

# Equality Analysis

*(Health Inequalities, Human Rights, Social Value)*

## Dementia Strategy 2023-2028

**Before** completing this equality analysis it is recommended that you:

- ✓ Contact your equality and diversity lead for advice and support
- ✓ Take time to read the accompanying policy and guidance document on how to complete an equality analysis

<b>Section 1. Background</b>
<b>EA Title: Dementia Strategy</b>
<b>EA Author: Michelle Dunne, Senior Equality, Diversity &amp; Inclusion Manager</b>
<b>Team: Equality, Diversity &amp; Inclusion, People Directorate</b>
<b>EA Version: V0.1</b>
<b>Date Completed: 13<sup>th</sup> January 2023</b>
<b>1.1 What are the intended aims and outcomes of this work?</b>
<p>The strategy is a plan for how everyone working in health and social care will work together across Birmingham and Solihull to improve the lives of people with dementia and those who look after them. The strategy and action plan will be used to hold the organisations accountable for the improvements to be made over the coming five years.</p> <p>The aims of the strategy are to enable all people with dementia and those who care for them, to have the best possible health and social care support through their dementia journey.</p> <p>The strategy will be achieved through 4 key priorities:</p> <ul style="list-style-type: none"> <li>• Information which focuses on prevention, early intervention and support.</li> <li>• Access to a timely diagnosis with pre- diagnostic and post-diagnostic support.</li> <li>• Prevention of crisis and supporting people with dementia, their families and communities.</li> <li>• Improving the quality of personalised care and support planning for people with dementia, including advanced care planning.</li> </ul>
<b>1.2 Who will be affected by this work and how?</b>
<p>There are currently 850,000 people living with dementia in the UK. This is set to rise to 1.6 million by 2040. The scale and the need to prevent, diagnose, support, live and die well with dementia will only become greater. The NHS have a national target to diagnose 66.7% of individuals with dementia.</p>
<p>There are currently an estimated 13,000 people living with Dementia in Birmingham and Solihull. It is estimated there will be over 17,000 people living with Dementia in Birmingham and Solihull by 2040. Currently we are underperforming against the national target at 58.6%. Nationally and locally dementia diagnosis rates have reduced due to the impact of the Covid-19 pandemic. This doesn't mean that fewer people have been developing dementia, it is likely that people have not been coming forward for diagnosis, and the assessment for dementia has been taking longer. However the diagnosis rate in Birmingham and Solihull has been slowly recovering over the last 15months.</p>

Dementia is an umbrella term used to describe a range of progressive neurological disorders. Alzheimer's disease and vascular dementia are the most prevalent, accounting for 79% of all diagnoses.

Other forms include frontotemporal, Lewy body, Parkinson's disease, corticobasal degeneration, Creutzfeldt–Jakob disease and young-onset dementia (Alzheimer's Society 2017, Dementia UK 2017). Symptoms include change of thinking speed, mental agility, language, understanding, judgement as well as memory loss, but each affected person will experience dementia differently.

Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes. The symptoms of dementia will usually get gradually worse. How quickly this occurs will depend on the general health of the person with dementia and on the type of dementia they have.

- There are 850,000 people with dementia in the UK, with numbers set to rise to over 1 million by 2025.
- 225,000 will develop dementia this year, that's one every three minutes.
- 1 in 6 people over the age of 80 have dementia. There are over 40,000 people under 65 with dementia in the UK.

There are currently around 8,000 people with a diagnosis of dementia across the Birmingham and Solihull area and we know that this is an inaccurate representation of the true numbers with dementia. National data shows that numbers are underdiagnosed in Birmingham by around 40%. This would mean a real figure of around 11,000. Of these many will rely on the help of family and informal carers to maintain their independence and stay in their own homes.

**Section 2. Research - What evidence have you identified and considered?** This can include national research, surveys, reports, NICE guidelines, focus groups, JSNA, Clinical Experts or other equality analyses.

Health Aging Consensus Statement PHE/Centre for Better Ageing, 2019.

State of Ageing in 2020 – Centre for Better Ageing, 2020.

Build Back Better – Out Plan for Health and Social Care, HM Government, 2021.

Brain Health: A New Way to Think About Dementia Reduction, Alzheimer's Research UK/RSPH, 2021.

Alzheimer's Research UK – Women and Dementia: A Marginalised Majority.

Alzheimer's Society UK – LGBTQ+: Living with Dementia.

POPPIE data on dementia prevalence

PANSI data on early onset dementia prevalence

ONS – 2018 based subnational principal population projections for local authorities and higher administrative areas in England.

Trends in dementia diagnosis rates in UK ethnic groups: analysis of UK primary care data – ncbi.

Alzheimer’s Society – Local Dementia profile: Birmingham

Alzheimer’s Society – Local Dementia profile: Solihull

[Facts and figures - Dementia UK](#)

[DOCUMENT RESOURCES | dementiaace \(demace.com\)](#) The Dementia Alliance for Culture and Ethnicity (DemACE)

Blachir Report: [BLACHIR report | Birmingham City Council](#)

**Section 3. Impact and Evidence** In the following boxes detail the findings and impact identified (positive or negative) within the research detailed above; this should include any health inequalities that exist in relation to this work.

**Age:** describe age related impact and evidence.

Birmingham has a younger population, with only 13% aged over 65 years; Solihull has an older population, with 22% aged 65 years and over.

There are currently an estimated 13,000 people living with dementia in Birmingham and Solihull. It is estimated there will be over 17,000 people living with Dementia in Birmingham and Solihull by 2040.

There is a national government target to diagnose 66.7% which we (ICB) are currently under-performing against; our diagnosis rate is 58.6%.

Dementia is an umbrella term for a range of progressive conditions that affect the brain.

Each type of dementia stops a person’s brain cells (neurones) working properly in specific areas, affecting their ability to remember, think and speak.

Doctors typically use the word “dementia” to describe common symptoms – such as memory loss, confusion, and problems with speech and understanding – that get worse over time.

Dementia can affect a person at any age but it’s more common in people over the age of 65.

There are over 200 subtypes of dementia. The most common are Alzheimer’s disease, vascular dementia, Lewy body dementia, frontotemporal dementia and mixed dementia.

## Older People and Dementia

A risk factor is something that increases your likelihood of developing a condition. The diseases that cause dementia are complex. In most cases, it is likely that our age, genes, medical history and lifestyle all contribute to our risk of dementia. The biggest risk factor for dementia is age and the older you are the more likely you are to develop the condition, but it is not an inevitable part of ageing.

- ¾ of people are unaware that they can affect their risk of developing dementia.
- Around a third of a person's risk of developing Alzheimer's disease may be due to modifiable lifestyle factors.
- Lifestyle changes to improve cardiovascular health can reduce the risk of dementia.

National Dementia statistics:

- 7.1% of all people over the age of 65 have dementia.
- A person's risk of developing dementia rises from one in 14 over the age of 65, to one in six over the age of 80.

It is a common misconception that dementia is a condition of older age, over 42,000 people under 65 years old have dementia in the UK.

## Younger People and Dementia

Young onset dementia is any type of dementia where symptoms develop before the age of 65. You might hear it described as 'early onset dementia' or 'working age dementia.' It's thought that about five percent of people with dementia have young onset dementia.

The most common types of dementia amongst younger people are Alzheimer's disease, vascular dementia and frontotemporal dementia. Rare and genetically inherited types of dementia like Parkinson's disease and Huntington's disease are also more common in younger people.

Problems with language, vision, behaviour and/or personality may be the first symptoms, rather than memory loss. This can result in a delay in diagnosis as the symptoms may be wrongly attributed to another problem such as depression, work stress or relationship difficulties.

The Alzheimer's Society (2014) reports there are over 850,000 people living with dementia in the UK today. Of these, approximately, 42,000 are people with young onset dementia, which affects people under the age of 65. The actual figure is likely to be higher because of the difficulties of diagnosing the condition and might be closer to 6-9% of all people living with dementia

Prevalence rates for young onset dementia in black and minority ethnic groups are higher than for the population as a whole. People from black, Asian and minority ethnic backgrounds are less likely to receive a diagnosis or support.

People with a learning disability are at greater risk of developing dementia at a younger age. Studies have shown that one in ten develop young onset Alzheimer's disease between the

age of 50 to 65. The number of people with Down's syndrome who develop Alzheimer's disease is even greater

### **Diagnosis of young onset dementia**

As dementia is frequently, and wrongly, thought of as a condition that is just associated with old age, the early symptoms of young onset dementia are not always recognised and may be attributed to other causes including depression, stress, menopause, physical health problems and relationship issues. This can lead to a significant delay (on average four years) in getting an accurate diagnosis and access to appropriate support. This can have a negative impact on not just the person with dementia's life but also the whole family.

- On average, a person may see between two and five different consultants before a diagnosis is made
- The average time to diagnosis is 4.4 years in younger people compared to 2.2 years for people aged over 65
- In England in August 2018, the estimated dementia diagnosis rate for under 65s was 41%, compared to 68% for people aged over 65
- Awareness amongst GPs is still relatively low and when people are younger, symptoms are often attributed to stress, anxiety, depression or menopause
- People who are under 65 are more likely to be diagnosed with a genetically inherited form of dementia or a rarer dementia that can be difficult to recognise.

### **Common types of dementia in younger people**

There are differences in the types of dementia commonly diagnosed in younger people with dementia compared to those of an older age.

- Alzheimer's disease is the most common form of dementia in younger people, accounting for around a third of younger people with dementia, in comparison to about 60% in the older age group
- Vascular dementia is the second most common form of dementia in young people. Around 20% of younger people with dementia have vascular dementia
- Around 12% of younger people with dementia have frontotemporal dementia, compared with just 2% in older people. It most commonly occurs between the ages of 45-65. In about 40% of cases there is a family history of the condition
- Korsakoff's syndrome – around 10% of dementias in younger people are caused by a lack of vitamin B1 (thiamine), most commonly associated with alcohol abuse
- Around 10% of younger people with dementia have dementia with Lewy bodies
- Around 20% of young people with dementia have a 'rarer' form of the condition. Examples include conditions that can lead to dementia including Parkinson's disease, Huntington's disease and Creutzfeldt Jakob disease
- Younger people are more likely to have rarer familial forms of dementia caused by genetic mutations including: familial Alzheimer's disease, familial frontotemporal dementia and familial vascular dementia.

### **The impact of dementia for younger people and their families**

- Although younger people experience similar symptoms to older people with dementia, the impact on their lives is likely to be greater
- Younger people are more likely to still be working when they are diagnosed
- Many will have significant financial commitments such as a mortgage
- They often have children to care for and dependent parents too
- Their lives tend to be more active and they have hopes, dreams and ambitions to fulfil up to and beyond their retirement

### **The importance of language**

Dementia is described as 'young onset' when symptoms develop before the age of 65, usually between 30 to 65 years of age. It is also referred to as 'early onset' or 'working age' dementia, but these terms can cause confusion. 'Early onset' can be interpreted as the early stages of dementia and 'working age' is now less defined as retirement age is more flexible.

- The language used to talk about dementia can strongly influence how others treat or view them, and how they feel about themselves
- For example, referring to people with dementia as 'sufferers' or as 'victims' implies that they are helpless. This not only strips people of their dignity and self-esteem, it reinforces inaccurate stereotypes and heightens the fear and stigma surrounding dementia; we should use the term 'people living with dementia'.
- Young onset dementia is not necessarily the defining aspect of someone's identity. They are a person first and should always be described, and treated, as such. Life does not stop when dementia starts
- Using the correct terms avoids confusion. There are many forms of dementia. Alzheimer's disease is just one of them and the terms are not interchangeable
- Young onset dementia is a preferable term to 'early onset' dementia so as to avoid confusion with the early stages of dementia generally.

### **What differences are there to late onset dementia?**

When compared to older people, younger people affected by dementia are more likely to:

- have a rarer form of dementia affecting behaviour and social functioning
- have a familial/inherited form of dementia
- report significantly higher psychological and physical distress
- experience employment issues
- have significant financial commitments such as a mortgage
- have a younger and more dependent family
- have additional caring responsibility for parents

There are differences in the types of dementia commonly diagnosed in younger people with dementia compared to those of an older age. For example, only about a third of dementias diagnosed in younger people are of the Alzheimer's type in comparison to about 60% in the older age group.

### **The needs of people affected by young onset dementia**

People living with young onset dementia and their family members state that they need:

- early recognition of the signs and symptoms suggestive of dementia
- accurate and timely diagnosis
- awareness of their condition, especially from health and social care professionals
- specialist information at the time of diagnosis
- identification of a person who specialises in young onset dementia to support them and their family to work on a support plan to meet their needs
- better communication between agencies
- access to a specialist helpline
- support around employment issues
- emotional support and relationship counselling
- age-appropriate information, advice and support to stay active and maintain independence
- age-appropriate meaningful occupation and activities
- to feel connected to others
- peer support groups
- support to retain a life beyond caring

Early recognition and timely accurate diagnosis of dementia, combined with appropriate specialist support, can reduce the distress experienced by the person with young onset dementia and their family.

### **BSol ICS Dementia Strategy**

The strategy does reference young onset dementia. Individuals are identified, monitored and supported through a number of teams within the Birmingham and Solihull Mental Health Trust, including the rare dementia team and Adult Community Mental Health team. The Trust is exploring the development of a consistent pathway for younger people.

Within BSol we are raising awareness of dementia, using the 'Healthy Brain' public health campaign to promote of awareness of healthy lifestyle choices and key dementia prevention messages.

The Strategy aims to incorporate an innovative, personalised and adaptable approach to the dementia journey which will meet the needs of all communities in Birmingham and Solihull, based on the Well Pathway. The actions are designed for all age recognising younger/early onset dementia to our elderly people.

Through the 'compassionate communities' work we aim to raise awareness and understanding of early on-set dementia, linking into [The Dying to Work Campaign | Dying to Work](#)

**Disability:** describe any disability related impact and evidence. This can include attitudinal, physical, communication and social barriers as well as mental health, learning disabilities and cognitive impairments.

### **Disability Profile Birmingham and Solihull**

The 2011 Census included two measures of health – general self-rated health and limiting long-term illness. These two measures are commonly used in health studies, as they are a predictor of mortality and health service use.



According to 2011 census data across Birmingham 9.1% of the population have a disability that limits their day-to-day activities a lot, compared to 8.2% for Solihull and 8.3% for England. When you look at activities limited a little, the figure for Birmingham is the same as England at 9.3%, though the figures for Solihull are higher at 9.7%.

### **Learning Disability Prevalence**

Learning Disability is relatively common, affecting 2% of the national population.

The number of patients on the Learning Disability register in Birmingham in 2015/16 was 4324, which is in line with the national average of 4.3 per 1,000 populations.

Learning disability figures for Birmingham and Solihull (are we able to access more up to date information? – number on register, locally, both Birmingham and Solihull?)

### **Learning Disabilities and Dementia**

Information taken from the Social Care in Excellence website ([Learning disabilities and dementia - SCIE](#)) states that people with a learning disability (LD) are living longer and are more likely to develop illnesses associated with older age. In addition to this, they are at a greater risk of developing dementia as they get older compared with the general population (Cooper, 1997).

People with LD, particularly those with Down's syndrome, are at increased risk of developing dementia. If a person with a learning disability develops dementia, they will face different and additional challenges to people who do not have a learning disability.

Furthermore, the British Psychological Society highlights that in addition to the significantly increased risk people with Down's syndrome it is likely to occur at a much earlier age.

Dementia generally affects people with learning disabilities in similar ways to people without learning disabilities. However, there are some important differences.

People with a learning disability:

- are at greater risk of developing dementia at a younger age – particularly those with Down's syndrome
- often show different symptoms in the early stages of dementia
- are more likely to have other physical health conditions which are not always well managed
- are less likely to receive a correct or early diagnosis of dementia and may not be able to understand the diagnosis
- may experience a more rapid progression of dementia, although this can be complicated by difficulty or delay in diagnosis
- may have already learned different ways to communicate (for example, more non-verbal communication if their disability affects speech)
- may already be receiving social care in the family home, or be in a supported living environment, where they are given help to allow them to live independently
- will need specific support to understand the changes they are experiencing, and to access appropriate services after diagnosis and as dementia progresses. These may

be specialist services for those with a learning disability or general services for older people.

The most common form of dementia in people with Down's syndrome is Alzheimer's disease. It is known that the brain pathology of Alzheimer's disease is almost universally found in later life in people with Down's syndrome. Vascular disease, and therefore the risk of dementia of a vascular origin, is rare.

Studies have estimated that 1 in 50 people with Down's syndrome develop dementia in their 30s, rising sharply to more than half of those who live to 60 or over. By comparison, the number of people among the population without learning disability aged 60–69 years who develop dementia is about 1 in 75. These studies, therefore, show a greatly increased risk of developing dementia among people with Down's syndrome, compared with the general population without a learning disability.

Studies have also shown that by the age of about 40, almost all people with Down's syndrome develop changes in the brain associated with Alzheimer's disease. However, not all go on to develop clinical symptoms of dementia. The reason for this increased risk has not been fully identified, however it is thought to be linked to the extra copy of chromosome 21 which most people with Down's syndrome have. This chromosome carries the amyloid gene thought to play a role in Alzheimer's disease.

### **Other learning disabilities and dementia**

Studies suggest that approximately 1 in 10 people aged 50 to 65 with learning disabilities other than Down's syndrome have dementia. This rises to more than half of those aged 85 or over. This suggests the risk is less than for people with Down's syndrome but still between two and three times greater than for the general population.

### **BSol ICS Dementia Strategy**

Within the strategy each action committed to will be considered through the lens of those impacted with a form of dementia, e.g. young onset / those with a learning disability. People with a learning disability are referenced within the health inequalities element of the strategy.

**Gender reassignment (including transgender):** Describe any impact and evidence on transgender people. This can include issues such as privacy of data and harassment.

There is a lack of good quality statistical data regarding trans people in the UK. Current estimates indicate that some 650,000 people are "likely to be gender incongruent to some degree"

Research evidence indicates that trans people experience fear and discrimination when accessing health services.

### **Dementia and Transgender**

Much of the research material reviewed linked Transgender with sexual orientation when describing the issues and impact of dementia. The Alzheimer's Society states "if you are trans, you may have complex bodily needs as a result of medical procedures or your body

may not align with your gender identity. You may be undergoing long-term hormone therapy, for example. You may experience memory loss or problems with planning that can make it harder to remember to take medicines and tablets.”

As dementia progresses, older memories are likely to stay with you longer than newer memories. This means that you might remember your childhood better than the past few years. This can cause very distressing symptoms. If you are trans, you may go back to a time before you transitioned. This can be problematic both practically and emotionally. It can be very distressing and can also make day-to-day things like going to the toilet confusing and difficult.

If you have experienced prejudice, discrimination or harassment earlier in your life, these memories can become more pronounced, and this can cause distress.

Older Transgender people in the UK have experienced significant changes in the law, and in society's attitudes towards Transgender people. Transgender people of any age will be aware of this history and it can have an impact on all LGBT people. For example:

In 1980, 'gender identity disorder' was added to the list of disorders in the manual used by mental health professionals in the UK.

More recently:

In 2004, the Gender Recognition Act was introduced, allowing transgender people the opportunity to have their chosen gender legally recognised via a gender recognition certificate.

Although these more recent changes have provided greater equity, it is important to remember that the person is likely to have lived through many of the negative experiences. They may have affected the person's identity or understanding of the world. They may also have an impact on how they cope day to day.

Transgender people may be less likely to access the care and support they need, and may feel they are likely to experience discrimination. This can put the person and those supporting them under a lot of strain. It is important to be aware of the experiences that they may have had as an Transgender person in the past and how they may affect them today.

As an overview the key issues for Transgender people are:

- they are less likely to have family members and children who can support them to deal with the disability
- More likely to live on their own and be single, than heterosexual people
- Fear that mainstream care services will not be willing or are not able to understand how to meet their needs
- Fear that as their dementia develops to a greater extent, their privacy will be exposed or staff will not understand their personal history.
- Fear that as dementia progresses it may be difficult to stop yourself disclosing your gender identity by mistake.

See also, the section on Sexual Orientation for further analysis.

## BSol ICS Dementia Strategy

Within the strategy each action committed to will be considered through the lens of those impacted with a form of dementia. LGBTQIA+ communities are referenced within the health inequalities element of the strategy, where it is acknowledged that in Birmingham and Solihull health inequalities have meant some of our communities have poorer access to information, appropriate services and planning for end of life care.

**Marriage and civil partnership:** Describe any impact and evidence in relation to marriage and civil partnership. This can include working arrangements, part-time working, and caring responsibilities:

Impacts in relation to working arrangements and caring responsibilities are covered under Sex and Carers.

**Pregnancy and maternity:** Describe any impact and evidence on pregnancy and maternity. This can include working arrangements, part-time working, and caring responsibilities:

No specific impacts identified.

**Race:** Describe race related impact and evidence. This can include information on different ethnic groups, Roma gypsies, Irish travellers, nationalities, cultures, and language barriers

### Local Statistics for Birmingham and Solihull:

Across Birmingham and Solihull, 53.9% residents were White (Census 2021 figures); 4.6% were from a mixed/multiple ethnic group; 27.9% from Asian/Asian British ethnic group; 9.5% from a Black/African/Caribbean/Black British ethnic group and 4.05% from Other Ethnic group. Overall, there is a black, Asian and Minority Ethnic population of 46% with BSol area.

Ethnic Group (Census 2021)	Birmingham & Solihull %
<b>White (overall)</b>	<b>53.9%</b>
English, Welsh, Scottish, Northern Irish or British	48.5%
Irish	1.5%
Gypsy or Irish Traveller	0.05%
Roma	0.1%
Other White	3.8%
<b>Asian/Asian British</b>	<b>27.9</b>
Bangladeshi	3.6%
Chinese	1.04%
Indian	5.7%
Pakistani	14.9%
Other Asian	2.6%
<b>Black/Black British</b>	<b>9.5%</b>
African	5%
Caribbean	3.4%
Other Black	1.08%
<b>Mixed or Multiple ethnic groups</b>	<b>4.6%</b>
White and Asian	1.1%
White and Black African	0.4%
White and Black Caribbean	2.1%
Other Mixed or Multiple ethnic groups	1%
<b>Other ethnic group</b>	<b>4.05%</b>
Arab	1.5%
Any other ethnic group	2.6%
<b>Totals</b>	<b>1361162 (no.)</b>

## Ethnicity and Dementia

Information taken from the Social Care Institute for Excellence ( [Black and minority ethnic \(BME\) communities and dementia - SCIE](#)) indicates that - more than 25,000 older black and minority ethnic (BAME) people live with dementia in the UK, in part due to vascular risk factors such as hypertension often found in African-Caribbean and South Asian UK populations. In other ethnic groups such as Irish and Jewish, there is a demographically-older population so with the link between age and dementia, prevalence is likely to be higher.

Minority ethnic communities experience high rates of other risk factors for dementia, such as cardiovascular diseases and deprivation. This strategy aims to reach out to these communities more proactively, and to diagnose earlier.

Further, studies suggest the prevalence of dementia varies according to ethnicity, even when other factors are accounted for. Black women and Black men were found to be 25% and 28% more likely to receive a new dementia diagnosis compared to the white ethnic group, respectively, in research. By contrast it was found that compared with the white ethnic group, Asian women were 18% less likely and Asian men 12% less likely to have a new dementia diagnosis.

**BLACHIR Report** ([BLACHIR report | Birmingham and Lewisham African and Caribbean Health Inequalities Review \(BLACHIR\) | Birmingham City Council](#)) includes data which shows that people from Black African and Caribbean communities are at risk of developing vascular dementia 10 years earlier than other groups and some gaps in the system mean that Black African and Caribbean people are being diagnosed much later.

As the symptoms of dementia develop and individuals begin to lose their short-term memories, longer-term memories may come more to the fore. This may be distressing for people who migrated to the UK during the mid-twentieth century and experienced hostility and racism. It will also make reminiscence work, which can be therapeutic for many people with dementia, very difficult as it may stir up memories of a difficult period in people's lives.

In the inquiry 'Dementia does not discriminate' (All-Party Parliamentary Group on Dementia the Experiences of Black, Asian and Minority Ethnic Communities), it is noted that although there is a lack of monitoring data, "it is likely that dementia will be more common among Asian and Black Caribbean elders. This is because high blood pressure, diabetes, stroke and heart disease, which are risk factors for dementia, are more common in these communities.

"African Caribbean populations have about double the risk of stroke compared to similarly-aged European-origin people, as well as high levels of hypertension and diabetes. This is also true for South Asians, who also have a high level of diabetes and have a raised risk of stroke, although not quite as high as African Caribbean populations." (source: Professor Rob Stewart for the inquiry 'Dementia does not discriminate').

Some of the key issues identified in relation to Minority Ethnic communities and dementia are:

- An unfamiliarity with living with dementia. They may not have seen or cared for someone with dementia in their family if they left their country of origin for work when young.
- Negative perceptions of dementia resulting from poorly-translated terms.
- Stigma around dementia for some cultures/communities. Myths and stigma associated with dementia can result in many people affected by the condition isolating themselves from their own communities. This is particularly the case for Chinese and Pakistani people, for whom community pressures are profound.
- Dementia information needs to be made relevant to minority ethnic communities – more targeted.
- Staff training and educating communities is required; culturally sensitive dementia services.
- It is important to collect evidence of needs and what works for people from minority ethnic communities.
- People from minority ethnic communities with dementia need encouragement to seek help earlier and be supported to do this through advocacy where necessary.
- People from minority ethnic groups may be particularly reluctant to attend support groups, where people can share experiences and gain support. ‘Talking therapies’ are not part of many cultures. Also the taboos associated with dementia mean people are reluctant to admit publicly that someone in their family has the condition.
- However, service providers suggested that, where such groups exist for people from minority ethnic groups, they do participate in them. It would seem that although there may be initial reluctance to participate in such groups, once people have had this experience they do benefit from them.

## Language and Dementia

The 2021 Census showed that there are a range of languages are spoken within Birmingham. After English, the main languages are Urdu, Panjabi, Bengali and Arabic.

Birmingham - Main Language	Number	%
English	929445	81.2%
Urdu	25131	2.2%
Panjabi	17765	1.6%
Bengali (with Sylheti and Chatgaya)	13903	1.2
Arabic	12758	1.1%
Romanian	10573	0.9%
Pakistani Pahari (with Mirpuri and Potwari)	9446	0.8%
Polish	7907	0.7%
Somali	7374	0.6%
Pashto	6993	0.6%
British Sign Language	691	0.06%

Within Solihull 92.5% have English as their main language, with Panjabi and Polish speakers the next highest.

Solihull Main Language	Number	%
English)	200119	92.5%
Panjabi	1163	0.5%
Polish	719	0.3%
Gujarati	665	0.3%
Urdu	664	0.3%
Romanian	492	0.2%
Arabic	453	0.2%
Tamil	411	0.2%
British Sign Language	72	0.03%

There is a recognised link between poor health outcomes and English language needs.

There is evidence that people from minority ethnic communities are not sure where or how to find information about dementia (source: Social Care Institute for Excellence [Black and minority ethnic \(BME\) communities and dementia - SCIE](#) This is exacerbated by language barriers or when people have lost cognitive skills, or if online information is not available in community languages. People may confuse the symptoms of dementia with 'normal ageing' and not seek the support that is available. Access to organisations which can support navigation of the system is very important.

It is likely that people with dementia who have English as a second language will revert back to their primary language as the condition progresses. For care and support teams this means communication may become more challenging. (source: [Dementia and diversity - a guide for leaders and managers \(skillsforcare.org.uk\)](#))

There is no term for dementia in South Asian languages. It is often referred to in terms such as 'not being able to remember things', 'being forgetful' or 'losing memory'. Among the Chinese there was a way of describing dementia, but the description was very derogatory (Alzheimer's Society).

An example of how the Dementia Strategy is opening up communication and meeting the needs of local people is through the Community Champions; asking Councillors in each ward to become champions for dementia in their communities.

**Religion or belief:** Describe any religion, belief or no belief impact and evidence. This can include dietary needs, consent and end of life issues:

There is stigma around dementia in some cultures; it may be regarded as a punishment for past misdemeanours or a family member with dementia may damage the marriage prospects of a young relative.

Little information is available specifically on religion and dementia other than the need to ensure that service provision is culturally sensitive and the stigma surrounding dementia that exists due to misconceptions and a lack of understanding in some communities.

The action to involve local councillors in becoming dementia champions will support overcoming misconceptions of dementia and assist in addressing cultural needs. Further actions on the health brain campaign and utilisation of local radio stations, including those focused on local minority communities will also support fostering better relations and understanding.

**Sex:** Describe any impact and evidence on men and women. This could include access to services and employment

Data source: Sex and Dementia [Prevalence by gender in the UK - Dementia Statistics Hub](#)

Women are more likely than men to develop dementia in in their lifetimes. One of the main reasons for the greater prevalence of dementia among women is the longer life expectancy of women.

- 15.4% of women died due to Alzheimer's disease and other dementias in 2016 in the UK. It was the leading cause of death for women.
- 8.0% of men died due to Alzheimer's disease and other dementias in 2016 in the UK. It was the second leading cause of death for men
- 65% of people living with dementia are women.

**Facts about women and dementia** - [Why is dementia different for women? | Alzheimer's Society \(alzheimers.org.uk\)](#) –

- More women are affected by dementia than men. Worldwide, women with dementia outnumber men 2 to 1.
- Brain scans tell us that the rate at which brain cells are dying in the brain is faster in women than in men.
- Women are more likely to live longer than men. However, although risk increases with age, dementia is caused by diseases of the brain not age alone.

The 2015 report 'Women and Dementia: A Marginalised Majority' by Alzheimer's Research UK ([Women and Dementia: A Marginalised Majority - Alzheimer's Research UK \(alzheimersresearchuk.org\)](#)) highlights the huge toll of dementia on women in the UK. Dementia has not only become the leading cause of death among British women, but they are far more likely to end up as carers of those with the condition than men. As a result, many suffer physical and emotional stress, while some also lose jobs in the process.

See section on Carers for more information on the impact on women.

**Sexual orientation:** Describe any impact and evidence on heterosexual people as well as lesbian, gay and bisexual people. This could include access to services and employment, attitudinal and social barriers:

**Sexual Orientation Profile National figures**



Office for National Statistics ([Sexual orientation, UK - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk)) reports:

- The proportion of the UK population aged 16 years and over identifying as heterosexual or straight was 93.6% in 2020; there has been a decreasing trend since the series began in 2014.
- An estimated 3.1% of the UK population aged 16 years and over identified as lesbian, gay or bisexual (LGB) in 2020, an increase from 2.7% in 2019 and almost double the percentage from 2014 (1.6%).
- The proportion of men in the UK identifying as LGB increased from 1.9% to 3.4% between 2014 and 2020; the proportion of women identifying as LGB has risen from 1.4% to 2.8% over the same period.
- People aged 16 to 24 years continue to be the most likely to identify as LGB in 2020 (8.0%) reflecting an increasing trend for this age group since 2014; this breaks down to 2.7% identifying as gay or lesbian, and 5.3% identifying as bisexual.
- In 2020, women (1.6%) were more likely than men (0.9%) to identify as bisexual but were less likely to identify as gay or lesbian (1.1% compared with 2.5%); these differences between men and women are more pronounced in the younger age groups.
- Among those identifying as LGB in 2020, almost three-quarters (72.5%) had never been married or in a civil partnership, while just under one-quarter were married or in a civil partnership (23.7%); this may reflect the younger age structure of the LGB population and that the legislation for same-sex civil partnerships and same-sex marriage is relatively recent.

Birmingham Lesbian, Gay, Bisexual and Transgender (LGBT) organisation stated in their report 'Out and About: Mapping LGBT lives in Birmingham' ([outandaboutreportfinalweb.pdf \(blgbt.org\)](https://www.outandaboutreportfinalweb.pdf)) that whilst there are no agreed figures as to the percentage of the LGBT population, estimates of between 6% and 10% are popularly used. Accepting this range, means the local LGBT population to be between 60,000 and 100,000 people.

## **Sexual Orientation and Dementia**

LGBTQ+ is the acronym for lesbian, gay, bi, trans, queer, questioning and ace (source: [List of LGBTQ+ terms \(stonewall.org.uk\)](https://www.stonewall.org.uk)).

For LGBTQ+ people, living with dementia can be additionally stressful. Not only are LGBTQ+ people less likely to have family members and children who can support them as they deal with the disability, they are also more likely to live on their own and be single than heterosexual people. Even with a 'family of choice', LGBTQ+ people often have an increased need to use social care services for support and help as their disease progresses. Many fear that mainstream care services will not be willing or are not able to understand how to meet their needs. (source: [LGBT+ communities and dementia - SCIE](https://www.scie.org.uk))

Memory problems are a common early symptom in dementia. If you identify as LGBTQ+, they can be more difficult to deal with. If you are LGBTQ+, you may have to make decisions on a day-to-day basis about whether to disclose your sexual orientation or gender identity – whether to be 'out'. As your dementia progresses, you may lose your ability to make this decision. You may also be unable to stop yourself disclosing your orientation or gender identity by mistake. For example, you may refer to a partner without meaning to. This could mean that you are 'out' without choosing to be.

As your dementia progresses, older memories are likely to stay with you longer than newer memories. This means you might remember your childhood better than the past few years.

If you have experienced prejudice, discrimination or harassment earlier in your life, these memories can become more pronounced, and this can cause you distress.

Some of the treatments for dementia aim to improve a person's memory by getting them to talk about events from their past. These are known as 'reminiscence' therapies, and are often done in a group. This can be difficult if you have ever experienced prejudice, discrimination and rejection and you may want to think about whether this is something you want to do.

As an LGBTQ+ person, you may feel reluctant to access services. You may be worried about having to disclose your sexual orientation or gender identity, or having to go back 'in the closet'. You may also worry about stigma and discrimination, or that your identity and needs will not be properly understood. You may feel that you will become isolated from the things that are important to you, and you may worry about being lonely because your experiences are different to other people's.

Often services assume that people are heterosexual. For example, they may run reminiscence sessions where you look back at times in your life. These will often focus on a family and children which may not be relevant for you. If you've not opened up about your sexuality or mentioned your partner (if you have one), you might feel uncomfortable talking about them. You could feel that you have to hide a very important part of your life. (source: [LGBTQ+: Living with dementia | Alzheimer's Society \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/about-us/lgbtq+-living-with-dementia))

### **Changes in society for LGBTQ+ people**

Many people with dementia are over 65. However, it is possible for people under 65 to develop dementia. Older LGBTQ+ people in the UK have experienced significant changes in the law, and in society's attitudes towards LGBTQ+ people. LGBTQ+ people of any age will be aware of this history and it can have an impact on all LGBTQ+ people. For example:

Until 1967, sex between men was against the law in England and Wales (and until 1982 in Northern Ireland).

- Until 1973, homosexuality was listed as a mental illness in the manual used by mental health professionals in the UK.
- In 1980, 'gender identity disorder' was added to the list of disorders in the manual used by mental health professionals in the UK.
- In the 1980s, the AIDS epidemic developed, which affected large numbers of gay men in the UK. It also affected people's attitudes towards gay men.
- In recent years, there have been a number of positive changes in the law for LGBT people:
- In 2004, the Gender Recognition Act was introduced, allowing transgender people the opportunity to have their chosen gender legally recognised via a gender recognition certificate.
- In 2004, the Civil Partnerships Act was also introduced, allowing same-sex couples to have their relationships legally recognised.
- In 2013, the Marriage (Same Sex Couples) Act was introduced in England and Wales, enabling same-sex couples to get married.

Although these more recent changes have been much more positive, it is important to remember that the person is likely to have lived through many of the negative experiences listed above too. They may have affected the person's identity or understanding of the world. They may also have an impact on how they cope day to day.

LGBTQ+ people may be less likely to access the care and support they need, and may feel they are likely to experience discrimination. This can put the person and those supporting them under a lot of strain. It is important to be aware of the experiences that they may have had as an LGBTQ+ person in the past and how they may affect them today.

### **BSol ICS Dementia Strategy**

Within the strategy each action committed to will be considered through the lens of those impacted with a form of dementia. LGBTQIA+ communities are referenced within the health inequalities element of the strategy, where it is acknowledged that in Birmingham and Solihull health inequalities have meant some of our communities have poorer access to information, appropriate services and planning for end of life care.

There is representation from third sector organisations on the Dementia Steering Group who will be able to ensure that appropriate support is contained in all actions and that any particular needs are covered.

**Carers:** Describe any impact and evidence on part-time working, shift-patterns, general caring responsibilities.

It is estimated that one in three people will care for a person with dementia in their lifetime. Half of them are employed and many people cut their working hours to make time for caring or have to leave work altogether. Many people with dementia don't feel part of their communities and feel lonely; there is a similar impact on carers as they become isolated in their caring role.

Dementia has a greater impact on women as the majority of carers are women (Alzheimer's Society):

- 60 to 70% of carers for people with dementia are women
- 20% of female carers have gone from full time to part time employment as a result of their caring responsibilities and 17% felt penalised at work.
- Women are 2.3 times more likely to provide care for someone with dementia for over 5 years.

In the report [Women-and-Dementia-A-Marginalised-Majority1.pdf](#) ([alzheimersresearchuk.org](http://alzheimersresearchuk.org)) the following impact on women carers is described:

Not only are women more likely to have Alzheimer's disease or another form of dementia, they are also more likely to be caregivers of those with dementia. Generally, a carer is someone providing support on an unpaid basis, and it can be a mentally and physically exhausting task. Most carers do not choose or plan to take on the role, but have it develop out of necessity either from a sudden crisis or over time as a loved one's health and independence deteriorates. Between 60 and 70% of all unpaid dementia carers are women.

According to surveys of unpaid carers for people with dementia, there are 2.5 times more women than men who provide intensive, on-duty care for someone 24-hours a day. Of those women, half found their caring responsibilities to be physically stressful, while even more, 62%, found the experience emotionally stressful.

Women are also more likely than men to help with the more personal aspects of care, such as bathing, dressing, using the toilet, and managing incontinence. Among carers, women are 2.3 times more likely than men to have been providing care to someone with dementia for more than five years. The figures show that women make up a large portion of the carers who are supporting someone with advanced dementia, who may be incapable of communicating or be confined to a bed or chair.

Research shows that women who care for people with dementia also feel less supported than their male counterparts. Wives caring for their husbands with severe dementia reported receiving less support from friends and family than husbands caring for their wives in similar circumstances. Many carers experience feelings of isolation, but for women these feelings are more likely to be linked to depression, which in itself may be a risk factor for dementia.

Women who work and care for someone with dementia face the significant and very real possibility of negative impacts to their career. They may not be in a position to choose between their work and caring responsibilities, and so are forced to do both simultaneously.

However, surveys of working women carers indicate that they are not receiving adequate support in either role. Added to these professional challenges, women taking on caring responsibilities for someone with dementia may experience further disadvantages. According to recent research, nearly 19% of women who care for someone with dementia have had to quit work either to become a carer or because their caregiving duties became a priority. Among working women carers, 20% have gone from working full time to part time, compared with only 3% of working male carers.

The Social Care Institute for Excellence article -[Black and minority ethnic \(BME\) communities and dementia - SCIE](#) reports that there is evidence that minority ethnic carers are more likely to be isolated from mainstream services. Some may view using a service as a source of shame. In Islam, Hinduism and Sikhism the duty of care is apparent or is regarded as a 'test from God' (Rauf, A (2011) Caring for Dementia: Exploring good practice on supporting South Asian carers, Bradford Metropolitan District Council.).

The Dementia Strategy will support carers, and specifically women and minority ethnic carers; the first part is around scoping available carer support services and understanding how these can be expanded to support under-served communities.

**Other disadvantaged groups:** Describe any impact and evidence on groups experiencing disadvantage and barriers to access and outcomes. This can include lower socio-economic status, resident status (migrants, asylum seekers), homeless, looked after children, single parent households, victims of domestic abuse, victims of drugs / alcohol abuse: (This list is not exhaustive).

## **Substance Misuse**

Can alcohol consumption increase dementia risk? (source: [Alcohol and dementia | Alzheimer's Society \(alzheimers.org.uk\)](https://www.alzheimers.org.uk))

Excessive alcohol consumption over a lengthy time period can lead to brain damage, and may increase your risk of developing dementia. However, drinking alcohol in moderation has not been conclusively linked to an increased dementia risk, nor has it been shown to offer significant protection against developing dementia.

As such, people who do not currently drink alcohol should not be encouraged to start as a way to reduce dementia risk.

Conversely, those who drink alcohol within the recommended guidelines are not advised to stop on the grounds of reducing the risk of dementia, although cutting back on alcohol consumption may bring other health benefits.

### **What does the evidence say about alcohol and dementia?**

Two reviews of the available evidence conducted by Alzheimer's Disease International and the National Institute for Health and Care Excellence (NICE) scrutinised multiple research studies of alcohol consumption and the development of dementia.

These reviews found that individuals who drank heavily or engaged in binge drinking - where a person consumes a large quantity of alcohol in a short time period - were more likely to develop Alzheimer's disease or any other form of dementia than those who engaged in moderate alcohol consumption.

### **[Dementia and Substance Abuse - The Recovery Village Drug and Alcohol Rehab](#)**

Chronic use of alcohol, prescription opioids, anticholinergic drugs, and drugs like marijuana can increase the risk of dementia. Dementia and addiction can be treated simultaneously for the best therapeutic outcome.

Dementia is a clinical syndrome involving cognitive impairment and is generally associated with old age. The cognitive impairment and other behavioural and psychological symptoms observed in dementia arise due to neuronal damage caused by a variety of diseases. Chronic use of alcohol, illicit drugs and prescription medications can also increase the risk of cognitive impairment and dementia. Although substance use can cause or increase the risk of dementia, the role of dementia in substance abuse is not well studied.

### **Deprivation**

Birmingham and Solihull has some of the poorest areas in the country alongside some of the most affluent. 40% of Birmingham and 12% of Solihull residents live in the most deprived decile on the Index of Multiple Deprivation.

### **Birmingham**

Birmingham suffers from high levels of deprivation, with 43% of the population living in LSOAs in the 10% most deprived in England, and 51% of children (under 16s) living in the 10% most deprived areas.

Birmingham is ranked the 7th most deprived local authority in England. The city is also the most deprived authority in the West Midlands Metropolitan area. Birmingham is ranked the third most deprived English Core City after Liverpool and Manchester.

While there are pockets of deprivation in all parts of the city, deprivation is most heavily clustered in the area surrounding the city centre.

Hodge Hill is the most deprived constituency in the city; Sparkbrook & Balsall Heath East, Bordesley Green and Lozells are the top 3 most deprived wards. Sutton Coldfield is the least deprived part of the city.

### **Solihull**

The 2019 Index of Multiple Deprivation (IMD) 2019 shows that Solihull is the 32nd least deprived upper tier Local Authority in England, ranking the borough in the 2nd top quintile nationally.

Solihull is the least deprived upper tier Local Authority in the West Midlands; Solihull is relatively polarised between large parts of the borough that rank among the least deprived areas of England and a concentration of neighbourhoods in North Solihull among the most deprived; Over one in 10 Solihull residents live in the most deprived 10% of neighbourhoods in England (one in 20 in the bottom 5%). Nearly one in three Solihull residents in the least deprived 10% in England; Over half of the North Solihull population live in the most deprived 10% of neighbourhoods in England. One in five live in the most deprived 5%; Deprivation in Solihull is most apparent in terms of Employment, Education and Income. There is very little deprivation in Solihull in respect of Access to Housing & Services and the Living Environment;

### **Air pollution**

Health outcomes differ greatly between areas of affluence and those of high deprivation – for example, Birmingham city centre is surrounded by high deprivation wards, with major traffic routes going through them into the city. These wards are affected by an increase in air pollution, as well as over-crowded and poor standard of housing and limited green space for mental wellbeing and exercise. All these factors can increase the likelihood of serious disease such as COPD and cancer.

[factsheet\\_risk\\_factors\\_for\\_dementia.pdf \(alzheimers.org.uk\)](#)

Certain forms of air pollution increase a person's risk of dementia. These include very small particles from traffic fumes and from burning wood in the house, for example in a fireplace. If a person breathes in these particles, the particles may cause damage to blood vessels in the person's brain, as well as a build-up of substances that can cause Alzheimer's disease.

Birmingham City Council website, page on [Health effects of air pollution | Air pollution affecting me and my family | Birmingham City Council](#) states that "[People living near busy roads are also more likely to get dementia](#)", but more research is needed to be sure this is caused by air pollution.

## **Section 4. Health Inequalities**



Describe how this work contributes to reducing health inequalities. Include a description of known health inequalities, identify if there will be an impact for particular groups or communities.

Nationally and locally dementia diagnosis rates have reduced due to the impact of the Covid-19 pandemic. This doesn't mean that fewer people have been developing dementia, it is likely that people have not been coming forward for diagnosis, and the assessment for dementia has been taking longer.

In Birmingham and Solihull differences in health equity have meant some of our communities have poorer access to information, appropriate services and planning for end of life care.

In Birmingham and Solihull we have identified greater differences in access to information and services in the following communities:

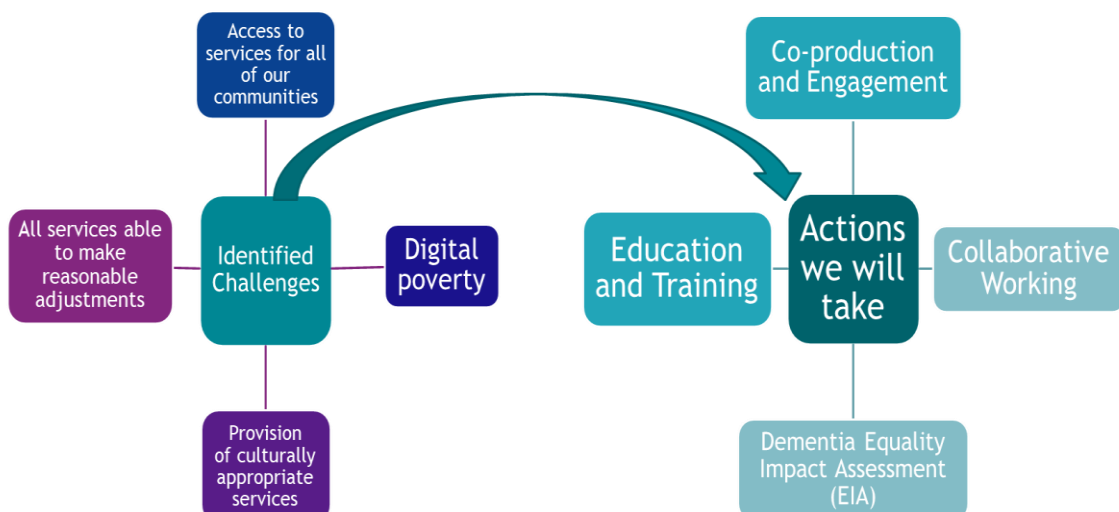
- Asylum Seekers and Migrant communities
- Minority Ethnic communities
- Gypsy, Irish Traveller and Roma communities
- Homeless people
- People with a learning disability
- LGBTQIA+ people

The strategy has a specific section on reducing health inequalities, stating:

We value the importance of equity for our differing Communities. We are determined to take actions to reduce Health inequalities being experienced by our most vulnerable people.

We have identified the challenges we want to tackle in the next two years and the actions we will take in all of our work to enable this to happen.

The strategy includes the following diagram, which identifies the challenges and actions they will take.



## Section 5. FREDA Principles/Human Rights

**FAIRNESS** – fair and equal access to services. How will this work respect a person's entitlement to access services?

The Strategy aims to enable all people living with dementia and those who care for them, to have the best possible health and social care support through their dementia journey.

The strategy will be achieved through four key priorities of:

**Information** which focuses on prevention, early intervention and support.

**Access** to timely diagnosis with pre-diagnostic and post-diagnostic support.

**Prevention** of crisis and supporting people with dementia, their families and communities.

**Improving** the quality of personalised care and support planning for people with dementia, including advanced care planning.

**RESPECT** – right to have private and family life respected. How will the person's right to respect for private and family life, confidentiality and consent be upheld?

Key priority of the strategy is: **Improving** the quality of personalised care and support planning for people with dementia, including advanced care planning.

**EQUALITY** – right not to be discriminated against based on your protected characteristics. How will you ensure that people are not discriminated against, and have their needs identified and met? Will this affect a person's right to freedom of thought, conscience and religion?

Key priorities of the strategy are: **Access** to timely diagnosis with pre-diagnostic and post-diagnostic support and **Improving** the quality of personalised care and support planning for people with dementia, including advanced care planning.

**DIGNITY** – the right not to be treated in a degrading way. How will you ensure that individuals are not being treated in an inhumane or degrading way?

Key priority of the strategy is: **Improving** the quality of personalised care and support planning for people with dementia, including advanced care planning.

**AUTONOMY** – right to respect for private and family life; being able to make decisions and choices. How will individuals be involved in discussions and decisions about their own healthcare?

Key priorities of the strategy are: **Information** which focuses on prevention, early intervention and support and **Improving** the quality of personalised care and support planning for people with dementia, including advanced care planning.



<b>Right to LIFE</b> – will or could this work affect someone’s right to life? How?
No impact.
<b>Right to LIBERTY</b> – will or could someone be deprived of their liberty? How?
No impact.

<b>Section 6. Social Value</b>	<b>What actions are you able to build into the procurement activity and/or contract to achieve wider public benefits? (improve health and reduce health inequalities)</b>
<b>Marmot Policy Objective</b>	<b>Response</b>
Enable all people to have control over their lives and maximise their capabilities	No procurement
Create fair employment and good work for all	
Create and develop health and sustainable places and communities	
Strengthen the role and impact of ill-health prevention	

**Section 7. Engagement, Involvement and Consultation.** Identify how you have involved those affected by this area of work to inform your decision making.

**For each engagement activity, identify when it took place and who it was with.**

June-July 2022: engagement with the people and stakeholders of Birmingham and Solihull.

**For each engagement activity, state the key feedback received and how this will shape the policy/service (for example; you said...we will...)**

The results of the engagement have shaped the final strategy; the main themes of the feedback were:

- Design of the strategy
- Health inequalities

- Cohorts
- Stakeholders
- Well Pathway
- Outcomes

Just under 70% of those engaged, agreed with the four priorities within the strategy.

A detailed engagement report is available. With the highlights in the table below:

Theme identified	Feedback Comments & Suggestions	Action(s) Taken/ to be taken
<b>Design of the Strategy</b>	Comprehensive detail provided Simpler, user friendly, NHS Jargon and language to be reviewed Graphics & pictures to be included to be engaging to the reader	Language reviewed and adjusted to make it simpler Feedback Quotes added to Document Executive Style Document produced with key messages which will form the main Document Appendix slides – including Pathway & detailed Action Plan
<b>Health Inequalities</b>	Acknowledgement and actions addressing is positive Use correct terminology Community engagement regularly required Poverty & Deprivation to be included – underlying causes Faith importance and services Language considerations of communities Digital poverty and inclusion of all Prisoners to be included	Acknowledgement of wider determinants and regular engagement with communities to understand needs ICS approach to Health inequalities
<b>Cohorts</b>	All age approach, Young Onset Dementia to be referenced Consideration for LD Patients, Rare Dementia Ethnic Communities and need for inclusion, engagement Types of Dementia to be outlined	Referenced and Action Plan implementation will include consideration of all these Cohorts Dementia EIA being undertaken & findings will be actioned upon
<b>Stakeholders</b>	Integration and collaboration of organisations – how will this work? Involvement & participation across ICS Approach Stakeholder Organisations wanted to be added to Pathway Mapping Voluntary Sector Organisations importance to be featured	Added to Pathway mapping & circulation across system Ensure collaborative working & ICS approach communicated and effective use of the Dementia Steering Group
<b>Well Pathway</b>	Action Plan detail and considerations. Holistic approach to be taken Clearer Goals and Actions Dementia Symptoms explained To be clear what does this mean for someone with Dementia, carers and loved ones Environment & lifestyle factors Timely diagnosis; MAS waiting lists & increasing capacity Education & Training highlighted as important across health and social care staff and citizens Distinguishment between Birmingham and Solihull services	Actions in the Well Pathway adjusted to show how they fit in with the 4 key priorities Education & Training emphasised – with Framework in development Effective utilisation of current resources (i.e. finance, workforce, technology) and adopt System approach in all actions

	More focus on treatment & interventions Compassionate Communities work & network to be referenced Importance of co-ordinated approach between Health & social care	
<b>Outcomes</b>	Underlying causes to be understood – health outcomes & overall patient experience Area analysis & targeted interventions National target rate explained – it's not just about hitting a diagnosis rate	Data Analysis, quantitative & qualitative metrics to be established Needs Analysis regularly reviewed, with EIA input

## Section 8. Summary of Analysis

Considering the evidence and engagement activity you listed above, please summarise the findings and impact of your work.

### Summary of the impact of Dementia on particular characteristics:

**Age:** Dementia can affect a person at any age but it's more common in people over the age of 65; it is a common misconception that dementia is a condition of older age, over 42,000 people under 65 years old have dementia in the UK

**Sex:** - women are more likely than men to develop dementia (possibly due to longer life expectancy), this is reflected in the numbers of current service users. Women are also more likely to be responsible for caring for someone with dementia.

**Sexual Orientation:** LGBTQ+ people living with dementia are likely to experience additional stress particularly related to disclosure of sexual orientation and concerns over stigma and discrimination.

**Race:** the figures for current service users are overwhelmingly White British (81.6%), which is significantly higher than the local population (53%). It is likely that dementia will be more common among Asian and Black Caribbean older people. This is because high blood pressure, diabetes, stroke and heart disease, which are risk factors for dementia, are more common in these communities. Some of the key issues in relation to Black Asian and Minority Ethnic (BAME) communities include an unfamiliarity with dementia; negative perceptions resulting from poorly translated terms; stigma. There is a need for culturally sensitive services which can meet the language needs of the local population (there is some evidence that people with dementia who have English as a second language will revert back to their primary language as the condition progresses).

**People with Learning Disability (LD)** – people with learning disabilities, particularly those with Down's syndrome are at an increased risk of developing dementia at a younger age. It is unclear how many of current service users have a learning disability. People with LD will need specific support to understand the changes they are experiencing and to access appropriate services after diagnosis and as dementia progresses.

**Gender Reassignment/Transgender** – some of the concerns for Trans people are similar to those shared by LGBTQ+ people (additional stress around disclosure, stigma and discrimination). Transgender people are less likely to have family members and children who can support them to deal with the disability, are more likely to live on their own, fear that

as their dementia develops, their privacy will be exposed and mainstream services might not be willing or able to understand how to meet their needs.

**Carers** –Carers are typically women who often have had to reduce employment working hours to become a carer; carers often feel isolated. There is some evidence that minority ethnic carers are more likely to be isolated from mainstream services.

## Section 9. Mitigations and Changes

Outline of what you are going to do, based on the gaps, challenges and opportunities you have identified in the summary of analysis section. This might include action(s) to mitigate against any actual or potential adverse impacts, reduce health inequalities, or promote social value. Identify the **recommendations** and any **changes** to the proposal arising from the equality analysis

Initial recommendations were captured as part of the engagement work and are reflected within the final strategy.

It is recommended that when looking at provision of services that resources are targeted to areas of high deprivation, where communities are experiencing poorer health outcomes and experience.

Improve data collection to understand prevalence and experiences by different protected characteristics.

Assurances have been provided that actions taken will be considered through an equality lens to understand the impact on particular characteristics – this ‘sense checking’ could be enhanced by engaging with 3<sup>rd</sup> sector organisations and charities who represent members with a particular characteristic or from a particular community.

## Section 10. Contract Monitoring and Key Performance Indicators

Detail how and when the service will be monitored and what key equality performance indicators or reporting requirements will be included within the contract (refer to NHS Standard Contract SC12 and 13):

Not applicable

## Section 11. Procurement

Detail the key equality, health inequalities, human rights, and social value criteria that will be included as part of the procurement activity (to evaluate the providers ability to deliver the service in line with these areas):

## Section 12. Decision Making and Publication

The Committee, Programme Board or Working Group responsible for taking the decision to commission/de-commission, implement the policy etc **MUST** have sight of the completed Equality Analysis to inform their decision making. This is a statutory requirement of the ICB to ensure that we demonstrate 'due regard' to the Public Sector Equality Duties. This is in addition to the requirement to take clinical policies to the Clinical Policy Sub-Group.

**This EA will be shared with: Dementia Interface Steering Group on:** 19<sup>th</sup> January 2023

Following the decision being taken the finalised EA should be sent to for publication on the Internet. Email a PDF copy to: [communications.bsolicb@nhs.net](mailto:communications.bsolicb@nhs.net)

## Section 13. Quality Assurance by EDI Team

The Equality Analysis will need to be quality assured prior to being submitted for decision making.

**EDI Team Assurance:** Please send to [Michelle Dunne](#), [Mandy Johal](#) or [Juliet Herbert](#), Equality, Diversity and Inclusion for Quality Assurance

Name: Michelle Dunne Date: 13/01/2023