

Equality Delivery System Report: Dementia Commissioning

1. Introduction

The main purpose of the national Equality Delivery System (EDS) is to help local NHS organisations, in discussion with local partners including local people, to review and improve their performance for people with characteristics protected by the Equality Act 2010.

During 2014/15 we have used the Equality Delivery System in two ways:

- Concentrating on two of our six clinical priority areas to focus our application of Equality Delivery System: Cancer and Dementia. Engagement with patients, carers and the public which had already taken place around our clinical priorities of Cancer and Dementia influenced our self-assessment in these areas.
- A more general self-assessment across the organisation based on our existing engagement work and the patient experience data that we collate.

This report focusses on the outcomes from our “deep dive” into Dementia Services Commissioning using the Equality Delivery System as a tool.

The purpose of delivering this EDS exercise is to establish a series of objectives relating to dementia equality groups and dementia that would provide a basis to measure change, whether positive or negative.

Commissioners, clinicians, patients and local communities alike want to see continued progress across the pathway: from high quality data collection to intelligence on dementia by equality groups. To do this we need to broaden our understanding of where differences by equality groups exist so that we can work to reduce inequalities. The collation and analysis of meaningful dementia data will ensure data is routinely analysed, interpreted and published on as many equality groups as practicable. NHS Doncaster CCG will strive to ensure attention is focused on targeted working and doing it right first time when commissioning services for marginalised groups.

Desired outcomes from this EDS exercise:

- Make better use of evidence to achieve improved outcomes for Dementia services in both commissioning and delivery.
- Utilise knowledge of the measurement tools available.
- Implement new initiatives to boost the evidence base.
- Hear case studies that demonstrate direct impact on commissioning intentions and decisions.

Indicators of success:

- The availability and quality of national and local data is improving.
- Our understanding of patient’s experiences is evolving.
- Our knowledge of the disease and differences by equality groups is increasing

2. The national and local perspective

2.1. National perspective

The term 'dementia' describes a set of symptoms that include loss of memory, mood changes, and problems with communication and reasoning. The most common types of dementia are Alzheimer's disease and vascular dementia. Dementia is progressive, which means that people with dementia and their carers are coping with changing abilities over time. Eventually people with dementia will need help with all their daily activities.

Key facts:

- By 2015 there will be 850,000 people with dementia in the UK.
- There are 40,000 younger people with dementia in the UK.
- There are 25,000 people with dementia from black and minority ethnic groups in the UK.
- There will be 1 million people with dementia in the UK by 2025.
- Two thirds of people with dementia are women.
- The proportion of people with dementia doubles for every five-year age group.
- One in six people aged 80 and over have dementia.
- 60,000 deaths a year are directly attributable to dementia.
- Delaying the onset of dementia by five years would reduce deaths directly attributable to dementia by 30,000 a year.
- The financial cost of dementia to the UK is £26 billion per annum.
- There are 670,000 carers of people with dementia in the UK.
- Family carers of people with dementia save the UK £11 billion a year.
- 80 per cent of people living in care homes have a form of dementia or severe memory problems.
- Two thirds of people with dementia live in the community while one third live in a care home.
- Only 44% of people with dementia in England, Wales and Northern Ireland receive a diagnosis

The Department of Health's National Dementia Strategy is one which requires us to transcend existing boundaries between health and social care and the third sector, between service providers and people with dementia and their carers. The vision is for a system where all people with dementia have access to care and support that they would benefit from. As the Strategy is implemented, the Department of Health looks to a time when the public and professionals alike are well informed, and where the fear and stigma associated with dementia have been decreased. It will be a system where families affected by dementia know where to go for help and what services to expect, where the quality of care is high and equal wherever they might live, and where people seek help early for problems with memory and are encouraged to do so. They have heard clearly that knowledge is power with respect to diagnosis, giving those affected and their families an understanding of what is happening and the ability to make choices themselves. Making the diagnosis early

on in the illness means that there is the chance to prevent future problems and crises and to benefit more from positive interventions.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf

The Department of Health conducted an impact assessment of the national strategy to identify equality impact. All of the nine protected, characteristic, groups are considered to be equally important in respect of paying due regard to those deemed 'marginalised' within them.



DoH DEMENTIA
Equality Impact Assse

Age: Age discrimination inevitably impacts on people with dementia. The prevalence of dementia increases steadily with age, with the proportion of people with dementia doubling for every five year age group. There are widespread, mistaken assumptions that dementia is merely "getting old", rather than a serious disease. This could lead to unequal treatment for people with dementia, such as lower rates of diagnosis or a lack of services. Over 17,000 people in the United Kingdom have [young onset dementia](#) and are strongly affected by mistaken attitudes that dementia is solely an older people's condition. This creates serious barriers to diagnosis for younger people with dementia. There is a national shortage of age-appropriate services for those people who develop dementia before the age of 65. This means that it is particularly difficult for younger people with dementia to access care and support that addresses their specialized concerns. For example, younger people are more likely to have dependent children at the time of their diagnosis, may experience greater difficulty rationalising loss of skills at a younger age and may have greater capacity for physical activities. However, the majority of dementia services are aimed at older people and are not always appropriate or satisfying for younger people. The result of this is that younger people with dementia and their families are particularly at risk of becoming socially isolated, as young-onset dementia is less common and not well understood.

Gender: 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.

Ethnicity: 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 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. There is also an issue as to whether current services for people with dementia and their family carers adequately take account of cultural differences. It is also important to note that the number of people with dementia from black, Asian and minority ethnic groups is expected to rise significantly and society is not necessarily geared up to respond to this pressure. Current estimates suggest there is nearly 25,000 people with dementia from Black and Minority Ethnic (BAME) communities in England and Wales and that this number is expected to grow to nearly 50,000 by 2026 and over 172,000 people by 2051. This represents nearly a seven fold increase.



Alz_Soc_APPG_Repo
rt_2013_update.pdf



BME & Dementia -
Briefing 35.pdf

Disability: National surveys 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.

Religion & Belief: 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.

Sexual Orientation: 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.



Dementia leaflet.pdf

2.2. NHS Doncaster CCG, Local perspective

Commissioning: Local commissioning intentions and decisions are largely based on utilising local intelligence. The analysis of local and regional data, alongside other supporting information and data available, both assists and supports commissioning managers to determine the most appropriate direction of travel for commissioning and implementing health service initiatives or plans. Within this process for

commissioning services locally, NHS Doncaster CCG has responsibility for identifying and implementing the relevant systems and processes for monitoring and evaluating the quality and effectiveness of commissioned services. This is achieved by taking into account feedback received from service providers, service users and patient & public members across the population of Doncaster.

Strategy: NHS Doncaster CCG's strategy has been developed including a particular focus on dementia. A local dementia strategic action plan has been developed taking into account local need and encompassing recommendations from the National Dementia Strategy. The Doncaster Dementia Strategic Partnership is taking forward the Doncaster Dementia Strategy Action Plan. Doncaster is also signed up to the National Dementia Declaration involving local partnerships to be involved with the implementation of the National Dementia Strategy.

Service Redesign: Dementia services operating in Doncaster are presently undergoing a process of service development to both determine and ensure any planned service changes impact favourably upon the current service provision. These changes will be progressed in tandem with the pre-identified local needs and with assurance that planned changes to provision do not disproportionately disadvantage, vulnerable individuals or marginalised groups. The main focus of this development work focuses upon increasing the numbers of patients, referred or accessing dementia services by earlier detection. This will also include providing patients and carers with the necessary treatments and support which may assist with them to deal with the symptoms for dementia conditions within appropriate and responsive timescales. Local, statistical data indicates a high proportion of the local, expected prevalence of dementia had been identified, with RDaSH services working to and beyond National Institute of health & Clinical Excellence (NICE) guidance for assessment and rapid access. Highlights included multidisciplinary team assessment and care planning, a purposeful care environment that supports patients, working with other local services for diversity of care, external peer review of services and benchmarking. The Governing Body identified a potential lack of integration / coordination / navigation between the plurality of providers and agreed further work in this area. Continual improvements on local targets are being achieved, despite the significant challenges faced.

Dementia awareness campaigns & engagement activities: As part of the redesign processes, NHS Doncaster CCG in partnership with Doncaster Metropolitan Borough Council (DMBC) is leading on a significant programme of awareness campaigns and engagement activities with regard to dementia including the Dementia Friendly Community initiative and Dementia Friends training programme. The links to information below provide examples of the work of NHS Doncaster CCG with regard to the delivery of local awareness campaigns and engagement activities.



Dementia Friends
Programme.pdf

Provision: NHS Doncaster Clinical Commissioning Group and Doncaster Metropolitan Borough Council commission some of the services; detailed within the Directory of Services guidance/ information.

A sample of the directory of services, for people with Dementia and their Carers may be viewed by clicking on the following link:



Doncaster Directory
of Dementia of Servic

3. Results

The analysis using the Equality Delivery System as a tool identified the following within the dementia commissioning process.

In summary:

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

In detail:

Goal	Ref	Description of outcome	Self-assessment	Potential further development	
Better health outcomes	1.1	Services are commissioned, procured, designed and delivered to meet the health needs of local communities	Dementia services are designed to meet the needs of local health communities. Ongoing patient feedback is received through the Dementia Forum which assists to support the patient/carer voice and representation.	Utilise both national and local data or any supporting strategic guidance to inform and influence areas of work which may assist to identify a best/good practice approach for engaging and addressing the needs of marginalised groups within dementia service provision and any other support services provided across Doncaster.	G
	1.2	Individual people’s health needs are assessed and met in appropriate and	Each assessment is individual and care plans designed to meet the needs of the person.	Identify the challenges/barriers for marginalised groups whom have very little understanding of the current referral	A

Goal	Ref	Description of outcome	Self-assessment	Potential further development	
		effective ways		pathway/system or limited access to community services which may aid/support patients to 'live well' and maintain a level of independence.	
	1.3	Transitions from one service to another, for people on care pathways, are made smoothly with everyone well-informed	Transitions are smooth. Pathways are in place and transition processes from one service to another. People are informed at all times of the process	Further exploration/scrutiny of the referral pathway to determine the gaps/shortfalls in groups who are less likely to access or deemed 'more marginalised' within the areas of dementia and their access to support services – identify improvements for dealing with 'hard to reach'. Information provision should be adapted/provided which meets the needs of the user to ensure 'equity' within the supply of information– this will ensure all parties are reasonably informed throughout their assessment and any planned follow up treatment.	G
	1.4	When people use NHS services their safety is prioritised and they are free from mistakes, mistreatment and abuse	NICE guidance is adhered to. All appropriate policies and procedure in place.	Explore further the possible development of the systems & processes for reporting and recording concerns to identify/understand any themes or trends for particular groups.	G
	1.5	Screening, vaccination and other health promotion services reach and benefit all local communities	Yes all people who could benefit from screening, vaccination and HP services are offered appropriate services.	Scrutinize the marketing strategy or approach identified, to ensure dementia, health promotion or awareness campaigns are 'equitable' for all potential users. Analyse the data available to identify shortfalls in participation by protected characteristic groups. Ensure initiatives such as dementia friends reach and benefit all local communities. Explore how partnerships can be maximised to progress in this.	A
Improved patient access and experience	2.1	People, carers and communities can readily access hospital, community health or primary care services and	Access is never denied where the access criteria are met.	Examine any data/information available to determine if access has been denied to people, carers and communities. Implement the necessary systems and processes for	G

Goal	Ref	Description of outcome	Self-assessment	Potential further development	
		should not be denied access on unreasonable grounds		capturing feedback in regard to this. Identify, remove or address any barriers to access Explore areas such as: Complaints / Patient experience feedback.	
	2.2	People are informed and supported to be as involved as they wish to be in decisions about their care	Patient centred care is pivotal in all dementia services. Individual care/treatment plans are devised involving patients & carers based on individual needs. Consent of the patient /carer must be obtained prior to making progress on any planned or proposed course of action.	Develop a quality review process to determine/highlight case study examples for 'good practice' within this area.	G
	2.3	People report positive experiences of the NHS	Yes, via case studies, patient and carer feedback on an ongoing basis.	Can we identify groups omitted from this. across protected characteristic groups?	A
	2.4	People's complaints about services are handled respectfully and efficiently	Yes - complaints procedures are in place.	It is difficult to 'evidence' the 'effectiveness' of the complaints process and whether complaints are handled respectfully and efficiently for all protected groups.	G

4. Recommendations

In conjunction with our predetermined equality objective:

Make effective use of equality data within the commissioning cycle to prioritise commissioning of services and embed equality within Provider contracts

it is recommended that NHS Doncaster CCG endeavours to clearly identify any disadvantage in access, experience and outcomes for users from across protected characteristic groups .

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