

Equality Analysis

(Health Inequalities, Human Rights, Social Value)

Dementia Navigators

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

1. Background

EA Title	Dementia Navigators Service 2018		
EA Author	Michelle Dunne	Team	Nursing
Date Started	11 th April 2018	Date Completed	21 st May 2018
EA Version	V0.2	Reviewed by E&D	Yes

What are the intended outcomes of this work? Include outline of objectives and function aims

This equality analysis (ea) is a refresh of previous ea's completed on the service and has come about following an external review of the current service provision and prior to a re-tendering of the service.

The aim of the Dementia Navigator service is to provide timely information, advice and support to individuals and their family, friends or carers throughout their journey with dementia, enabling them to live well as long as possible. This includes people who are worried about their memory, individuals newly diagnosed and those who have been living with dementia for some time but who could benefit from support.

Objectives:

- To provide a highly responsive, individualised information and signposting service to people with a diagnosis of dementia and/or to their carers/families.
- To provide ongoing support, information and guidance to people with dementia and/or to their carers/families; helping to maintain their independence, improve their sense of well-being, and gain more control of their lives.
- To assist people with dementia and their carers to identify their needs and increase access to services.

The Dementia Navigators service will consist of a team of Dementia Advisers, Support Workers, managers and administrative support. Staff will enable and empower service users to find opportunities to lead a new life which has meaning, value and purpose. The service will be delivered by a holistic/integrated approach and will consider the whole person, not simply symptoms and disease.

The service will operate across the entire span of an individual's dementia journey including End of Life care and will work directly with carers, even when the person with dementia does not desire support or is no longer able to participate in support sessions. The service will provide early intervention/preventative support through:

- A single point of access for information and advice about dementia, information about what support is available pre and post-diagnosis, and how to access this support.
- Signposting to other support services available.
- Practical and low level emotional support to promote greater emotional resilience in service users by creating a sense of safety and an atmosphere of calm.
- Empowering healthier lifestyle choices in local communities (Making Every Contact Count).

- Practical coaching and support to people with dementia and their carers around best strategies and good practice to live well with the condition.
- Advise on and facilitate access to peer-led group support.

Short term support will be offered to service users who are under the care of the Community Mental Health Team or the Rare Dementias Service (BSMHFT) and who have a named nurse or care coordinator, who will thereafter be able to offer support equivalent to that which the Dementia Navigators provide.

Who will be affected by this work? e.g. staff, patients, service users, partner organisations etc. Explain how they might be affected.

This service will cover the whole of Birmingham. Solihull Metropolitan Borough Council plan to procure a Dementia Navigators Service within the next few months with a view to the service provider being in place by 1st April 2019. It is hoped that the service specification can be agreed with Birmingham so that there is a consistent approach to this service across the STP area.

The service will proactively engage with black and minority ethnic communities, enabling access to information and advice that is appropriate to the needs and cultural values of these communities.

Acceptance criteria:

- Adults with a diagnosis of dementia from a consultant or nurse within a specialist mental health team, or from a GP.
- Adults seeking a diagnosis of dementia i.e. people not yet diagnosed but already pursuing a diagnosis e.g. worried about their memory and reported symptoms to GP.
- Informal carers or family members of those above.

The person living with dementia and/or the carer must be registered to a GP within Birmingham covered by the following CCG's:

- Birmingham and Solihull CCG
- Sandwell and West Birmingham CCG

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 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.

2. Research

What evidence have you identified and considered? This can include national research, surveys, reports, NICE guidelines, focus groups, pilot activity evaluations, clinical experts or working groups, JSNA or other equality analyses.

Research/Publications	Working Groups	Clinical Experts
5 year forward view	Dementia Navigators	
Social Care Institute for Excellence	Service Project Board	
Alzheimer's Society		
Skills for Care		
Dementia Action		
British Psychological Society		

3. Impact and Evidence:

In the following boxes detail the findings and impact identified (positive or negative) within the research detailed above; this should also include any identified health inequalities which exist in relation to this work.

Age: Describe age related impact and evidence. This can include safeguarding, consent and welfare issues:

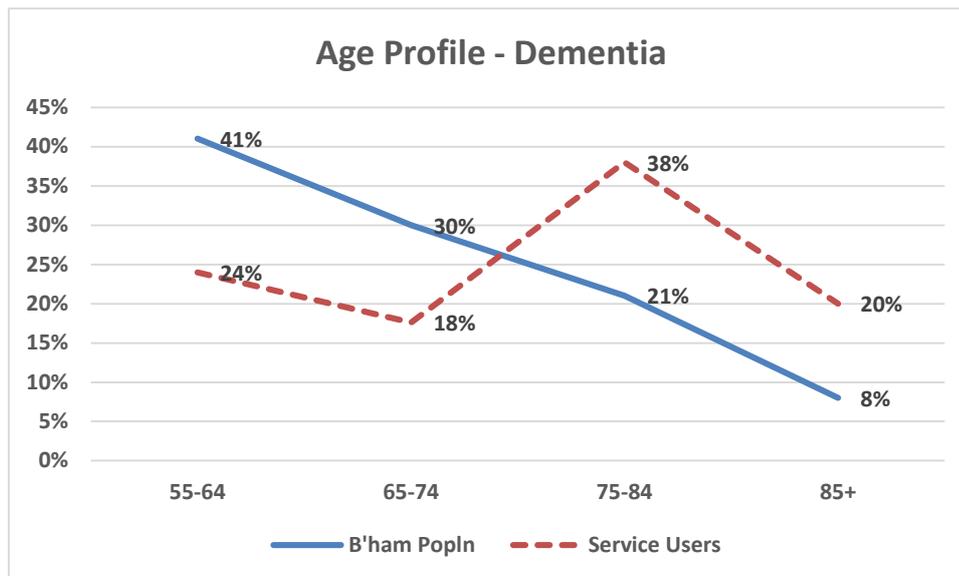
Age Profile Birmingham

Birmingham is characterised by its young population, which is especially true in the inner city areas. While the population of England is projected to age, our population aged over 64 is set to remain stable with many retirees continuing to move out of the City. At the time of the

3. Impact and Evidence:

2011 Census around 13% of Birmingham's population were aged 65 and over (138,213 people).

The youngest age group recorded for the Dementia Navigators review was 55-64. The graph below shows a comparison of the Birmingham population aged 55 and over compared to the Dementia Navigator service users.



This graph shows that of the people of Birmingham aged 55+, 41% are aged between 55-64 and that this age band represents 24% of the Dementia Navigators service usage. In comparison only 8% of the local population are aged 85+, but 20% of service users are in this age band.

Age 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:

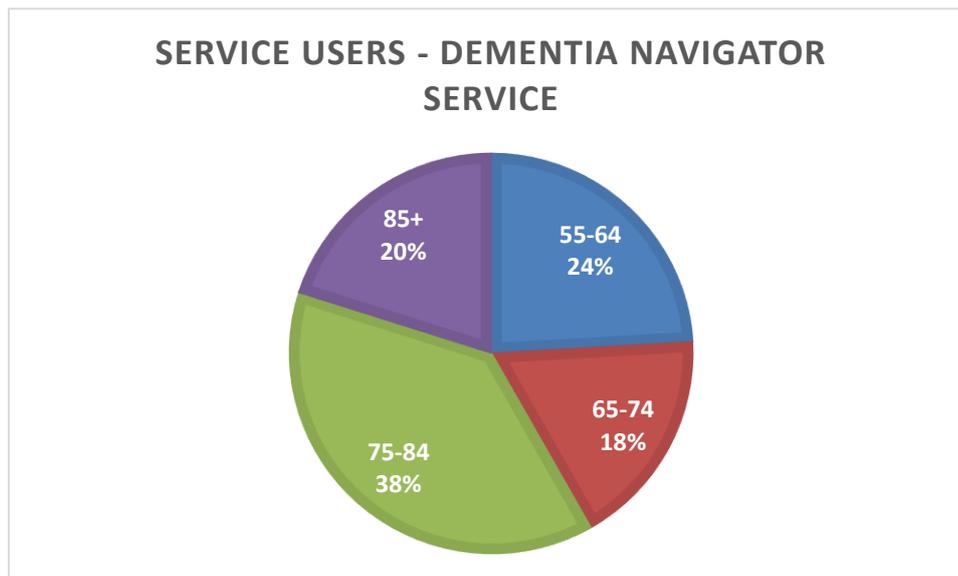
- 7.1% of all people over the age of 65 have dementia.

3. Impact and Evidence:

- 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.

Age of Service users

The chart below shows the age profile of service users of the Dementia Navigators services over the period 2016 – 17 and 6 months of 2017-18



The majority of service users have been in the 75-84 age group, followed by 55-64.

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

Disability Profile Birmingham

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.

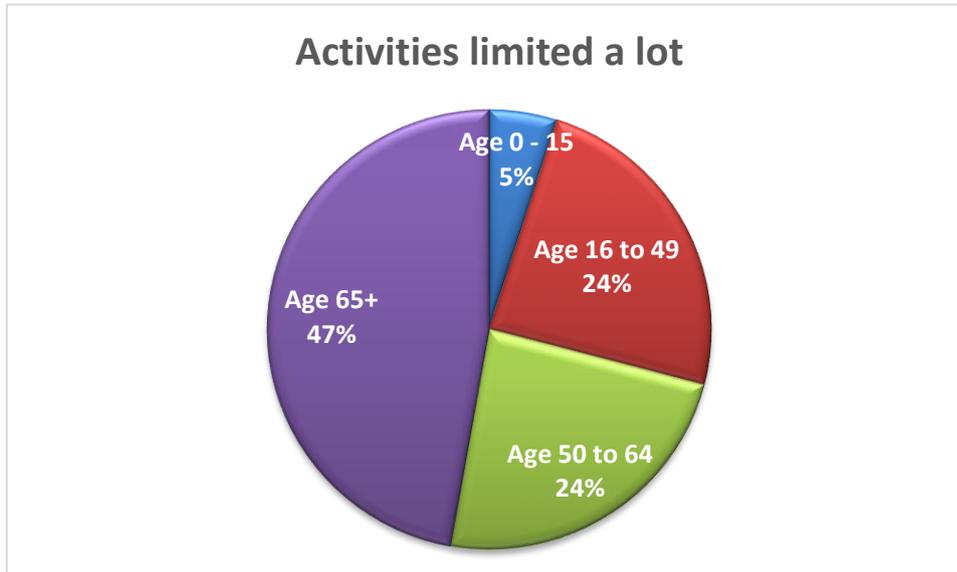
Limiting long-term illness:

This census question asked – “Are your day to day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? include problems related to old age”. Response options were – Yes, limited a lot, Yes, limited a little and No.

9.1% of respondents said that their activities were limited a lot (9.3% limited a little and 81.6% not limited).

3. Impact and Evidence:

In total 98,181 people stated that their day to day activities were limited a lot, the pie chart below shows how day to day activities are increasingly limited by age:



Disability and Dementia

No details were captured though the external review of the dementia navigator project in relation to disability.

Learning Disabilities and Dementia

Information taken from the Social Care in Excellence website

(<https://www.scie.org.uk/dementia/living-with-dementia/learning-disabilities/>) 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.

The Alzheimer's Society factsheets state - 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.

3. Impact and Evidence:

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.

3. Impact and Evidence:

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.

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.

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

Gender reassignment profile

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.

In the Evaluation of the Dementia Care Navigator Project no services users identified as being Transgender.

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. Dementia can make it harder to manage these problems. 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

3. Impact and Evidence:

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. For more information, see 'Gender recognition certificate' below.

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. 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 may be unable to stop yourself disclosing your gender identity by mistake

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:

Issues around caring and working arrangements are picked up in the Carers section.

The Dementia Navigator service proposed does not appear to signal any direct or indirect discriminatory impacts in relation to marriage and civil partnership.

3. Impact and Evidence:

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

Issues around caring and working arrangements are picked up in the Carers section. The Dementia Navigator service proposed does not appear to signal any direct or indirect discriminatory impacts in relation to pregnancy and maternity.

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

Race Profile Birmingham
The table below shows the percentage of the population in Birmingham by race, taken from the 2011 census.

Race	B'ham
White British	53.14%
White Irish	2.05%
Gypsy/Irish Traveller	0.04%
White Other	2.70%
White & Black Caribbean	2.30%
White & Black African	0.30%
White & Asian	1.04%
Other Mixed	0.79%
Asian Indian	6.02%
Asian Pakistani	13.48%
Asian Bangladeshi	3.03%
Asian Chinese	1.18%
Asian Other	2.90%
Black African	2.79%
Black Caribbean	4.44%
Black Other	1.75%
Arab	1.02%
Other	1.02%

Race and Dementia
Information taken from the Social Care Institute for Excellence (<https://www.scie.org.uk/dementia/living-with-dementia/bme/>) 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.

3. Impact and Evidence:

The majority of the older BAME population belong to Indian, Pakistani, Chinese, White Irish and Black Caribbean communities. Many of them migrated to the UK in the late 1950s – early 1960s and usually lived and worked within their own communities (*source: Dementia has no boundaries, Mary Dawood RN, BSc (Hons) MSc Consultant Nurse, Research Article Open Access Diversity and Equality in Health and Care (2015)*).

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 BAME 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 BAME 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 BAME communities.

3. Impact and Evidence:

- People from BAME communities with dementia need encouragement to seek help earlier and be supported to do this through advocacy where necessary.
- People from BAME 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 BAME 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.

Race Profile of Current Service Users

The table below shows the percentage of Dementia Navigator service users by aggregated race figures and Birmingham population figures (as at 2011 census).

Aggregated Population data - %	B'ham	Dementia Navigator Service Users
White	57.9%	85.3%
Asian	26.6%	8.5%
Black	9.0%	5.8%
Mixed	4.4%	0.4%
Other	2.0%	0%

Full details by each race was captured and reported in the Evaluation of the Dementia Care Navigator Project report, however the figures are overwhelmingly White British (81.6%). The next largest groups of service users by race, were Black Caribbean at 5.5%, Pakistani at 5% and then White Irish at 2.9%.

The vast majority of service users are White British and significantly higher proportions than that of the local population.

Language Profile Birmingham

Proficiency in English %	Birmingham		
	Male	Female	Total
Main language is English	85.13%	84.29%	84.70%
Main language is not English	14.87%	15.71%	15.30%
Where English is not their main language:			
Can speak English very well	37.90%	31.04%	34.31%
Can speak English well	39.92%	31.78%	35.66%
Cannot speak English well	19.22%	28.29%	23.97%
Cannot speak English	2.95%	8.89%	6.06%

3. Impact and Evidence:

The table above details proficiency in English for Birmingham, extracted from the Census 2011 data. The data shows that 84.7% of the population had English as their main language. Where English was not their main language residents were asked to identify their proficiency in English. Just over 30% stated that they could either not speak English well or at all, this represents 47,005 people (out of the 156,553 people who stated that English was not their main language).

The top 10 languages (at the time of the 2011 Census; and other than English) were:

	Language	No.	%
1	Urdu	29960	2.45%
2	Punjabi	22014	1.80%
3	Bengali	14933	1.22%
4	Pakistani Pahari	10864	0.89%
5	Polish	9390	0.77%
6	Somali	8158	0.67%
7	Arabic	7153	0.58%
8	Pashto	6189	0.51%
9	All other Chinese	5983	0.49%
10	Gujarati	5489	0.45%

Language and Dementia

There is evidence that people from BAME communities are not sure where or how to find information about dementia (*source: Social Care Institute for Excellence* (<https://www.scie.org.uk/dementia/living-with-dementia/bme/>) - *Black and minority ethnic (BME) communities and dementia*). 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: https://www.skillsforcare.org.uk/Documents/Topics/Dementia/Dementia-and-diversity-a-guide-for-leaders-and-managers.pdf*)

3. Impact and Evidence:

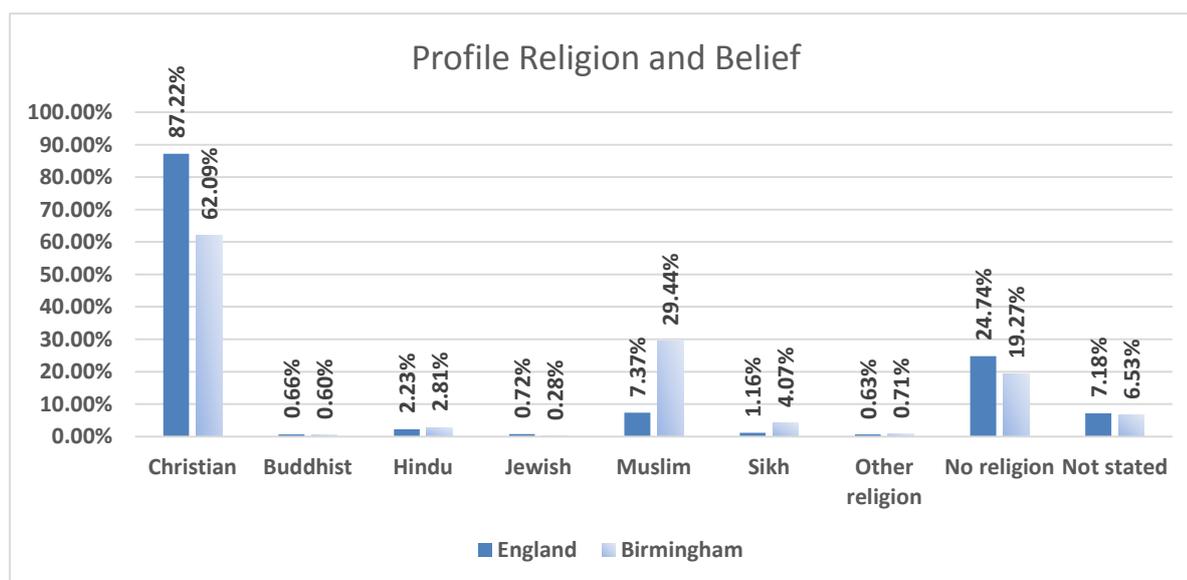
There is no term for dementia in South Asian languages. It is often referred to in terms such as ‘not being able to remember things’, ‘being forgetful’ or ‘losing memory’. Among the Chinese there was a way of describing dementia, but the description was very derogatory (*Alzheimer’s Society*).

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

Religion Profile Birmingham

Data taken from the 2011 Census; In Birmingham 74.19% of the resident population stated that they had a religion, compared to 68.09% of England as a total.

Of the population in Birmingham who have stated a religion, 62.09% identified with Christianity the next largest religion identified was Islam by 29.44% of the population.



Religion	England	Birmingham
Christian	87.22%	62.09%
Buddhist	0.66%	0.60%
Hindu	2.23%	2.81%
Jewish	0.72%	0.28%
Muslim	7.37%	29.44%
Sikh	1.16%	4.07%
Other religion	0.63%	0.71%
No religion	24.74%	19.27%
Not stated	7.18%	6.53%

3. Impact and Evidence:

Religion and Dementia

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.

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

Sex Profile Birmingham

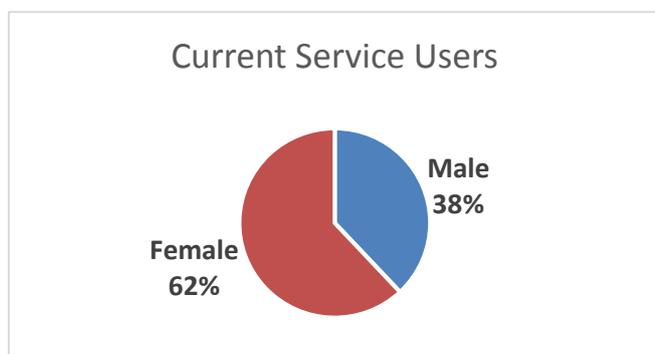
%	Male	Female
B'ham	49.19%	50.81%

Sex and Dementia

Women are more likely than men to develop dementia 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
- In 2014, there were more than twice the number of deaths due to all cancers than dementia. By 2040, more people will die due to dementia.
- In the UK, dementia is the only condition in the top 10 causes of death without a treatment to prevent, cure or slow its progression.
- 65% of people living with dementia are women.
- The numbers of people expected to die due to dementia are expected to quadruple by 2040, from 59,199 in 2014 to 219,409.

Sex Profile of Current Service Users



Significantly higher proportion of women using the service than men;

3. Impact and Evidence:

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 Birmingham/National

Birmingham Lesbian, Gay, Bisexual and Transgender (LGBT) organisation stated (in their report *'Out and About: Mapping LGBT lives in Birmingham'*) 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.

According to ONS, in 2015, 1.7% of the UK population identified themselves as lesbian, gay or bisexual (LGB).

- More males (2.0%) than females (1.5%) identified themselves as LGB in 2015.
- Of the population aged 16 to 24, there were 3.3% identifying themselves as LGB, the largest percentage within any age group in 2015.
- The population who identified as LGB in 2015 were most likely to be single, never married or civil partnered, at 68.2%.

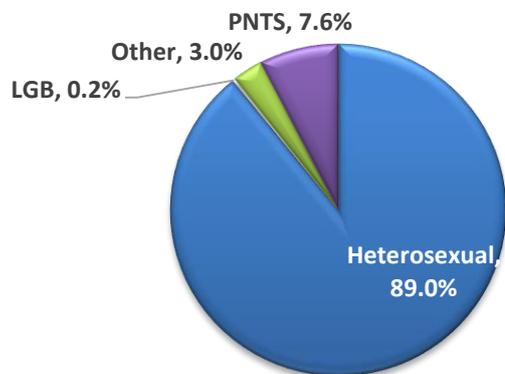
Sexual Orientation Profile of Current Service Users

The chart below shows that the majority of service users identified as Heterosexual, with only 0.2% being Lesbian, Gay or Bisexual (LGB), 3% indicated Other sexual orientation and 7.6% Preferred not to state (PNTS) their sexual orientation.

The terminology currently used to describe sexual orientation may not be relevant to older people, who may not describe sexual orientation in terms of Lesbian, Gay or Bisexual; hence this may be the reason for 3% stating Other.

3. Impact and Evidence:

Sexual Orientation of Current Service Users



Sexual Orientation and Dementia

For lesbian, gay, bisexual and transgender + (LGB&T+) people, living with dementia can be additionally stressful. Not only are LGB&T+ 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', LGB&T+ 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:

<https://www.scie.org.uk/dementia/living-with-dementia/lgbt/> - LGB&T+ communities and dementia)

Memory problems are a common early symptom in dementia. If you identify as LGBT, they can be more difficult to deal with. If you are LGB or T, 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 'remembrance' therapies, and are often

3. Impact and Evidence:

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 LGBT 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: https://www.alzheimers.org.uk/info/20029/daily_living/1190/lgbt_living_with_dementia/3)

Tips for supporting an LGBT person with dementia

- Treat the person as an individual and respect their wishes.
- Talk to the person about letting those who are important to them know that they have dementia. This will help them to understand what is happening and to support both the person and you.
- Talk to the person about how they want to express themselves to others – for example, they may identify as a bisexual man, or a trans woman – and make sure they feel supported to make the decision.
- Support the person to be open about their gender identity or sexual orientation with whoever they choose to be. If there is anyone they don't want to tell, respect this too.
- Talk to the person about their wishes as early as possible – around treatment and care, other needs and who they want to make decisions. Make sure these wishes are recorded, to help ensure they are met later on when the person is no longer able to make decisions. For more information, see 'Planning ahead'.

Changes in society for LGBT people

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

3. Impact and Evidence:

- 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. For more information, see 'Gender recognition certificate' below.
- 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.

LGBT 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 LGBT person in the past and how they may affect them today.

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

Carers and Dementia

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

3. Impact and Evidence:
<ul style="list-style-type: none"> • 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. <p>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’. (Source: <i>Social Care Institute for Excellence</i> (https://www.scie.org.uk/dementia/living-with-dementia/bme/) - <i>Black and minority ethnic (BME) communities and dementia</i>).</p>
<p>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)</p> <p>This service focuses on all carers or people with dementia.</p>

4. Health Inequalities	Yes/No	Evidence
Could health inequalities be created or persist by the proposals?	No	This project supports carers of people with dementia, who often have other co-morbidities. The focus shouldn't lead to health inequalities.
Is there any impact for groups or communities living in particular geographical areas?	No	The service is being rolled out across Birmingham to reduce current disparity that exists based on where someone lives.
Is there any impact for groups or communities affected by unemployment, lower educational attainment, low income, or poor access to green spaces?	No	The project supports carers and therefore will inevitably support carers who are unable to work due to caring commitments.
<p>How will you ensure the proposals reduce health inequalities?</p> <ul style="list-style-type: none"> • Clear monitoring using demographic data • Service user feedback • Proactive planning 		

5. FREDA Principles/ Human Rights	Question	Response
Fairness – Fair and equal access to services	How will this respect a person's entitlement to access this service?	Additional capacity will improve access to service.
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?	Service will respect private and family life and also improve access to information to support informed decision making and future planning, 'capacity' advocacy and safeguarding as appropriate.
Equality – right not to be discriminated against based on your protected characteristics	How will this process ensure that people are not discriminated against and have their needs met and identified?	Principles around equality will be embedded in contract and monitored through the contract review structure.
	How will this affect a person's right to freedom of thought, conscience and religion?	Service will respect people's right to choose.
Dignity – the right not to be treated in a degrading way	How will you ensure that individuals are not being treated in an inhuman or degrading way?	Quality standards will be embedded in contract and monitored through the contract review structure.
Autonomy – right to respect for private & family life; being able to make informed decisions and choices	How will individuals have the opportunity to be involved in discussions and decisions about their own healthcare?	The service is designed to inform and support people to make decisions that impact on them.
Right to Life	Will or could it affect someone's right to life? How?	No
Right to Liberty	Will or could someone be deprived of their liberty? How?	No

6. Social Value	
Consider how you might use the opportunity to improve health and reduce health inequalities and so achieve wider public benefits, through action on the social determinants of health.	
Marmot Policy Objective	What actions are you able to build into the procurement activity and/or contract to achieve wider public benefits?
Enable all people to have control over their lives and maximise their capabilities	The service seeks to inform and support people with dementia to make decisions through informed choice.
Create fair employment and good work for all	Where applicable the service will support people with dementia and their carers in employment/

6. Social Value	
Create and develop health and sustainable places and communities	The service will work with others to create and develop sustainable places and communities.
Strengthen the role and impact of ill-health prevention	This service will promote ill-health prevention and support early access to information.

7. Engagement, Involvement and Consultation

If relevant, please state what engagement activity has been undertaken and the date and with which protected groups:

Engagement Activity	Protected Characteristic/ Group/ Community	Date
Dementia Patient Engagement	Current Service Users/carers/ families	9 th May 2018
Evaluation of the Dementia Care Navigator Project	As above	March 2018

For each engagement activity, please state the key feedback and how this will shape policy / service decisions (E.g. patient told us So we will):

Bright Red Creative Solutions Ltd conducted an evaluation of the dementia care navigator project with the following aims:

1. To assess the impact of the initiative for its key stakeholders through a quantitative and qualitative analysis of existing data (e.g. demographic data, referrals, attrition and diversion rates; feedback from users and carers) and additional qualitative data obtained throughout the evaluation period (e.g. feedback from GPs and other professionals)
2. To assess whether the aims and the outcomes of the service have been achieved.
3. To articulate to what extent the service has addressed the individual needs of people using the service
4. To make recommendations for the commissioner.

The findings of the report in terms of data/service user protected characteristics has been incorporated where available in section 3 (Impact and Evidence) of this equality analysis and is summarised below:

- **Age:** the age profile was similar for most providers. The majority of people were in the 75-84 age group, followed by 55-64.
- **Sex:** the sex of service users was around 60% female.
- **Sexual orientation:** overwhelmingly heterosexual.
- **Ethnicity:** overwhelmingly White British, though several other groups were recorded (mainly Caribbean, Indian and Pakistani).

Each of the service areas reviewed received ratings of 'Excellent' or 'Good' by more than 84% of respondents (range 84-96%), and more than 50% gave a rating of 'Excellent' (range 51-73%).

In all over 76% said it was 'Extremely Likely' and 16% 'Likely' that they would recommend the service to friends and family. There was only one response of 'unlikely'.

When asked how the first visit left respondents feeling, 40 said 'Supported' 39 said 'Increased Wellbeing', 33 said 'Informed', 24 said 'Reduced Isolation', 17 were 'Reassured' and 12 felt 'Understood'.

The following findings/recommendations/developments were made within the report (only those relevant to equality analysis included):

- The referrals for service users from Black, Asian and other ethnic minority backgrounds were lower compared to other groups and local demographics; this requires urgent review by the project team.
- The level and depth of data collected needs to be improved – whilst the service has (in the last year), started taking the NHS number this has the potential for 'tracking' patient cohorts. In addition to routine monitoring, workers should be engaging in ongoing activities to measure changes for the service users; these techniques can also open dialogue between the service user and Dementia Care Navigator, and encourage the service user to reflect on changes. In addition, deeper statistical analysis, alongside financial analysis, can take place to identify differences in experience between gender, age and ethnic group of the particular area.

The Patient Focus Group held on 18th May 2018 was well attended with 18 patients/carers contributing to the event. Attendees were diverse (with a broad range of races, gender, religions and disability characteristics represented). The feedback was that overall the current service was useful and well received. The biggest gap identified was around GP knowledge of dementia and of the Dementia Navigator service – though this was dependant largely on which CCG an individual's GP practice was sited (the original DN service was well publicised and utilised by Birmingham South Central CCG, due to the work undertaken to promote the service).

8. Summary of Analysis

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

Age: the biggest risk factor for dementia is age and the older you are the more likely you are to develop the condition. The largest age group of service users was those aged between 75 and 84 – 38%.

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: the current service user profile is overwhelmingly heterosexual. Care needs to be taken when equality monitoring sexual orientation to ensure that the terminology used is relevant to older people. LGB 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 (53.14%). 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 LGB 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. No service users identified as being Transgender.

Carers – the limited monitoring currently undertaken does not appear to capture carer views. 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.

9. Mitigations and Changes :

Please give an 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.

Recommendations:

- Equality monitoring (age, disability, race, sexual orientation, gender reassignment, religion, caring status, sex) Provider to ensure that this data is captured and reported upon to the Commissioner. This will enable a better understanding of who is using the service and to identify any gaps in terms of reach and representation.
- Engagement and promotional work (both CCG and Service Provider) – this will need to include both GP Practices and work in the wider community to promote the Dementia Navigator service. This work will need to be with diverse groups across Birmingham, to include (but not limited to) Carers, LGBT groups, a wide range of religious and cultural groups and Learning Disability organisations. The work should include a range of activities.
- Specific targeted sessions (LGBT, BAME, LD) – the Provider will need to have a plan of action to demonstrate how they will tailor the service to meet the needs of specific target groups.
- Staff Training (Culture, Religion and Faith, LGBT, LD) – Provider will need to demonstrate that staff involved in delivering the Dementia Navigator service have received training on understanding diverse communities, their needs and barriers to access.
- Promotional Material (including Terminology – LGB terms/cultural terms) – information used to promote the service will be inclusive, relevant to the local diverse communities and accessible.

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):

- Equality Profile – service users and carers – detailed anonymous equality monitoring of service users.
- Improving Access (CQUIN) – payment for understanding barriers to access, having a plan for improving access with under-represented groups and for improving GP’s knowledge of the service as well as demonstrable and evidenced improvement’s achieved over the period of the contract.
- Accessible Information Standard – provider will need to demonstrate an understanding of the standard and be able to provide examples of reasonable adjustments made to meet the information and communication needs of service users and their carers.
- Translation/Interpreting Service provision – provider will need to demonstrate how they will meet the language needs of service users and their carers.
- Service User and Carer feedback – monitoring of feedback on experience of the service.

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):

- **Translation/Interpreting Service provision** – provider will need to demonstrate how they will meet the language needs of service users and their carers
- **Accessible Information Standard** – provider will need to demonstrate an understanding of the standard and be able to provide examples of reasonable adjustments made to meet the information and communication needs of service users and their carers.
- **Equality Monitoring** – provider will need to demonstrate how they will use equality monitoring to improve access to the service for a diverse population; including LGBT, LD and BME communities.
- **Staff Training** (Culture, Religion and Faith, LGBT, LD) – Provider will need to demonstrate that staff involved in delivering the Dementia Navigator service will/have received training on understanding diverse communities, their needs and barriers to access
- **Equality Policy** in place which covers both employees and service users.

12. Publication

How will you share the findings of the Equality Analysis?

This can include: reports into committee or Governing Body, feedback to stakeholders including patients and the public, publication on the web pages.

Publication on BSol webpages.
EA will go to Quality and Safety Committee

13. Sign Off

The Equality Analysis will need to go through a process of **quality assurance** by the Senior Manager for Equality and Diversity or Manager for Equality and Diversity **and** signed-off by a delegated committee

	Name	Date
Quality Assured By:	<i>Bal K Everitt</i>	21 May 2018
Which Committee will be considering the findings and signing off the EA?	Quality and Safety Committee	2 nd November 2018
Minute number (to be inserted following presentation to committee)		