

Equality Analysis Form

Subject of equality analysis	Dementia – commissioning priority area	
Type		Tick
	Policy	
	Strategy	X
	Business case	
	Commissioning service redesign	
	Contract / Procurement	
	Event / consultation	
Owner	Name:	Wayne Goddard
	Job Title:	Head of Strategy & Delivery – Integrated Lead for Dementia
Date	November 2015	
Assessment Summary	<p>NHS Doncaster CCG and the Health and Wellbeing Board (HWB) have confirmed that Dementia will remain a priority and as such plans are held to account through a CCG Delivery Plan and a HWB outcome based accountability template (OBAT) framework. The last CCG equality assessment of the impact of dementia commissioning was conducted in November 2014. This assessment aims to update the original assessment with any new evidence and/or impacts and consider any further actions required.</p>	
Stakeholders		Tick
	Staff	
	General public	X
	Service users	X
	Partners	X
	Providers	X
Data collection and consultation	<p><u>Local data:</u></p> <ul style="list-style-type: none"> • There are 850,000 people living with dementia in the UK, with an estimated prevalence of 3514 people 65 and over living in Doncaster. The current diagnosis rate is 73.4% (as at October 2015) with an estimated gap of 1065 people including under 65) who have no diagnosis. • Dementia has been identified as one of the CCG’s main clinical priorities and part of the Health and Wellbeing Board Strategy and priorities. • A CCG dementia delivery plan and a HWB OBAT have been 	

developed taking into account local need and encompassing recommendations from the National Dementia Strategy and the more recent Prime Ministers Challenge 2020 on Dementia released in April 2015. The Doncaster Dementia Strategic Partnership (DDSP) is taking forward the Doncaster Dementia Strategy 2015, titled “Getting There”, and focuses on five key themes:

- Pre diagnosis information and support
 - Assessment and treatment
 - Peri and Post diagnostic care and support
 - Care Homes
 - End of Life
- Doncaster is also signed up to the National Dementia Declaration involving local partnerships to be involved with the implementation of the Doncaster Dementia Strategy.
 - NHS Doncaster CCG in partnership with Doncaster Metropolitan Borough Council (DMBC) is leading a Dementia Friendly Communities programme which includes a range of awareness campaigns and engagement activities with regard to dementia including the Dementia Friends Information initiative. A Local Directory of Services for Dementia has been produced.
 - Local statistical data indicates a high proportion of the local, expected prevalence of dementia had been identified, with local services (primarily provided by Rotherham Doncaster & South Humber NHS Foundation Trust) working to National Institute of health & Clinical Excellence (NICE) guidance for assessment and rapid access.
 - NHS Doncaster CCG in partnership with DMBC and other Dementia care service providers are launching a new Admiral Service (January 2016) which will support people with dementia and their families in post diagnostic dementia care giving everyone an immediate point of contact for help and support.

Previous assessment in November 2014:

A full assessment in November 2014 identified that:

- There was a positive focus on service redesign and improvement which takes into account patient needs from across the protected characteristics.
- There was targeted activity within protected characteristic groups who may be disadvantaged e.g. men who tend to present later with a dementia diagnosis.
- There was evidence of positive engagement to raise awareness of, build dementia friendly communities and redesigning of services to meet the local needs.
- Equalities guidance was generally being applied by a ‘broad brush approach’ when being incorporated within specifications or tenders. The principles of the Act were deemed to be embedded within the requirements of the specifications and did not identify whether additional specific action was required

focused on the more disadvantaged / marginalised within our communities.

- Potential areas for further development were identified as:
 - Identify the challenges/barriers for marginalised groups whom have very little understanding of the current referral pathway/system or limited access to community services which may aid/support patients to 'live well' and maintain a level of independence.
 - Scrutinise the marketing strategy or approach identified, to ensure dementia, health promotion or awareness campaigns are 'equitable' for all potential users.
 - Identify whether we can we identify groups omitted from patient experience data of dementia across protected characteristic groups.
 - Create data sets to ensure data is captured in relation to the protected characteristics.

National data:

In 2009 the Department of Health conducted an impact assessment of the national strategy to identify equality impact.



DoH DEMENTIA
Equality Impact Assse

In 2015 Public Health England commissioned a systematic review of the literature on the prevalence of dementia in population groups by protected characteristics.



Dementia_Equalities_
Literature_Review_M

The literature review concluded in summary that:

- Dementia was more common in people from African-American, black-Caribbean or Hispanic background. There was no information published on people from south-east Asian backgrounds.
- Dementia is more common in women. There was no information to help understand if religion or sexual orientation changed the prevalence of dementia. Learning disability and lower socio-economic position both increased the prevalence.
- Risk factors known to increase dementia (diabetes, stroke and depression) also increase dementia in groups with increased prevalence, and education remains protective against dementia.

Data by protected characteristic:

Age

- The 2009 Department of Health equality analysis identified that one of the misapprehensions of both the public and professionals alike is that dementia is a normal part of the aging process, and simply a consequence of getting old. The incidence of dementia undoubtedly increases with age, but it is far from being inevitable and is certainly not a natural consequence of the aging process.
- Although dementia is primarily an illness associated with older people, there are also a significant number of people, currently around 15,000, who develop dementia earlier in life and services for dementia should reflect this fact. Younger people with dementia and their family carers may have issues around childcare, employment and peer support.
- The prevalence of dementia increases steadily with age, with the proportion of people with dementia doubling for every five year age group.

Disability

- The 2009 Department of Health equality analysis identified national surveys which show that dementia is one of the major causes of disability in the elderly, affecting personal care, everyday cognitive activities, and social behaviour. Early diagnosis and better quality of care can therefore make a major contribution to the postponement of disability in old age. People with dementia also have other disabling conditions unconnected with the dementia itself, which will complicate the nature of the care they require. This is particularly true of people with learning disabilities. Considering the particular needs of people with learning disabilities is important when commissioning and providing services for people with dementia.
- In the 2015 literature review, it was noted that Shooshtari et al (2011) focused their case-control study on adults with developmental disabilities. This study suggested that those developmental disabilities give rise to a more than four-fold increase in dementia. Associations between Alzheimer's disease and syndrome specific neurological phenotypes are well recognised. All individuals with Down's syndrome have the characteristic neuropathology of Alzheimer's disease by the age of 40, and although not all will develop dementia, it is extremely common (Lott, 2012, Zigman, 2013).
- The 2015 literature review identified four risk factors that recurred in the evidence regarding people with protected characteristics. Those four risk factors were diabetes, stroke, education and depression. Diabetes doubles an individual's risk of dementia (Ott et al, 1999) (odds ratio 1.17 (Husaini et al, 2013)). Type 2 diabetes has a Hazard Ratio of 1.6 for dementia and cognitive impairment. Stroke appears to be a strong risk factor for dementia (Odds Ratio 8.5 (Husaini et al, 2013))

especially where mediated through hypertension (Odds Ratio 1.9 (Husaini et al, 2013)). Levels of education are strongly inversely associated with dementia (Gurland et al, 1999, Adelman et al, 2011). Increased early life education, is associated with reduced risk of dementia (Meng and D'Arcy, 2012). However, after controlling for age and education differences in rates between ethnic groups are no longer consistent. A diagnosis of depression was less common in very elderly people with dementia (Borjesson-Hanson et al, 2011). Although this could be due to a number of reasons; the primary reason appears to be that psychiatric diagnoses are heavily reliant on self-reporting, which become increasing unreliable with increasing severity of dementia. When patients with dementia are excluded from samples the apparent decline in depression in the very elderly disappears (Saunders et al, 1993).

Gender

- The 2009 Department of Health equality analysis identified that there are differences in the incidence of dementia according to gender with a higher proportion of men in the ages 65-74 years and a higher proportion of women aged over 75 having dementia. There will also be differences in the nature of care required according to the gender of individuals, and in the approach of caregivers to the provision of care. Male and female caregivers can respond differently to their caregiving role in terms of depression, burden, stress, and substance abuse. There is a need for these factors to be taken into account in the care provided for people with dementia.
- In the 2015 literature review, it was noted that gender has long been widely reported as associated with the prevalence of dementia. The differential prevalence reported in the studies included in this review is in keeping with the much larger and longer standing body of evidence. Borjesson-Hanson et al (2011) reported that a much greater proportion of the over-95-year-olds in Gothenburg, Sweden with dementia were women (85%) and a greater proportion of the women had dementia (56% vs 37% of men). Bernardi et al (2012) report a greater proportion of women having dementia even at younger ages.
- Dementia is the leading cause of death in women and the third leading cause among men, according to new mortality statistics released by the Office of National Statistics today (29 October 2014). 31,850 women died with dementia in 2013 compared to 26,075 deaths from ischemic heart diseases, the second leading cause of death in women. 15,262 men died with dementia in the same year. Terry (2014) reported that there will be 225,000 people developing dementia every year and numbers are set to soar, dementia is one of the biggest health and social care challenges the UK faces.

Race/Ethnicity

- The 2009 Department of Health equality analysis identified that people from all ethnic groups are affected by dementia. The number of people with dementia in minority ethnic groups is estimated to be around 15,000 in England (approximately 3% of the estimated overall number of people with dementia) and there may be a lower degree of knowledge of dementia amongst some ethnic groups. This compares with the proportion of minority ethnic groups in the population in England as a whole of 9% (2001 NHS census), but it should be noted that the number of people from ethnic minorities with dementia, and their proportion of the population as a whole, is set to rise sharply with the aging of ethnic minority populations.
- During the Department of Health's consultation process for the National Dementia Strategy they sought the views of the public and professionals, who did not raise ethnicity as a significant factor, however, the National Dementia Strategy addresses the issue of ethnicity. The Strategy emphasises that services should take account of the fact that the needs of people from minority ethnic groups may be different from those of the majority population and may require specifically-tailored approaches. To help assess the particular needs and concerns of black and minority ethnic groups, the consultation process included a number of targeted consultation events involving Asian men, Asian women, and the Chinese community and views on the draft Strategy were sought from a range of relevant stakeholder organisations. Respondents said that the Department of Health should make the Strategy relevant to ethnic minority populations and this was reflected in the Strategy which states that all services should be tailored, where appropriate, to meet the needs of ethnic population groups.
- In the 2015 literature review, only studies focused on dementia in people from African-American (black-Caribbean) or Hispanic ethnic groups were found. The literature review suggested that diagnostic and screening tools need to be culturally appropriate (Adelman et al, 2011). When the diagnostic and screening tools are not culturally appropriate, over-diagnosis or misclassification (Kennedy, 2012) are potentially significant issues. This is a separate and distinct issue from the under diagnosis that is caused from failure to consider the possibility of dementia and therefore put people forward for potential diagnosis. Black and minority ethnic people with dementia may be at particular risk of misdiagnosis, particularly of being labelled as 'mentally ill' and treated with (inappropriate) medication (Blood and Bamford, 2010).

Religion & Belief

- The 2009 Department of Health equality analysis identified that

religion is closely associated with the cultural and ethnic differences described in the section on Ethnicity above and care provided for people with dementia should respect religious and other beliefs. Although there is no obvious religious dimension to dementia, feedback from the Department of Health consultation showed that religion may play an important part in the lives of people with dementia and religious organisations may be able to provide a link between individuals and health and social care services.

- In the 2015 literature review, different ethnic groups, especially Hispanic and African-American groups, received delayed and inadequate health care services for dementia (Chin et al, 2011). Efforts to narrow this health disparity will require understanding of how the cultural beliefs of these communities influence their understanding of dementia and their willingness to seek support from health services for these conditions. Across a wide range of countries and cultures gender, education and assets do not explain the variations in health service utilisation. Dementia is usually inversely associated with health service use (Albanese et al, 2011). Some of the culturally specific conceptualisations of dementia as a normal part of ageing or of having a spiritual, psychological or social Prevalence of dementia in population groups by protected characteristics cause have prevented many groups from seeking support (Mukadam et al, 2011, Mukadam et al, 2013). Specific work in Australia (Garvey et al, 2011) suggests that some of the causes are due to culturally mediated misconceptions and that culturally appropriate campaigns and educational interventions may be part of the approach needed. This is an area that has not been fully addressed in any of the literature available for this review.

Sexual Orientation

- The 2009 Department of Health equality analysis identified that studies on the experience of lesbian, gay, bisexual and trans-gender individuals have not been identified in relation to dementia. However, lesbian women and gay men are likely to face particular challenges in caring for partners or friends with dementia which are not faced by others in Society. No robust data is available on carers by sexual orientation, and indeed this is a generally under-researched topic where more information is required. An advisory leaflet lesbian, gay, bisexual and trans-gender individuals *Dementia Doesn't Discriminate* has been produced as a helpful reference point.
- In the 2015 literature review, although there were no studies published in the time period for the review that address the differential prevalence of groups classified by their sexual orientation or gender reassignment, an important issue was raised in the grey literature. This issue raised relates to people being unwilling to declare their sexuality on admission to

	<p>residential care (Peel and McDaid, 2015). This would prevent diagnoses of dementia from being linked with sexual orientation data and therefore impede the ability of health services to identify issues that relate to dementia and sexual orientation.</p> <p>Gender reassignment</p> <ul style="list-style-type: none"> • There is no commentary in the literature. <p>Pregnancy & Maternity</p> <ul style="list-style-type: none"> • There is no commentary in the literature. <p>Marriage & Civil Partnership N/A</p> <p>Social Inclusion / Community Cohesion</p> <ul style="list-style-type: none"> • There is no commentary in the literature. • Lifestyle choices e.g. alcohol misuse is known to increase the onset of dementia – i.e. alcohol induced dementia.
--	---

Protected characteristic	Positive	Neutral	Negative	Negative: What are the risks? Positive: What are the benefits / opportunities?
Age	X			The delivery plan recognises young onset dementia as well as dementia associated with age.
Disability	X			The delivery plan recognises that dementia tends not to be an isolated condition, but part of a range of co-morbidities. There is the opportunity to align the dementia plan to emerging work on learning disabilities.
Gender	X			More women than men are diagnosed with dementia.
Race	X			The delivery plan aims to target dementia communications, raise awareness and reduce stigma into black and minority ethnic communities via community engagement channels.

Protected characteristic	Positive	Neutral	Negative	Negative: What are the risks? Positive: What are the benefits / opportunities?
Religion & Belief		X		Although there is no obvious religious dimension to dementia, Department of Health consultation showed that religion may play an important part in the lives of people with dementia and religious organisations may be able to provide a link between individuals and health and social care services. Opportunity to build on the work with faith communities within Doncaster particularly around raising awareness and reducing stigma.
Sexual Orientation		X		It has been identified that people may be unwilling to declare their sexuality on admission to residential care (Peel and McDaid, 2015). This may impact the personalised care provided.
Gender reassignment		X		
Pregnancy & Maternity		X		
Marriage & Civil Partnership		X		There is the potential for people in civil partnerships or those who cohabit and/or provide care and support to people with dementia - (unofficial advocates) to face problems with data sharing when seeking help form services.
Social Inclusion / Community Cohesion			X	

<p>Conclusion & Recommendations including any resulting action plan</p>	<p>Potential equality impact has been identified across a range of protected characteristics, with the greatest impact on:</p> <ul style="list-style-type: none"> • Age • Disability • Race <p><u>Action plan:</u></p> <ol style="list-style-type: none"> 1. A focus on age gives us an opportunity in our communications to focus on dementia not being a natural progression with age, and focus on young onset dementia. 2. A focus on disability gives us an opportunity to link to learning disability services – a priority for the Doncaster Health & Wellbeing Board. A Board to Board is planned for early 2016. 3. A focus on race gives us the opportunity to consider targeting dementia communications in culturally sensitive ways into black and minority ethnic communities via community engagement channels. 4. Developing a robust data set which identifies the ethnicity of people diagnosed with dementia on GP registers. 5. Develop a robust data set to establish ethnicity of people referred into the Memory service in RDaSH. 6. Continue to identify patient experience of dementia across protected characteristic groups. 7. Undertake engagement to establish why people across the protected characteristics may be not accessing services. 8. Ensure the post diagnostic services are culturally sensitive and their data collection captures the protected characteristics in the evaluation. 9. Commissioners and providers of health and care services to fully consider those groups with protected characteristics who are at greatest risk of developing and are living with dementia in their population, when commissioning and providing services. 10. A focus on targeting the more higher risk groups by raising awareness and reducing their risk of dementia.
<p>Review date</p>	<p>December 2016</p>