 2019/20



Source: PHE Public Health Profiles

Figure 30: Emergency hospitalisations following falls in people aged 65-79 years 2010–2020 Emergency hospital admissions due to falls in people aged



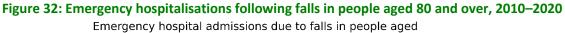
<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values Source: PHE Public Health Profiles

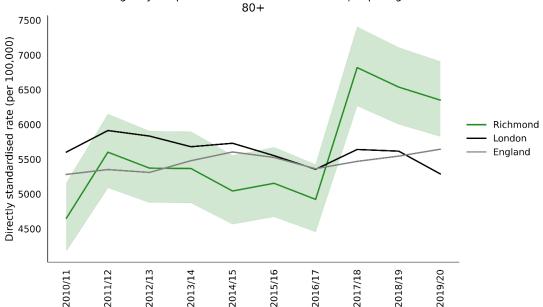
Richmond's latest rate of emergency hospitalisations following a fall in residents aged 80+ was 6350.4 (n=545, 4th highest rate in London, **Figure 29**), which was 12.5% higher than the England average and 20.1% higher than London average. The latest Borough figure was also 36.5% higher from year 2010/11, in comparison with a 6.9% increase in England's rate in the equivalent time period (**Figure 30**). As in other age ranges, hospitalisations for falls have increased substantially in 2017/18 and, although some reductions had taken place since then, falls still remains substantially above the averages for England and London.

Directly standardised rate (per 100,000) Emergency hospital admissions due to falls in people aged 80+, 2019/20 England London 6000 4000 2000 0 Ealing Enfield Camden Hammersmith and Fulham Brent Barking and Dagenham Richmond Croydon Harrow Nandsworth Barnet Islington Kingston Southwark Hillingdon **Tower Hamlets** Bexley ewisham Greenwich Kensington and Chelsea Westminster Redbridge Havering Waltham Forest Hounslow Lambeth Newham Bromley Haringey Hackney

Figure 31: Emergency hospitalisations following falls in people aged 80 and over by local authority, 2019/20

Source: PHE Public Health Profiles





<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values Source: PHE <u>Public Health Profiles</u>

### **Hip Fractures**

Hip fracture, in many cases a result of a fall, substantially affects mobility of older people – only around 30% of affected patients return to the levels of independence prior to the fracture and one in three ends up leaving their own home and moving to long-term care<sup>42</sup>.

Richmond's latest rate of hip fractures in people aged 65+ was 501.6/100,000 population (n=165, 10th highest rate in London, Figure 33), which was 12.2% lower than the England average and 6.1% higher than London average. The latest Borough figure was also 16.7% lower from year 2010/11, in comparison with a 7.1% decrease in England's rate in the equivalent time period (Figure 34).

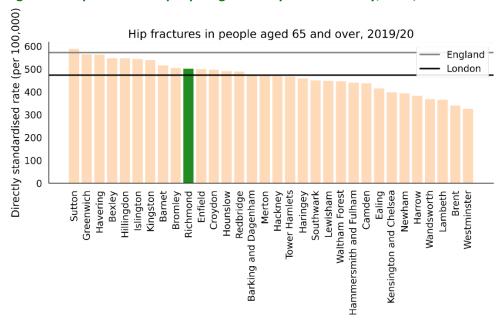


Figure 33: Hip fractures in people aged 65+ by local authority, 2019/20

Source: PHE Public Health Profiles

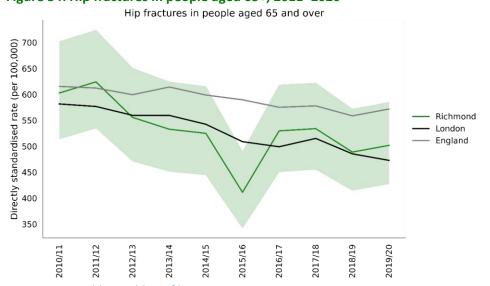


Figure 34: Hip fractures in people aged 65+, 2011-2020

Source: PHE, <u>Public Health Profiles</u>

<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values

<sup>&</sup>lt;sup>42</sup> National Hip Fracture Database (NHFD), National Hip Fracture Database. National report 2013. Available

### **Current Services on Offer**

In Richmond, there is an Integrated Falls and Bone Health Service which aims to reduce the rate and risk of falls and fragility fractures amongst Richmond adults, and to improve the health and mobility of older people and sustain their independence. The service targets people who have had recurrent or occasional falls, those who feel at risk or afraid of falling and those aged 50+ for bone health management<sup>43</sup>.

Additionally, several voluntary and community organisations provide strength and balance exercises as listed below:

- Age UK (falls prevention classes, strength and balance and Tai Chi classes at Age UK)
- Teddington Pools (falls prevention exercise classes for referrals only from Falls service)
- The Richmond Charities (strength and balance classes)
- The Cambrian Community Centre (a gym in Richmond offering exercise referral for Tai Chi classes)

Of note, key stakeholders from Kingston and Richmond, led by the CCG, are currently in the process of improving the current falls pathway in order to create a more integrated and streamlined approach to falls prevention.

#### **Evidence-based Interventions**

NICE and Public Health England lead on providing evidence-based guidance with regards to falls prevention, outlining approaches to interventions and activities helping to prevent falls and fractures in older people.

#### **NICE Clinical Guideline**

Falls in older people: assessing risk and prevention, CG161, June 2013

Strength and balance training is recommended as part of an individualised multifactorial intervention. Those most likely to benefit are older people living in the community with a history of recurrent falls and/or balance and gait deficit. A muscle-strengthening and balance programme should be individually prescribed and monitored by an appropriately trained professional<sup>44</sup>.

#### **Public Health England**

Falls and fracture consensus statement, Supporting commissioning for prevention, PHE, January 2017 Falls and fracture consensus statement: resource pack, PHE, July 2017

The National Falls Prevention Coordination Group's <u>Falls and fracture consensus statement</u> (2017) advocates a collaborative and whole system approach to prevention, response and treatment. This includes:

- promoting healthy ageing across the life-course
- evidence-based case finding and risk assessment
- evidence-based strength and balance exercise programmes and opportunities for those at low to moderate risk of falls
- ensuring safe homes
- demonstrating actions to reduce risk in high-risk health and care environments
- fracture liaison services
- evidence-based collaborative care for falls-related severe injury.

<sup>43</sup> https://www.hrch.nhs.uk/our-services/services-directory/services-in-richmond/falls-and-bone-health/

<sup>44</sup> https://www.nice.org.uk/guidance/cg161/chapter/Introduction

Interventions for older people living in the community with a low to moderate risk of falling should include strength and balance exercise programmes. These programmes are effective for primary and secondary falls and non-vertebral fractures in older people, but more effective for those who have a history of recurrent falls or who have a balance or gait deficit.

While there is evidence that walking has numerous health benefits for older people in general, it should not be included in programmes for participants considered at high risk of falling as this may result in further falls.

In order to be effective, programmes must:

- be continued over a duration of at least 50 hours
- be carried out two to three times a week
- challenge balance and improve strength through resistance training and exercise in a standing position
- be sufficiently progressive
- be tailored to the individual, pitched at the right level, taking falls history and medical conditions into account
- be delivered by specially trained instructors.

At the end of the programme, older people should be assessed and offered a range of follow-on classes. These should suit their needs and abilities, include strength and balance, and support their progression<sup>45</sup> <sup>46</sup>.

Falls prevention requires a collaborative and comprehensive approach, by the possible model of a falls prevention care pathway published by Age UK (Figure 35).

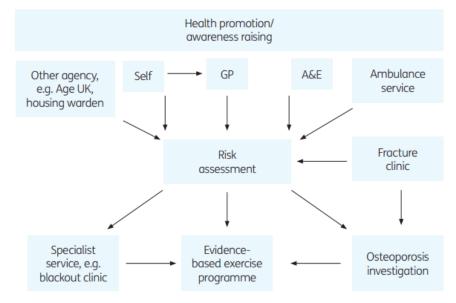


Figure 35: Falls prevention - collaborative model

Source: Age UK

<sup>&</sup>lt;sup>45</sup>https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/586382 /falls and fractures consensus statement.pdf

<sup>&</sup>lt;sup>46</sup>https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/628732 /Falls and fracture consensus statement resource pack.pdf

Age UK advises that services should offer a choice of referral to an evidence-based exercise programme such as the Otago Exercise Programme or Postural Stability. For those who have not had a fall, effective exercise programmes can also include Tai Chi, dancing and other general exercise classes that include components of strength and balance<sup>47</sup>.

There is evidence of cost-effectiveness for certain falls prevention interventions includes:

- Falls Management Exercise (FaME) group programme
- Otago home exercise
- Tai Chi group exercise
- Home assessment and modification (HAM) in which professionals complete a risk assessment
  of a person's usual place of residence to identify environmental hazards and carries out
  actions to reduce the possible risks.

A tool, commissioned by PHE, was developed to assess the return on investment (ROI) for these four programmes. The findings from this analysis indicate that all four interventions could be considered cost-effective when compared with usual care (i.e., no falls prevention service) in an English setting. It was noted that one out of the four interventions (home assessment and modification) should produce a positive financial return. For the remaining three interventions (Otago, FaME and Tai Chi) it was noted that, whilst not providing a positive financial ROI, there would be a positive societal return (i.e., improved quality of life) on the initial investment<sup>48 49</sup>.

An internal falls prevention exercise evidence review (2019), carried out by Richmond and Wandsworth Public Health team, found literature to support Otago and Tai Chi. Evidence was found to support Tai Chi for reducing falls, or risk of falls, among elderly people, although, not for those who are frail. There was also evidence to suggest that alternative models of Otago in the community could be effective; although it was noted that further studies would be required to confirm and develop these findings.

Group-based exercise has been shown to be effective. However, this should be targeted group exercise that has been individually prescribed. Evidence also showed that home-based exercise could reduce the risk and rate of falls, which could benefit those unable or reluctant to attend group classes.

Overall, the optimum approach for older people living in the community at risk of falling should include strength and balance exercise. Evidence-based exercise programmes recommended are FaME, Otago, and Tai Chi, and should be prioritised for consideration for local falls prevention exercise programmes. Other interventions reviewed provide benefits for strength and/or balance, such as dance, pilates, yoga and Nordic Walking. More research is needed to confirm their effectiveness in preventing falls among older people.

Falls prevention requires a multi-disciplinary, collaborative and whole-systems approach, with priority towards recognising individuals at risk and adopting a personalised yet multi-faceted approach to falls prevention.

<sup>&</sup>lt;sup>47</sup>https://www.ageuk.org.uk/documents/en-gb/campaigns/stop\_falling\_report\_web.pdf?dtrk=true\_

<sup>&</sup>lt;sup>48</sup>https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/679885 /Structured\_literature\_review\_report\_falls\_prevention.pdf

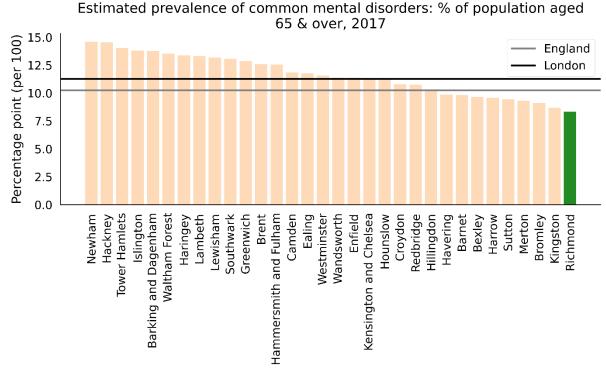
<sup>&</sup>lt;sup>49</sup>https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/679856 /A\_return\_on\_investment\_tool\_for\_falls\_prevention\_programmes.pdf

### 5.2 Common Mental Disorders

Estimated prevalence of common mental disorders (CMD) in elderly provides a valuable support in planning of preventative mental health interventions, such as psychological therapies. The indicator is designed to estimate local prevalence of CMD using national survey estimates for specific population cohorts and applying them to local demography. Mental health problems have detrimental impact on mobility of older adults<sup>50</sup>.

Richmond's 2017 estimate of proportion of people aged 65+ with CMD was 8.3 per 100 (n=2514, lowest rate in London, **Figure 36**), was 18.7% lower than the England average and 26.2% lower than London average. No time trend information is available for the estimates.

Figure 36: Estimated prevalence of common mental disorders in people aged 65+ by local authority, 2017



Source: PHE <u>Public Health Profiles</u>

## 5.3 Care and Support Services for Older People

When an older person finds themselves requiring care and support, they can arrange their care privately or through the local authority. The local authority will financially support people eligible needs. Care and support can either be provided in the community or in accommodation-based settings. Richmond Council will first explore the opportunities with community-based care as they enable the person to live independently in their own home for as long as possible. In turn, this helps the individual to build resilience and have more choice and control. Wherever a person can receive care in the community, depends on their level of need. Those with lower level needs will be supported to live safely and independently at home.

-

<sup>&</sup>lt;sup>50</sup> Rethink Mental Illness, Lethal Discrimination, 2013

These services for older people include:

- home care
- blitz clean
- delivered meals
- specialist day centre for adults with dementia
- specialist day centre for adults with a physical disability and older people
- open access centres
- advocacy services
- community equipment, including telecare.

An older person may require help with preparing food, cleaning or personal care. An appropriate services might be delivered meals or a support worker to provide help at set times throughout the day. Additional support can also be provided through simple aids and equipment, such as walking frames, handles and washing aids, which can assist people to live independently in their own home to prevent accidents and personal neglect. This may also include the use of assistive technologies and telecare (please more information below). More complex needs can be supported through the Disabled Facilities Grant (DFG), such as housing renovations including, ramps, stairlifts and door widening. The most common DFG is the level access shower, helping people to maintain their personal independence. All these services help people to complete practical daily tasks, however other day services are focused on wider wellbeing of the person.

Older people are encouraged to participate in the community through day centre provisions located across the borough. Depending on the scope of the service, they engage in their interests, socialise, learn new skills and can access hot meals. Many of these services are run by the voluntary sector. Richmond upon Thames has a vibrant voluntary sector for older people coordinated by the Community Independent Living Service (CILS). The CILS Health and Wellbeing partnership of twenty charities provides varied services and support through the central access point of the CILS Information Navigation Service. Charities who provide these services include Richmond AID, Age UK and Mind<sup>51</sup>. Age UK Richmond upon Thames is well established within the borough. An example of their services is community outreach that targets older people unable or reluctant to access support, particularly isolated older men<sup>52</sup>. As Richmond Council works to align its services towards a prevention agenda, the role of the voluntary sector will continue to be of critical importance.

Community-based support is not safe or appropriate for all older people. Individuals with higher levels of need may receive more intensive accommodation-based services, which fall into three main types of services:

- Extra Care
- Residential Care
- Nursing Homes.

Specialist services for older people with learning disabilities and sensory impairments are also available in both community and accommodation settings. In Richmond, there are 34 commissioned care homes, 2 commissioned day services for older people and 2 commissioned extra care services. Please note that this does not include services that local authority does not commission. (Figure 37).

<sup>&</sup>lt;sup>51</sup> Directory of Wellbeing and Voluntary Sector Services in Richmond upon Thames, CILS, 2019.

<sup>&</sup>lt;sup>52</sup> Age UK, Richmond upon Thames, 2020. Available at: <a href="https://www.ageuk.org.uk/richmonduponthames/">https://www.ageuk.org.uk/richmonduponthames/</a>.

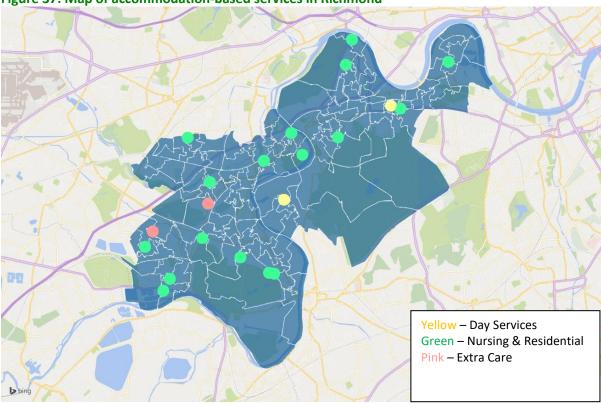


Figure 37: Map of accommodation-based services in Richmond

The services above for older people are either available for all older people or means tested depending on the type of service. For someone to receive accommodation-based and home care services they must meet the conditions set out in the Care Act and have less than £23,250 in capital/and or savings, to receive council funded care and support services. However, the challenge to meet demand will continue to grow alongside the estimated growth in the population of older people, including those aged 85 years and over who tend to have the highest care and support needs. Therefore, there will be a future unmet need in services for older people if service capacity remains at present levels.

Furthermore, Covid-19 has significantly impacted older people, the extent of which is not yet fully understood. For example, Covid-19 may impact on population predictions due to the higher death rates in 2020 of people aged 65 years and over. Many older people may be living with the symptoms of long-term Covid-19. Furthermore, many older people may experience cognitive decline or mental health issues from having to live in isolation from other people. At this stage, it is unknown how farreaching the impact of Covid-19 has been on older people, but it is expected to be significant. Richmond Council will need to continue to support people by ensuring the aspirations of the Care Act 2014 are embedded into the care system and commissioning of services.

### 5.4 Interventions aimed at Improving Mobility in Older People

The Care Act 2014 lays out the responsibility for local authorities to 'prevent, reduce and delay' the development of needs for care and support<sup>53</sup>. Richmond Council is developing preventative and community interventions to promote independence and self-care such as use of assistive technology, equipment and adaptations, reducing reliance on more intensive health and social care support. It has adopted a strengths-based approach to social work practice and services. This is a holistic and multidisciplinary approach to harness an individual's abilities, strengths and interests as the focus of interventions. By building up positive aspects in a person's life it is hoped that they will develop resilience and independence to cope better with challenges. For example, slowing the onset of frailty has a positive impact on a person's quality of life and ability to live independently. A strengths-based approach is achieved in close collaboration with family, friends and the community. Prevention is also at the centre of the strengths-based approach. By improving the health and wellbeing of individuals throughout their life will also reduce their risk of developing life-limiting conditions that can have a detrimental impact on their independence. Ultimately, prevention will reduce the number of people who will require health and social care support later in life.

Social connections also have wide reaching benefits for older people as studies have found that frequent social contact with close family and friends are beneficial for lessening the impact of frailty<sup>54</sup>.

Ultimately, it is important that professionals recognise and address the wider determinants of health because early interventions effectively promote health and wellbeing. Furthermore, in the future, there will be an increasing focus on assistive technology, which has a strong evidence base demonstrating its ability to increase well-being, maintain people's independence for longer, and prevent the need for more intensive and costly health and care interventions. Assistive technology is an umbrella term covering devices, online and behavioural approaches, and apps that can help deliver health and care more efficiently, whilst maintaining or improving an individual's independence.

### 5.5 Data Sources

Within the chapter most of the data was taken from:

- Greater London Authority (2017); GLA 2018-based Housing-led Ethnic Group Population Projections
- Office for National Statistics (2013). Data extracted from 2011 census
- Projecting Older People Population Information (2018-19)
- Public Health England (2020). Data extracted from health profiles.

https://www.legislation.gov.uk/ukpga/2014/23/pdfs/ukpga 20140023 en.pdf.

<sup>&</sup>lt;sup>53</sup> The Care Act 2014, Chapter 23. Available at

<sup>&</sup>lt;sup>54</sup> Chamberlain A et al., Social and behavioural factors associated with frailty trajectories in a population-based cohort of older adults, British Medical Journal, 2016. Available at: https://bmjopen.bmj.com/content/6/5/e011410.

# 6. Adult Social Care Outcomes

The Adult Social Care Outcomes Framework (ASCOF) measures how well care and support services achieve the outcomes relevant to the service users and carers. The ASCOF is used both locally and nationally to set priorities for care and support and measure progress against a set of social care indicators<sup>55</sup>. This section reports Richmond's performance on ASCOF indicators, including the latest ASC survey results, for service users and carers aged 65 years and over.

### 6.1 Reablement Following Hospital Discharge

The proportion of older people aged 65 years and over offered reablement services following discharge from hospital captures the volume of reablement offered locally<sup>56 57</sup>. When combined with the measure determining whether an individual remains living at home 91 days following discharge, it helps to quantify the success of the reablement service offered within Richmond and compare it to other local authorities in London. Ideally, the number of reablement services offered to residents aged 65+ is high while the proportion of successful reablement services preventing residents from leaving their homes is also high.

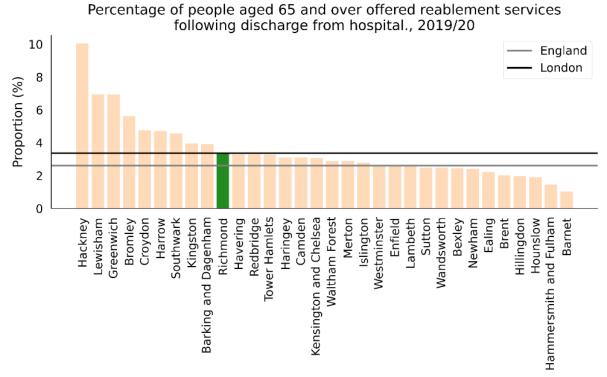
In 2019/20, Richmond's percentage of people aged 65 years and over offered reablement services following discharge from hospital was 3.4% (n=149, 10th highest rate in London, **Figure 38**), which was 28.9% higher than the England average and 0.2% lower than London average. The latest Borough figure was also 120.7% higher from year 2010/11, in comparison with a 12.3% decrease in England's rate in the equivalent time period (**Figure 39**). The percentages for Richmond have been decreasing from the peak level of 7% in 2013/14.

<sup>55</sup> NHS Digital. Adult social care outcomes framework (ASCOF). 2021

<sup>&</sup>lt;sup>56</sup> This is Adult Social Care Outcome Framework (ASCOF) Indicator 2B(2). Further details are provided in the ASCOF Handbook of Definitions available <u>here</u>.

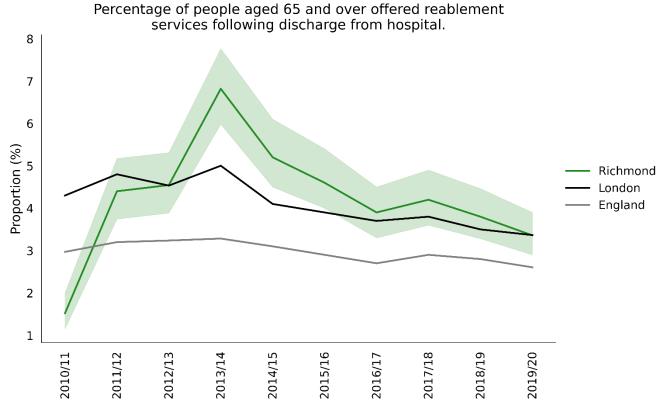
<sup>&</sup>lt;sup>57</sup> ASCOF Indicator 2B(2) data from: <a href="https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-outcomes-framework-ascof">https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-outcomes-framework-ascof</a>

Figure 38: Proportion of people aged 65+ offered reablement services following discharge from hospital by local authority, 2019/20



Source: PHE Public Health Profiles

Figure 39: Proportion of people aged 65+ offered reablement services following discharge from hospital, 2011–2020



<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values

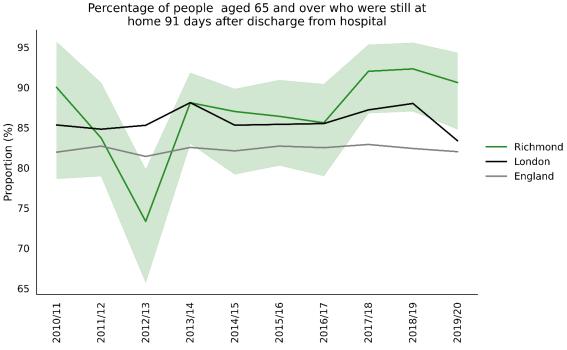
Richmond's latest percentage of people aged 65 years and over who were offered reablement services and were still at home 91 days after discharge from hospital was 90.6% (n=135, 10th highest rate in London, **Figure 40**), which was 10.5% higher than the England average and 8.7% higher than London average. The latest Borough figure was also 0.7% higher from year 2010/11, in comparison with a 0.1% increase in England's rate in the equivalent time period (**Figure 41**).

Figure 40: People aged 65+ who were offered reablement and were still at home 91 days after discharge from hospital by local authority, 2019/20

Percentage of people aged 65 and over who were still at home 91 days after discharge from hospital, 2019/20 80 Proportion (%) 60 England London 40 20 0 Richmond Hillingdon Kingston Newham Ealing Barnet Croydon Kensington and Chelsea Merton Brent Enfield Hammersmith and Fulham Redbridge Bexley Havering Barking and Dagenham Waltham Forest Hounslow Islington Southwark Sutton Tower Hamlets Mandsworth Harrow Greenwich Lewisham Hackney Westminster Camden Haringey

Source: PHE Public Health Profiles

Figure 41: People aged 65+ who were offered reablement and were still at home 91 days after discharge from hospital, 2011–2020

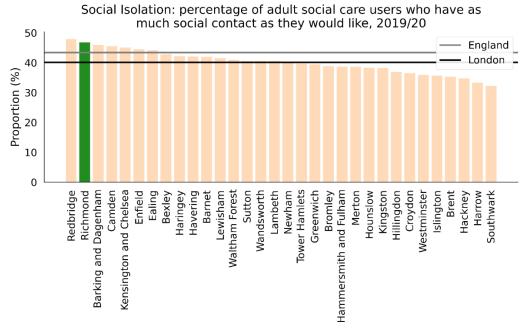


<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values

### 6.2 Social Isolation

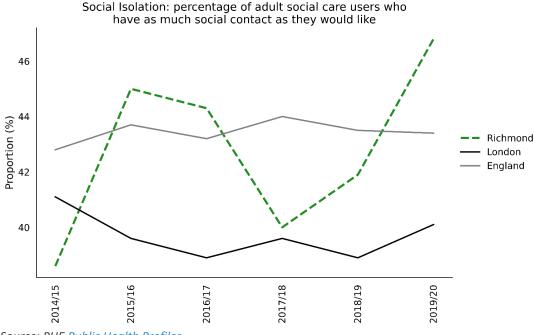
In 2019/20 in Richmond the percentage of adult social care users who have as much social contact as they would like was 46.8% (n=430, 2nd highest rate in London, **Figure 42**), which was 7.8% higher than the England average and 16.7% higher than London average. The latest Borough figure was also 21.2% higher from year 2014/15, in comparison with a 1.4% increase in England's rate in the equivalent time period (**Figure 43**).

Figure 42: Social care users that reported having as much social contact as they would like by local authority, 2019/20



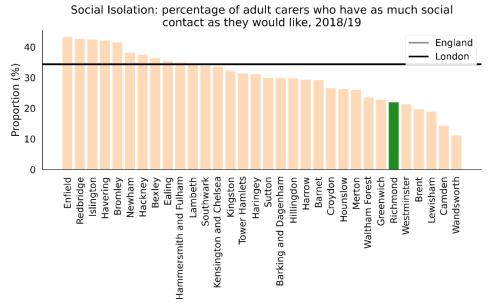
Source: PHE Public Health Profiles

Figure 43: Social care users that reported having as much social contact as they would like, 2011–2020



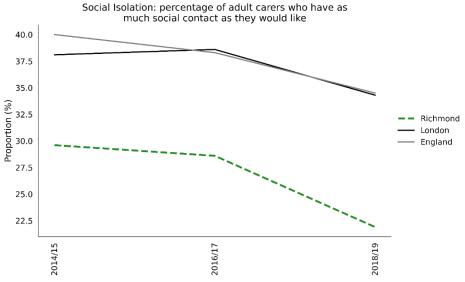
Richmond's latest percentage of adult carers who have as much social contact as they would like <sup>58</sup> <sup>59</sup> was 21.9% (n=15, 6th lowest rate in London, **Figure 44**), which was 36.5% lower than the England average and 36.2% lower than London average. The latest Borough figure was also 26.0% lower from year 2014/15, in comparison with a 13.8% decrease in England's rate in the equivalent time period (**Figure 45**).

Figure 44: Adult carers aged 65+ who have as much social contact as they would like by local authority, 2018/19



Source: PHE Public Health Profiles

Figure 45: Adult carers aged 65+ who have as much social contact as they would like, 2015–2019



Source: PHE Public Health Profiles

<sup>58</sup> Latest year published by PHE is 2018/19 and was sourced from <u>Personal Social Services Survey of Adult Carers in England (NHS Digital)</u>

<sup>&</sup>lt;sup>59</sup> Indicator definition: The percentage of respondents to the Personal Social Services Carers Survey who responded to the question "Thinking about how much contact you have had with people you like, which of the following best describes your social situation?" with the answer "I have as much social contact I want with people I like".

# 7. Vaccinations

Vaccination coverage is the best indicator of the level of protection a population will have against vaccine preventable communicable diseases. There are three vaccinations routinely offered to people aged 65 years and over: seasonal flu vaccine, pneumococcal polysaccharide vaccine (PPV) and shingles vaccine.

### 7.1 Seasonal Flu Vaccine

In 2019/20, Richmond's flu vaccination coverage among people aged 65 years and over was 67.6% (n=20512, 9th highest rate in London, **Figure 46**), which was 6.7% lower than the England average and 2.1% higher than London average. The latest Borough figure was also 11.9% lower from year 2010/11, in comparison with a 0.6% decrease in England's rate in the equivalent time period (**Figure 47**).

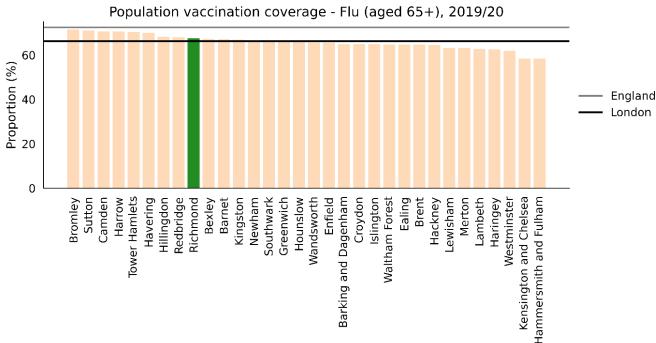


Figure 46: Flu vaccination coverage in people aged 65+ by local authority, 2019/20

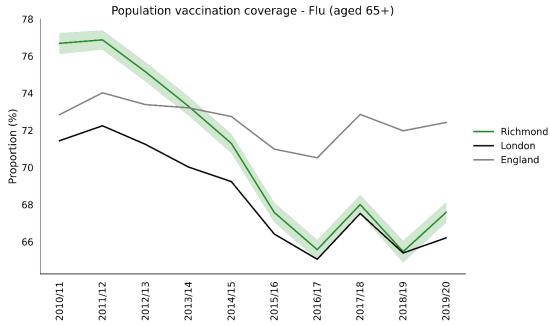


Figure 47: Flu vaccination coverage in people aged 65+, 2011–2020

Source: PHE, Public Health Profiles

## 7.2 Pneumococcal Polysaccharide Vaccine

Richmond's latest pneumococcal polysaccharide vaccine (PPV) vaccination coverage in people aged 65+ was 62.5% (n=21,398, 12th lowest rate in London, **Figure 48**), which was 9.4% lower than the England average and 1.8% lower than London average. The latest Borough figure was also 16.2% lower from year 2010/11, in comparison with a 2.1% decrease in England's rate in the equivalent time period (**Figure 49**).

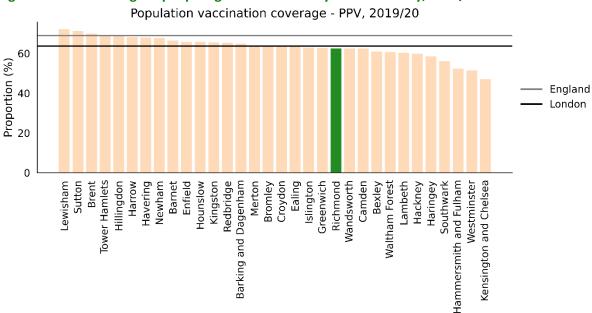


Figure 48: PPV coverage in people aged 65 and over by local authority, 2019/20

<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values

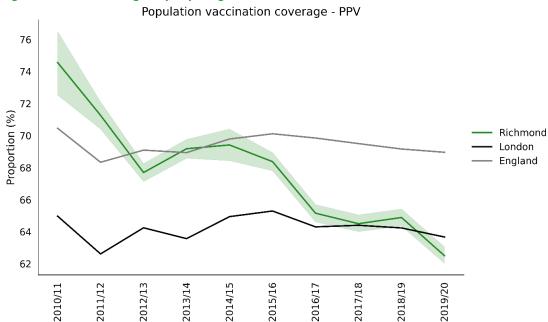


Figure 49: PPV coverage in people aged 65 and over, 2011–2020

Source: PHE, Public Health Profiles

## 7.3 Shingles Vaccine

In 2018/19, shingles vaccination coverage in people aged 71 in Richmond was 49.1% (n=951, 11th highest rate in London, Figure 50), which identical to the England average and 6.8% higher than the London average. There is no time series data for this indicator.

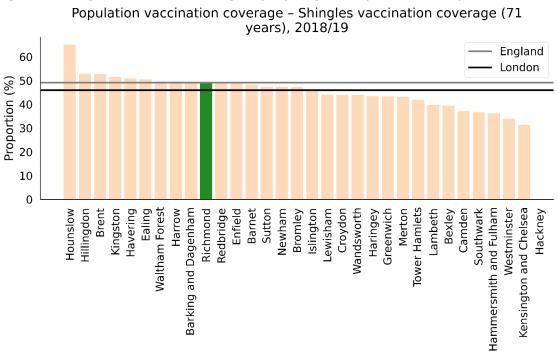


Figure 50: Shingles vaccination coverage in people aged 71 by local authority, 2018/19

<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values

# 8. Dementia Prevention and Care

This dementia section builds on the 2019 Dementia health needs assessment and provides a common view of health and care needs for local dementia residents and carers. It documents current service provision, identifies gaps in health and care services, identifies unmet needs, and details evidence of effectiveness for different health and care interventions. Furthermore, it draws on a wide range of quantitative and qualitative data to bring together information from different sources and partners to create a shared evidence base, which supports health and social care service planning, decision-making, and delivery. It can also be utilised by other organisations, including the voluntary and community sector, to collaboratively plan services that meet the needs of the local population.

Important resources that have been used to compile the JSNA include the following as well as additional background information, data, and intelligence:

- Public Health Outcomes Framework (PHOF)
- Public Health England (PHE) data and analysis tools
- Quality and Outcomes Framework (QOF)
- Projecting Adult Needs and Service Information (PANSI)
- Projecting Older People Population Information (POPPI)
- NHS Digital
- Office for National Statistics
- NHS England Statistics
- DataWand

Dementia is a progressive disease often associated with complex health and social care needs. These needs are expected to increase in Richmond, as a result of expected increases in numbers of older adults living in the Borough. There are several gaps and opportunities that should be addressed to improve the dementia offer across Richmond. Therefore, enacting a comprehensive dementia prevention and care support offer for residents affected by and living with dementia remains a key focus for Richmond Council alongside partners across the health and social care arena.

### 8.1 Dementia Definition

Dementia is a neurological syndrome and an umbrella term which refers to a group of conditions. Although often thought of as a disease of older people, around 5% of people with Alzheimer's disease are under 65 years old. This is called early-onset or young-onset Alzheimer's and usually affects people in their 40s, 50s and early 60s, with around 5% of people with Alzheimer's disease under 65 years old. Early onset dementia is caused by generally similar diseases to dementia in older people (known as 'late-onset dementia'), but there are differences to note. There is a wider range of diseases that cause young-onset dementia, and a younger person is much more likely to have a rarer form of dementia. Alzheimer's is the most common cause of early-onset dementia. However, there are other causes in younger people, such as frontotemporal dementia (FTD) and much rarer causes such as Huntington's disease and Creutzfeldt-Jakob disease (CJD). A person with young-onset dementia may experience different symptoms from the memory loss usually associated with dementia in older people. They could have, for example, problems with behaviour, vision, or language.

There is no cure for dementia and the progressive deterioration that it causes results in high morbidity and, invariably, an earlier death.

### 8.2 Causes of Dementia

Dementia is not a single disease but is a term used to describe the symptoms that occur when there is a decline in brain function. Several different diseases can cause dementia (Figure 51). Many of these diseases, such as in Alzheimer's, are associated with an abnormal build-up of proteins in the brain. This build-up causes nerve cells to function less well and ultimately die. As the nerve cells die, different areas of the brain shrink. In vascular dementia, if the oxygen supply to the brain is reduced because of narrowing or blockage of blood vessels, some brain cells become damaged or die; in dementia with Lewy bodies tiny abnormal structures (Lewy bodies) form inside brain cells, disrupting the chemistry of the brain and lead to the death of brain cells.

Figure 51: Dementia sub-types<sup>60</sup>

### Dementia sub-types

- •Alzheimer's disease: The most common form of dementia, accounting for approximately 60% of all dementia cases. Alzheimer's typically starts with impairment of episodic memory before affecting other brain functions.
- Vascular dementia: The second most common cause of dementia, accounting
  for approximately 20% of cases of dementia in the UK. Vascular dementia
  typically presents with a stepwise deterioration in brain function, occasionally
  with localised weakness or reduction in vision.
- Dementia with Lewy bodies (DLB): The third most common form of dementia, it
  accounts for approximately 15% of dementia cases. DLB is often associated with
  delusions, hallucinations and transient loss of consciousness. Occasionally DLB
  can cause difficulty mobilizing.
- •Frontotemporal dementia (FTD): <5% of cases of dementia are due to FTD in the UK. FTD is associated with gradual development of personality change and behavioural disturbance.
- •Other: There are other, less common, forms of dementia.

Dementia is associated with complex needs and, in the later stages of the condition, with high levels of dependency and morbidity and therefore is one of the major causes of disability and dependency among older people worldwide. This is the case not only for the people who have the condition, but also results in challenges for carers and families. In England and Wales, dementia accounts for every 1 in 8 deaths<sup>61</sup> making it the leading cause of death nationally. In 2018 it was estimated that there were around 850,000 people living with dementia, with this number expected to rise to over 1 million by 2025<sup>62</sup>; dementia therefore represents a significant current and, even greater, future challenge for all aspects of our society, with its effects being felt throughout not only the health and social care system, but also within communities, families and by individuals and carers.

<sup>&</sup>lt;sup>60</sup> Dementia - NICE CKS [cited 2019 Oct 18]; Available at: https://cks.nice.org.uk/dementia

<sup>&</sup>lt;sup>61</sup> Deaths registered in England and Wales - Office for National Statistics [cited 2019 Oct 16]; Available at: <a href="https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2018">https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2018</a>

<sup>&</sup>lt;sup>62</sup> Dementia: applying All Our Health. GOV.UK [cited 2019 Oct 16]; Available at: <u>https://www.gov.uk/government/publications/dementia-applying-all-our-health/de</u>

A national study<sup>63</sup> suggested that almost 7 in 10 people with dementia also have one or more other health conditions. It reports that patients with dementia are more likely to have multiple health conditions. A total of 22% live with three or more comorbidities and 8% live with four or more comorbidities, compared to 11% and 3% respectively in the all-patient group.

The impact of dementia on health and wellbeing is significant and is progressively negative. The Alzheimer's Society have reported that people fear dementia more than any other disease. The loss of cognitive functions leads directly to reduced quality of life, increasing ill-health and early death for those living with the condition. A dementia diagnosis, however, does not only impact the affected individual, but it also impacts their family, friends, work-colleagues, and the community and can be physical, emotional, and financial.

Family and friends are often affected through the need for provision of additional care and support, many take on the role of informal carers, carers that are not paid for their services. This results in additional personal strain for them but also loss of earning as they often must remain at home to care for their loved ones. Alzheimer Society estimates that the percentage of carers caring for more than 100 hours per week has increased from 40% to 50% since March 2020<sup>64</sup>. In a wider context, Carers UK's estimates that the average carer is now spending 65 hours a week on caring responsibilities<sup>65</sup>.

The scale of the challenge that dementia poses to communities, local councils and national governments therefore is not to be underestimated, and it is for this reason that it has been identified as being the greatest global challenge for health and social care in the 21st Century.

### 8.3 Dementia Prevalence

In 2020 Richmond's recorded prevalence of dementia in people aged 65+ was 4.0% (14th lowest recorded prevalence in London, **Figure 52**), which was 1.0% higher than the England average and 3.9% lower than London average. The latest Borough figure was also 6.6% lower from year 2017, in comparison with an 8.3% decrease in England's rate in the equivalent time period (**Figure 53**).

<sup>&</sup>lt;sup>63</sup> PHE Dementia Co-morbidities in patient's data briefing, 2019

<sup>&</sup>lt;sup>64</sup> Worst Hit: Dementia During Coronavirus (September 2020)

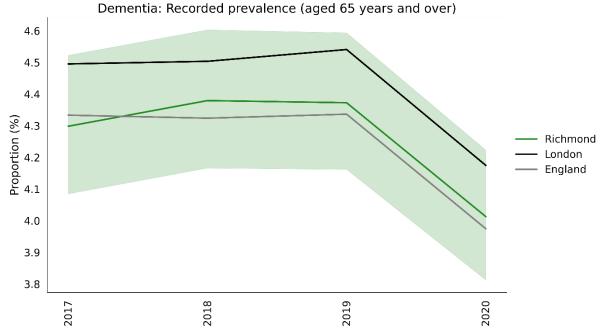
<sup>&</sup>lt;sup>65</sup> Behind Closed Doors, Carers UK (October 2020)

Dementia: Recorded prevalence (aged 65 years and over), 2020 England 5 London Proportion (%) 1 0 Brent Sutton Ealing **Fower Hamlets** Redbridge Kensington and Chelsea Barnet **Waltham Forest** Merton Barking and Dagenham Greenwich Hammersmith and Fulham Islington Wandsworth Croydon Lambeth -ewisham Westminster Bexley Hillingdon Richmond Southwark Harrow Hounslow Kingston Havering Bromley Hackney

Figure 52: Recorded prevalence of dementia in population aged 65+ by local authority, 2020

Source: PHE Public Health Profiles





<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values Source: PHE <u>Public Health Profiles</u>

Based on dementia prevalence estimates, Richmond's health services are identifying and diagnosing 70.1% of the estimated cases (15<sup>th</sup> lowest proportion in London, **Figure 54**), which was 4.0% higher than the England average and 1.7% lower than London average. The latest Borough figure was also 1.0% higher from year 2017, in comparison with a 0.7% decrease in England's rate in the equivalent time period (**Figure 55**).

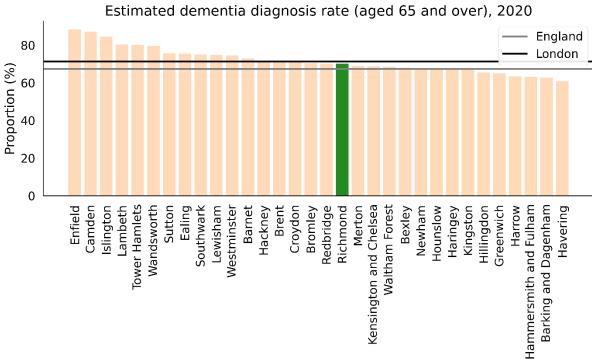
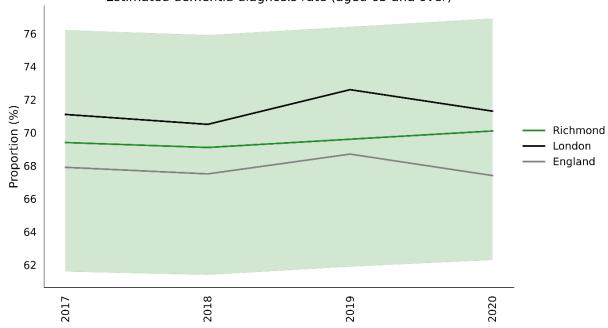


Figure 54: Dementia diagnosis rate in population aged 65+ by local authority, 2020

Figure 55: Dementia diagnosis rate in population aged 65 and over, 2017–2020 Estimated dementia diagnosis rate (aged 65 and over)



<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values Source: PHE <u>Public Health Profiles</u>

### 8.4 Emergency Admissions for Dementia

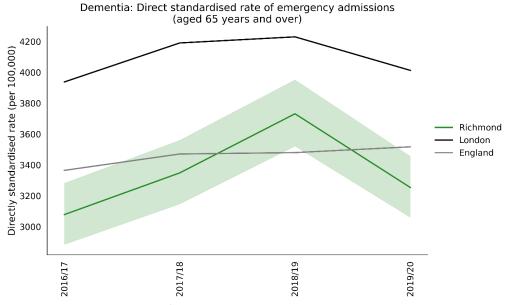
Richmond's latest rate (2019/20) of emergency admissions of people aged 65+ diagnosed with dementia was 3,253.6/100,000 population (n=1065, 6th lowest rate in London, **Figure 56**), which was 7.5% lower than the England average and 18.9% lower than London average. The latest Borough figure was also 5.7% higher from year 2016/17, in comparison with a 4.5% increase in England's rate in the equivalent time period (**Figure 57**). The rate has dropped substantially from the previous year.

Directly standardised rate (per 100,000) Dementia: Direct standardised rate of emergency admissions (aged 65 years and over), 2019/20 6000 England London 5000 4000 3000 2000 1000 0 Bromley Hammersmith and Fulham Sutton Ealing Brent Barking and Dagenham **Tower Hamlets** Islington Hackney Bexley Hillingdon Newham **Kensington and Chelsea** Redbridge Richmond Waltham Forest Enfield Hounslow Wandsworth Merton -ewisham Camden Greenwich Croydon Westminster Barnet Kingston Haringey

Figure 56: Emergency admissions of people aged 65+ with dementia mentioned as a diagnosis by local authority, 2019/20

Source: PHE Public Health Profiles





Source: PHE, <u>Public Health Profiles</u>

<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values

### 8.5 Mortality from Dementia

Richmond's latest directly standardised mortality rate of people aged 65+ living with dementia was 679.6 per 100,000 population (10th lowest in London, Figure 58), which was 20.0% lower than the England average and 5.9% lower than London average. The latest Borough figure was also 9.5% higher from year 2016, in comparison with a 1.9% decrease in England's rate in the equivalent time period (Figure 59).

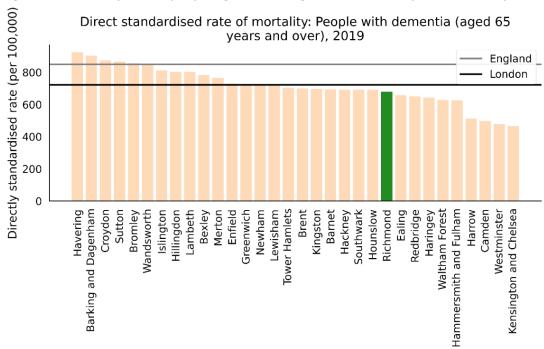


Figure 58: Mortality rate of people aged 65+ living with dementia by local authority, 2019



Figure 59: Mortality rate of people aged 65+ living from dementia, 2016–2019

<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values Source: PHE Public Health Profiles

In 2019 in Richmond 67.3% of dementia deaths occurred in the usual place of residence (5th highest rate in London, **Figure 60**), which was 4.3% lower than the England average and 0.0% higher than London average. The latest Borough figure was also 25.6% higher from year 2016, in comparison with a 3.2% increase in England's rate in the equivalent time period (**Figure 61**). The proportion for Richmond has been consistently increasing year by year since 2016.

Figure 60: Proportion of deaths of dementia patients aged 65+ that occurred in the usual place of residence (home or care home) by local authority, 2019

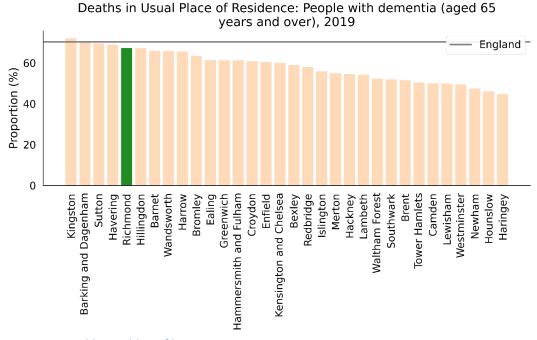
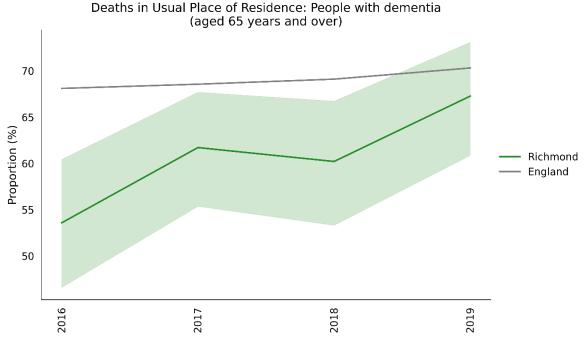


Figure 61: Proportion of deaths of dementia patients aged 65+ that occurred in the usual place of residence (home or care home), 2016–2019



<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values Source: PHE <u>Public Health Profiles</u>

### 8.6 National Policy Context for Dementia

Dementia is a national priority<sup>66</sup>. There are many policy drivers for transforming dementia care, with a long-standing commitment in England to address dementia across all aspects of dementia pathways from pre-diagnosis to end of life care.

The first strategy of its kind, The National Dementia Strategy, 'Living Well with Dementia' (Department of Health, 2009)<sup>67</sup> was backed up by the Five Year Forward View, published in October 2014<sup>68</sup> which recognised dementia as a priority area. This further highlighted an aim to improve earlier diagnosis of dementia to slow the progression of the disease with treatment. To achieve this, the NHS Five Year Forward View focused on why there was a need for provision of a consistent standard of care for patients, improved support for clinicians and advisors, and focus on personalised care plans developed in partnership with patients and their families.

Following the publication of the Five Year Forward View, NHS England along with national partners, launched a New Models of Care programme in 2015<sup>69</sup>. The programme encouraged a more integrated care approach, which would present an opportunity to transform dementia care and support. Furthermore, the Next Steps NHS Five Year Forward update plan in 2017<sup>70</sup> focused on specifying what this integrated care model for dementia would look like within the established sub-regional Sustainability and Transformation Partnerships, as a mechanism to delivering the Five Year Forward Plan.

Building on the ambitions of both the National Dementia Strategy and the Five Year Forward View, the Department of Health's Prime Minister's Challenge on Dementia 2020, further highlighted the importance of good dementia care, describing the need to improve recognition and quality of care for people with dementia and support for carers. This included challenges to improve public awareness of dementia, ensuring health and social care staff receive appropriate training for their role, ensuring continuity of care and that any care package is 'meaningful' after diagnosis, as well as improving public awareness and understanding of dementia. Emphasis was particularly made on the role of "dementia friendly communities" and on local authorities' engagement with dementia action alliances. The Prime Minister's Challenge was further supported by a call to action across all aspects of dementia diagnosis, care and support by the Department of Health's publication, 'Dementia: A state of the nation report on dementia care and support in England<sup>71</sup>.

The Prime Minister's Challenge also highlighted the continued need to expand the evidence base investigating dementia treatment and prevention through increasing the capacity for high-quality research.

In 2014 the Care Quality Commission published their themed review of care for people with dementia, Cracks in the Pathway<sup>72</sup>, as they move between care homes and hospitals. They highlighted that quality of care for people living with dementia varies greatly across England and raised a need for the

<sup>&</sup>lt;sup>66</sup> Prime Minister's challenge on dementia 2020. Available at: https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020

<sup>&</sup>lt;sup>67</sup> The National Dementia Strategy, 'Living Well with Dementia' (Department of Health, 2009)

<sup>&</sup>lt;sup>68</sup> NHS England, Five Year Forward View, October 2014

<sup>&</sup>lt;sup>69</sup> NHS England, New Models of Care Programme, January 2015

<sup>&</sup>lt;sup>70</sup> NHS England Next Steps on the NHS Five Year Forward View, March 2017

<sup>&</sup>lt;sup>71</sup> Department for Health Dementia (2013) A state of the nation report on dementia care and support in England

<sup>&</sup>lt;sup>72</sup> Care Quality Commission, Cracks in the Pathway (2014)

reduction of such variability and emphasised the personalised approach and knowledgeable staff is available throughout England's health and care system.

NICE have also provided a range of guidance on dementia, including quality standards for supporting people to live well with dementia<sup>73</sup>, guidance with recommendations for the identification, treatment and care of people with dementia. NICE emphasise the principles of a person-centred approach<sup>74</sup>. It also published a guidance covering mid-life approaches to delay or prevent the onset of dementia, disability and frailty in later life, and to increase the amount of time that people can be independent, healthy and active in late life<sup>75</sup>.

There have been many other policies and guidelines in place to improve health and promote healthy behaviours within the population. However, it has not been clearly stated that by improving individual's health it reduces the risk of dementia, disability and frailty. Therefore, the role of local authorities was further highlighted by Public Health England (PHE) in 2018 which emphasised their critical role in reducing dementia risk as well as the overall societal impact through the promotion of healthy lifestyles, age and dementia friendly built environment, maximising signposting opportunities, and promoting opportunities to improve cardiovascular health through the "what's good for your heart is good for your brain" campaign.

The NHS Long Term Plan<sup>76</sup> published in 2019, commits to further improving the care provision for people with dementia, whether in hospital or within the home setting. It re-emphasised the focus on dementia by including it in its "biggest killers and disablers of our population" list. Community multidisciplinary teams (MDTs) provide care in the community to retain independence of people living with dementia through collaboration.

### 8.7 Local Policy Context for Dementia

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 carers. Overall, the policy context in Richmond describes a recognition of people with dementia, and carers, in addition to acknowledging the need for improved service accessibility, whether that is access to medical care, housing and social activities. The most relevant of which is the Richmond Joint Dementia Strategy<sup>77</sup> developed between the London Borough of Richmond upon Thames Council and Richmond CCG and published in 2016. This Joint Dementia Strategy set out a five-year vision for people with dementia and carers in the London Borough of Richmond upon Thames. It includes five key strategic objectives to improve dementia prevention and care including preventing well, diagnosing well, living well, supporting well, dying well. The strategy aimed to capture the existing framework of comprehensive service provision in one place, demonstrate the choice and range of services available to people living with dementia and carers, and highlighted where more work was needed.

<sup>&</sup>lt;sup>73</sup> NICE Dementia [QS184] Published June 2019 Available at: https://www.nice.org.uk/guidance/qs184%20%5bAccessed%2015.5.2020

<sup>&</sup>lt;sup>74</sup> Dementia: assessment, management and support for people living with dementia and their carers NICE guideline Published: 20 June 2018. Available at: <a href="https://www.nice.org.uk/guidance/ng97">www.nice.org.uk/guidance/ng97</a>

<sup>&</sup>lt;sup>75</sup> Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset NICE guideline [NG16] Published date: 20 October 2015. Available at: <a href="https://www.nice.org.uk/guidance/ng16">https://www.nice.org.uk/guidance/ng16</a>

<sup>&</sup>lt;sup>76</sup> NHS Long Term Plan Available at: https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf

<sup>77</sup> https://www.richmond.gov.uk/media/13380/joint dementia strategy 2016 21.pdf

It also set out how health and social care services for people with dementia and carers would develop over the next five years from 2016-2021.

The visions of the Richmond Joint Dementia Strategy were 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 for as long as possible
- carers of people with dementia are given the support they need
- people with dementia can live well in Richmond.

**Table 6** provides an overview of Richmond's policy with relation to dementia.

Table 6 Summary of Richmond policy and strategy documents related to dementia

Table 6 Summary of Richmond policy and strategy documents related to dementia					
Document	Key points related to dementia	Year			
Joint Mental Health Strategy Implementation Plan for Adults and Older People for Richmond	dementia could avoid "a considerable number of unplanned acut				
Better Care Closer to Home – Richmond Out of Hospital Care Strategy	<ul> <li>Describes the disproportionate impact of dementia on hospital resources - Acknowledges current pressures on carers Aims to improve coordination between hospitals and care homes, improve care home staff training and make Richmond a dementia friendly borough</li> </ul>	2014			
Learning Disability Strategy "Our Big Plan"	<ul> <li>Acknowledges the importance of health promotion for those with learning difficulties Commits to the provision of an appropriate service response to support people with early onset dementia. Acknowledges that older people should be able to make informed decisions about accommodation options appropriate to their needs.</li> <li>Commits to promote older people's access to community services.</li> <li>Commits to "undertake innovative projects to combat isolation and loneliness".</li> <li>Commits to "provide advice, support and advocacy to help people identify entitlement, make claims and appeal where necessary" in relation to finance.</li> </ul>				
Promoting wellbeing and independence – a framework for prevention	<ul> <li>Acknowledges the capacity for preventative activities to address the rising prevalence of dementia Aims to ensure that each community in the borough works towards becoming a dementia friendly village (community).</li> </ul>				
Joint Health and Wellbeing Strategy	- Acknowledges the relationship between loneliness and dementia Refers to the value of dementia friendly villages (communities)."				
Housing and Homelessness Strategy	Recognises the need for affordable extra care accommodation in the borough Describes a need for dementia friendly accommodation.	2018			
End of Life Care Programme (Kingston and Richmond CCGs)	End of Life Care Programme (Kingston and Richmond CCGs)	2018			
SW London Dementia Action Plan	<ul> <li>Action plan that focuses on activities to support:         <ul> <li>Diagnosing dementia</li> <li>Providing support to people living with dementia</li> <li>Supporting carers and helping them to meet the needs of people with dementia</li> <li>Provide support to people with dementia and their carers</li> </ul> </li> </ul>	2019- 2020			

### 8.8 The Financial Cost of Dementia to the UK

Annually, the direct healthcare cost of dementia in the UK is estimated to be approximately £26 billion, the equivalent of £32,250 per person per year; £11.6 billion of costs come from unpaid care (**Figure 62**). As expected, social care costs account for a significant portion with £5.8 billion being privately funded by individuals (23% of total cost) and the rest, £4.5 billion, by the state.

More than half of these costs however come from unpaid care, which is valued at £11.6 billion. However, it is thought that this may well increase in future, specifically as more people leave employment to undertake care activities. The cost of this early loss of employment is estimated to be around £3 billion by  $2030^{78}$ .

Approximately 25% of hospital beds are occupied by people living with dementia. Their length of stay is often longer than of people without dementia. The delays in supporting people living with dementia to leave hospital are also more frequent<sup>79</sup>.

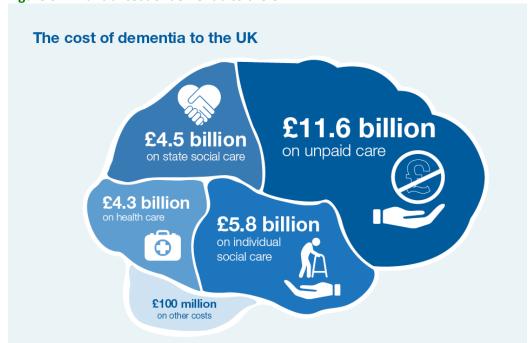


Figure 62 Financial cost of dementia to the UK

Source: Public Health England Guidance: Health matters: midlife approaches to reduce dementia risk, 2016<sup>80</sup>

<sup>&</sup>lt;sup>78</sup> Knapp M, Comas-Herrera A, Wittenberg R, Hu B, King D, Rehill A, et al. Scenarios of dementia care: what are the impacts on cost and quality of life? [Internet]. 2014 [cited 2019 Oct 21]; Available from: http://www.pssru.ac.uk/

<sup>&</sup>lt;sup>79</sup> Dementia Statistics Hub. Available at: https://www.dementiastatistics.org/statistics/hospitals/

<sup>&</sup>lt;sup>80</sup> PHE (2016) Public Health England Guidance: Health matters: midlife approaches to reduce dementia risk, 2016

### 8.9 Dementia in Richmond?

There are 9.9 new diagnoses of dementia per 1,000 people aged 65 and over per year in Richmond, like the London (10.3 per 1,000) average. Nevertheless, given that approximately 31% of cases with dementia are undiagnosed in the Borough, the true incidence rate and therefore prevalence is likely to be far higher.

In January 2021, 1,145 people aged over 65 years on Richmond GP registers had a recorded diagnosis of dementia, accounting for 3.6% of the total Richmond's  $\geq$ 65's population. This figure climbs to 1,722 (5.48% of the  $\geq$ 65's population) if estimates of those living with undiagnosed dementia are added<sup>81</sup>. These most up to date data sets must take into consideration of the country's circumstances from 31st January 2021.

Based on these prevalence figures and 2012/13 average dementia care cost prices, the total cost of dementia in 2019 for Richmond is estimated to be £73m, of which £28.5m is attributable to social care and £11.6m to healthcare costs. Importantly, given that there is expected to be a 47% increase in the number of people aged 65 years and above affected by dementia by 2035, the costs associated with care for this cohort of patients will likely rise more steeply. There is also a wider system pressure on activity and finances, such as the falls agenda, where Richmond have falls history taken in the memory clinic, indicating an additional pressure on resource, time, and expertise across the wider system.

One of the reasons the London Borough of Richmond upon Thames considers dementia a priority is because this rate of increase can be reduced with effective reductions in dementia risk factors. Current evidence suggests that up to 30% of the most common forms of dementia can be prevented or delayed simply by addressing these risk factors. A delay of two years in dementia onset can result in a 22% reduction in costs by 2050, with a 5-year delay resulting in a 36% reduction in costs.

Additionally, slowing dementia progression also reduce the severity of disease for patients. Compared to baseline (normal progression) a delay in dementia progression by 25% would reduce the number of severe dementia cases in 2050 by approximately 43%, whereas a 50% reduced rate of disease progression would reduce this by approximately 86%.

### 8.10 Risk of Developing Dementia

The risk of developing dementia is associated with a mixture of factors, some of which can be avoided (modifiable risk factors) and others that are virtually impossible to control (non-modifiable risk factors).

It is estimated that 21% of the public cannot identify any risk factors for dementia, despite 59% knowing someone who was living with it. The risk of developing dementia can be affected by lifestyle, genetics, vascular reasons, or drug and medicine related.

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<sup>&</sup>lt;sup>81</sup> Based on projected population over 65as of 2020 in Richmond, GLA.

#### Non-modifiable Risk Factors for Dementia

These are risk factors that as the name implies, cannot be changed as they are inherent in each person.

- **Age**: Age remains as the single biggest and non-modifiable risk factor for dementia with a person's risk doubling approximately every 5 years<sup>82</sup> above the age of 65 years currently estimated to be 32,403 aged 65+ (16.2% of population in 2021, and estimated that this number will increase by 41% to 45,784 (22% of total population) in next 20 years (by 2041)
- **Gender**: Alzheimer's disease is more common in women than men even after accounting for the greater life expectancy in women. This is not seen for other dementia types (e.g., vascular, LBD or FTD). This is reflected in Richmond where 63% (n=1,416) of dementia patients over 65 years are women, even though women make up 56% (17,000) of the total over 65 years population. Women are far more likely than men to become carers of those with dementia. 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.
- Ethnicity: The Social Care Institute for Excellence (SCIE) has estimated that more than 25,000 older Black and Minority Ethnic people live with dementia in the UK. Further research suggests that South Asian, African, and Afro-Caribbean ethnic groups have higher rates of dementia than other ethnicities<sup>83</sup>. The increased rate is thought to be due to the higher prevalence of high blood pressure, diabetes, and strokes within these ethnic groups. This is particularly relevant in Richmond given that although only 6% of the 65 year + population identify as Black, Asian and Minority Ethnicity, 16.3% of Richmond residents that died due to dementia in 2016 were born outside the UK.
- Other: Other: Learning disabilities, particularly Downs Syndrome significantly increase the risk of developing dementia and earlier onset dementia. In 2018/19 there were 561 people, known to their GP, affected by a learning disability in Richmond. When people with Down's Syndrome develop dementia, this is usually due to Alzheimer's disease. However, there is a growing awareness that people with Down's Syndrome can develop other forms of dementia<sup>84</sup>. n 2017/18, there were 10 people with learning disabilities living with dementia and accessing ASC services in Richmond. We currently do not have robust data on the actual number of dementia patients with a disability. It is difficult to be exact with the number of people with a learning disability both nationally and locally because there are a range of complex factors that underlie the predictions.

### Modifiable risk factors for dementia

There are a modifiable risk factors in terms of treatable medical conditions and lifestyle choices that play a role in developing dementia. These risk factors are partially in control of the individual, family, or community and, therefore, are the focus of many interventions. Recent studies have determined that improvements to lifestyle habits and management of comorbidities may lead to a lower risk of dementia. Management of cardiovascular risk factors (such as diabetes, obesity, smoking, and

<sup>&</sup>lt;sup>82</sup> Alzheimer's Society. Risk factors for dementia - Factsheet 450LP [Internet]. 2016; Available at: <a href="http://www.alzheimers.org.uk/sites/default/files/pdf/factsheet">http://www.alzheimers.org.uk/sites/default/files/pdf/factsheet</a> risk factors for dementia.pdf%20

<sup>&</sup>lt;sup>83</sup> Pham Trah My, Petersen I, Walters K, Raine R, Manthorpe J, Mukadam N, Cooper C. Trends in dementia diagnosis rates in UK ethnic groups: analysis of UK primary care data. Clinical Epidemiology. 2018.

<sup>&</sup>lt;sup>84</sup> https://www.alzheimers.org.uk/about-dementia/types-dementia/learning-disabilities-dementia?documentID=103 accessed 15.5.2020

hypertension) and participation in regular physical activity, can reduce the risk of cognitive decline and may reduce the risk of dementia.

Health inequalities are exacerbated by the circumstances and environment in which we live, and often these health inequalities tend to persist into old age. There is growing evidence that many of the modifiable risk factors for dementia are indirectly associated with socio-economic disparities in mortality and morbidity. For example, there is a strong link between cigarette smoking and socio-economic groups<sup>85</sup>. Smoking is one of the biggest modifiable risk factors for dementia doubling the risk of developing the condition. There is also evidence that low socio-economic situations can result in lack of physical activity, another risk factor for developing dementia<sup>86</sup>. The socio-economic circumstances can have a major effect on physical and mental health and can create or close off the opportunities to make healthy choices<sup>87</sup>.

**Table 7** outlines the common types of modifiable risk factors and the prevalence within Richmond compared to London.

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<sup>&</sup>lt;sup>85</sup> Baumgart M., Snyder H. M., Carrillo M. C., Fazio S., Kim H., Johns H. (2015). Summary of the evidence on modifiable risk factors for cognitive decline and dementia: a population-based perspective. Alzheimer's Dement. 11, 718–726. 10.1016/j.jalz.2015.05.016 [PubMed]

<sup>&</sup>lt;sup>86</sup> Farrell, L et all (2014). The socioeconomic gradient in physical inactivity: Evidence from one million adults in England, in Social Science & Medicine Volume 123, December 2014, Pages 55-63

<sup>&</sup>lt;sup>87</sup> PHE Strategy 2020-25, Public Health England (2019)

Table 7: Modifiable risk factors for dementia

	Risk Factor	Description	Prevalence in Richmond	Prevalence in London	Modelled ARP [95% CI] +
Modifiable Risk Factors	Physical inactivity	<ul> <li>Less than 30 minutes physical activity per day</li> <li>Even low intensity exercise (e.g. walking) reduced personal risk by up to 40%</li> </ul>	17.2%	22.9%	9.8% [2.5%- 18.5%]
	Low educational attainment	<ul> <li>Linked to low physical inactivity</li> <li>Highlights life-course approach to reducing risk</li> </ul>			7.2% [4.5%- 13.3%]
	Smoking	<ul> <li>Increases risk of dementia by 50-80%</li> <li>Also contributes to development of other risk factors (below)</li> </ul>	9.8%	14.6%	5.4% [1.5%- 10.3%]
	High blood pressure	Shared risk factors: diet, physical inactivity	(14,775)		3.6% [1% - 6.9%]
	Depression	<ul> <li>Shared risk factors: loneliness, physical inactivity, substance misuse, smoking, low educational achievement</li> </ul>	23,369++		3.1% [2.1%- 4.4%]
	Obesity	Shared risk factors: diet, physical inactivity	12,137	55.9%	2.2% [1.3%- 3.4%]
	Diabetes	Shared risk factors: diet, physical inactivity	47.7%	8.5%	1.5% [0.6%- 2.4%]
	Stroke	<ul> <li>Shared risk factors: diet, physical inactivity, smoking, substance misuse</li> <li>Dementia risk doubled for those with previous history of stroke</li> </ul>	7.0%		
	Loneliness and isolation	<ul> <li>Social isolation is the inadequate quality and quantity of social relations with other people at the different levels where human interaction takes place.</li> <li>Loneliness is a subjective, unwelcome feeling of a lack or loss of companionship.</li> <li>Both are linked with dementia</li> </ul>			
	Alcohol	Regular alcohol intake above NHS guidelines increases risk of dementia	48.3% of adult social care users feel they could have more social contacts	544 alcohol related hospital admissions per 100,000 population	
	Sensory impairment	<ul> <li>Reduction in visual and/or hearing ability</li> <li>Increases care needs due to reduced independence</li> <li>Prevalence expected to increase by over 50% by 2035.</li> </ul>	35.1% of adults drink to harmful levels		

<sup>+</sup> attributable risk percentage refers to the percentage of disease cases (dementia) which are caused by exposure to risk factor ++ based on Quality Outcomes Framework (QOF) data

### 8.11 Evidence-based Interventions

Dementia is currently incurable and the number of symptomatic treatments available are limited. However, dementia research is a key element of the Prime Minister's challenge on dementia. PHE Dementia Intelligence Network are tasked with collating new and existing data on dementia enabling public health agencies to have a better understanding of prevalence and how it affects the population. Significant improvements were made over the recent decades in making more readily available treatment options. The widespread dementia screening in routine assessments will result in a more 'dementia-friendly' clinical culture and society.

Both secondary and tertiary prevention strategies have benefits to those living with dementia, by slowing progression and improving quality of life, maintaining an individual's independence for longer<sup>88</sup>. The WHO published guidelines for the risk reduction of cognitive decline and dementia, whereby most of the recommendations align with current guidelines for the treatment of pre-existing health conditions and dependencies in the UK. For example, for cognitive outcomes in healthy adults, WHO identified physical activity interventions have a positive effect, and interventions for tobacco cessation may reduce the risk of cognitive decline and dementia as well as other health benefits. The report also recommends a healthy, balanced diet. However, much is still unknown about the long-term effect of treatment of older people and prevention through risk factor reduction<sup>89</sup>.

Further evidence of good practice can be drawn from a Good Practice Compendium (2011)<sup>90</sup>, which demonstrates how local delivery of the National Dementia Strategy can be supported, to improve outcomes for people with dementia and carers. Similar content can be found in a recent Alzheimer's Society report published in October 2020<sup>91</sup>. Some of the evidence-based recommendations are included below, across the whole dementia journey.

### **Preventing Dementia**

NICE recommends that national organisations and any local government departments that influence public health, should develop and support initiatives to reduce the risks of dementia. Prevention and slowing of progress remain the mainstay of dementia management. A range of interventions have been suggested to be useful in supporting people with dementia to slow the progression of the disease and maintain their independence for longer<sup>92</sup> through promoting healthy lifestyles. These include encouraging healthy behaviours, reduction in smoking, increasing physical activity, reduce alcohol intake, as well as achieving and maintaining a healthy weight and a healthy diet.

Prevention is better than cure and this is critical for avoiding the onset of dementia more so than in other disorders. Although, we cannot influence the most significant risk factor (age), key interventions aimed at influencing and reducing cardiovascular risk, improving physical and mental health, addressing social isolation and loneliness<sup>93</sup>, and combating drug and alcohol misuse are all important.

<sup>&</sup>lt;sup>88</sup> Lewis F, Schaffer S, Sussex J, O'Neill P, Cockcroft L. The Trajectory of Dementia in the UK – making a Difference, 2014

<sup>&</sup>lt;sup>89</sup> WHO Risk reduction of cognitive decline and dementia: WHO guidelines, 2019

<sup>&</sup>lt;sup>90</sup> DH (2011) Living well with dementia: A National Dementia Strategy Good Practice Compendium - an assets approach

<sup>&</sup>lt;sup>91</sup> From diagnosis to end of life: The lived experiences of dementia care and support. Available at: <a href="https://www.alzheimers.org.uk/about-us/policy-and-influencing/from-diagnosis-to-end-of-life">https://www.alzheimers.org.uk/about-us/policy-and-influencing/from-diagnosis-to-end-of-life</a>

<sup>&</sup>lt;sup>92</sup> Dementia, disability, and frailty in later life – mid-life approaches to delay or prevent onset. NICE guideline [NG16] Published date: 20 October 2015. Available at <a href="https://www.nice.org.uk/guidance/ng16">https://www.nice.org.uk/guidance/ng16</a>

<sup>&</sup>lt;sup>93</sup> Alzheimer's Society. (2018) Tacking Loneliness in People Living with Dementia.

The Blackfriars Consensus published in 2014<sup>94</sup> acknowledged that sufficient evidence exists, with which people can be empowered to reduce their risk of dementia through reduction of cardiovascular disease risk and improving brain health.

### **Diagnosing Dementia**

Referral to dementia specialist diagnostic services ensures that a diagnosis is both timely and accurate. Different types of dementia can be identified quickly to ensure targeted and tailored support is in place in a timely manner. Memory Assessment Services (memory clinics) are recommended by NICE guidance<sup>95</sup> as a single point of referral for early diagnosis of dementia. They can be provided in several different settings, including a psychiatric or general hospital, as part of community mental health services or in primary care. This single point of access can then act as a lever for further investigation of dementia sub types.

### **Support After a Diagnosis of Dementia**

The Department of Health published guidance on what to expect from health and care services for those recently diagnosed with dementia. It outlines the different stages of support a person and their carer may require; it is also a good building block for identifying what is good practice<sup>96</sup>. NICE guidance indicates that service provision should ensure that people living with dementia have 'equivalent access to diagnosis, treatment and care services for co-morbidities as people who do not have dementia'. There is associated NICE guidelines on multi morbidity<sup>97</sup>, older people with social care needs, and multiple long-term conditions<sup>98</sup>.

### **Care Planning**

The use of care plans is recognised by NICE as a method of empowering patients to maintain their own independence following a diagnosis. Care plans should be drawn up and reviewed annually in face-to-face meetings with GP's and should consist of the following core "D.E.M.E.N.T.I.A" components:<sup>99</sup>

- Diagnosis review
- Effective support for carers review
- Medication review
- Evaluate risk
- New symptoms enquiry
- Treatment and support
- Individuality
- Advance care planning.

<sup>&</sup>lt;sup>94</sup> Livingston G, Sommerlad A, Orgeta V, Costafreda SG, Huntley J, Ames D, et al. Dementia prevention, intervention, and care. The Lancet 2017;390(10113):2673–734

<sup>95</sup> https://www.nice.org.uk/guidance/ng97

<sup>&</sup>lt;sup>96</sup> Department of Health and Social Care. After diagnosis of dementia: what to expect from health and care services

<sup>&</sup>lt;sup>97</sup> Multimorbidity: clinical assessment and management. NICE guideline [NG56] Published date: 21 September 2016

<sup>&</sup>lt;sup>98</sup> Older people with social care needs and multiple long-term conditions. NICE guideline [NG22] Published date: 04 November 2015

<sup>99</sup> NHS England. Dementia: Good Care Planning. 2017

### **Hospital Care**

The NICE guidance<sup>100</sup> on dementia addresses the transition from hospital to community settings (be it at home or a care home setting) for adults with social care needs including the quality of care people should expect when they are admitted and discharged from hospital. This includes involving people in their own care planning.

An example of good practice within the hospital setting is having a multidisciplinary team that links directly with community services, to avoid unnecessary admissions. This drives a 'home first' approach, based on recognising that patients, being in their familiar environment whenever possible, optimises patient recovery and delivers better outcomes. One example of this is the 'therapy at the front door' initiative, which brings therapists into Accident and Emergency. Senior therapists assess patients frailty and can advise those who can then be discharged on the same day, or those who may only require a short admission. By carrying out a risk assessment, they can immediately arrange rapid support to keep the patient safely at home.

#### **Social Care**

Adult social care is provided in three main settings: residential care homes, nursing care homes and in the community. Adult social care helps people with dementia to feel supported to live their life as they want. To ensure good practice, NICE produces quality standard on dementia which states that people with dementia should be given the opportunity to discuss any advance care planning at diagnosis, and at each health and social care review. Further quality standards are given on measuring people's experience of using adult social care services<sup>101</sup>. It is recommended as good practice to ensure that people have the necessary support to enable their active involvement in decisions about them in relation to their care and support.

#### **Non-pharmacological Support**

Non-pharmacological techniques, such as cognitive stimulation therapy (CST) and cognitive behavioural therapy (CBT) are also offered to dementia patients. CST is recommended by NICE for mild to moderate dementia whereas CBT is often used for those who are also experiencing depression and anxiety.

### **Pharmacological Interventions**

The mainstay of treatment for dementia is improving quality of life and maintaining independence for as long as possible. For some forms of dementia, pharmacological (medication) is available in the early stages. A range of pharmacological interventions have been linked to support treatment and prevention of cognitive and behavioural conditions related to dementia<sup>102</sup>. Dementia treatment options remain limited, with known dementia treatments diminishing in efficacy after the first few years.

#### **Enabling a Fulfilling Life with Dementia**

There is a wealth of evidence of good practices in provision of support and care for people with dementia and their carers to maintain independence for as long as possible including:

### **Dementia Friendly Communities and Organisations**

Dementia friendly communities (DFC) and organisations (DFO) have become widely accepted in local and national policy as playing an important role in improving the lives of people with dementia.

<sup>100</sup> https://www.nice.org.uk/guidance/ng97

<sup>&</sup>lt;sup>101</sup> Dementia Quality standard [QS184] Published date: 28 June 2019

<sup>&</sup>lt;sup>102</sup> Managing medicines for adults receiving social care in the community. NICE guideline [NG67] Published date: 30 March 2017

In 2014 Public Health England (PHE) and Alzheimer's Society launched a major campaign promoting *Dementia Friends*. <sup>103</sup>

The Alzheimer's Society defines a dementia friendly community as "a city, town or village where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia friendly community people will be aware of and understand dementia, and people with dementia will feel included and involved, and have choices and control over their day-to-day lives" 104.

Both the LGA<sup>105</sup> and the Alzheimer's Society have also published criteria and guidance on what should constitute a Dementia Friendly Community or Dementia Friendly Organisation <sup>106</sup> and best practice. Criteria include good access to community services, such as befriending and engagement services and adjusting the practicalities of daily life, such as housing, travel, and local businesses to be dementia aware, responsive, and respectful.

The Kings Fund, as part of their Enhancing the Healing Environment series, published self-assessment tools in 2014 and updated them in 2020 for housing, care-homes, health centres and hospitals to inform them of how dementia friendly each setting. The tool assesses 7 domains, providing a score, which reflects the "friendliness" of the setting for those with dementia (Figure 63)<sup>107</sup>.

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 $<sup>{}^{103}\,\</sup>underline{www.gov.uk/government/news/new-dementia-campaign-launches-as-research-reveals-the-true-cost-to-business-of-dementia}$ 

<sup>&</sup>lt;sup>104</sup> Building Dementia Friendly Communities – a Priority for Everyone – Alzheimer's Society 2013, Accessed at: <a href="http://actonalz.org/sites/default/files/documents/Dementia friendly communities full report.pdf">http://actonalz.org/sites/default/files/documents/Dementia friendly communities full report.pdf</a>

<sup>&</sup>lt;sup>105</sup> Dementia friendly communities. Guidance for councils, LGA and Innovations in Dementia (2015) Accessed at: <a href="http://www.local.gov.uk/sites/default/files/documents/dementia-friendly-communi-8f1.pdf%20%5b">http://www.local.gov.uk/sites/default/files/documents/dementia-friendly-communi-8f1.pdf%20%5b</a> [Accessed 19.5.2020]

<sup>&</sup>lt;sup>106</sup> Dementia-friendly communities. Alzheimer's Society [cited 2019 Oct 25]; Available at: <a href="https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities">www.alzheimers.org.uk/get-involved/dementia-friendly-communities</a>

<sup>&</sup>lt;sup>107</sup> Is your care home dementia friendly? EHE Environmental Assessment Tool Available from: <a href="https://ext-webapp-01.worc.ac.uk/kings">https://ext-webapp-01.worc.ac.uk/kings</a> fund/files/Is%20your%20care%20home%20dementia%20friendly.pdf

Figure 63: Is your care home dementia friendly? Taken from 'EHE Environmental Assessment Tool Domains'



Source: The Kings Fund 'Is your care home dementia friendly?' 2020 (redesigned)

#### **Dementia Champions**

Championing the dementia cause, is needed across a range of settings. Skilling up staff through dementia awareness training on the signs and symptoms of dementia can contribute to staff becoming more responsive to dementia needs, lead them to a better understanding of the issues related to the disease, and championing the dementia agenda.

#### **Peer Support and Dementia Cafes**

Research shows that people with dementia express the need to stay connected to their families, friends and communities, and be able to engage in activities that they enjoy. Unfortunately, some community groups find it difficult to accommodate people with dementia.

The National Dementia Strategy promotes the establishment and maintenance of local peer support networks for people with dementia and their carers These types of initiatives<sup>108</sup> are also supported by

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<sup>&</sup>lt;sup>108</sup> Dementia Cafes - Halley, E., Boulton, R., McFadzean, D., & Moriarty, J. (2005). The Poppy Cafe: A multiagency approach to developing an Alzheimer cafe. Dementia: The International Journal of Social Research and Practice, 4(4), 592-594

the Prime Minister's Challenge<sup>66</sup>. Furthermore, the Care Act 2014<sup>109</sup> stipulates that improvements are required in delivering early interventions from care and support systems to support individuals to retain or regain both their skills and confidence, and to prevent or delay deterioration. Additionally, NICE guidance recommends people are signposted to support groups post-diagnosis and their carers also have access to peer support. The Health Innovation Network produced a resource pack to bring together examples of good practice and evidence-based guidance on peer support, to help groups and organisations better support people with dementia in their communities<sup>110</sup>.

### **Assisted Technology**

There has been a great deal of promise in how assisted technology, 'electronic' or 'intelligent' assistive technology, may help address the individual, family and societal challenges presented by dementia, and to support people with dementia to live more independently and, ideally, with improved quality of life in a cost-effective way. The challenge is that there is no real evidence available that can confirm such claims. More robust evaluations are required to help understand what works, for whom and how as well as the impact of these technologies in the context of dementia 111 112.

#### **Supporting Carers**

Carers of people with dementia face additional challenges to ensure that their own physical and mental health needs are being recognised and met, both because of the demands of the caring role, but also because of difficulties with accessing support. It is essential that carers have good support to enable them to manage the stresses and demands of their caregiving. NICE guidelines recommend that services make provision for carers to be supported in their roles<sup>113</sup>. Informal carers are particularly important, given the significant contribution they make to the people they care for and to the community. Nevertheless, informal carers are also at risk of personal psychosocial distress, which must be monitored, identified, and managed promptly. Evidence of good practice in supporting carers includes offering education and skills training to carers. Some carers may require their own care plans to address their needs too, which can include, but not be limited to, psychological therapies (e.g., CBT), peer-support groups, training courses and respite care.

### **Ensuring Dignity and Comfort for Those Dying with Dementia**

People with dementia have the same right to a good death as people with other health conditions. The Department of Health (2008) indicates that a good death would involve being treated as an individual, with dignity and respect, without pain and other symptoms, in familiar surroundings and in the company of close family and friends. However, it has been reported that often, people with dementia do not receive this level of dignified care and treatment, resulting in people with dementia not being referred for specialist end of life care. They may receive inappropriate treatment and, in some cases, ending their lives in pain<sup>114</sup>.

<sup>&</sup>lt;sup>109</sup> http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted [Accessed 15.5.2020]

<sup>&</sup>lt;sup>110</sup> file://ssa.root.lan/Dfs/Users/tamatha.macey/Downloads/Peer-Support-Resource-Pack-FINAL-Version.pdf

<sup>&</sup>lt;sup>111</sup> lenca M, Fabrice J, Elger B, et al. (2017). Intelligent assistive technology for Alzheimer's disease and other dementias: a systematic review. Journal of Alzheimer's Disease 56(4) 1301-1340. [PubMed abstract]

<sup>&</sup>lt;sup>112</sup> Fleming, R., & Sum, S. (2014). Empirical studies on the effectiveness of assistive technology in the care of people with dementia: a systematic review. Journal of Assistive Technologies, 8(1), 14-34.

<sup>&</sup>lt;sup>113</sup> Supporting adult carers. NICE guideline [NG150] Published date: 22 January 2020

<sup>&</sup>lt;sup>114</sup> My life until the end. Dying well with dementia, Alzheimer's Society, 2012. Available at:

https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/my\_life\_until\_the\_end\_dying\_well\_with\_dementia.pdf

There are quality standards that cover the clinical care of adults (aged 18 years and over) who are dying, during the last 12 months of their life<sup>115</sup>, and during the last 2 to 3 days of life<sup>116</sup>, which are supported by The Alzheimer's Society who advocate a need for advance planning for end of life care, with improvements needed in the co-ordination of a good death, ensuring that health and social care professionals are trained in providing high-quality, person-centred care to improve dignity and quality of life, even when communication has declined.

The digital care planning service 'Coordinate My Care' (CMC), facilitates electronic sharing of urgent care plans between healthcare providers, including the London Ambulance Service (LAS) to enable sharing of core information such as preferred place of death, cardiopulmonary resuscitation status, advice regarding ceilings of care, and other patient preferences.

#### Community and Stakeholder Views on Dementia

On a national level, the Dementia Attitudes Survey carried out by Ipsos MORI for the Alzheimer's Society<sup>117</sup> shows that, despite public awareness of dementia being relatively high, the range of symptoms of dementia are not as fully understood by the public, which has also very limited knowledge of the breadth of people, who are affected by dementia. There is a general misconception of dementia being a condition of old age rather than a cause of death, as well as a low level of understanding of risk factors that affect people with dementia. This contributes to a reduced recognition of physical contributors to dementia risk compared to factors like less mental activity, loneliness, depression and stress. The survey also identifies that the public want to know more about their brain health, especially within the younger and mid-life generation, to plan for future support and care.

There is public support for research into cure and prevention more so than research on improving quality of life for those affected with dementia, which demonstrates an appetite for increased knowledge on preventative action. The Dementia Attitudes Survey<sup>118</sup> also highlighted the importance of culturally sensitive messaging and support in future campaigns that should be informed by input from Black, Asian and Minority Ethnic communities.

Between July and September 2019, local focus groups and engagement sessions with residents living with dementia, carers, friends, and family provided additional insight into the lived experiences related to living with dementia. Residents voiced a need for more day centre resources and support to navigate the system. Importantly, many participants in the engagement sessions were not aware of care-plans and did not recall having constructed one with a healthcare professional. All felt that this would have been useful although no consensus was reached about who should take responsibility.

A recent HealthWatch report for Richmond reported on 75 experiences collected via community outreach from those with dementia, carers, family members as well as professionals who care for those with dementia (unpublished). GPs were reported to be sensitive and understanding towards individual needs, proving suitably reactive in providing urgent care when necessary. There were some reports of those with dementia experiencing difficulties or distress attending GP surgeries, either due to a lack of suitable transport or reluctance on the part of the patient. Delivering services such as the flu jab via community services (e.g., district nursing) could address this need.

<sup>&</sup>lt;sup>115</sup> End of life care for adults. Quality standard [QS13] Published date: 28 November 2011 Last updated: 07 March 2017

<sup>&</sup>lt;sup>116</sup> Care of dying adults in the last days of life. Quality standard [QS144] Published date: 02 March 2017

<sup>&</sup>lt;sup>117</sup> Alzheimer's' Society Dementia Attitudes Monitor Wave 1, 2018

<sup>&</sup>lt;sup>118</sup> Public attitudes towards dementia, Alzheimer's Research UK and Dementia Statistics Hub. Available at: <a href="https://www.dementiastatistics.org/attitudes/">https://www.dementiastatistics.org/attitudes/</a> [Accessed August 2020]

Other issues identified in patient experiences included:

- difficulties accessing assessments from the Occupation Therapy Team
- delays with Adult Social Services in the provision of support
- lack of information on the pathway's process and how services work
- people with dementia being distressed by carers arriving late, affecting their ability to cope, and limiting the care they could receive
- frustration of those who felt they should receive services and did not meet the eligibility criteria
- carers and family members reported difficulties in coordinating different services and highlighted a lack of communication between services which meant each service did not take full responsibility for the patient.
- carers of those with dementia felt isolated and that they needed more support and respite opportunities
- The process of applying for Deprivation of Liberty Safeguards (DOLS) was described as frightening and intrusive.

Feedback from Clinical Dementia Specialists (via HealthWatch Richmond) also highlighted several areas of unmet need including:

- inconsistency in the quality of social workers for patients with dementia
- a lack of information following diagnosis
- a lack of support for carers
- a lack of information on the criteria for accessing NHS Continuing Healthcare.

## 8.12 Level of Need in The Richmond population

#### **Prevalence**

In January 2021, 1,145 people aged over 65 years on Richmond GP registers had a diagnosis of dementia, accounting for 3.6% of the total Richmond over 65 years population This figure climbs to 1,722 (5.48% of the over 65 years population) if estimates of those living with undiagnosed dementia are added.

The rate of mortality for people aged 65 years and over with dementia in Richmond, is 621 per 100,000 population. This is a significantly lower rate than that for London (775 per 100,000) and England (868 per 100,000). 237 Richmond residents with dementia died in 2017/18.

#### **Early Onset Dementia**

Early onset dementia demands particular attention, as services designed for those with older onset dementia are often unsuitable for people with young-onset dementia. Amongst those aged under 65 years on Richmond practice registers, dementia accounts for 2.3% of dementia cases in the borough. (n=35)<sup>119</sup>.

#### **Dementia and Ethnicity**

Regarding recorded dementia diagnosis by ethnicity, the data may not be as accurate because many ethnicities have not been defined in reporting. The HNA indicates that South Asian, African, or Afro-Caribbean ethnic groups have higher rates of dementia than other ethnicities. This increased rate is

<sup>&</sup>lt;sup>119</sup> Please note this does not include people diagnosed with YOD who are now aged 65 and over

thought to be due to the higher prevalence of high blood pressure, diabetes, and strokes within these ethnic groups. This is particularly relevant in Richmond given that although only 6% of the over 65 years population identify as Black, Asian and Mixed Ethnicity. This suggests a highly disproportionate representation of people from ethnic minorities amongst those with a diagnosis of dementia in Richmond. However, 90% of people with a diagnosis of dementia in the borough do not have their ethnicity recorded. Consequently, whilst these figures may rationalize further investigation, they should be interpreted with extreme caution. There are increasing indications that the prevalence of dementia and depression in Black African- Caribbean and South Asian UK populations are greater than the white UK population.

Although not related to Richmond specifically, research has indicated that there is parity of access to memory clinics between Caucasian and BME communities in London overall. Research has found that within 13,166 referrals to memory services across London, the percentage of people from Black, Asian, and Minority Ethnic groups was higher than would be expected, indicating that generally people from Black, Asian, Minority Ethnic groups are accessing memory services. Seventy-nine percent of memory services had high uptake among Black, Asian, and Minority Ethnic groups. When there were fewer referrals then expected, the largest difference in percentage for an individual ethnic group was 3.3%.

Referrals for the Memory Assessment Service (MAS) also records ethnicity when agreed or provided by the service user, but again, these figures should be interpreted with caution. The current MAS caseload in May 2020 reported 72.7% as White 23.3% as Asian, 3% as 'other' and 0.5% recorded not stated and 0.5% left the answer blank<sup>120</sup>. As data on the borough ethnicity in based on 2011 figures, it is difficult to draw conclusions about any discrepancy between expected and actual referrals for the Black, Asian and Ethnic community to the MAS clinic, as this data would not be relevant to the existing dementia referrals in 2020. With a national census completed in early 2021, it would be advisable to align the upcoming census data with the current MAS caseload data when published.

#### **Dementia in Relation to Co-morbidities**

Rather than being the primary reason for emergency admissions, dementia is most often a secondary or tertiary diagnosis in Richmond, emphasising dementia's relationship to comorbidities<sup>121</sup>.

There are dementia specialist nurses available in the Borough to support the recognition of mismanaged comorbidities. However, the dementia specialist practitioners will only engage with nursing homes if the GP has made the referral for the patient.

#### **Geographic Variation**

Due to differences in population size and case finding practices between GP's, obtaining accurate data regarding the geographic prevalence of dementia diagnoses is difficult. Nevertheless, some overarching themes have been identified through triangulation of data from primary care, adult social care (ASC) services and ward demographic profiles (Figure 64).

Generally, dementia prevalence is higher in the southwest and north/central areas of the Borough, reflecting the higher proportion of the over 65 year old residents who live in those areas. Wards such as Hampton (19.6%), Hampton North (18.9%) and Teddington (17.2%) in the South West and Ham, Petersham and Richmond Riverside (17.3%) in the centre of the Borough all have relatively high prevalence rates of dementia. ASC usage data similarly shows that patients who access the service and have dementia are generally from the aforementioned areas of the Borough.

<sup>120</sup> Wandsworth MAS Caseload as of May 2020.

<sup>121</sup> National Health Service England. Hospital Episode Statistics. 2018.

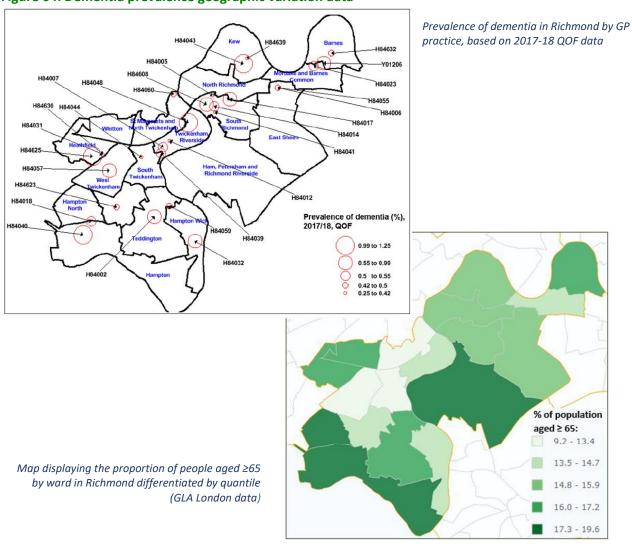


Figure 64: Dementia prevalence geographic variation data

In 2016, 129 Richmond residents died, with dementia being considered the underlying cause of death. The four wards with the most residents from this cohort include Twickenham Riverside (18), Hampton (17), Whitton (15) and Barnes (10). 56% of these 129 people died in a care home (72), 35% died in hospital (46) and 9% died in a private residence (11). Most of these Richmond residents who died in West Middlesex Hospital (19) or Kingston Hospital (17).

The size of this intra-borough variation, in both disease prevalence and risk factor prevalence, highlights the importance of considering geographic location when allocating resources related to dementia.

#### **Residential Status of Dementia Patients**

Having dementia does not mean that people cannot live independently, and Dementia UK estimates that 63.5% of people with late onset dementia live in their own home with variations in age. Local data from 2017/18 showed that 80% of ASC users with a documented dementia diagnosis lived in the community, a reduction from 89% from the previous year.<sup>122</sup>

<sup>122</sup> Wandsworth Local Authority. Mosaic Adult Social Care Database. 2019

550 people receiving ASC services in Richmond in 2017/18, 44.4% had a diagnosis of dementia recorded. When including those not accessing ASC services, those with a diagnosis of dementia not recognised by the ASC team and those living with dementia who do not have a diagnosis, the figure is likely to be much larger.

Richmond has a lower proportion of care home beds per 100,000 people aged 65 years and over in South West London (2,800 per 100,000). There are 46 care homes in Richmond, 29 cater for those aged 65 years and older, totaling 845 care home beds for those aged over 65 years. PHE calculate that, for every 100 people with a registered diagnosis of dementia in Richmond, there are 41.5 care beds. This is less than the average ratio of beds available in London (51.3 per 100) and England (69.2 per 100).

Although few, the quality of care beds in Richmond are significantly higher (100% good or outstanding) than the average in London (51.3%) and England (69.2%). We also hear from local carers for people with dementia, who voice a need for more day centre capacity across the Borough.

Most people affected by dementia live in private accommodation. Many of those with mild dementia will live independently in this context. However, for people living in private accommodation who are not independent, their care will come from informal sources, formal home care provision and daycentre services. In Richmond, receiving formal home care is less than is provided on average regionally and nationally, proportional to population size.

At present, there are four centres which provide day care in the Borough. However, the data describes a deficit in the capacity of these services. In 2013/14, 48.1 per 100,000 population (n=220, adults received day care services in Richmond, significantly fewer than average in London and England (268.3 and 301.1 per 100,000 adults respectively).

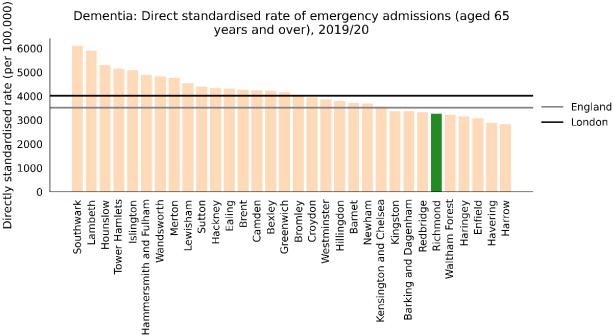
Estimates based on expected dementia prevalence in these care settings suggests that Richmond residential homes and nursing homes have 89 and 11 residents respectively who are living with dementia, which is either unrecorded for ASC purposes, or undiagnosed. This highlights a need for improved completeness of data collection and improved access to diagnostic services in care homes in the Borough.

#### **Emergency Admissions**

Although not usually a primary reason for admission, dementia is often a secondary or contributing factor in unplanned hospital admissions amongst the elderly. The increasing number of people with dementia living longer has resulted in a significantly higher likelihood that they will require care in acute hospitals.

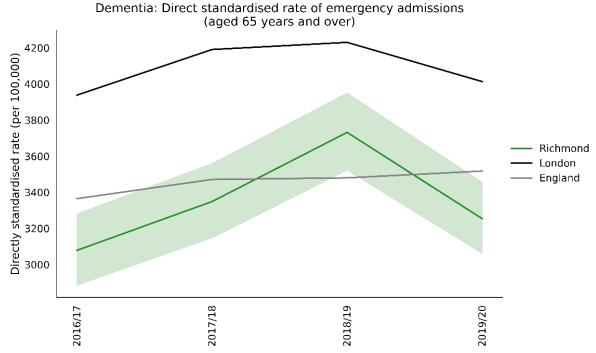
In 2019/20, Richmond's rate of emergency admissions for dementia of people aged 65 and over was 3253.6 per 100,000 (n=1065), which is the 6th lowest rate in London (Figure 65), 7.5% lower than the England average and 18.9% lower than the London average. The latest Borough figure was 5.7% higher than in 2016/17, in comparison with a 4.5% increase in England's rate in the equivalent time (Figure 66). The latest admission rates for Richmond and London have been lower than in the previous year (2018/19), whilst the England average rate has continued to increase in 2019/20.

Figure 65: Dementia emergency hospital admissions of people aged 65 years and over by local authority, 2019/20



Source: PHE, <u>Public Health Profiles</u>

Figure 66: Dementia emergency hospital admissions of people aged 65 years, 2016/17–2019/20



Source: PHE, <u>Public Health Profiles</u>

A higher percentage of those with dementia admitted as emergency cases from Richmond have short stays, less than 1 night in hospital (31.7%), compared to averages in London (28.9%) and England (28.2%). This high proportion of short stays suggests that clinical complexity on presentation may be lower than average regionally and nationally, or that emergency care is more effective locally.

<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values

One of the aims of the NHS Long Term Plan was to help prevent unnecessary hospital admissions by providing great healthcare closer to home and this highlights a potential need to focus on improving the home care provision. The key is prevention, therefore early detection of the problem with primary care being involved at an early stage is imperative. There are various teams in Barnes that provides crisis interventions for people with dementia to prevent admission.

To further address increases in demand for urgent and emergency care, carrying out assessment as early as possible is vital for the avoidance unnecessary admissions. This drives a home first approach based on recognising that patients being in their familiar environment optimises patient recovery and delivers better outcomes. One example of this is the 'therapy at the front door' initiative, which is a tactic that brings therapists into Accident and Emergency. Senior therapists (such as physiotherapists) assess patients with frailty and advise who can be discharged on the same day or may only require a short admission. By carrying out a risk assessment, they can immediately arrange rapid support to the return patient safely to home.

#### **Use of Antipsychotic Drugs in Dementia Patients**

In January 2020, the total dementia population registered for the Richmond area was 1459 (1424 over 65 years) with 120 of those on antipsychotic medication in the six weeks prior, although only 13 people had a diagnosis of psychosis<sup>123</sup>. Data is now produced at a SWL CCG level and is not broken down to Richmond specific data for January 2021 and therefore caution must be made on the availability of data. Although this data cannot be used to directly compare different areas across London or across the country, it does seem to indicate a significantly low level of antipsychotic medication prescribing in January 2020, an indication for further investigation.

## Future Projections in People Living with Dementia and Need for Social Care

A 74% increase in the number of people aged over 65 years living with dementia is predicted in Richmond between 2018 and 2035 (**Figure 67**), with an estimated 1,594 expected to require care home facilities.

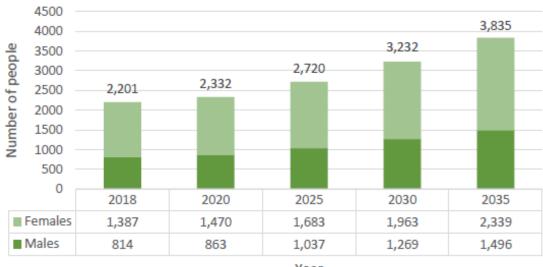


Figure 67. Predicted number of people by gender with dementia in Richmond (2019-2035)

Year

<sup>&</sup>lt;sup>123</sup> Recorded Dementia Diagnoses - January 2019. Available at: https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/january-2019#summary [accessed 22 October 2020]

Based on the estimated increase in dementia prevalence, it is thought that the cost of dementia care in Richmond in 2035 will be approximately £125.75 million based on 2012/13 prices, with the cost of social care accounting for £49m.

#### **Unpaid Caring for People with Dementia**

Undeniably, any unpaid caring can therefore have significant costs. Without appropriate support it can affect an unpaid carers emotional and physical health, have detrimental effects on their ability to work, and subsequent long-term finances. Unpaid carers can often be providing substantial levels of care, but carers have been hit particularly hard due to the COVID-19 pandemic. The present challenges include recognising the additional burden upon unpaid carers and to avoid carers neglecting their own health and wellbeing. On a national level, the 2011 Census and the more recent GP patient survey by NHS England have shown that carers were more likely than non-carers to have poor health before the COVID-19 pandemic.

Furthermore, both the Richmond Carers Needs Assessment and resident engagement sessions in 2019 with people with dementia and their carers have highlighted the local needs of unpaid carers. There is a need for clear guidance on what support is available, the need for carers to understand medical planning, psychological support for carers, and the need for more flexible carers respite. It was suggested by some that the impact on families should be included in care planning. Therefore, it is vital that accessing social care and social support services is key to supporting the well-being of unpaid carers looking after people living with dementia.

#### **Limitations to the Dementia Data/Information**

The data on many metrics for dementia care, particularly those related to equity of access, are limited. Consequently, it is not possible to achieve any conclusive insights into service equity in the Borough. Consideration of action to resolve this is included in the dementia HNA recommendations.

We currently do not have robust data on the actual number of dementia patients in Richmond with a disability. It is also difficult to be exact with the number of people with a learning disability both nationally and locally because there are a range of complex factors that underlie predictions in numbers of people.

Predicting future population trend on the impact of migration has not been considered.

Whilst there is comprehensive data available for older people, several data sets are unclear or missing from current data. These sets include statistics on dementia in relation to gender reassignment, sexual orientation, religion, and marital status. The 2011 census did not have a specific question regarding sexual orientation. Although census data relating to Civil Partnerships shows that 665 people (0.35% of the population in the Borough) responded as being in a registered same sex civil partnership. The HNA highlighted that the collection of data on sexual orientation and gender amongst Adult Social Care users is not sufficient to understand how needs related to sexual orientation and gender are distributed across the Borough in relation to dementia. Estimates of the prevalence and incidence of gender dysphoria and transsexualism are difficult to quantify due to the lack of robust national data.

#### **Dementia Within the Landscape of COVID 19**

The landscape of COVID 19 is constantly changing at the time of writing, however, there are some emerging key issues and challenges around people with dementia and carers in relation to COVID-19. Some population groups have a higher risk of dying from COVID-19 than others. COVID-19 mortality rates are affected by age: mortality rates rise sharply with age, gender: mortality rates are higher among men than women and co-morbidities: mortality rates are significantly higher among people with pre-existing conditions such as dementia and Alzheimer's disease. The number of people with dementia dying from the coronavirus is substantial (more than a quarter of those who died in England

and Wales had dementia, meaning it is the most common pre-existing condition for coronavirus deaths<sup>124</sup>.

#### Impact Of COVID-19 On Dementia in The Community

The initial closures of day services and social support groups remains a challenge. These community-based services provided people living with dementia and carers with a much needed additional support pre and post diagnosis. With the initial loss of the day care centre provisions across the Borough there is a need for more outreach support, and training of support workers on the needs of people living with dementia and carers. The Alzheimer's Society reported that people with dementia are experiencing a rapid cognitive decline, losing physical activity, and raising safeguarding concerns by staff. In addition, self-isolation has disproportionately affected elderly individuals, whose only social contact is often outside the home.

Further challenges include recognising the additional burden upon unpaid carers that often leads to them neglecting their own health needs. Another challenge is related to dementia conditions deteriorating in lockdown period, with people living with dementia becoming more unpredictable due to the changes in routines.

#### Impact Of COVID-19 On Dementia in Care Homes

For those who live in a care home, or are hospitalised, relatives and friends have often not been allowed to see a person in a care home, which can have a detrimental effects. Good practice guidance was published on supporting people with dementia throughout COVID-19, including the use of technology to improve communication between families both at home and in care homes<sup>125</sup>.

People living with dementia, both diagnosed and undiagnosed, in care homes or at home, are vulnerable and at high risk of poorer outcomes from COVID-19. The number of people with dementia dying from COVID-19 is substantial (approx. 27% of all coronavirus deaths) across England<sup>126</sup>. Initial reports from community nurses stated that the initial closure of day services and social support groups remains a challenge, and that additional support is required for the family pre- and post-diagnosis. Further identified issues include:

- Day Service Centres, including the specialist centre at the Woodville Centre, are being reopened consistent with safety measures and guidelines, and risk assessment restrictions in numbers of users at centres and transport.
- Staff have been calling on regular users daily since first-wave shutdown in March 2020
- Psychological needs for client and carer increased during this period
- Lack of respite care created added stress on carers who may be struggling themselves, with an increase in behavioral issues reported by clients, and a request by carers for coping strategies
- Access to computers/laptop
- Deterioration of clients living alone even with packages of care but no longer receiving regular visits from family, resulting in care home placements
- End of life unable to visit to say goodbye, causing extreme psychological distress.

<sup>&</sup>lt;sup>124</sup> Alzheimer's UK, personal communication. 25/06/2020

<sup>&</sup>lt;sup>125</sup> COVID-19: Dementia and cognitive impairment briefing. Available at:

https://www.bgs.org.uk/resources/covid-19-dementia-and-cognitive-impairment and the recent Government statistics around Covid 19 and Dementia (published on 15.5.2020)

<sup>&</sup>lt;sup>126</sup> Alzheimer's UK, personal communication.25/06/2

#### **Current Dementia Services on Offer in Richmond?**

There are 5 priority phases across the dementia pathway. They are described as preventing dementia, diagnosing dementia, supporting after a diagnosis of dementia, enabling a fulfilling life with dementia, and ensuring dignity and comfort for those dying with dementia, and it is with these phases that we can begin to map what is already happening in Richmond.

#### **Preventing Dementia**

There are many different exposures that can increase dementia risk. Consequently, dementia prevention can be considered as any activity which actively reduces these modifiable risks, whether it is explicitly designed with a focus on dementia or not. In terms of our local response, Richmond continues to provide NHS Health Checks which support recognition of the importance for identifying potential modifiable risk factors, in addition to screening for dementia itself. These are free to access for those between 40 -74 years old. For those service users aged 65-74 who have an NHS health Check, they are made aware of the signs and symptoms of dementia and can be signposted to local memory services if appropriate. A separate leaflet is given to these individuals to support the raising awareness of dementia and the services available for people who may be experiencing memory difficulties. It should be noted that the intention of this is to raise awareness only and is not about assessing individuals for memory difficulties at this stage. Awareness of how the risk factors that increase the development of CVD also increase the propensity for dementia are discussed. Service users are encouraged to make healthier lifestyle changes.

In addition to the health checks programme, the Public Health team has several interventions including delivery of dementia awareness and training to SSA staff, and they continue to use resources available within Making Every Contact Count work to increase frontline workforce awareness of dementia and the potential for prevention. Public Health also ensure that smoking cessation and diet improvement resources are widely available, reviewing new licensing applications to reduce alcohol-related risk, and provide advice on risk reduction activities, such as smoking cessation and diet improvement.

The Joint Dementia Strategy 2016 – 2021 additionally considered the Richmond Dementia Action Alliance as a critical vehicle to create a dementia-friendly community in the borough to enable those with dementia, and carers, to maintain and develop their involvement in, and contribution to, their community. Richmond's Dementia Action Alliance (RDAA) was launched in March 2014 to help local businesses and organisations to become dementia friendly. In April 2017, the Alliance boasted almost 100 members including voluntary organisations and community centres, representation from the public sector, private companies, community interest groups, GP surgeries, hospitals, emergency services, and representation from the arts and heritage sector. This initiative has been recently reenergised for April 2021 and rebranded as Dementia Friendly Richmond.

Through the support of the original Richmond Dementia Action Alliance, the London Borough of Richmond upon Thames is officially recognised by the Alzheimer Society as part of the national Dementia Friendly Communities programme. They previously distributed the "Working to Become Dementia Friendly" logo to its members, to able them to publicise their commitment to creating a dementia friendly Borough.

The Community Dementia Practitioners at Hounslow and Richmond Community Healthcare NHS Trust (HRCH) have produced an accessible online and printable dementia service directory of services available across the dementia pathway, launched in 2020.

#### **Diagnosing Dementia**

In Richmond, there are two memory assessment clinics serving different parts of the Borough, overseen by Consultant Psychiatrists; Teddington memory clinic at the Health and Social Care Centre 18 Queens Road, Teddington, and the Barnes Hospital South Worple Way, both provided by South West London and St Georges Mental Health Trust. This is a specialist diagnostic service for people who are experiencing signs of memory and cognitive impairment. The service provides expertise around dementia investigations, diagnosis, and differential diagnoses. The Memory Assessment Service provides preliminary advice and support for people post diagnosis and refer on to other services if appropriate. Anyone who uses the services is provided with an assessment of their mental health needs and a plan of the care and support they will receive. They will also have one named person who co-ordinates their care and support. This person will be called either a named professional or a care coordinator. If there are complex mental health issues involved, the case is allocated to the older person team where a care coordinator is allocated.

Following a diagnosis of dementia, a person with dementia should have a care plan. This should set out what sort of care the person and people who care for the individual will need. The care plan should include how the person can continue doing the things that are important to them for as long as possible. They will be given information about services that can help and how to access them. Any health conditions the person may will be regularly reviewed. The name of a health or social care person who coordinate the different kinds of support the person may need and this could be from your GP, Care manger, Specialist Dementia nurses, or a care coordinator from the older person service. A person's care plan should be reviewed at least once a year by the professional who have the most contact with the person and the carer and shared with the GP who holds the responsibility for carrying out a yearly review and updating the care plan. A yearly physical health checks should also be carried out at this review.

The main purpose of memory assessment services (MAS) is to diagnose dementia and initiate treatment. If they are to do this effectively, they need to ensure that people with cognitive problems but without dementia get quick access to the interventions they need. Some patients present with memory complains due to a range of non-dementia causes. The London Dementia Clinical Network have produced a guidance document<sup>127</sup> aimed at commissioners and clinicians within memory services and primary care to ensure that other conditions that are not dementia, such as mild cognitive impairment (MCI) or Functional cognitive disorder (FCD).

#### **Care and Support After Diagnosis**

The Dementia Practitioner Service provided by HRCH and the Barnes Team, have an overarching aim to case find and deliver highly responsive and personalised emotional and practical support to people with diagnosis of dementia and carers. The objectives of the service are to contribute to the whole multidisciplinary approach to locality-based care delivery. They provide home visits to assess and discuss needs, liaison with other professionals and refer on to appropriate services if required and they promote wellbeing by helping patients and carers make plans and provide crisis planning to avoid/prevent hospital admission.

Services for carers currently are commissioned by Richmond Council and/or Richmond Clinical Commissioning Group through the Better Care Fund include the Richmond Carers Hub Service (a service provides universal and specialist information and advice services, informal individual and group emotional support, a caring café for carers and people they care for living with dementia) and

<sup>127</sup> Non-Dementia Pathways Guidance from the London Dementia Clinical Networks, January 2020. Available at: https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2019/07/Final-non-dementia-pathways-V2.pdf [accessed 16 October 2020]

the shared lives carer scheme, which helps carers of people with dementia by providing a Shared Lives Carer to look after the person.

The Alzheimer's Society has in place a peer support service delivered by to support young people with dementia and carers in community, acute settings, and care homes.

#### **Enabling A Fulfilling Life with Dementia**

Richmond Council currently offer a range of day opportunities for older people and people with physical and sensory disabilities. The existing Richmond day services widely offer:

- Opportunities for social interaction to reduce isolation
- Training and skills development to support independence
- · Provision of social and recreational activities
- Supported stimulating activities for those with multiple disabilities
- Personal and/or practical care to those unable to access the community independently
- Respite for carers

#### **Ensuring Dignity and Comfort for Those Dying with Dementia**

Most of the Palliative Care in Richmond is provided through the community provider Hounslow and Richmond Healthcare Trust (HRCH). The hospice provision is provided by Princess Alice Hospice, serviced by 6 palliative clinical nurse specialists, and supported by a small team of carers for emergency situations to provide advice and support symptom control. A nationwide tool to improve end of life care is 'Coordinate My Care' (CMC). This is an IT resource on which the needs and wishes of people with various medical conditions are logged. 93% of those who have a CMC record in Richmond have their preferences related to death recorded (i.e., preferred place of death).

**Table 8** and **Table 9** display an overview of other local services related to dementia risk reduction and support for Richmond residents. As of the time of writing, some of these services may be halted due to COVID-19 restrictions.

Table 8: Examples of local services supporting dementia risk reduction and support in Richmond

	Risk Factor	Service	Provider	Description	Service utilisation data
	Physical activity	Leisure centres	LBRuT	6 Leisure centres offer a range of sports and fitness activities in the borough	2500 members with 200 group exercise classes per week
		Richmond Inclusive Sport and Exercise (RISE)	LBRuT	part of the strategic work within the leisure centres focused on supporting those with disabilities access lifestyle service	
		Park Space	LBRuT	Largely maintained by Richmond local authority Used by private and charity organizations to provide fitness activities, including activities aimed at those aged 50+. Community-based lifestyle activities delivered by local community groups and facilitated by the council.	
_		Health Walks	LBRuT Funded	A free service supporting group walks for light exercise and social contact, are available locally.	
Prevention	Education & cognitive stimulation	Adult education courses		Adult education courses are available at Richmond Adult Community College.	
	Smoking	Stop Smoking Service	LBRuT	Provides professional support and advice related to multiple aspects of the quitting process. This is funded through LBRuT and is free of charge for residents. This includes access to nicotine replacement therapy.	
	Loneliness and isolation	Companionship service	Age UK		
	Alcohol	Richmond Integrated Recovery Service	LBRuT	Funded by the local authority, via the public health grant, to treat people with substance misuse issues, including those related to alcohol consumption.	626 residents as of March 2018

Table 9: Example of services currently available to dementia patients and their carers

	Service / Funding Provider		Description	
	Life after diagnosis	Age UK	<ul> <li>4-week programme with peer involvement intended to facilitate communication and co-support between people recently diagnos dementia.</li> </ul>	
	Carers information and Support Programme (CrISP)		<ul> <li>4-week course which aims to provided carers with the information about dementia required to most effectively support somebody liv dementia</li> <li>Include information about dementia, advice on important actions in the context of dementia, such as how to establish a lasting power of a and guidance on what other services are available in the borough.</li> </ul>	
	CrISP 2		Similar to above programme but aimed at aiding those caring for somebody with dementia after a period of disease progression	
Care	Caring café Dementia support groups Carer support	LBRuT	<ul> <li>Environments where people affected by dementia can develop social support networks and obtain information relevant to their needs.</li> <li>Multiple attendees at a recent carers meeting in Richmond felt that such social networks are vital for their ongoing wellbeing whilst carir</li> </ul>	
		Age UK	<ul> <li>Dementia support worker (2.5)</li> <li>Dementia friendly activities/signposting (1)</li> </ul>	
	Richmond CiLS contract	RAID/INS	Service use:	
	Voluntary income	Alzheimer's society	<ul> <li>Community dementia support (6)</li> <li>Hospital dementia support (5)</li> <li>Service use: 359 people with dementia and carers</li> </ul>	
Care	Richmond Carers Contract	Alzheimer's society	<ul> <li>2 dementia support workers</li> <li>Support for carers (1)</li> <li>Carer support groups (4 monthly)</li> <li>Service use: <ul> <li>1-to-1 support: 82</li> </ul> </li> </ul>	
	Care	Carers information and Support Programme (CrISP)  CrISP 2  Caring café Dementia support groups Carer support  Richmond CiLS contract  Voluntary income	Life after diagnosis Age UK  Carers information and Support Programme (CrISP)  CrISP 2  Caring café Dementia support groups Carer support  Age UK  Richmond CiLS contract  RAID/INS  Voluntary income  Alzheimer's society	

		Peer support: 58
CCG (Young People with Dementia)	Alzheimer's society	<ul> <li>Dementia support worker</li> <li>Support for people with dementia and carers (0.5)</li> <li>Peer and carer support groups (0.5)</li> <li>Service use: People with dementia and carers: 41</li> </ul>
SWLStG	Alzheimer's society	<ul> <li>Dementia Advisor embedded in Barnes MAS (5)</li> <li>Service use: 175-200 people with dementia</li> </ul>
	Homelink	<ul> <li>A charitable day care centre for people with dementia, and those without dementia, located in Whitton. It caters for those with milder dementia and can host 28 clients per day, between 10am and 3pm, Monday to Friday. Homelink is staffed by nurses and healthcare assist provides exercise classes, cognitive stimulation and advice related to benefits. In addition to day care, Homelink host a monthly supper c to any carers in the area. 'Carers tea' is also provided to support carers.</li> </ul>
Day Care Centres	Woodville Centre	<ul> <li>A day care centre for those with moderate to severe dementia located in Ham. A referral from adult social services is required to attend W centre. The centre has capacity for 35 people to attend from Monday to Friday, with 15 people able to attend on Saturday and Sunday, f Activities in the centre include cognitive stimulation and physical exercises. Woodville centre is primarily staffed by health care assistants</li> </ul>
	Sheen Lade Day Centre	<ul> <li>A day care centre primarily for those with physical and/or learning disabilities. This centre has capacity for 25 people to attend from Moreover Priday between 9-5.</li> </ul>
	Elleray Hall	<ul> <li>A charitable day-time social centre which provides food and activities for clients, in addition to facilitating access to chiropodists and hair     "Alleviating loneliness in our local community" is the main objective of the centre.</li> </ul>

## **Improvement Opportunities in Dementia Prevention and Care**

The management and reduction of dementia risk factors with population-level initiatives, particularly targeted at mid-life age groups, is recommended by NICE clinical guidance (NG16) and the subsequent improvements opportunities in Richmond are outlined in **Table 10**. The improvements with regards to patients already with dementia and for carers of people with dementia were also assessed against NICE guideline 97<sup>128</sup> and framed around the principles of person-centred care in the context of dementia, as described in and **Table 11**.

In addition, the impact that COVID-19 has had on people with dementia and their carers cannot be ignored. Health and social care professionals are seeing more challenges for unpaid carers due to the lack of respite care and a reduction in care packages. This reduction has created added stress on unpaid carers who may be struggling themselves, especially with how to deal with new behaviours they are seeing, such as when their loved one goes 'wandering' in social distancing times. In addition to physical protection from the virus infection, the psychosocial needs for client and unpaid carers which have increased during the COVID-19 pandemic remains fully unknown, and therefore, unmet.

<sup>&</sup>lt;sup>128</sup> Dementia: assessment, management and support for people living with dementia and their carers NICE guideline Published: 20 June 2018 www.nice.org.uk/guidance/ng97 [accessed 16 October 2020]

Table 10: NICE guidance 16 recommendations, actions, and service gaps relevant to local authority activity aimed at preventing dementia

Recommendation Action Unmet need in Richmond

activity	Recommendation	Action	Unmet need in Richmond
	Encouraging healthy behaviours	Develop and support population level initiatives.	No initiatives explicitly related to lowering dementia risk.
	Integrating dementia risk reduction prevention policies	Incorporate dementia into other health-related policy documents.	Limited reference to dementia risk factors in WBC policy documents.
	Raising awareness of risk of dementia, disability, and frailty	Commission local campaigns to show how dementia risk can be reduced, even in earlier life	No current local campaigns to increase awareness of dementia and related risk factors beyond that achieved via NHS Health Checks.
	Producing information on reducing the risks of dementia, disability, and frailty	Provide advice on risk reduction activities, such as smoking cessation and diet improvement.	Smoking cessation and diet improvement resources available, however limited reference to dementia risk.
	Preventing tobacco use	Extend smoke-free areas and continue commissioning smoking cessation services.	Smoking cessation services available with 'smoke-free area' support existing for NHS services
	Improving the environment to promote physical activity	Use traffic management and new developments to encourage active travel.	No current activity related to the 'healthy street' approach.
	Reducing alcohol-related risk	Utilise early morning restriction orders and cumulative impact policy as necessary to influence licensing.	There is no active cumulative impact policy in Richmond.
Prevention	Supporting people to eat healthily	Limiting the number of unhealthy food outlets and improving access to healthy food.	Food licensing strategy active to limit proximity of unhealthy food outlets to schools but limited in other strategies.

Table 11: NICE guideline 97 recommendations, actions, and service gaps, in relation to local authority activity

	Recommendation	Action	Unmet need in Richmond
	Involving people with dementia in decisions about their care	<ul> <li>Provide relevant and accessible information and encourage involvement in decision making</li> <li>Offer early and ongoing opportunities for involvement in advanced decision making.</li> </ul>	<ul> <li>There is a referral to the carers centre as part of the MAS pathway, however, there is limited evidence regarding the <i>extent</i> of involvement of people with dementia in decision making.</li> </ul>
	Care coordination	<ul> <li>Provide people living with dementia with a single named health or social care professional who is responsible for coordinating their care who should be involved in developing a care and support plan.</li> <li>Ensure information can be easily transferred between care settings. Design services to be accessible as possible</li> </ul>	<ul> <li>Historically structurally fragmented care provision. Dementia advisors available but increasingly overstretched and do not provide a complete 'co- ordination' role. The introduction of Dementia Service as of April 2020 will change this.</li> </ul>
	Interventions to promote cognition, independence and wellbeing	<ul> <li>Offer a range of activities to promote wellbeing which can be tailored to an individual's needs, including group cognitive stimulation therapy.</li> <li>Consider offering cognitive rehabilitation, occupational therapy and group reminiscence therapy.</li> </ul>	<ul> <li>Limited formalised availability of regular cognitive stimulation therapy and other evidence-based activities in Richmond. Richmond are currently unable to provide CST according to the SWL and St George's Trust Memory Services Audit.</li> </ul>
Care	Assessing and managing other long-term conditions	Ensure that people living with dementia have equivalent access to diagnosis, treatment and care services for comorbidities as those who do not have dementia	There are dementia specialist nurses available in the borough to support the recognition of any mismanaged comorbidities
	Palliative care	<ul> <li>For people living with dementia who are approaching the end of life, use an anticipatory healthcare planning process involving the person, their carers and their family.</li> <li>Support eating and drinking and consider involvement of speech and language therapy.</li> </ul>	<ul> <li>Limited completion of advanced directives. For example, in care homes all residents should have a PACT plan which includes a section on Advanced Care Planning and End of Life Care (and only 32% of people living in Richmond care homes have a CMC record). EACH PACT plan should include the CMC record.</li> <li>Limited utility of tools to coordinate End of Life Care, such as CMC, although the Enhanced Health in Care programme has helped improve this.</li> </ul>

Supporting carers	<ul> <li>Offer carers for people living with dementia psychoeducation and skills training intervention.</li> <li>Ensure that support provided to carers is personalized, accessible and available after diagnosis and beyond.</li> <li>Whilst services do exist, the data suggests that the support is not reaching everyone who needs it—carer reported QoL in Richmond was significantly lower than London and England scores.</li> <li>Psychoeducation provision is not formalised.</li> </ul>	
Moving to different care settings	<ul> <li>Review the person's needs and wishes (including any care and support plans and advance care and support plans) after every transition.</li> <li>Unclear of formal consideration of advanced decision making at points of care transfer, as different systems are used depending on the point of transfer (for example, CMC records, or the 'Red Bag' scheme in care homes)</li> </ul>	
Staff training	<ul> <li>Care and support providers should provide all staff with training in person-centred and outcome-focused care for people living with dementia."</li> <li>Lack of clarity regarding proportion of frontline staff that have received appropriate dementia training. Particularly in relation to advanced decisions making</li> </ul>	
Care planning	<ul> <li>Care plans should be created and updated to maximise independent activity, enhance personal and social function, and minimize the need for additional support.</li> <li>They should be reviewed annually in a face-to-face setting.</li> </ul> Variation in performance of GP practices against target of annual care plan reviews for patients with dementia.	

In Richmond, the existing Joint Dementia Strategy (2015-2021) and the Richmond Dementia Pathway Leadership Group (DPLG), established in November 2019 to better understand dementia care and support by framing all actions, showcases the breadth of work on dementia across Richmond, and is in place to ensure it delivers the overall dementia offer effectively. This collaborative approach to improving outcomes has shown how enacting a comprehensive dementia prevention service, and care support offer for residents remains a key focus for London Borough of Richmond.

## 9. End of Life Care

## 9.1 The Overview of End of Life Care

Death is inevitable and a guaranteed part of life. It affects not only the individual concerned, but also the person's family, friends, and their community. In the context of an expected death, as result of ageing or disease when, and where someone dies can be influenced, in line with the national and local policies and practices. Optimising the clinical and social care offer is part of the policy drivers. It must be noted that service improvement and transformation can facilitate a more peaceful, or perhaps more positive, experience for an individual and their loved ones. End of Life Care needs to be recognised and celebrated in a similar manner to when a baby is born.

Around 500,000 people die in England every year with approximately 1,200 being Richmond residents<sup>129</sup>. More than 50% of these deaths are caused by cancers, circulatory and respiratory diseases, with cancers in particular playing a larger role in Richmond than nationally. The majority of these deaths, both nationally and locally, occur in hospital, although national data shows that most patients would prefer to die at home<sup>130</sup>.

National evidence suggests that those with long-term conditions and older people are more likely to experience lower quality of care, and that the presence of comorbidities also increases the complexity of care needs at the end of their life. Due to the increasing numbers of people requiring this care, in part due to the ageing population from the 'baby boomer era' after the Second World War, thinking about health and care needs of the ageing population has become a national priority. The focus has also moved towards equipping local communities and voluntary sector organisations with resources to support this process.

It should be noted that death is not only a feature of ageing or illness, as it can happen at any point in the human life-course. Often death happens without notice, referred to as a 'sudden and unexpected' death, where an investigation by the police and/or a coroner may be required to establish causes, especially if a medical doctor is unable to issue a Medical Certificate of the Cause of Death<sup>131</sup>.

Some elements of death in relation to drugs and alcohol, suicide and infectious diseases are covered in their respective chapters. Overlaps within other parts of the JSNA are also referenced herein, such as the terminal illnesses usually leading to plannable deaths e.g., dementia, cancer, circulatory disease, respiratory disease, community voice, amongst others.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/922344/Dealing\_with sudden unexpected death.pdf

<sup>&</sup>lt;sup>129</sup> Public Health England: Public Health Profiles. 2019

<sup>&</sup>lt;sup>130</sup> Public Health England (2019) Atlas of Variation for Palliative and End of Life Care. [Internet]. [Accessed on 1 July 2019]. Available from: http://tools.england.nhs.uk/images/EOLCatlas/atlas.html

<sup>&</sup>lt;sup>131</sup> College of Policing Limited (2019) [Internet]. Practice Advice: Dealing with sudden unexpected death [Accessed on 23 October 2020]. Available from:

This Richmond JSNA subsection refers to people with imminent deaths as a result of disease or ageing, which can be planned for, with End of Life Care as treatment and/or care put in place to support the person. Sudden and expected deaths, where there is an inability to plan for them, are not included.

## 9.2 Definitions and Scope of End of Life Care

End of Life Care is defined by Marie Curie specifically as the "treatment, care and support for people nearing the end of their life"132, and is provided for those who are expected to be living in their last year, although this is not always predictable and may only be provided in last weeks or days of someone's life (ibid).

The General Medical Council (GMC) clarifies patients needing End of Life Care as being those with one or more of the following:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events<sup>133</sup>.

End of Life Care supports a patient, their family and friends from a terminal diagnosis, through to bereavement and may include medical, psychological, social, spiritual and practical support including:

- managing a patient's physical symptoms, including pain
- providing emotional support for the patient and their family and friends
- discussing and agreeing on a patient's expectations, wants and wishes
- providing practical support to make a Will or gaining financial support
- enabling the last few days, months or year(s) to be as comfortable as possible
- ensuring where necessary, care is increased closer to death (ibid).

There are a range of professionals involved in End of Life Care, who work collaboratively to provide the support a patient needs. These professionals can include nurse specialists, counsellors, physiotherapists, dieticians, social workers, occupational therapists and doctors. They may be employed by a range of agencies including the voluntary sector (e.g., Macmillan Cancer Support), local authority Adult Social Care and NHS organisations within hospital trusts and community providers (ibid). End of Life Care can range from a patient permanently moving to a care home for around the clock support and care, home visits by social workers, or making plans to die in their own home, surrounded by loved ones.

Palliative Care is defined by Marie Curie, the UK's leading charity that provides support to people with terminal illness, as the "treatment, care and support for people with a life-limiting illness, and their family and friends". Life-limiting illnesses are those that are incurable and likely to cause death. Dementia and advanced cancer are examples of these illnesses (ibid). In some instances, there is no movement between the two definitions, particularly around emotional support with coping with a diagnosis. Palliative Care is therefore related to terminal illness diagnoses, rather than the fact death is forthcoming.

<sup>&</sup>lt;sup>132</sup> Marie Curie (2018) [Internet]. What are palliative care and end of life care? [Accessed on 23 October 2020]. Available from: https://www.mariecurie.org.uk/help/support/diagnosed/recent-diagnosis/palliative-care-end-of-life-care

<sup>&</sup>lt;sup>133</sup> General Medical Council (GMC) (2010) [Internet]. Treatment and Care towards the end of life: good practice in decision-making [Accessed on 23 October 2020]. Available from https://www.gmc-uk.org/-/media/documents/treatmentand-care-towards-the-end-of-life---english-1015 pdf-

## 9.3 National Policy Context for End of Life Care

The End of Life Care Strategy by the Department of Health was published in 2008<sup>134</sup>. Since then, two key quality standards have been published by the National Institute of Health and Care Excellence (NICE), including QS13: End of Life Care for Adults<sup>135</sup> and QS144 Care of Dying Adults in the Last Days of Life<sup>136</sup> that support providers and commissioners to improve the quality of End of Life Care. They provide guidance on identifying gaps and areas for improvement, measuring quality of care, understanding how to improve care, demonstrating quality care is being provided, and commissioning high-quality services.

In recent years, the national policy focus has been on the importance of facilitating patient choice and providing a person-centred approach. Enabling individuals to achieve their preferred place of death, and ensuring equity of access, have also been vital elements of these developments.

In 2015, an independent review was undertaken by The Choice in End of Life Care Programme Board<sup>137</sup>, which highlighted that around 5% of End of Life Care patients would have complex needs requiring specialist input, and 30% would require a targeted offer with the remainder supported by universal provision. Targeted support includes patients with repeat hospital admissions (many of which are within 90 days of their death).

This review supported the development of a national framework for NHS England, which moved from a population health perspective towards a more individual approach. NHS England published The End of Life Care Programme<sup>138</sup>, which includes guidance provides the Comprehensive Personalised Care Model, with 6 evidence-based components, that aims to involve patients at all stages, in ways which meet their individual needs:

- · shared decision making
- personalised care and support planning
- enabling choice, including legal rights to choose
- social prescribing and community-based support
- patient activation and supported self-management
- personal health budgets and integrated personal budgets<sup>139</sup>.

<sup>&</sup>lt;sup>134</sup> Department of Health (DoH) (2008). [Internet]. End of Life Care Strategy: Promoting High Quality Care for All Adults At End Of Life [Accessed on 23 October 2020]. Available from:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/136431/End\_of\_life strategy.pdf

<sup>&</sup>lt;sup>135</sup> NICE (2011) End of Life Care For Adults Quality Standard QS13 [Internet]. [Accessed 18 March 2021']. Available from: https://www.nice.org.uk/guidance/qs13

<sup>&</sup>lt;sup>136</sup> NICE (2017) Care of Dying Adults in the Last Days of LIFE Quality Standard QS144 [Internet]. [Accessed 18 March 2021] Available from: https://www.nice.org.uk/guidance/QS144

<sup>&</sup>lt;sup>137</sup> The Choice in End of Life Care Programme Board (2015) [Internet]. What's Important to Me. A Review of Choice in End of Life Care [Accessed on 23 October 2020]. Available from: <a href="https://www.gov.uk/government/publications/choice-in-end-of-life-care">https://www.gov.uk/government/publications/choice-in-end-of-life-care</a>

<sup>&</sup>lt;sup>138</sup> NHS England (undated) End of Life Care [Internet]. [Accessed on 18 March 2021]. Available from https://www.england.nhs.uk/eolc/

<sup>&</sup>lt;sup>139</sup> NHS England (undated) Personalised End of Life Care [Internet]. [Accessed on 18 March 2021]. Available from https://www.england.nhs.uk/eolc/personalised-care/

At the start of 2019, The NHS Long Term Plan<sup>140</sup> was issued by NHS England, outlining the needs for the NHS to operate in a cost-efficient and targeted manner, fit for modern society, including investments in technological developments, and greater joined-up working. In the context of End of Life Care, this document specified a need for differentiated support, providing personalised budgets for individuals so they can act as purchasers for their care and training for clinicians and social care staff to support these shifts proactively, to improve outcomes for End of Life Care patients. It listed reducing emergency admissions and enabling more people to choose where they die as prime outcomes. It also outlined an opportunity for match-funding proposals for CCGs to increase the funding available for children's hospices.

Whilst there is no formalised strategic national guidance or official expectations for local areas to implement End of Life Care strategies, the most effective driver for local areas remains the outcomes of the local JSNA alongside the focus of the NHS Long Term Plan (ibid).

## 9.4 Local Policy Context for End of Life Care

There is currently no Richmond End of Life Care Strategy, although there have been plans to undertake this exercise, to provide strategic approach to delivery of this work. Delays have likely been caused by the pandemic. There is an End of Life Care Programme for South West London Health and Care Partnership, following the creation of this 6-borough alliance in April 2020. The emergency of the COVID-19 pandemic has delayed some developments of this work.

## 9.5 End of Life Care in Richmond

In the next 20 years the numbers and proportion of older people within the population is predicted to increase substantially, from 32,403 (16.2% of population in 2021) to 45,784 (22.0% of population in 2041)<sup>141</sup>. As a result, there will be a growing pressure on services for older people and those with terminal diagnoses across the life course. This is likely to affect those services supporting the frailer and older population as they approach the end of their lives. The increasing population of older people is likely to increase the prevalence of dementia and multimorbidity, potentially straining the local health and social care economy. Richmond has relatively high levels of recurrent emergency hospital admissions for patients in the last 90 days of life (ibid).

End of Life Care has a role to play in managing resources and supporting people's quality of life in their last days. Having an effective strategy and ensuring it is widely used, could provide unnecessary hospital deaths and increasing the percentage of residents in South West London who die in their care home by 1% would lead to savings of approximately £65,000 per year<sup>142</sup>, saving money and also supporting people to 'die better'.

In 2019, 1,231 people died in Richmond, of these 599 males and 632 females with 68.3% aged 75 or older at the time of their death. Due to the projected increases in the older people in Richmond, the number of people reaching the end of life each year will also be increasing.

For more details about the Richmond demography and life expectancy, please see the People chapter.

<sup>&</sup>lt;sup>140</sup> NHS England (2019). The NHS Long Term Plan. [Internet]. [Accessed on 01 July 2019]. Available from: https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/

<sup>&</sup>lt;sup>141</sup> Wandsworth Accommodation-Based Care Commissioning Statement 2018-19, Commissioning Programme and Business Intelligence, September 2020.

<sup>&</sup>lt;sup>142</sup> South West London Sustainability and Transformation Partnership (STP) (2018) South West London STP Care Home Data Pack [Internet]. [Accessed on 30 October 2020]. Available from: <a href="https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2020/03/SWL-care-home-data-pack-2019.pdf">https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2020/03/SWL-care-home-data-pack-2019.pdf</a>

Social factors can affect a person's wishes as well as their individual experiences (and that of their family and friends) at the end of their life, such as their ethnic background, language barriers and religion. These factors can impact on the quality and provision of services and as Richmond has a diverse population with hundreds of languages and cultures, need to be included in local planning and policy for End of Life Care.

## 9.6 Equity in End of Life Care

In 2015, Marie Curie commissioned an independent review covering literature and national data which solidified concerns of policy makers, commissioners, care givers and clinicians around fairness of accessibility and options in End of Life Care nationally. The review highlighted the inequities in palliative care across services, ethnic groups, ages, diagnoses and locations. The review also highlighted that any additional costs to improving reach of palliative care to those underserved, were likely to be offset by savings associated with reduced need for acute care and fewer hospital death<sup>143</sup>.

The Care Quality Commission (CQC) has also explored inequalities in provision, through analysis of numerous data sources including from commissioners and staff. Factors influencing their End of Life care were identified as background, sexual orientation, gender identity, disability and social circumstance. The CQC identified 10 groups of adults who often received inequitable End of Life Care, most of whom are covered by The Equality Act (2010)<sup>144</sup>:

- people with conditions other than cancer
- older people
- people with dementia
- people from Black, Asian and Minority Ethnic groups
- lesbian, gay, bisexual and transgender people
- people with a learning disability
- people with a mental health condition
- people who are homeless
- people who are in secure or detained setting
- gypsy and travelling communities.

As a result of the above, the CQC requested commissioners to improve access to End of Life Care<sup>145,</sup> noting that this is a vital need nationally, given the volume of people within the general population who will fit into at least one of these categories.

<sup>&</sup>lt;sup>143</sup> Personal Social Services Research Unit London School of Economics and Political Science (2015) Equity in the Provision of Palliative Care in the UK: Review of Evidence. [Internet] Accessible online. [Accessed 08 July 2019]. Accessible at: <a href="https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf">https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf</a>

<sup>&</sup>lt;sup>144</sup> Equality Act (2010) [Internet.] [Accessed 18 March 2021]. Available from: https://www.legislation.gov.uk/ukpga/2010/15/contents.

<sup>&</sup>lt;sup>145</sup> The Care Quality Commission (2016) A different ending: End of Life Care Review. [Internet] [Accessed on 16 July 2019] Available from: https://www.cqc.org.uk/publications/themed-work/different-ending-end-life-care-review

## 9.7 The Level of Need for End of Life Care

#### **Death Rates**

The local all ages all causes standardised mortality rate has been decreasing in Richmond since 2001. It remains lower than the London average at 721.3 people per 100,000 population in 2019, compared to 809.1 per 100,000 in London as a whole<sup>146</sup>.

The major causes of death in Richmond are listed in the mortality sub-section.

#### **Place of Death**

The location of death for Richmond residents varies significantly compared to England's averages. A greater proportion of residents in Richmond died at home compared to the English average (26.6% compared to 24.4%), It is important to consider the impact of place of death has on someone's experience towards the end of their life, and is important to recognise when planning, commissioning and delivering services.

Furthermore, in 2019 more people of all ages died in a care home compared to England's average (19.5% compared to 22.5%)<sup>147</sup>.

Richmond has a higher percentage of care home deaths in people over 85 years when compared to the London average. Richmond's latest proportion of deaths of residents aged 80+ that occur in a care home was 31.7/100 (n=167, 6th highest rate in London, **Figure 68**), which was 15.4% lower than the England average and 21.0% higher than London average. The latest Borough figure was also 87.2% higher from year 2009, in comparison with an 18.5% increase in England's rate in the equivalent time period (**Figure 69**).

<sup>&</sup>lt;sup>146</sup> NOMIS. Mortality statistics. 2019

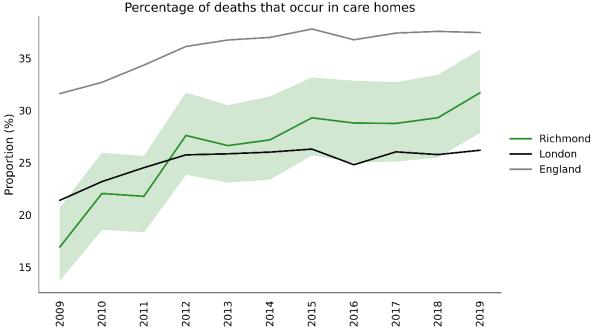
<sup>&</sup>lt;sup>147</sup> Public Health England (2019) Atlas of Variation for Palliative and End of Life Care. [Internet]. [Accessed on 01 July 2019]. Available from: <a href="http://tools.england.nhs.uk/images/EOLCatlas/atlas.html">http://tools.england.nhs.uk/images/EOLCatlas/atlas.html</a>

Percentage of deaths that occur in care homes, 2019 40 England -- London Proportion (%) 30 10 0 Merton Barnet Bexley Ealing Sutton Richmond Redbridge Islington Brent Kingston Barking and Dagenham Croydon Enfield Kensington and Chelsea Harrow Hammersmith and Fulham Greenwich Lambeth Southwark Lewisham Camden **Tower Hamlets** Havering Hillingdon **Waltham Forest** Westminster Hounslow Wandsworth Bromley Hackney Newham

Figure 68: Proportion of Care Home Deaths amongst 85+ population by local authority, 2019

Source: PHE, Public Health Profiles

Figure 69: Proportion of Care Home Deaths amongst 85+ population, 2009–2019

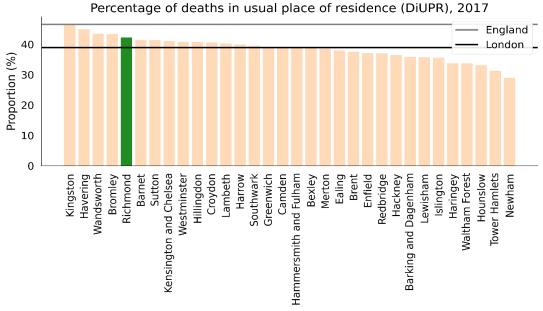


Source: PHE, Public Health Profiles

Richmond's percentage of deaths in usual place of residence (DiUPR) in 2017 was 42.3% (n=502, 5th highest rate in London, Figure 70), which was 9.2% lower than the England average and 8.5% higher than London average. The latest Borough figure was also 68.5% higher from year 2004, in comparison with a 32.6% increase in England's rate in the equivalent time period (Figure 71).

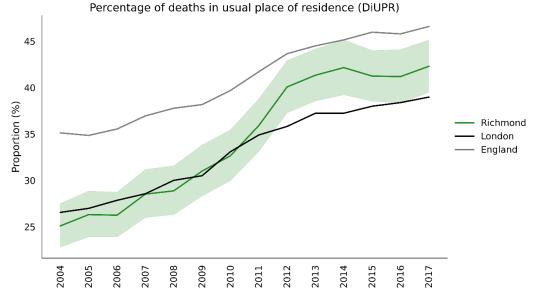
<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values

Figure 70: Proportion of people who die in their usual place of residence by local authority, 2017



Source: PHE, Public Health Profiles

Figure 71: Proportion of people who die in their usual place of residence, 2004–2017



Source: PHE, Public Health Profiles

The rising trend in the percentage of people dying in their usual residence (either their home or their care home), resulted in a greater proportion of Richmond's residents dying at home or care home (46.1% vs. 45.3% of residents dying in hospitals, see **Figure 72**). By comparison, the proportions in England have also reversed, 46.9% and 44.9% respectively. London's proportions are as follows, 39.9% died in their usual residence whilst 51.1% of Londoners died in hospitals<sup>148</sup>.

<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values

<sup>&</sup>lt;sup>148</sup> Public Health England (2019) Atlas of Variation for Palliative and End of Life Care. [Internet]. [Accessed on 01 July 2019]. Available from: http://tools.england.nhs.uk/images/EOLCatlas/atlas.html

Places of death (% of total), 2019 2.5 Other 2.9 2.3 5.8 Hospice 6 6.3 24.4 Home 24.8 26.6 22.5 Care home 15.1 19.5 44.9 Hospital 51.1 45.3 0 10 20 30 40 50 60 ■ England ■ London ■ Richmond

Figure 72: Places of death in Richmond, London and England, 2019

Source: ONS Data, 2015, Accessible on PHE's End of Life Care Atlas

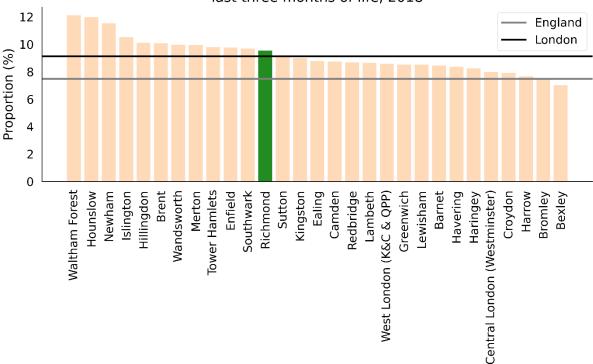
#### **Hospital Admissions at The End of Life**

Patients often find emergency hospital admissions disruptive and distressing, this is similar for their friends and family. NICE recommends the first stage of advanced care planning is to identify options within the community.

Richmond's latest proportion of deaths in people with three or more emergency admissions in the last three months of life was 9.5% (12th highest in London, Figure 73), which was 27.5% higher than the England average and 4.6% higher than London average. The latest Richmond's figure was also 3.4% higher from year 2015, in comparison with an 8.8% increase in England's rate in the equivalent time period (Figure 74).

Figure 73: Proportion of deaths with 3+ emergency admissions in final 90 days of life by CCG, 2018

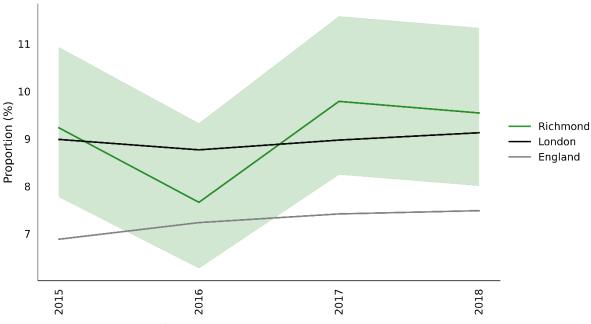
Percentage of deaths with three or more emergency admissions in the last three months of life, 2018



Source: PHE, Public Health Profiles

Figure 74: Proportion of deaths with 3+ emergency admissions in final 90 days of life, 2015–2018

Percentage of deaths with three or more emergency admissions in the last three months of life



Source: PHE, <u>Public Health Profiles</u>

Richmond, specifically, has the highest ratio of ambulance call outs for residents from care homes across South West, with 1.06:1 compared to 0.92:1 respectively. This could be related to the quality of care within care homes

<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values

although when looking at the admissions lasting more than 1 day, this is similar to the London average (30.5% compared to 29.9%)<sup>149</sup>.

#### **National Demographic Shifts**

The ageing population and the rise of chronic illness amongst the local and general population are likely to increase the need for end of life care.

A recent study which looked at the mortality statistics for England and Wales from 2006-2014, suggested that if the age and sex specific mortality rates remained the same as in 2011, the number of people requiring End of Life Care nationally would grow by 25% by 2040, and with the upward trend observed nationally between 2006-2014 this could be in excess of 40% (42.4% by 2040)<sup>150</sup>.

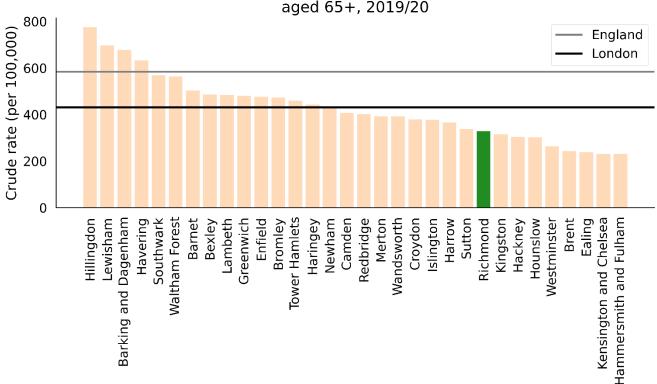
#### **Permanent Admissions to Residential and Nursing Care Homes**

In 2019/20, Richmond's rate of permanent admissions of people aged 65+ to residential and nursing care homes was 328.1/100,000 population (n=103, 9th lowest rate in London, Figure 75), which was 43.8% lower than the England average and 23.9% lower than London average. The latest Borough figure was also 47.7% lower from year 2006/07, in comparison with a 27.0% decrease in England's rate in the equivalent time period (Figure 76).

Figure 75: Permanent admissions to care homes or nursing care homes by local authority, 2019/20

Permanent admissions to residential and nursing care homes per 100,000

aged 65+ 2019/20



Source: PHE Public Health Profiles

<sup>&</sup>lt;sup>149</sup> South West London STP. South West London STP Care Home Data Pack see previous

<sup>&</sup>lt;sup>150</sup> Etkind, Bone et al (2017). 'How many people will need palliative care in 2040? Past trends, future projections, and implications for services. BMC Medicine 2017. 15:102 <a href="https://doi.org/10.1186/s12916-017-0860-2">https://doi.org/10.1186/s12916-017-0860-2</a>

Permanent admissions to residential and nursing care homes per 100,000 aged 65+ 800 Crude rate (per 100,000) 700 600 Richmond London England 500 400 300 2017/18 2018/19 2006/07 2009/10 2011/12 2012/13 2013/14 2014/15 2007/08 2008/09 2010/11 2015/16 2019/20 2016/17

Figure 76: Permanent admissions to care homes or nursing care homes by local authority, 2007–2020

Source: PHE, Public Health Profiles

## 9.8 Care Home and Nursing Care Beds Capacity

Richmond's latest rate of care home beds per 100 residents aged 75+ was 6.7 (n=943, 15th lowest rate in London, Figure 77), which was 30.1% lower than the England average and 6.6% lower than London average. The latest Borough figure was also 19.3% lower from year 2011, in comparison with a 11.1% decrease in England's rate in the equivalent time period (Figure 78). Richmond is increasingly placing residents in care home beds outside (but within a 5 mile radius) of the Borough, because of the high comparative cost of private provision within the Borough.

The shift in social care policy towards providing care at home, rather than in residential care, may explain some of the fall in bed availability. The number of people admitted to residential and nursing care homes has declined in recent years. However, there is no reliable data on the number of people receiving care at home, so it is difficult to measure changes in service provision.

The decrease in bed availability could also indicate a significant fall in social care provision for older people, which comes at a time of expected growth in demand due to the increase of the ageing population. A downward trend in the registration of new care homes, combined with an upward trend in closures, has resulted in a net reduction in the number of beds available<sup>151</sup>.

<sup>\*-</sup> green ribbon shows 95% confidence interval around Richmond's indicator values

<sup>&</sup>lt;sup>151</sup> Nuffield Trust: <u>Care home bed availability</u>. 2021.

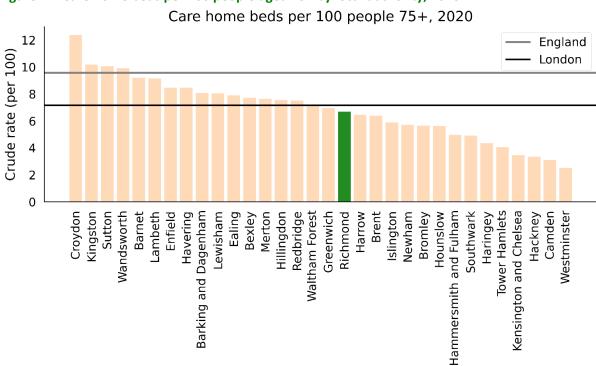


Figure 77: Care home beds per 100 people aged 75+ by local authority, 2020

Source: PHE <u>Public Health Profiles</u>

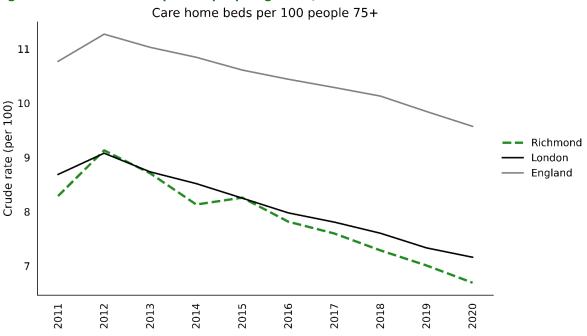


Figure 78: Care home beds per 100 people aged 75+, 2011–2020

Source: PHE, Public Health Profiles

Richmond's latest rate of nursing home beds per 100 residents aged 75+ was 3.4 (n=474, 10th lowest rate in London, **Figure 79**), which was 27.9% lower than the England average and 19.6% lower than London average. The latest Borough figure was also 23.5% lower from year 2011, in comparison with a 6.3% decrease in England's rate in the equivalent time period (**Figure 80**).

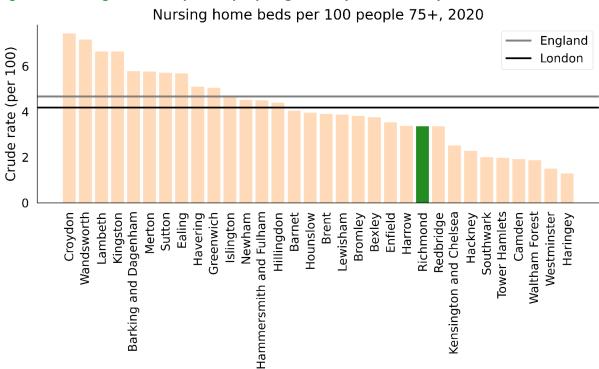


Figure 79: Nursing home beds per 100 people aged 75+ by local authority, 2020

Source: PHE Public Health Profiles

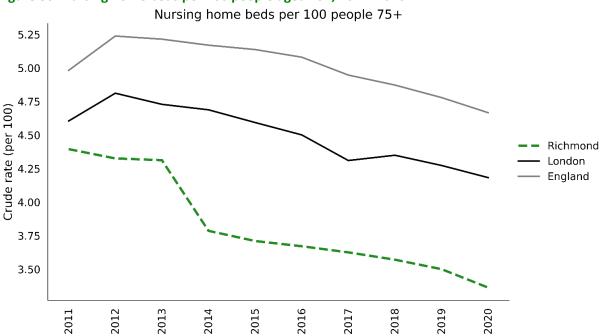


Figure 80: Nursing home beds per 100 people aged 75+, 2011–2020

Source: PHE <u>Public Health Profiles</u>

## 9.9 Limitations to The Data and Information on End of Life Care

In terms of national data on the experiences of people who are close to death, this information can be difficult to gather, particularly when related to symptoms at this time for many including cognitive impairment and

fatigue. In addition, gathering data from the patient's friends and family just before their death or when they are grieving may be even more difficult due to the sensitivities, emotional wellbeing, practical steps they need to put in place regarding the Will, last wishes and funeral arrangements. Local information is also limited regarding the absence of community feedback to HealthWatch, the CCG and the voluntary sector. However, there are a few miscellaneous points of feedback from which to form recommendations for planning, commissioning and providing End of Life Care.

#### 9.10 Causes of Unmet Need

#### **Choice of Place of Death**

75% of the country's population would prefer to die at home, whilst only a third actually do<sup>152</sup>. The preference for death at home is likely to be underestimated, as not all patients may have their wishes recorded on health and care data systems.

Ensuring that individuals die in their preferred place of death is a key national aim for good End of Life Care. Comparatively, data from the bereaved family and friends, suggests that they felt hospital was the right place for them to die, with 74% of respondents stating this compared to 3% recognising their relative wanted to die in hospital<sup>153</sup>. This concept is little understood; perhaps individuals are less aware of the practicalities of dying at home, perhaps family and friends are anxious about how they might manage this and feel hospital is more appropriate and supportive.

#### **Sharing Data**

There is a digital care planning service in place called Coordinate My Care (CMC), which operates across London. It facilitates electronic sharing of urgent care plans between healthcare providers, including the London Ambulance Service (LAS), allowing for the coordination of patient care and improving care outcomes. This service enables sharing of core information, such as preferred place of death, cardiopulmonary resuscitation status, advice regarding ceilings of care and other patient preferences. The gap in awareness of patient preference could increase the proportion of people dying in hospital rather than at home.

#### **Specific Groups and Health Inequalities**

#### **Black, Asian, and Minority Ethnic Groups**

A national survey showed that care for Black, Asian and Minority Ethnic groups in their last 3-months of life, compared to White British people, were:

- more or as likely to receive help at home
- less likely to rate overall care as outstanding or excellent, particularly among those who had spent time in a care home or hospice
- more likely to die in hospital than a care home.

<sup>152</sup>https://www.nice.org.uk/guidance/ng142/evidence/c-barriers-to-accessing-end-of-life-care-services-pdf-6955526992

<sup>&</sup>lt;sup>153</sup> Voices Survey (as previously)

National research indicates that the barriers to accessing care include misunderstandings about what End of Life Care is, a general mistrust of health and care staff (which may already be present within sub-communities) and a lack of cultural awareness by providers<sup>154</sup>.

Some of these misunderstandings about care creates a perceived fear about meeting the needs of the patient, especially those with difficulties in communicating in English. The presumption that services cannot meet the cultural needs can often result in self-discharge or in some cases return to the country of origin.

The lack of language interpreters puts friends and family under pressure to translate how the patients are feeling, which poses additional issues around confidentiality and being able to explicitly name their wishes. Expressing the desire for additional support could be an issue in some cultures where a patient may not feel comfortable expressing this to their family member to translate for them.

Experiences of spiritual and bereavement services are also mixed, with some families reporting lack of access to appropriate chaplaincy and others reporting no bereavement resources available in their language.

#### People who are homeless

Research has suggested that End of Life Care services are often not suitable for people who are homeless. For those who live in hostels, the environment is often inappropriate for providing such services in cramped, chaotic, noisy, less equipped to support the specific needs. Information sharing can become problematic as hostel staff may not be recognised as next of kin and they may require their own emotional support.

People who are homeless may have a greater number of co-morbidities or dual-diagnosis (such as the presence of a substance use and mental health need concurrently), presenting a greater level of specialist need for which specialist services may not exist, and which may exclude the person from meeting the criteria for a residential care home. In addition, they could be younger than the typical age for referral into a residential care home.

#### **Dementia**

Quality care for people with dementia can be affected due to the lack of early conversations about planning their end of life care, before a patient deteriorates and therefore has reduced capacity to express their wishes 156.

#### Lesbian, gay, bisexual, transgender, questioning and intersex (LGBTQ+) community

People from the LGBTQ+ community experience a higher incidence of life-limiting illness than the general population, alongside higher rates of physical and mental ill health and risk behaviours<sup>157.</sup> Some of these challenges are considered in more detail in the sexual health section of this JSNA.

Patients from the LGTBQ+ community have expressed their identity as a barrier to accessing End of Life Care services, and often report mixed previous experiences of health and social care, with some feeling that their

<sup>&</sup>lt;sup>154</sup> Dixon J, King D, Matosevic T, Clark M and Knapp M (2015) Equity in Palliative Care in the UK, PSSRU, London: London School of Economics/Marie Curie

<sup>&</sup>lt;sup>155</sup> St Mungo's and Marie Curie Palliative Care Research Unit at University College London (2011) Supporting homeless people with advanced liver disease approaching the end of life, May

<sup>&</sup>lt;sup>156</sup> People with Dementia. A different ending: Addressing Inequalities in End of Life Care. Care Quality Commission 2017. [Accessed on 01 July 2019] Available from: <a href="https://www.cqc.org.uk/publications/themed-work/different-ending-end-life-care-review">https://www.cqc.org.uk/publications/themed-work/different-ending-end-life-care-review</a>

<sup>&</sup>lt;sup>157</sup> Almack K, Moss B and Smith T, Research and policy about end of life care for LGBT people: identifying implications for social work services, in Fish J and Karban K, eds, Social Work and Lesbian, Gay, Bisexual and Trans Health Inequalities: International Perspectives. Bristol: Policy Press, 2015, p173-186.

preferences were assumed based on their sexual orientation, and others feeling excluded in communal establishments, which may be in part due to more prejudicial views of their peers.

Additionally, in some circumstances, the partners of homosexual patients were not as included as the heterosexual partners<sup>158</sup>. As a result, patients from these communities may experience fear of disclosing their sexual orientation, and national studies show that many care home residents choose not to reveal this with staff.

#### **People with a Learning Disability**

People with a learning disability have a lower life expectancy and are more likely to die prematurely or avoidably than the general population. This, coupled with the recognised challenge of identification of deterioration or dying in this population, often leads to late identification with limited opportunity to explore wishes and preferences and to involve family<sup>159</sup>.

The CQC report on the experience of those with learning disabilities at the end of life identified the of lack of awareness, communication challenges, and the importance of coordination of care as core themes for this population. Poor understanding of learning disabilities could result in misattribution of cause of symptoms and late diagnosis of illness, impacting on the success of treatment. Additionally, early and continuous involvement of staff who knew the individual, and use of a care coordinator, were thought to be of value in ensuring high quality and coordinated care. Therefore, training and support for early identification of those approaching the end of life in this population was recommended as a focus for commissioners and providers<sup>160</sup>.

#### **People with Mental Health Conditions**

Mental health is a recognised cause of premature death, in part because people with mental health conditions may have physical needs overlooked and symptoms may be misattributed. Mental health disorders can reduce individual's motivation and ability to engage in health lifestyle behaviours. As a result, people with serious mental illnesses (excluding dementia) die on average 20 years earlier than the rest of the population. As with those who are homeless or have a learning disability, this early onset of end of life care needs is often missed, leading to late identification resulting in patients not having enough time to plan their End of Life Care appropriately<sup>161</sup>.

In Richmond, an estimated 20,430 adults have a common mental health problem, which equates to 13.2% adults. There are overlaps of mental health problems with other vulnerability factors such as sexual orientation, deprivation, and homelessness. Mental health conditions also disproportionately affect people from Black, Asian and Minority Ethnic groups and they are more than twice as likely to experience psychosis and commit suicide.

#### Children and young people

While child deaths are relatively less common, approximately 2,500 children die annually, as a result of a life-limiting or life-threatening condition. There are an estimated to 49,000 children and young people under 18 years old living with a life-limiting or life-threatening condition in the UK. These numbers are expected to rise due to medical advances in testing, screening and recognition of signs and symptoms, and increasing life

<sup>&</sup>lt;sup>158</sup> Care Quality Commission (2017) Lesbian, Bisexual and Transgender People. A different ending: Addressing Inequalities in End of Life Care. [Internet]. [Accessed on 16 July 2019] Available from: <a href="https://www.cqc.org.uk/publications/themed-work/different-ending-end-life-care-review">https://www.cqc.org.uk/publications/themed-work/different-ending-end-life-care-review</a>

<sup>&</sup>lt;sup>159</sup> Heslop P, Blair P, Fleming P, Hoghton M, Marriott A and Russ L, Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD), Final report, 2013

<sup>&</sup>lt;sup>160</sup> People with Disabilities. A different ending: Addressing Inequalities in End of Life Care. Care Quality Commission 2017. Accessible from: <a href="https://www.cqc.org.uk/publications/themed-work/different-ending-end-life-care-review">https://www.cqc.org.uk/publications/themed-work/different-ending-end-life-care-review</a>

<sup>&</sup>lt;sup>161</sup> Rethink Mental Illness, Lethal Discrimination, 2013

expectancy. Children and young people with life-limiting conditions are more likely to need palliative care, that is specialist services long before their death 162.

## 9.11 Evidence-based Interventions

The UK policy makers are currently heavily focussed on a number of key strands of End of Life Care. Ensuring provision of care is appropriate and taking individual differences into account have positive impacts on a patient's quality of life in their last years, months and days of life.

In 2016, the National Palliative and End of Life Care Partnership published a national framework for action, with six key ambitions to support people in their last months<sup>163</sup>. These are outlined in (Figure 81) and reflect an increased focus on empowering and enabling local communities to contribute to End of Life Care services and seeing each person as an individual.

<sup>&</sup>lt;sup>162</sup> How many children and young people are affected by a life-limiting or life-threatening condition? Together for Short Lives. Available online. [Accessed 11/07/2010]. Available at:

https://www.togetherforshortlives.org.uk/resource/numbers-of-children-affected-by-life-limiting-or-threatening-conditions/

<sup>&</sup>lt;sup>163</sup> The National Palliative and End of Life Care Partnership. Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020. [Internet]. 2015. [Accessed on 02 July 2019]. Available from: http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf

Figure 81: The Six Ambitions for Palliative and End of Life Care

## Each person is seen as an individual

01

I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.

02

#### Each person gets fair access to care

I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

03

### Maximising comfort and wellbeing

My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

#### Care is coordinated

04

I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

05

### All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

06

#### Each community is prepared to help

I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

Source: Ambitions for Palliative & End of Life Care 'A national framework for local action 2015-2020

The figure above clearly shows the expectations of high quality and appropriate End of Life Care, to meet the needs of all patients in their last years, months and days of life.

Firstly, each person needs to be seen as an individual, which marks a stark change to focusing on planning population-wide interventions over previous decades. Each person has a completely different life experience, and as such, is highly likely to have a different experience of dying and death.

Considering the cultural context, including language and specific social and religious practices in advance, not just at the time of death and in the stages of bereavement is very important. Communicating in a manner which is understood by the patient, their friends and family is vital. This would apply for all vulnerable groups, particularly those from Black, Asian and Minority Ethnic groups and the LGBTQ+ community, given the cultural and identity components which when excluded can have a huge detrimental impact on quality of life in its final stages.

Secondly, all patients need to be provided with access to care. It is interesting to note that those who are more affluent often receive better quality of care.

Thirdly, wellbeing and comfort are addressed as core elements of care, involving reduction in distress in order for the end of life to be as comfortable as possible.

Fourthly, coordination of care, including data sharing and communication between medical, social and voluntary sector staff, as well as between the family and friends is critical. This would reduce any gaps or duplication in gathering information and increase the likelihood of a person's wishes regarding where and how they die to be widely known and honoured.

Fifthly, all staff involved in End of Life Care are fully competent, ensuring they are equipped with the necessary personal skills enabling then to provide compassionate care.

Finally, communities should be involved in the support and care, people feel confident in having conversations about dying and death, and practical support is provided.

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## Acronyms

ADL Activities of Daily Living

ASC Adult Social Care

ASCOF Adult Social Care Outcomes Framework
BAME Black, Asian And Minority Ethnic Groups

BMI Body Mass Index

CBT Cognitive Behavioural Therapy

CILS Community Independent Living Service

CJD Creutzfeldt Jakob Disease
CMC Coordinate My Care

CMD Common Mental Disorders

COPD Chronic Obstructive Pulmonary Disorder

CQC Care Quality Commissioning
CST Cognitive Stimulation Therapy
DFC Dementia Friendly Communities
DFG Disabilities Facilities Grant

DFO Dementia Friendly Organisations
DiUPR Deaths in Usual Place of Residence

DLB Dementia With Lewy Bodies

DOLS Deprivation of Liberty Safeguards
DPLG Dementia Pathway Leadership Group

EHCH Enhanced Care in Care Homes
FaME Falls Management Service
FTD Frontotemporal Dementia
GBD Global Burden of Disease
GMC General Medical Council

HAM Home Assessment Modification

HNA Health Needs Assessment HNA Health Needs Assessment

Hounslow and Richmond Community Healthcare NHS

HRCH Trust

IFBHS Integrated Falls & Bone Health Service
JSNA Joint Strategic Needs Assessment

LAS London Ambulance Service

LBRuT London Borough of Richmond upon Thames

LGA Local Government Association

LGBTQ+ Lesbian, Gay, Bisexual, Trans, Questioning +

MAS Memory Assessment Service

NICE National Institute for Clinical Excellence

PANSI Projecting Adult Needs and Service Information

PCN Primary Care Network
PHE Public Health England

PHOF Public Health Outcomes Framework

POPPI Projecting Older Peoples Population Information

PPV Pneumococcal Polysaccharide Vaccine

QOF Quality Outcomes Framework

ROI Return on Investment RTH Royal Trinity Hospice

SCIE Social Care Institute of Excellence STP System Transformation Plan

SWLCCG South West London Clinical Commissioning Group

WHO World Health Organisation YLD Years Living with Disability

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