Better care together

A partnership of Leicester, Leicestershire & Rutland Health and Social Care

Better Care Together

Equality Impact Assessment (EIA) Report

Please refer to the supporting BCT EIA Guidance when completing this report

Name of work stream / project	Leicestershire, Leicester City and Rutland's Joint Living Well with Dementia Strategy
Name of a) Senior Responsible Owner and b) Implementation Lead	Bev White, Leicester City Council
Name of officer leading on completion of this assessment	Bev White, Leicester City Council
Date EIA assessment started	23rd October 2017
Date EIA assessment completed	
Review date (eg 12 months following completion)	

Ver: 2.0 26/03/15 BCT PMO

1. Defining the work stream or project
Describe the work stream or project and the intended change or outcome for those targeted.
The Leicester, Leicestershire and Rutland's (LLR) Living Well with Dementia Strategy 2018-2021 sets the priorities across LLR for people living with dementia and their families and carers. It reflects the national strategic direction outlined in The Prime Minister's Challenge on Dementia which details ambitious reforms to be achieved by 2020, and supports the requirements of the Care Act 2014 for local authorities and health partners to work in partnership and integrate services where possible, in order to provide seamless support, avoid duplication and achieve best value for money. The strategy has been developed in partnership between the 3 Clinical Commissioning Groups, the 3 Local Authorities, NHS Provider Trusts and local voluntary sector organisations. An important focus of the strategy is to move towards delivery of personalised and integrated care. The NHS England Well Pathway for Dementia has been utilised to give a framework that puts the individual at the centre of service development and implementation across health and social care. As a partnership, there is a commitment to minimising the impact of dementia whilst transforming dementia care and support within the communities of Leicester City, Leicestershire and Rutland, not only for the person with dementia but also for the individuals who care for someone with dementia. The aim is to create a health and social care system that works together so that every person with dementia, their carers and families have access to and receive compassionate care and support not only prior to diagnosis but post diagnosis and through to end of life.

Outline who will be affected, and how will they be affected.
The Strategy is **informed by** what people have said about their experiences either as a person living with dementia or as a carer and is written **for** those people; specifically those with memory concerns, those with a dementia diagnosis, their families and carers and the organisations supporting them from all communities across Leicestershire, Leicester and Rutland. The priorities outlined within the Strategy aim to improve dementia care for all people across all protected characteristics. Under-represented groups have been identified through previous commissioning activities and commissioned services have been tasked with proactively targeting those groups to increase representation particularly by people from black and minority ethnic backgrounds in Leicestershire County and by male carers in both the County and Leicester City. Data in relation to religion and sexual orientation from commissioned providers working with people affected by dementia has in the past been incomplete and this has been addressed in order to ensure that work being undertaken is accessible and equitable for all. It is hoped that this attention to detail with commissioned providers will support the engagement of people affected by dementia even further with this strategy. Partner organisations who will be signing up to the LLR Dementia Strategy are: Leicestershire County Council, Rutland County Council, Leicester City, West Leicestershire and East Leicestershire & Rutland Clinical Commissioning Groups as well as Leicestershire Partnership Trust, University Hospitals of Leicester and a selection of voluntary sector organisations. The final strategy is expected to inform strategic planning in relation to dementia care and transformation within each partner organisation.
Is this linked to/dependent on any other work stream or project within your own or partner organisations? N/A
As part of the overarching Sustainability and Transformation Plan governance, the Dementia Strategy is expected to relate to a number of emerging plans across LLR, particularly the LLR Carers Strategy. The Dementia Programme Board will need to ensure the outcomes of the final LLR Dementia Strategy are aligned to the strategic objectives of the Home First Programme.

2. Information used to inform the Equality Impact Assessment
Has any research been undertaken? If so, what are the findings, and how can it be incorporated into the project and programme? What data have you used?

Data has been sourced from the Leicester Leicestershire and Rutland Joint Strategic Needs Assessment (LLR JSNA) 2016, the Clinical Commissioning Groups recorded Dementia Diagnosis rates, and from Office of National Statistics (ONS) Data as well as performance monitoring information from previously commissioned dementia support services.

There has been a review of dementia service use, using data gathered by each commissioning partner for contract monitoring purposes. (A newly commissioned service for people affected by dementia started across Leicester City & Leicestershire in October 2017 – the first quarter performance monitoring data is being analysed currently at the point of writing this document)

1. In January 2017, the number of people registered with GP practices with a diagnosis of dementia in Leicester, Leicestershire and Rutland was 8,404 people.

2. Both locally and nationally people with dementia tend, on average, to stay in hospital for twice as long as people over 65 without dementia

3. People with learning disabilities, particularly Downs Syndrome, are more likely to experience early onset of dementia

For Leicestershire:

- 2017: Data suggests that there are 9,458 people over the age of 65 years old living with dementia across Leicestershire – this figure is predicted to rise to 17,028 by 2035
- The population of Leicestershire aged 65 and over is currently 139,400 therefore 6.78% of this population have dementia
- 2017: There are 184 people between the age of 30 and 64 years old who are living with early onset dementia across Leicestershire

For Leicester City:

- 2017: Data suggests that there are 2,951 people over the age of 65 years old living with dementia within Leicester City – this figure is set to rise to 4,818 by 2035

- The population of Leicester City that is aged 65 and over is currently 41,700 therefore 7.07% of this population have dementia
- 2017: There are 75 people between the age of 30 and 64 years old who are living with early onset dementia within Leicester City

For Rutland:

- 2017: Data suggests that there are 695 people over the age of 65 years old living with dementia across Rutland – this figure is predicted to rise to 1,241 by 2035
- The population of Rutland that is aged 65 and over is currently 9,500 therefore 7.3% of this population have dementia
- 2017: There are 10 people between the age of 30 and 64 years old who are living with early onset dementia within Rutland

Data relating to people affected by dementia and their families and carers specifically highlighting demographics in particular the protected characteristic domains is patchy. There is some detail from contract performance but this is not conclusive. It demonstrates that some providers are not comfortable asking patients/service users about some of these domains particularly gender reassignment and sexual orientation. Commissioned providers do need to get better at asking these questions in order for equality issues to be identified and mitigated against as soon as possible.

The key risk factors for dementia are:

Ageing – Although possible to develop dementia earlier in life above the age of 65, a person's risk of developing Alzheimer's or vascular dementia doubles roughly every 5 years. This may be as a result of factors associated with ageing such as higher blood pressure, increased risk of strokes or heart disease, changes to nerve cells, DNA's and cell structure, weakening of the body's natural repair systems and changes in the immune system.

Gender – Women are more likely to develop Alzheimer's disease than men. Reasons for this remain unclear. For most other dementias though, men and women have much the same risk of developing the condition except for vascular dementia as men are more prone to stroke and heart disease which in some cases can cause vascular and mixed dementia.

Ethnicity – There is some evidence to suggest that people from certain ethnic communities are at higher risk of dementia than others. South Asian people seem to develop dementia particularly vascular dementia more often than white European people. This is largely due to South Asian people being at a higher risk of stroke, heart disease and diabetes which is thought to explain the higher dementia risk. Similarly, people of African or African Caribbean origin seem to develop dementia more often and more prone to diabetes and stroke. This has been linked to a mix of differences in diet, smoking, exercise and genes.

Medical conditions and diseases – There is very strong evidence that conditions that damage the heart, arteries or blood circulation all affect a person's chance of developing dementia, known as cardiovascular risk factors. Having cardiovascular disease or type 2 diabetes increases a person's risk of developing dementia by up to two times. Other medical conditions such as Parkinson's disease, multiple sclerosis and HIV can increase a person's chance of developing dementia. As does Down's syndrome and other learning disabilities. Evidence in relation to these are still emerging. Lifestyle factors – Physical inactivity, smoking, an unhealthy diet and excessive alcohol use all increase a person's risk of developing dementia such as Alzheimer's disease and vascular dementia. Excessive alcohol consumption at higher levels over a long period of time also increases the risk of developing Korsakoff's syndrome and alcoholic dementia. Head injuries especially injuries which have caused a person to become unconscious can increase the risk of later dementia. It has been identified that a fifth of professional boxers go on to develop a different form of dementia, thought to be caused by protein deposits formed in the brain as a result of a brain injury.
Have you consulted target groups, other stakeholder and secondary groups about the following? What did they say? ▪ Their current needs and aspirations and what is important to them regarding the proposal ▪ Any impacts that may arise as a result of the work stream or project ▪ Potential barriers they may face in accessing the programme
Engagement with people affected by dementia (June 2017 – January 2018) was undertaken through the LLR Dementia Programme Board where providers working directly with people affected by dementia contributed their view in the development of the strategy. Engagement with people affected by dementia (December 2016 – February 2017) was undertaken as part of the joint commissioning activity for the new Leicester and Leicestershire Dementia Support Service where visits to carers support groups, activity groups and dementia café sessions were carried out. Attendance at these groups was predominantly White British people and no specific issues relating to equality or diversity were identified by those present. The main barrier for people affected by dementia to accessing the strategy would be its availability. Although dementia support services could be utilised to engage with the Strategy and have been commissioned to improve representation in their services by people from BME backgrounds, because knowledge and understanding about dementia is very low amongst those communities, attempts must be made through public consultation to further engage with these groups to ensure that the key messages identified within the strategy are of importance to them. The strategy must be available in other languages and alternative formats. Consideration also needs to be given in relation to targeting LGBT communities to ensure any specific issues relating to sexual orientation can be identified.

Public consultation on this Strategy is planned for the end of March 2018, and the outcomes and information from that consultation will be used to finalise the Equality Impact Assessment and action plan.

3a. Equality Impacts
Based on the above evidence and findings, use the table below to identify those who have one or more of the **'protected characteristics',** and are likely to be affected by the proposed work stream or project. Describe what the impact is likely to be, and how significant that impact is for individual or group well-being.

	Positive Impact (Y/N)	**Negative Impact (Y/N)**	**Describe the impact of the work stream or project on people with this protected characteristic**	**For negative impacts, what mitigating actions can be taken? [Summarise in table 5]**

	Positive Impact (Y/N)	Negative Impact (Y/N)	Describe the impact of the work stream or project on people with this protected characteristic	For negative impacts, what mitigating actions can be taken? [Summarise in table 5]
Age	**Y**	**Y**	The majority of people diagnosed with dementia are 65+. The Strategy's main aim is to create a local health and social care system that works together so that every person with dementia their carers and families have access to and receive compassionate care and support not only prior to diagnosis but post diagnosis and through to end of life. Through the delivery plan within the Strategy, statutory and voluntary sector organisations demonstrate how they will work together to support people affected by dementia and their families and carers. Younger people with dementia require different advice and support – services have been commissioned to ensure that this advice / support is received across the area, but organisations must ensure younger people feature in their delivery plans as well.	Any consultation events that take place should be offered at various times and dates as working age adults with an interest or experience of dementia may be working during the day. There are support services that specifically target this group of people but attendance at this may only be a small proportion of the people diagnosed with early onset dementia. The strategy highlights information within it in relation to younger people diagnosed with dementia but the aim encompasses all people with dementia and their carers and families.

	Positive Impact (Y/N)	Negative Impact (Y/N)	Describe the impact of the work stream or project on people with this protected characteristic	For negative impacts, what mitigating actions can be taken? [Summarise in table 5]
Disability	**Y**	**N**	Dementia is one of the major causes of disability in the elderly affecting personal care, everyday cognitive activities and social behaviour. Access to earlier support may help to postpone disability in old age and this is one of the key actions in the strategy. The strategy is intended to target people diagnosed with dementia and their carers including people who are disabled by their condition. Improving awareness and access to support will also improve outcomes for people with disabilities or health conditions which increase their likelihood of developing dementia. The actions relating to the work regarding dementia friendly communities is in essence not dissimilar to being 'disability friendly' therefore the impact is to improve the quality of life of people disabled by dementia, their family and friends.	
Gender Reassignment	**Y**	**N**	There will be a small number of the target group who are gender reassigned. The Strategy will be equally available to those people and will be sensitive to their needs.	

	Positive Impact (Y/N)	Negative Impact (Y/N)	Describe the impact of the work stream or project on people with this protected characteristic	For negative impacts, what mitigating actions can be taken? [Summarise in table 5]
Marriage and Civil Partnership	**Y**	**N**	The strategy is designed for anyone affected by dementia regardless of their marriage or civil partnership status. There are actions within the delivery plan where providers will need to consider equality issues in their own organisational delivery plans particularly in relation to work with care homes and hospitals where assumptions could be made about a person's marriage or civil partnership based on their age. Training for staff in care homes has been identified as an action within the Strategy.	
Pregnancy and Maternity	**Y**	**N**	There may be a small number of the target group but these are more likely to be carers. Carers are identified separately below	

	Positive Impact (Y/N)	Negative Impact (Y/N)	Describe the impact of the work stream or project on people with this protected characteristic	For negative impacts, what mitigating actions can be taken? [Summarise in table 5]
Race	**Y**	**N**	There is some evidence to suggest that people from certain ethnic communities are at higher risk of dementia than others, and that there is lower take up of dementia support services amongst BME communities, where the condition is often denied or seen as a natural part of ageing within some communities, rather than brain impairment. This can lead to people with dementia being hidden away or labelled as mad. Current data from commissioned services, reveals low uptake of support from these communities therefore the Strategy seeks to ensure that work is done in partnership with GP's who will inevitably already be working with many of these families. The Strategy seeks to recognise and be responsive to the needs of people from minority ethnic groups, which may be different from those of the majority population and may require specifically tailored approaches. Delivery plans in each local authority area will draw out specific actions relating to the diverse population needs of each of them.	

	Positive Impact (Y/N)	Negative Impact (Y/N)	Describe the impact of the work stream or project on people with this protected characteristic	For negative impacts, what mitigating actions can be taken? [Summarise in table 5]
Religion or Belief	**Y**	**N**	Some religions and/or beliefs deny the existence of dementia and as with some cultures will consider symptoms a natural part of ageing or a mental illness to be hidden away. The Strategy seeks to overcome these barriers by the inclusion of a section relating to living well where there will be a focus on involvement with the dementia action alliances who continue to recruit dementia friends and create dementia friendly communities across a variety of faith groups. As with race, the Strategy seeks to recognise and be responsive to the needs of people from a variety of religions or belief systems, which may be different from those of the majority population and may require specifically tailored approaches. Delivery plans will identify specific actions relating to this in areas such as dying well for instance where it is vital that professionals working with families understand the differences in the way that death is managed.	

	Positive Impact (Y/N)	Negative Impact (Y/N)	Describe the impact of the work stream or project on people with this protected characteristic	For negative impacts, what mitigating actions can be taken? [Summarise in table 5]
Sex	**Y**	**N**	More women than men are diagnosed with dementia and also more women than men become carers of a person with dementia, however take up of current services is disproportionate in relation to male carers. The Strategy is designed for anyone affected by dementia regardless of their gender. Specific initiatives intended to support proportionate take-up of services have already been incorporated into commissioned services across LLR. Contract performance information will be reviewed by commissioners to monitor proportionality of service delivery and impact of any targeted initiatives, to inform ongoing service improvement.	
Sexual Orientation	**Y**	**N**	There will be a small number of the targeted group that may be from the LGBT communities. The consultation and the final strategy will be equally accessible to those people and will be required to be sensitive and address any specific needs.	

	Positive Impact (Y/N)	Negative Impact (Y/N)	Describe the impact of the work stream or project on people with this protected characteristic	For negative impacts, what mitigating actions can be taken? [Summarise in table 5]
Other groups [1] **Rural isolation**	**Y**	**N**	The Strategy is an LLR wide strategy. Partners from the Dementia Programme Board will need to consider how the priorities identified within their own organisation action plans will consider the needs of those living in rural areas. The consultation will be promoted by all partners via websites and support groups to raise awareness amongst isolated rural communities.	
Carers	**Y**	**N**	The Strategy is for people affected by dementia, which includes carers. The work that has been undertaken on the LLR Carers Strategy and the principles within that are also integral to this strategy and there are clear overlaps. The Strategy aims to ensure that carers can continue to care and access advice information and support as well as being supported to plan for the future in partnership with the person with dementia where appropriate.	

[1] *E.g. rural isolation, health inequality, carers, asylum seeker and refugee communities, looked after children, deprived or disadvantaged communities*

3b. Human Rights Impacts
Based on any evidence and findings, use the table below to specify if any particular articles in the **Human Rights Act 1998** apply (or 'are engaged') by your proposal. Will the human rights of individuals be affected by this proposal? Include positive and negative impacts as well as barriers in benefiting from the above proposal.

	Positive Impact (Y/N)	**Negative Impact (Y/N)**	**Describe the impact of the work stream or project on the human rights of individuals**	**For negative impacts, what mitigating actions can be taken? [Summarise in table 5]**
Right to life	**Y**	**N**	Local engagement supported by national research has highlighted that dementia as a condition can have a significant impact on opportunities to lead a fulfilling life. The key aim of this Strategy is focusing on being able to continue to live well with a dementia diagnosis. The actions within this go someway to demonstrate how health and social care will work to achieve this and puts the person affected by dementia and their carers firmly at the centre of any decision making.	

	Positive Impact (Y/N)	Negative Impact (Y/N)	Describe the impact of the work stream or project on the human rights of individuals	For negative impacts, what mitigating actions can be taken? [Summarise in table 5]
Right to respect for private and family life	**Y**	**N**	Engagement with people affected by dementia and carers has highlighted the difficulty in maintaining relationships with friends and family due to the nature of the condition and the strains it can put on relationships particularly in relation to caring and the blurring of identity (e.g. wife v carer). The Strategy aims to ensure that people with dementia and their carers are enabled to maintain other relationships aside from the condition and their caring role – this sits firmly within the living well guiding principle, as does the need for carers to be an integral part of the memory pathway for people living with dementia.	
Any other directly relevant Human Rights considerations[2] (please insert)				

[2] *Right not to be tortured or treated in an inhuman or degrading way; right not to be subjected to slavery/ forced labour; right to liberty and security; right to a fair trial; no punishment without law; right to freedom of thought, conscience and religion; right to freedom of expression*

3c. Public Sector Equality Duty
Which of the general aims of the **Public Sector Equality Duty (PSED)** are likely to be relevant to the project or programme?

	Positive Impact (Y/N)	Negative Impact (Y/N)	Describe the impact of the work stream or project on the aims of the PSED	For negative impacts, what mitigating actions can be taken? [Summarise in table 5]
Eliminate unlawful discrimination, harassment and victimisation	**Y**	**N**	The Strategy seeks to promote awareness and understanding of dementia. In particular the work of the Dementia Action Alliances, dementia friendly communities and that of dementia friendly GP's will support and eliminate unlawful discrimination, harassment and victimisation.	
Advance equality of opportunity between different groups	**Y**	**N**	The Strategy is designed to include and support people from all of the protected characteristic groups and will be available to all.	
Foster good relations between different groups	**Y**	**N**	The Strategy does seek to foster good relationships between different groups as it promotes understanding of dementia and the inclusion of people affected by dementia across all parts of the health and social care system as well as through the wider public arena through the work around dementia friendly communities.	

4. Evaluating the assessment
Summarise your findings and give an overview as to whether the work stream or project will meet public sector responsibilities in relation to equality, diversity and human rights.
The notion of a joint dementia strategy across LLR will ensure that there is a more streamlined approach to dementia and dementia care across the various footprints. The Strategy will join up all of the professional organisations that are working with people affected by dementia as well as the people affected by dementia themselves to demonstrate how improvements to the system can be made for the benefit of the people that use it. Individual organisations will undertake their own needs analysis to understand what the issues are for their specific area, and ensure that their delivery plans have specific actions that can be measured in relation to those issues. Each organisation will be responsible for addressing any issues in relation to underrepresented groups and be person centred around those needs through their delivery plans.
You will need to ensure that **monitoring systems** are established to check for impact on the protected characteristics, human rights and Public Sector Equality Duty. Describe the systems which are set up to: ▪ monitor impact (positive and negative, intended and unintended) for different groups ▪ monitor barriers for different groups ▪ enable open feedback and suggestions from different communities
The dementia programme board will monitor the over-arching delivery plan detailed within the Strategy itself. Meetings of the Dementia Programme Board occur on a bi-monthly basis and the delivery plan and associated gant chart will feed into this agenda. Individual organisations will feed into this process. Equality monitoring will be included in the consultation document so that analysis of this will identify whether people from the protected characteristics have contributed to the development of the Strategy. Consultation undertaken at groups that are commissioned by the statutory organisations will include equality monitoring information through the commissioned providers attendance registers. There will be ongoing monitoring of equalities in delivery of both the strategy and dementia services.

5. Improvement plan			
Please summarise actions proposed to address the **negative impacts** identified in sections 3a, 3b and 3c above.			
Protected characteristic or Human Right or PSED	**Mitigating action [from table 3a, 3b and 3c]**	**Officer Responsible**	**Completion date**
All	1. The dementia programme board will identify patient experience of dementia across protected characteristic groups, through focus groups, annual survey and ad hoc consultation, in order to ensure the Strategy is culturally sensitive.		
All	2. Ensure that equalities issues are built into the detailed design and improvement all organisational delivery plans. Particular issues to consider will be barriers to access experienced by protected groups and ensuring that as far as is practically possible support to engage is tailored to the specific needs and preferences of the individual.		
All	3. Consultation will be proactive in seeking the views of groups that are under-represented in current access to services, through engagement with staff and organisations already interacting with groups of people with protected characteristics.		

All	4. Delivery of the strategic action plan and dementia services will be monitored across all protected characteristics to ensure equality issues are addressed.		

6. Sign off and scrutiny
Upon completion, the lead officer completing this assessment is required to sign the document in the section below. It is required that this Equality Impact Assessment is reviewed by the Dementia Programme Board and signed off by the Chair of the Board. Once scrutiny and sign off has taken place, sections 1 to 5 of this EIA will be published online.
Work stream SRO: **…… (Name)** **Date:** **…….** **Chair, Leics County Council A&C Delivery Equalities Group: ……Ian Redfern…… (Name)**  **(Signature)** **Date:** **……23/02/2018……**