



EQUALITY IMPACT ASSESSMENT

*Living well with dementia
National Dementia Strategy*

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National Dementia Strategy

Prepared by the National Dementia Strategy Working Group at the Department of Health,
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Executive summary

This Equality Impact Assessment (EQIA) considers the possible impact of the National Dementia Strategy on people according to their age, disability, race religion and beliefs, gender and sexual orientation. The EQIA follows on from the equality screening assessment that was issued alongside the consultation on the National Dementia Strategy that ran from June to September 2008. The EQIA therefore aims to:

- identify any potential issues contained in the Strategy on any of these groups; and
- ensure that implementation of the Strategy takes account of the potential issues and informs continuing development to reduce inequality.

Dementia is one of the main causes of disability later in life, ahead of some cancers, cardiovascular disease and stroke. It is estimated that there are currently some 560,000 people in the England with dementia. An ageing population means numbers of people with dementia are set to rise to over 750,000 in England by 2020. Direct costs of dementia to the NHS are approximately £3.3 billion per year. The overall annual economic burden is estimated to be £14.3 billion per year, or £25,391 per head. Unpaid carers provide significant amounts of support to people with dementia, saving a cost of £5.2 billion a year. All of this indicates the scale of the social and economic cost of dementia, and the extent to which this will rise in the future.

The NAO report 'Improving services and support for people with dementia' was published on 4 July 2007, and identified the need for appropriate services for people with learning disabilities, people with young onset dementia and people from black and minority ethnic groups. This report, together with the Alzheimer's Society 'Dementia UK' report, which identified that black and ethnic minority groups have a higher than average proportion of people with early onset dementia, and that there was limited knowledge of dementia amongst some black and ethnic minority groups, has provided the evidence base for Government action. The final Strategy has identified the need for a public and professional awareness campaign that targets, and identifies, all population groups, and also recognises the need for the commissioning and provision of services appropriate to all population groups.

On 6 August 2007, Care Services Minister, Ivan Lewis, announced the launch of a one year project to develop a national dementia strategy and implementation plan. The draft strategy was launched on 19 June 2008 as part of a public consultation that ran until 11 September 2008 and received over 600 responses.

The national dementia strategy and implementation plan address the three key themes:

Improving public and professional awareness

Early Diagnosis and Intervention

Improving the Quality of Care for People with Dementia

Purpose and Intended Effect of the Equality Impact Assessment

This Equality Impact Assessment (EQIA) provides an initial overall assessment of the impact of the proposals contained in the Strategy. It outlines the potential impact of the proposals in the context of race, disability, gender, age, religion or belief and sexual orientation.

Summary and purpose developing a National Dementia Strategy

Background

Dementia is one of the main causes of disability later in life, ahead of some cancers, cardiovascular disease and stroke. It is estimated that there are currently some 570,000 people in the England with dementia, of which some 12,000 are people under 65 who have early onset dementia. An ageing population means numbers of people with dementia are set to rise to over 750,000 in England by 2020. Direct costs of dementia to the NHS are approximately £3.3 billion per year. The overall annual economic burden is estimated to be £14.3 billion per year, or £25,391 per head. Unpaid carers provide significant amounts of support to people with dementia, saving a cost of £5.2 billion a year. All of this indicates the scale of the social and economic cost of dementia, and the extent to which this will rise in the future.

A National Audit Office report 'Improving services and support for people with dementia' was published on 4 July 2007. This report, together with the Alzheimer's Society 'Dementia UK' report has provided much of the evidence base for Government action. On 6 August 2007, Care Services Minister, Ivan Lewis, announced the launch of a one year project to develop a National Dementia Strategy and Implementation Plan. The draft strategy was launched on 19 June 2008, with a twelve week period for public consultation.

The objectives of the project are to develop a Strategy and Implementation Plan which will address the following three key themes:

Improving public and professional awareness

There is currently a general low level of public and indeed professional understanding of dementia. There is also a widespread mis-attribution of symptoms to "old age" and a resultant unwillingness by some of those with dementia, and their families, to seek help. There also remains within society a real problem of stigma and fear associated with dementia which can delay early diagnosis and the accessing of good quality care.

Early Diagnosis and Intervention

Currently only a third of people with dementia receive a formal diagnosis at any time in their illness. When diagnoses are made, it is often too late for those with the illness to make choices. Alternatively, diagnoses are often made at times of crises, most of which could be avoided if diagnosis was made earlier.

Improving the Quality of Care for People with Dementia

Recent reports have emphasised the need to enhance joint health and social care mental health teams in the community so that people with dementia and their families and carers receive the support they need. These reports have also emphasised the need to improve support for people with dementia who are living at home or in care homes so they are involved in the planning and delivery of their care and achieve the best possible outcomes. This area of the programme will therefore focus on improving liaison services that will enable effective

management in hospital and intermediate care, as well as improving community services for people with dementia. It will also focus on building better skills and understanding of dementia in the health and social care workforce, which is fundamental to improving the quality of care.

Following the launch of the draft Strategy on 19 June 2008, a 12 week formal consultation took place, involving over 50 regional consultation events, and over 500 responses were received. The Government's response to the consultation, which includes a list of everyone who responded to the consultation, was published at the same time as the National Dementia Strategy.

The Strategy recommendations, and outcomes, are as follows:

1. Public information to increase public and professional awareness of dementia to encourage help seeking and appropriate referral

- **Outcome 1: Public information campaign.** Public and professional awareness and understanding of dementia to be improved and the stigma associated with it addressed. This should inform individuals of the benefits of timely diagnosis and care, promote the prevention of dementia, and reduce social exclusion and discrimination. It should encourage behaviour change in terms of appropriate help-seeking and help provision.

2. A good quality specialist diagnosis made early in the illness, communicated sensitively and followed by intervention and support as needed

- **Outcome 2: Good quality early diagnosis and intervention for all.** All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area.

3. Good quality information for people on dementia and services available

- **Outcome 3: Good quality information for those with diagnosed dementia and their carers.** Providing people with dementia and their carers with good quality information on the illness and on the services available, both at diagnosis and throughout the course of their care.

4. Easy access to a dementia advisor to signpost and facilitate health and social care input throughout life with dementia

- **Outcome 4: Enabling easy access to care, support and advice following diagnosis.** A dementia advisor to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers.

5. The ability to join, learn from and contribute to local peer support and learning networks

- **Outcome 5: Development of structured peer support and learning networks.** The establishment and maintenance of such networks will provide direct local peer support for people with dementia and their carers. It will also allow for people with dementia and their carers to take an active role in the development and prioritisation of local services.

6. Good quality community personal support

- **Outcome 6: Improved community personal support services.** Provision of an appropriate range of services to support people with dementia living at home and their carers. Access to flexible and reliable services, ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual. Accessible to people living alone or with carers, people who pay for their care privately, through personal budgets, or through Local Authority arranged services.

7. Good quality support for carers

- **Outcome 7: implementing the New Deal for Carers.** Family carers are the most important resource available for people with dementia. Active work is needed to ensure that the provisions of the Carers' Strategy are available for carers of people with dementia. Carers have a right to an assessment of their needs and can be supported through an agreed plan to support the important role they play in the care of the person with dementia. This will include good quality personalised short breaks.

8. Good quality of dementia care in general hospitals

- **Outcome 8: Improved quality of care for people with dementia in general hospitals.** Identifying leadership for dementia in general hospitals, defining the care pathway for dementia there and the commissioning of specialist liaison older people's mental health teams to work in general hospitals.

9. Good quality intermediate care for people with dementia

- **Outcome 9: Improved intermediate care for people with dementia.** Intermediate care which is accessible to people with dementia and which meets their needs.

10. Supportive housing and telecare for people with dementia

- **Outcome 10: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers.** The needs of people with dementia and their carers should be included in the development of housing options, assistive technology and telecare. As evidence emerges commissioners should consider the provision of options to prolong independent living and delay reliance on more intensive services.

11. Good quality dementia care for people in care homes

- **Outcome 11: Living well with dementia in care homes.** Improved quality of care for people with dementia in care homes by the development of explicit leadership for dementia within care homes, defining the care pathway there, the commissioning of specialist in-reach services from community mental health teams, and through inspection regimes.

12. Good quality end of life care for people with dementia

- **Outcome 12: Improved end of life care for people with dementia.** People with dementia and their carers to be involved in planning end of life care which recognizes the principles outlined in the Department of Health End of Life Care Strategy. Local work on the end of life strategy to consider dementia.

13. An informed and effective workforce, trained to identify and meet the needs of people with dementia and their carers

- **Outcome 13: An informed and effective workforce for people with dementia.** All health and social care staff involved in the care of people who may have dementia to have the skills needed to provide the best quality of care in the roles and in the settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia.

14. Local services to be commissioned jointly by health and social services to provide comprehensive care

- **Outcome 14: A joint commissioning strategy for dementia:** Local commissioning and planning mechanisms to be established to determine the services needed for people with dementia and their carers, and the how best to meet these needs. These should be informed by the Dementia World Class Commissioning guidance developed to support this strategy.

15. Services whose quality is assured and performance monitored by local and national processes

- **Outcome 15: Improved registration and inspection of care homes and other health and social care services for people with dementia and their carers.** Inspection regimes for care homes and other services that better assure the quality of dementia care provided.

16. Information from research on the causes, treatment and care for dementia.

- **Outcome 16: A clear picture of research evidence and needs.** Evidence to be available on the existing research base on dementia in the UK and gaps that need to be filled.

17. Regional and national support for the local development of services.

- **Outcome 17: Effective national and regional support for implementation of the strategy.** Appropriate national support to be available to advise and assist local implementation of the Strategy. Good quality information to be available on the development of dementia services over the five years of the strategy, including information from evaluations and development sites.

What problems is the draft Strategy intended to address?

The problem

A number of recent reports, most notably the National Audit Office report 'Improving services and support for people with dementia' the Alzheimer's Society 'Dementia UK' report have identified significant deficiencies in current health and social care services for people with dementia and their family carers.

Evidence of the problem

The National Audit Office report estimated that approximately two thirds of people with dementia do not receive a formal diagnosis, or have contact with specialist services, at any time in their illness. Such diagnosis and contact, when made, often only occurs late in the illness and in crisis when the opportunities for harm prevention and maximisation of quality of life are limited.

If dementia is not diagnosed, then the person with dementia and their family carers are denied the possibility of making choices themselves. They are unable to plan for their future and do not have access to the help, support and treatments (social and psychological, as well as pharmacological) which are available. Contrary to social misconception, there is a great deal that can be done to provide help for people with dementia and their carers and this has been well summarised in the Clinical Guideline on dementia jointly produced by the National Institute for Clinical Excellence and the Social Care Institute for Excellence. While there are undoubtedly possible negative reactions to diagnosis, the balance is very much in favour of early diagnosis, and the earlier such intervention is made in the illness the better. There is clear evidence that providing people with dementia with a diagnosis decreases their levels of depression and anxiety.

There are limitations to the data available, and the Strategy recognises the need to establish a baseline measure, but UK activity in terms of the diagnosis and treatment of people with dementia is generally at a low level. There are also significant variations between areas in a way that is not explained by the numbers of people with dementia in those areas, in general the prevalence of dementia is higher in rural and coastal areas than in urban areas. International comparisons suggest that the UK is in the bottom third of European performance with less than half the activity of France, Sweden, Ireland and Spain. The National Audit Office has recommended that services need to be redesigned so that dementia is diagnosed early and well and so that people with dementia and their family carers can receive the treatment care and support that will enable them to live as well as possible 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 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. Public information campaigns to support the Dementia Strategy will need to be targeted at all ethnic population groups to raise awareness of dementia.

There is also an issue as to whether current services for people with dementia and their family carers adequately take account of cultural differences. The Dementia UK report noted that ethnicity can be a significant factor in the extent to which dementia understood or acknowledged, or in people's willingness to seek help.

During the consultation process we 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. The Croydon Memory Service has a tailored approach to providing dementia care and has specific initiatives focussed on people from ethnic minority groups so that 27 per cent of the service's clients are from ethnic backgrounds other than white British. The Strategy also notes that professional training should enable an understanding of the differing needs of people from black and minority ethnic backgrounds. Local information campaigns should also be targeted at those communities where there is currently a lower level of awareness of dementia and this may be evidenced by a lower than expected prevalence of dementia in those communities.

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 told us that we should make the Strategy relevant to ethnic minority populations and this is reflected in the Strategy which states that all services should be tailored, where appropriate, to meet the needs of ethnic population groups. Both commissioners and providers may need to review their current service provision as well as planning future services and may find it useful to carry out an equality impact assessment as part of this process.

Disability

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. The Strategy acknowledges this and emphasises that the needs of people with disabilities may require specifically-tailored approaches to care. It also points to the fact that training should enable an understanding of the differing needs of people with dementia, including those with different disabilities.

Special consultation events were held in all of the NHS regions for people with learning disabilities and there were also a number of events addressing the particular needs of older people. Views on the Strategy were sought from a range of organisations with an interest in different types of disability, and they told us that it is vital that the strategy takes into account the needs of people with learning disabilities and that these needs are reflected in local service provision. These views have been reflected in the final strategy, which notes the necessity of considering the particular needs of people with learning disabilities when commissioning and providing services for people with dementia.

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 – support for carers is covered by the recently published Carer's Strategy. There is a need for these factors to be taken into account in the care provided for people with dementia, and training provided for professionals should reflect this.

Age

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 Strategy addresses this issue closely. 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. Implementation of the National Dementia Strategy will form part of a broad focus on older people's mental health services. Some localities currently interpret age equality in psychiatry services to mean a "one size fits all ages" approach, however there are many examples of good practice eg [DN example to be inserted] Services for people with dementia should not be used as an excuse for diluting specialist services for older people with other mental health needs.

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. Training for providers of dementia services should take account of the particular needs of younger people with dementia and their family carers, which might include issues around childcare, employment and peer support. .

Religion or 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 consultation told us 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 recognition of this, we have suggested in the Strategy that information campaigns targeted at public facing organisations include religious groups and that NHS and local authorities may want to provide some training or information sessions about dementia to religious and community organisations.

Sexual orientation

Studies on the experience of lesbian, gay, bisexual and trans-gender AHPs 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 underresearched topic where more information is required. At present it is impossible to make an evidence-based assessment of impact, and it is not clear from the way they are specified whether the proposed new measures in the Carer's Strategy, relating to information about carers would be capable of addressing this issue. The Department of Health (DH) commissioned Stonewall to undertake a project to explore why lesbian, gay, bisexual and trans-gender individuals may not report discrimination and homophobia in the NHS, social care or DH and this report, 'Being the Gay One', was published in 2007. There is no place for any form of discrimination in health and social care. The Department recognises the seriousness of the findings of this report and work is underway to meet the recommendations outlined in the report through the Better Employment workstream of the Department's Sexual Orientation and Gender Identity Advisory Group and through its broader equality and human rights work programme.

What outcomes do we want to see?

In the consultation, which attracted over 500 written responses, no-one has expressed concerns that the Strategy would discriminate against any of the population groups covered by this impact assessment. Respondents did comment that the Strategy should take into account

the needs of different population groups, and we have acknowledged that both here and in the final Strategy document

A successful outcome from the implementation of the dementia strategy would be improvements in dementia services across the whole of England, regardless of population group.

Public awareness of dementia needs to be raised to a uniform level amongst all population groups and local and national campaigns should be targeted at specific groups and organisations. Campaigns should take account of the fact that the needs of some groups (eg those with a learning disability and dementia, younger people with dementia, those from minority ethnic groups, or those from rural, island or traveller communities) may be different from those of the majority population, and may require specifically-tailored approaches.

People in all population groups with dementia should have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis sensitively communicated to the person with dementia and their carers; and immediate treatment, care and support following diagnosis. The system should have the capacity to see all new cases of dementia in the area, and should be tailored take account of the needs of specific groups whose needs are different from the majority population.

People in all population groups should have access to an appropriate range of services to support people with dementia and their carers, whether they are living at home, living in a care or nursing home or receiving care in a general hospital. Such services should be flexible and responsive, ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual. Services should be accessible to people living alone or with carers, people who pay for their care privately, through personal budgets, or through Local Authority arranged services, and should be tailored take account of the needs of specific groups whose needs are different from the majority population.

Governance arrangements for the National Dementia Strategy are still being finalised but it is likely that as part of any review of the implementation of the National Dementia Strategy, the Department of Health will revisit this equality impact assessment.

Monitoring by commissioners and providers

It is obviously important that those involved in commissioning or providing treatment and care to people who have dementia and their families and carers should have up-to-date knowledge and an understanding of equality issues including:

- age, religion, race, culture and belief, disability, sexual orientation and gender;
- an ability to identify, challenge, and where possible redress discrimination and inequality in all its forms in relation to approved practice in health and social care;
- an understanding of the need to promote sensitivity and actively promote equality; and
- an understanding of how cultural factors and personal values can affect judgements and decisions in the implementation of the new strategy.

Commissioners need to consider their responsibilities to dementia patients (for example, under the Disability Discrimination Act and other related legislation) and Strategic Health Authorities (SHAs) the monitoring of those responsibilities including all the legal equality duties in terms of service provision; ie, race, gender and disability. Primary Care Trusts (PCTs) are advised to conduct EQIAs of the implementation of the strategy and how the different needs of their communities will be met. SHAs will need to performance manage PCTs on their production of EQIAs and check to see that services are being developed in line with any actions identified in the assessments and any lessons learnt could be shared with the wider NHS and the Department of Health.

Local authorities may need to produce their own EQIAs in association with their health partners in order to maximise provision and assess the success of information and advice about local opportunities and resources including personal care, clubs, hobbies, leisure, education and sports facilities in connection with emotional recovery. Continuing health and social care packages need to take account of individuals' cultural and social needs.