NORTH YORKSHIRE COUNTY COUNCIL

CARE AND INDEPENDENCE OVERVIEW AND SCRUTINY COMMITTEE

2 September 2010

Dementia Strategy

1.0 Purpose of Report

1.1 To provide supporting information for the Committee's review of how the National Dementia Strategy has been interpreted nationally regionally and locally.

2.0 Introduction

2.1 In January 2009 the Committee completed its study on Dementia. The proposals that emerged followed those included in the National Dementia Strategy. The final version, slightly altered, received a positive response from the NYCC Executive, who agreed it should be adopted as the basis for further consultation with partners and as the framework of a joint commissioning strategy.

2.2 The Executive supported the Committee's intention to continue working alongside the Directorate, representatives of the PCT and third sector colleagues. This would be achieved through continuing contact with thee work of the new Dementia Network.

3.0 Purpose of Meeting

3.1 You agreed that this meeting will be turned over completely to consideration of Dementia.

3.2 The aim is to bring together practitioners, professionals and strategic leaders with users and carers so we have a genuine impression of what support for Dementia looks like. Issues the Committee wanted to cover include –

- A picture of what it looks like for people with Dementia, their carers and the wider NY community over a year on from the launch of the National Dementia Strategy (NDS)
- Assessment of progress - How has the NDS been reflected in local activity - what has changed, what has been done?
- How does this compare with the committee's findings conclusions and recommendations and what is their status now?
- Is the position the committee adopted over a year ago still relevant?

- What are the next steps areas now - especially for community interest?

4.0 **Papers Attached**

a)	Programme for the Day	Appendix 1
b)	Summary of the Committee's report/proposals	Appendix 2
c)	YHIP Regional report - The Case for Change	Appendix 3
d)	NDS Presentation to Network	Appendix 4
e)	Terms of Reference Dementia Network	Appendix 5
f)	NY Dementia Network Minutes Last Meeting	Appendix 6

5.0 **RECOMMENDATION**

5.1 The Committee is invited to take a view on how the National Dementia Strategy has been interpreted locally, what has changed and the relevance of the position the Committee adopted over a year ago.

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Head of Scrutiny and Corporate Performance

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Presenter of Report: Ray Busby

24 August 2010
Background Documents: None

APPENDIX 1

Care and Independence Overview and Scrutiny Committee

2 September 2010

Galtres Centres, Easingwold, coffee and tea on arrival at 9.30 am.

The aim is to hear from practitioners, professionals and strategic leaders with users and carers so we have a genuine impression and understanding of what peoples' experiences continue to be like on the ground in their families and in their communities. This will help us ensure that we are doing the right things as we try to influence priorities, shape the agenda and contribute fully to the Network.

ITEM/TIMING	TOPIC	LEAD
1. 9.30 am	Arrival - tea/coffee	
2. 10.00 am	Introductions & Scene Setting – Chairman	Tony Hall
3. 10.10 am	The National Picture. The planned national evaluation of the Dementia Strategy, Future Steps and National Intention. Regional view and previous work undertaken.	Representative of the Department of Health
4. 10.40 am	Yorkshire and Humber Improvement Partnership Regional Review and North Yorkshire in context.	Veronica Brown
5. 11.00 am	North Yorkshire Perspective a. Work leading up to the National Dementia Strategy. PCT, NYCC and Scrutiny Committee outlook. b. Work focused around the Dementia Network; how the Network functions, its workload and achievements to date.	Judith Knapton/Seamus Breen
6. 11.30 am	The Community perspective, how users and carers are represented and what has changed for people with Dementia and their carers.	Jill Quinn
7. 12.00 noon	How the picture will change, next steps and what the future will look like for people in North Yorkshire.	Seamus Breen
8. 12.15 pm	Committee conclusions around where it can contribute most effectively and influencing the shape of commissioning in a changing health environment.	Tony Hall
9. 12.30 pm	Close - end of meeting – lunch with representatives of the Dementia Network.	

CARE AND INDEPENDENCE OVERVIEW AND SCRUTINY COMMITTEE

ACCESS TO DEMENTIA SERVICES

EXECUTIVE SUMMARY OF PROPOSALS

1. **The Committee's report** represented months of work by Councillors from the Care and Independence Overview and Scrutiny Committee of the North Yorkshire County Council.

2. The main elements were:

   - The significance of dementia as an issue and the launch of the recent National Dementia Strategy.

   - What people have said in both local and national consultation events represents a good dementia service.

   - The steps and development areas identified by the Committee.

3. **Scale of the Problem**

4. Dementia is estimated to affect 575,000 people in England and is estimated to grow from 700,000 overall in the UK to more than 1 and three quarter million within the next four to five years. Within only 15 years, by 2025, a 38% rise is predicted bringing the total to over 1 million.

5. **What is Dementia**

6. The spotlight on dementia couldn't be greater as the numbers of people with this condition increases and people like the author Terry Pratchett share their experiences openly.

7. Dementia is the term used to define a collection of symptoms characterised by a progressive loss of intellectual functions, including memory, language, reasoning and the abilities to perform the most basic skills needed to carry out the tasks of everyday life. Although it is most common in older people, dementia is not a normal part of the ageing process, nor is it simply forgetfulness.

8. People diagnosed as having dementia can live for up to 10 years and beyond, which can impose a very considerable long term burden on carers unless there is appropriate additional care and support.

9. **Values and Principles of a Dementia Service**

10. A consensus emerged from the people we spoke to, on the values and principles that might underpin a good dementia service. One that is person centred and, puts the citizen first. The list of features drawn up in the report is far from comprehensive but can be a skeleton on which the County Council, the PCT and their partners can consult. **W**e concluded:

Committee Proposal 1: Values and Principles

The Adult and Community Services Directorate and the Primary Care Trust consult on adopting the following principles and values of a North Yorkshire Dementia Service

- *Citizen first – the care offered and given demonstrates a good knowledge of the individual. Supporting people with dementia should come from the perspective of the person being a citizen first and a person with dementia second. There needs to be an emphasis on individual needs assessment and person centred care that maximises independence and social inclusion.*
- *People with dementia should be empowered and informed.*
- *Integrated Care Pathways that are designed for people who have a diagnosis, up to and including continuing care.*
- *Local services should be based in the community but should be governed by minimum standards at national, regional and local levels. This should require a baseline assessment of current practices and services against which progress can be measured to establish outcomes and the achievement of minimum and best standard.*
- *Transparency in service design, provision, criteria for success, budget and strategic priorities.*
- *Services should be accessible, with all effort being made to create a "no wrong door" approach.*
- *There should be sufficient capacity in the system, particularly within the third sector, for services to respond effectively.*
- *Training for staff at all levels is a priority.*
- *There needs to be joined-up approach so that policies and guidance, such as that developed by the National Institute of Clinical Excellence (NICE), compliment and do not conflict with each other.*
- *Carers bear a heavy burden and should have the opportunity to be trained, informed and empowered.*

- *Services should reflect ethical practice, balancing risk and protection.*

- *Services should respond effectively in a crisis by being flexible and adaptable and available 24 hours a day, 7 days a week. The service should take account of the needs of particular groups – younger people, people with learning disabilities and BME communities.*

- *Short breaks (including the traditionally understood "respite") or any formal services with the purpose of providing a break from the usual routine for the person with dementia and/or their carer that are flexible and adaptable.*

- *Support for carers at an informal level through befriending schemes for example.*

A move to specialisation both in health and social care to address the unique implications of having dementia. Therefore, support services for individuals that are not just a part of the older people's service and/or mental health.

11. Dementia Network

12. We supported the creation of a network as a way of bringing together at a local level all of those people who have a part to play in improving the lives of people with dementia. For us, re-commissioning it on a substantive rather than short term basis is a priority. Arguably it should be a first call on any expenditure which accompanies government funding for progressing the aims of the National Dementia Strategy.

Committee Proposal 2:

The Adult Thematic Partnership of the NYSP as advised by appropriate professional and voluntary and community sector organisations, most notably the Alzheimer's Society should be asked to examine the work of the Dementia collaborative to date and report on the feasibility and appropriate level of support required for a dementia network for the County that:

- *Drives forward the aims and ambitions of the National Dementia Strategy and where appropriate the proposals in this report particularly.*

- *Increases the recognition of dementia, thus aiding earlier diagnosis and improving care management.*

- *Improves the provision of information given to people with dementia and their carers.*

- *Helps to ensure that dementia services are person centred.*
- *Improves systems to explore patient and carer experience.*
- *Helps to coordinate services between agencies particularly by being involved in the development of an effective commissioning strategy.*
- *Devises, Co-ordinates and ensures common standards and competencies in training programmes.*
- *Has a channel to report back findings to appropriate agencies.*

Comment - Should funding be made available to local authorities and PCTs to implement the recommendations in the National Strategy (below) we believe this should be afforded priority status.

13. The launch of the National Dementia Strategy aims, in a short period, to transform the way people with the illness are cared for. It is a recognition that things have to change and quickly. Fifteen recommendations are outlined, organised under the key themes of:

    - Improving awareness of dementia
    - Early diagnosis and intervention
    - Improving quality of care

14. The Committee drew up a series of proposals which are a response to these recommendations.

Committee Proposal 3:

That North Yorkshire County Council and PCT adopt the NDS and commit to delivering upon its aims as far as resources allow.

15. Proposals under each of the three themes of the Strategy are as follows:

16. IMPROVING AWARENESS OF DEMENTIA

NDS Recommendation 1: Increased public and professional awareness of dementia

17. Only by raising awareness of the condition can we begin to tackle the stigma and misapprehension that surrounds it. Much is being done nationally, but

there is scope for a local information campaign as part of a joint agency Education Programme

Committee Proposal 4: Education Programme

The Primary Care Trust and Adult and Community Services jointly support the development of an Education Programme to raise awareness of dementia as part of the National Dementia Strategy. A wide range of channels of communication should be considered possible features.

Many opportunities have been recently taken by the third sector to promote understanding. We would support a concerted, specific effort to pilot some joint agency promotion publicity at various times throughout the year. It is essential that if a national media and publicity awareness campaign is progressed that the County plays a full part in this.

Media and advertising – the media locally has a key role in raising awareness to dispel myths and provide positive images for the general public. On the back of a national high profile campaign, much can be done locally by posters, adverts in local newspapers and leaflets in GP practices, surgeries, chemists, libraries and shopping centres.

The development of an education programme locally within schools to help change belief systems and reduce stigma could be considered, together with a greater focus on intergenerational work to support positive interactions between young people and people with dementia. Road-shows at day centres, libraries and voluntary sector meetings, such as the Women's Institute could be sponsored. Much is already being done by the third sector organisations we met, however feedback we received leads us to conclude it is fragmented.

18. It is important to involve people from the outset: These awareness raising initiatives should be deployed with strong community engagement to increase levels of understanding and build supportive social networks. The existing infrastructure of Local Strategic Partnerships the NYSP and our Area Committees can be used to good effect -

Committee Proposal 5: Community Engagement

Our channels for community engagement through Local Strategic Partnerships, Area Committees and the North Yorkshire Strategic Partnership should be used. Co-ordination will be key, there is a case we feel for an infrastructure which allows for this to be approached with multi-disciplinary and agency commitment.

This should be part of a process that ensures that people with dementia and their families are involved in discussions on the organisation and further development of dementia services. The learning from the "Involve People with Dementia" element of the Dementia Collaborative should guide this process.

19. Raising the awareness of staff by training programmes was mentioned by everyone we spoke to, particularly representatives of the statutory and third sector. This should be based on the premise of training for all staff plus specialist training for some. The case for training is made repeatedly in the National Strategy. To ensure there is an informed and effective workforce for people with dementia. This means providing training for some non social care staff where appropriate, but mandatory, specialist training for professionals who have contact with people with dementia or their carers.

NDS Recommendation 2: An informed and effective workforce for people with dementia

Committee Proposal 6: ***Training Programme***

The opportunities for joint agency training and skills development should be explored further so we can be confident we are harnessing the specialist knowledge and expertise of the voluntary sector.

Packages of training for non-social care or health staff should be developed focused on training staff in core competencies in dementia care. This could include a broader group of staff than those in health and social care, for example housing staff

Training programmes for doctors, nurses, social workers, care home staff, other professionals and people who have contact with those with dementia and their carers should be reviewed for the accuracy of their content and whether they are relevant for these times.

Training programmes should be informed by the work on Dementia Care Pathways discussed later in this report.

Training manuals to be widely distributed and all materials should be kept under review to ensure common competencies.

Providing pre-diagnosis training is important, particularly for General Practitioners, home care workers, care home staff, day care centre staff, professionals in Accident and Emergency Departments and staff on Acute Medical Wards should be explored.

It is important that not only is this addressed through joint commissioning

strategies but that together with PCTs we are prepared to take advantage of the national drive for improving training of GPs, which will be announced sometime later this year.

20. EARLY DIAGNOSIS AND INTERVENTION

21. Opinions can differ on how a diagnosis should be arrived at. We firmly believe, as do most of the people we spoke to that early diagnosis is helpful. It helps care givers to understand and prepare. People with dementia can plan and make decisions about their affairs. In most instances it can be the only way to gain access to existing effective treatments. Opinions though can differ on how a diagnosis should be arrived at, so a debate is called for

NDS Recommendation 3: Good-quality early diagnosis and intervention for all

Committee Proposal 8: Diagnosis

A debate is needed on how diagnosis is approached in the county, particularly to understand the reasons for perceived difficulties and delays in the diagnosis process.

People told us that they would rather memory assessment continued to be performed at this primary care level; it is believed to be less stigmatising.

As part of the debate we would suggest focus upon diagnosis being made closer to primary care, but with more specialist input located in primary care settings.

22. A systematic approach to describing the services and interventions that follows diagnosis is important. The report emphasises the significance of developing common integrated care pathways. They are key to our proposals This exercise is best carried out by the newly created Dementia Network proposed earlier

Committee Proposal 9: Care Pathways

Local Partners guided by the Dementia Network should build on the work undertaken by the previous dementia collaborative and combine to develop common, integrated care pathways for people with dementia. These pathways should take account of the particular needs of people under 65.

Information on the Care Pathways should be targeted to a range of audiences but should also be made available in a wide variety of ways, including web based versions. They should be subject to ongoing audit.

Comment: This proposal is recorded at this point because it relates to a NDS recommendation. For us it is however a key priority. Its significance as a proposal, like that relating to the Dementia Network cannot be underestimated. Arguably, developing Care Pathways should dictate the approach to all our proposals.

23. Getting these care pathways right will depend in part, upon a more rounded and complete picture of local needs and services. Improved information and data collection at the point of diagnosis is suggested, especially if we are to examine claims there is inequity across the county Improved information and data collection at the point of diagnosis will help to build a more rounded and complete picture of local needs and services.

Committee Proposal 10: Data Collection

The Adult and Communities Services Directorate and PCT in conjunction with third sector partners, should review local data collection on services for people with dementia and their carers, both to inform local approaches to the organisations of care but to improve the range of planning, accountability, audit and review processes.

24. No-one should have to go through dementia alone. For some people there appears to be a care and support vacuum where people have to find their way without support, until needs mount and a crisis occurs. We therefore support the idea of a single focus for referrals from Primary care.

Committee Proposal 11: Single Focus for Referrals

We support the case made in the National Dementia Strategy for services which provide a simple, single focus for referrals from Primary Care.

25. People like the idea of Telecare and Assistive Technology devices as an enabler, helping people with dementia to live independently in the community.

> ***Committee Proposal 7: Telecare and Assistive Technology***
>
> *The commitment to harnessing the benefits of Telecare and Assistive Technology should be maintained; but further consideration should be given to promoting the benefits particularly to people with dementia and their carers.*

26. IMPROVING QUALITY OF CARE

NDS Recommendation 4: Good-quality information for those with dementia and their carers

27. People with dementia and their carers should be provided with good-quality information on the illness and on the services available – both at diagnosis and throughout the course of their care.

> ***Committee Proposal 12: Information***
>
> *In conjunction with particularly the Alzheimer's Society but also with other third sector organisations advice and information should be compiled which relates to Care Pathways and therefore focuses on the stages of dementia, interventions, planning for the future and services available.*
>
> *There is a need for some specialisation of information rather than this being seen as part of general information provided for carers. Such information could easily be accessible across the County at various locations and through various services.*
>
> *Current information packs provided by the Alzheimer's Society are a best practice example of what can be achieved.*

NDS Recommendation 5: Continuity of support and advice
Continuous support and advice to be provided for those diagnosed with dementia and their carers.

> ***Committee Proposal 13:***
>
> *At the time of diagnosis, support, information and advice tailored to match Care Pathways should be available to assist each person and their family with forward planning, and to establish continuing support.*

We should work towards this being a common countywide standard for information.

There is a need for common, easy to read information for service users and carers as a signposting guide.

NDS Recommendation 6: Improved quality of care in general hospitals
An improved quality of care to be provided in general hospitals for people with dementia.

28. The quality of care provided in general hospitals for people with dementia will be raised by enhanced training, but could also be improved by better discharge planning, dementia care champions on wards and carers having the opportunity to stay in hospital with the person with dementia.

Committee Proposal 14: Improving Care and Support

In addition to the training suggestions earlier in the report the Committee suggests consideration be given to the development of dementia care champions on general wards and this role be nurtured as part of the increase in training.

Many carers thought that they should have the opportunity to stay in hospital with the person with dementia as no-one knows the person better than them. There are opportunities currently, but they could be expanded.

Improved discharge planning was mentioned a number of times with the widespread belief that discharge planning should begin at the point of admission.

We support the proposal in the National Dementia Strategy which calls for a policy to be developed for improved management of people's dementia which should be written in consultation between user and carer organisations. This should specify core competencies for all staff who work in general hospitals who have contact with people with dementia.

NDS Recommendation 7: Improved home care for people with dementia
Home care services to better meet the needs of people with dementia and their carers.

29. There is a case for introducing specialist trained staff in home care services to better meet the needs of the two thirds of people with dementia who live a home

Committee Proposal 15:

Specialist home care services with staff trained to work with people with dementia might be the answer, with staff providing longer-term slots and visits based on need.
Comment: This has worked well in other regions, Leeds for example, where home care staff are closely attached to older People's Community Mental Health Teams.

NDS Recommendation 8: Improved short breaks for people with dementia and their family carers

30. Short breaks and respite help support families in the caring role in the community. This emerged as a priority in the Committee's consultation.

31. Breaks need to be flexible as people with dementia can live with the condition for a number of years and care needs change over time. Day care and respite should provide meaningful activities for people with dementia to facilitate social inclusion, leisure opportunities and stimulation. Specialist respite is required as the disease progresses. For planning and commissioning purposes what's available should be properly audited

Committee Proposal 16: Short breaks

In short, short breaks and respite is required from the onset of dementia to enable carers to attend events and activities throughout the care giving period. Specialist respite is required as dementia progresses and needs become more complex. We should therefore audit current arrangements and options in conjunction with partners.

32. The report offered comments on the remaining aspects of the strategy which address care in residential settings but Members recognised these were for further study by others.

NDS Recommendation 9: A joint commissioning strategy for dementia
Commissioning and planning mechanisms to be established to determine the services needed for people with dementia and their carers, and how best to meet their needs.

NDS Recommendation 10: Intermediate care for people with dementia
Intermediate care to be made accessible to people with dementia and to meet their needs.

NDS Recommendation 11: Improved dementia care in care homes
Quality of care in care homes to be improved for people with dementia.

NDS Recommendation 12: Improved registration and inspection of care homes
Inspection regimes for care homes to better assure the quality of the dementia care provided.

NDS Recommendation 13: Clear information on the delivery of the National Dementia Strategy
Good quality information to be available on the development of dementia services as the strategy is delivered.

NDS Recommendation 14: A clear picture of research evidence and needs
Evidence to be available on the existing UK research base on dementia, and on the gaps that need to be filled.

NDS Recommendation 15: Effective support for implementation
Appropriate national support to be available in support of local implementation of the strategy.

33. Any action taken by the council is conjunction with partners should be supported by national campaigns and access to the latest information and research. Clear information on the delivery of the National Dementia Strategy is required and additional resources should accompany it.

Committee Proposal 17:

i) Press the Government to issue detailed information on how the Strategy can be implemented.

ii) Locally the central focus for this would be best placed in the Adults Thematic Partnership of the NYSP advised by the Dementia Network.

iii) Recommend Government make all appropriate effort to support medical research on this condition.

34. The Committee would like to champion the notion of a one-stop-shop for people with dementia. A recognised holistic service for people with dementia and their families to turn to. A place where the diagnosis and ongoing treatment might be carried out away from a clinical environment. A place where there is peer support and up to date informed advice. This need not be all about a building but also about the 'virtual' team of people focussed on dementia and works to one end.

Committee Proposal 18:

That the notion of a one-stop-shop as part of integrated services be explored further especially by by commissioners and the dementia network

Comment – the Committee would have wished to examine this issue in much more detail. This is especially one theme the Committee would wish to stay involved with.

APPENDIX 3

Department of Health

Yorkshire & Humber Improvement Partnership

A Review of Services for People with Dementia

The Case for Change

Across Yorkshire and Humber

Contents

1.1 Executive Summary.

This report documents the outcomes from 15 locality reviews of dementia services across Yorkshire and Humber as well as a number of additional regional and national reports and there are a number of recurrent themes.

It is clear that there are significantly more people in Yorkshire and Humber living with dementia that we do not know about, than those we do. It is also clear that it is very likely that these people will gravitate quickly towards care in acute hospitals/care homes, and that on the whole a person's experience of care in these settings is poorer than we would wish.

It is also apparent from the views of those living with dementia and their carers that the role of carers and families are crucial in supporting people to live at home as independently as possible. The absence and/or loss of a carer is the single largest factor which leads a person living with dementia to be admitted to acute care or a care home setting.

The report sets out the current profile of expenditure on dementia across the region. Nationally, on average, 63% of all dementia spend goes on residential care. The report suggests that in this region that is probably even higher, yet only about 36% of people with dementia reside in this setting. It is also clear that the redistribution of money around a health and social care system is not easily achieved.

The report presents a compelling case for change and three of the highest priorities should be:

- To make the community of people living with dementia who are "unknown" to health and social care "known" and effectively supported, thereby reducing placement in acute care/care homes through invest to save schemes.
- That for a person living with dementia, their greatest "asset" is their carer and family and we need to rethink our approach to supporting them, and;
- We must find ways to redistribute current funding from acute hospital and care home settings to those parts of the health and social care system associated with better outcomes for people with dementia.

Despite the scale of change, some of the excellent practice across the pathway includes; early diagnosis in Bradford and Sheffield, minimal waiting times in North East Lincolnshire, individual budgets and assistive technology in North Yorkshire, reduced hospital admissions and length of stay in Leeds, care navigation in Barnsley, supporting carers in Kirklees, liaison services for acute hospitals and care homes in Doncaster, continence advisory services in Wakefield and reduction of prescribed drugs for care home residents, again in Kirklees. The adoption of this level of practice alone across the region would make a huge difference in terms of outcomes and cost. The starting point has to be the improved quality of life and outcomes for people living with dementia and their carers. It will be a significant challenge to leaders and partnerships at a local and regional level to collectively redesign the system to one which is characterised by the examples above.

Peter Flanagan, Acting Director, YHIP.

1.2 Introduction

Living Well with Dementia: A National Dementia Strategy[1] (NDS) was published by the Department of Health in February 2009 and is a key step towards developing effective health and social care for people with dementia.

This report presents the Case for Change across Yorkshire & Humber to achieve improvements in the quality of care for people with dementia, and their carers. The evidence presented illustrates some of the challenges that lie ahead for the region and the progress made to date. The report references relevant national reports, findings from the locality reviews, identifies areas for potential efficiencies and highlights some of the many examples of positive practice identified in the review.

The NDS contains 17 objectives, 7 of which have been identified as the key priorites for implementation in year one. These are:

- Early Diagnosis
- Community Personal Support Services
- Carers of People with Dementia
- Acute Care
- Care Homes
- Workforce
- Commissioning and Performance Management

The Regional Locality Review was structured around these 7 key priorities and the report is organised to reflect these findings.

Locality Review teams visited the 15 localities in the region to interview people with dementia and their carers, senior officers, commissioners, social care and clinical staff. They collected evidence of implementation progress made since the launch of the NDS.

The report begins with some data on the prevalence of dementia and then sets out the current position across the pathway.

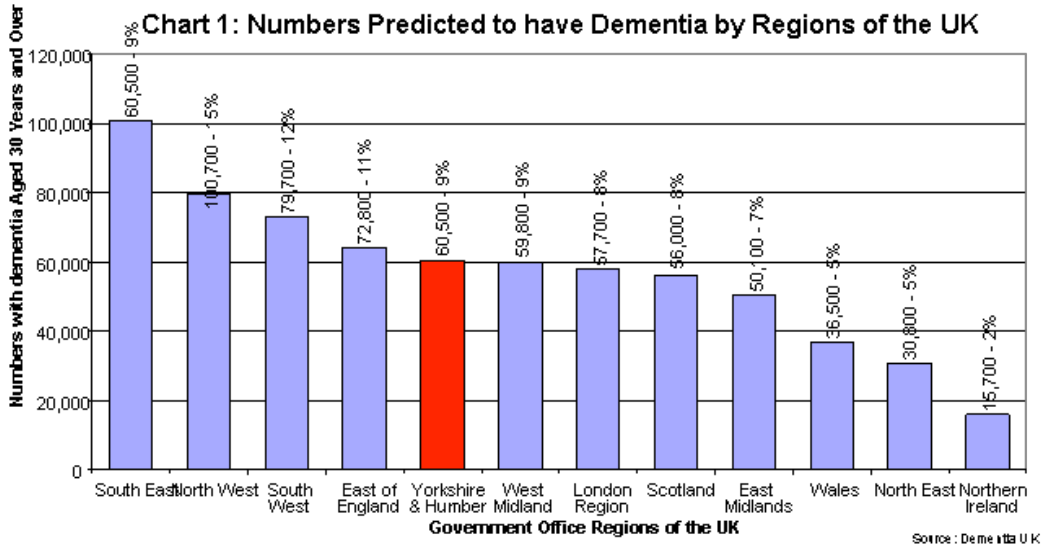
The report is supplemented by 'Inspiring Innovation in Dementia – A Regional Directory for Yorkshire & Humber' which illustrates over 60 positive practice examples from across the region which, if implemented, would give better outcomes and an improved return on investment. Each locality is represented in the directory For further information please go to www.yhip.org.uk/older-people/dementia

The teams who undertook the locality reviews were very clear that there is great enthusiasm and passion to drive implementation of the NDS forward, with some excellent examples of practice along the dementia pathway.

2. The Demographics of Dementia

The prevalence of dementia is associated with age, and older people are living longer. Over the next 15 years those predicted to have dementia across England is projected to increase by around 49%.

Yorkshire and Humber accounts for some 10% of the 601,000 individuals in England as a whole predicted to have dementia (see Chart 1, below).



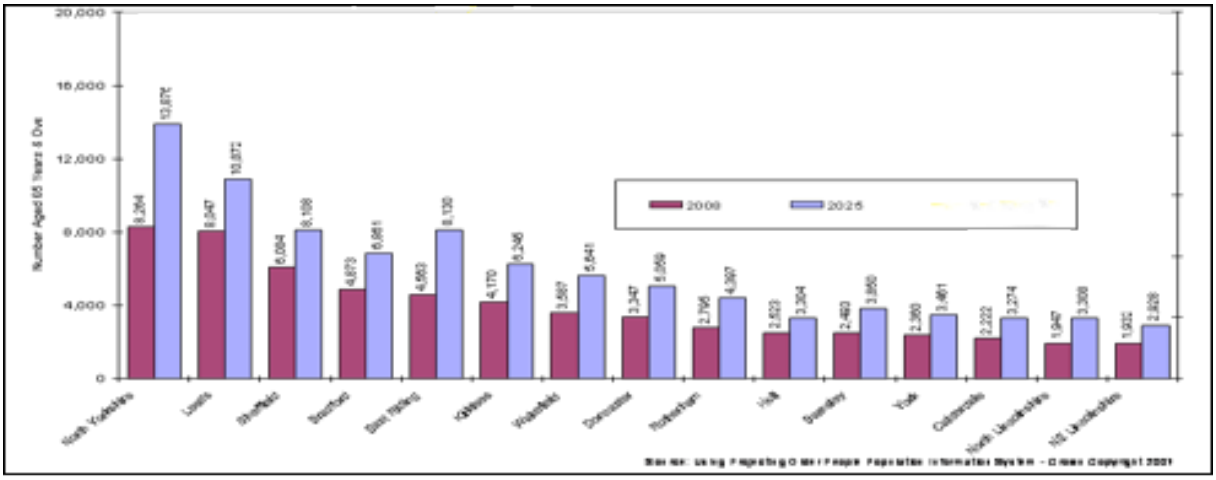
Today there are some 60,509[2] people over 65 years old living with dementia in Yorkshire and Humber. Over the next 15 years it is likely that this number will increase by 29,200 to 89,300.

The localities with the largest estimated numbers of people with dementia are North Yorkshire 8,264 (14%), Leeds 8,047 (14%) and Sheffield 6,084 (10%). Those with the fewest estimated numbers are North Lincolnshire (1,947) and North East Lincolnshire (1,932). These figures both account for 3% of the regional total.

The greatest percentage increase in the region is likely to occur in the East Riding locality with a projected increase of 78%, some 3,567 additional individuals. The increase is projected to be 70% (1,361) in North Lincolnshire and 68% in North Yorkshire. This increase in North Yorkshire is the largest in absolute numbers in the region, amounting to around 5,612 individuals and accounting for over one-sixth of the total projected increase in Yorkshire & Humber.

Across 60% of the region the percentage increase in the number of people with dementia is greater than the England average.

The chart below identifies the increasing number of people predicted to have a diagnosis of late onset dementia across the region between 2008 and 2025.



The variations in the projected increases in the numbers of people with dementia are based on the underlying demographic structure of the region. The smallest percentage increases (Hull, Leeds and Sheffield) are in the urban areas that generally attract younger people and the largest are in the rural localities where currently older people often reside.

The Dementia UK report[3] suggests that, of those with dementia, approximately two thirds live in the community and one third in care homes.

The 49% increase in the prevalence of dementia predicted across the region will exert an unsustainable pressure on the health and social care system.

3. Dementia Services in Yorkshire and Humber

3.1 Early Diagnosis – Addressing the Diagnosis 'Gap'

National Dementia Strategy Objective: 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.

The National Context

The National Audit Office (NAO)[4] interim report revisited the issue of 'the diagnosis gap' in England (i.e. the difference between the predicted numbers of people with dementia and actual diagnosis). It is estimated that only one third of those with dementia are formally diagnosed. Part of the problem is the perception among GPs and members of the public that little can be done. Early diagnosis is not being given the priority it deserves and treatments known to be cost-effective are not widely available.

Early diagnosis and intervention improves quality of life through enabling people with dementia to access suitable support services and to delay or prevent premature and unnecessary admissions into hospitals or care homes.

For those that do receive a diagnosis, quite often it is too late to enable the person with dementia to make choices regarding their care or any plans for the future. The fact that so many people with dementia do not have an accurate or timely diagnosis and/or are unknown to the health and social care system makes coordinating services to avoid hospital admission yet more difficult.

Department of Health - Demonstrator Sites
Bradford, Kirklees, Leeds and Wakefield are NDS Demonstrator Sites. The key objective is to test out the effectiveness of two service models proposed within the NDS; namely the Dementia Advisor Service and Peer Support Service Networks.

In Kirklees – There is a growing South Asian community accounting for 12% of the population. At present there is an under representation from the South Asian communities accessing mainstream older people mental health services. This dementia Advisor project is aiming to increase dementia awareness, early diagnosis and support for the South Asian Communities across both North and South Kirklees.

Progress to date – Two dementia advisors have been recruited. The service is now up and running, with clinics organised in GPs practices. The Advisors are also making links and raising awareness within local communities. Plans are also underway to recruit volunteers from local communities to support the development of culturally appropriate information and identification of support which is respectful of the South Asian culture. The project is planning a local evaluation as well as contributing to the national evaluation.

Positive Practice Example: Wakefield Memory Service

The need for and recognition of the benefits of earlier diagnosis of dementia has been addressed in Wakefield through the development of the Wakefield Memory Service. This service has developed over the past 10 years in line with national policy and local need.

The service now offers a responsive person centred service which provides access to assessment, diagnosis, treatment and support for people with dementia including younger people with dementia and people with learning disabilities and dementia. The service has a well established service user pathway that includes liaison with both the Alzheimer's Society and Age Concern. Further innovative ways of working include, New Ways of Working, non-medical prescribing, nurse diagnosis, nurse led clinics, a telephone monitoring service, service user and carer network groups, and input to memory cafes.

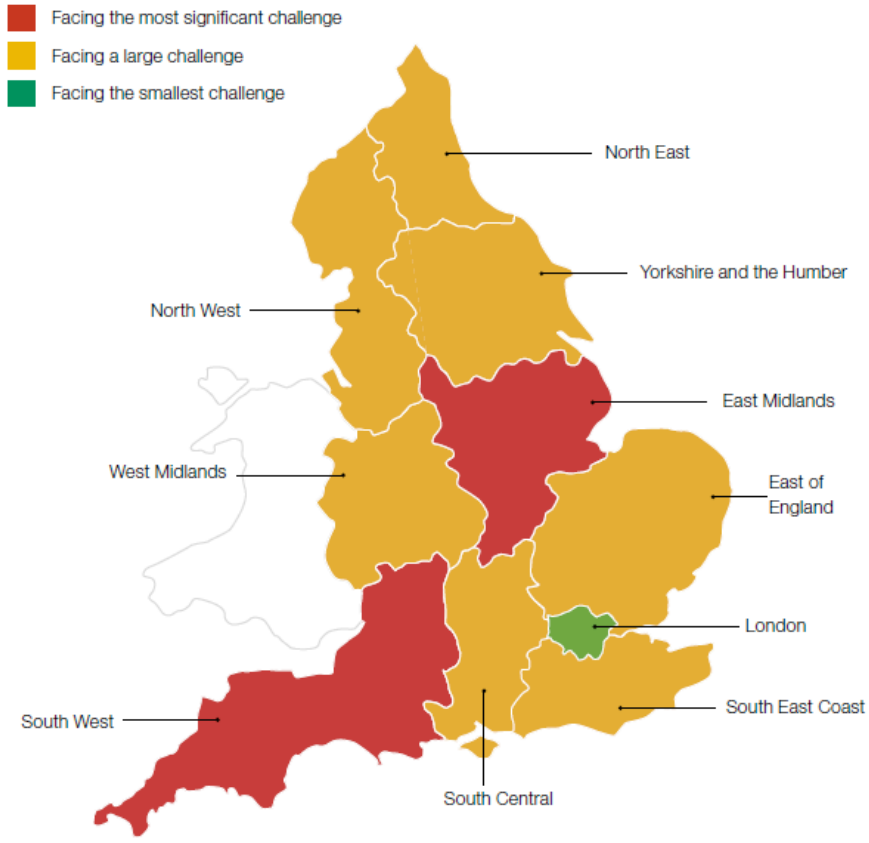
Through a variety of mechanisms including shared prescribing agreements and innovative diagnostic protocols, the memory service team has developed a highly valued partnership with primary care services. In addition, the team has been recognised and utilised as an education resource by primary care, social services, the voluntary sector and local acute trust and it has made a significant contribution to the research agenda.

Learning and evaluation to date:

- Referral rates to the service have consistently risen with 690 referrals to the service between April 2008 and March 2009.
- Service users and carers have been regularly consulted to provide feedback on the service provided. Specific research and projects have provided focused evaluations. For example, one recent project has led to the development of more community orientated services, with people with dementia now having a greater choice of home or clinic based appointments. A further evaluation project has resulted in improved transport services after detailed consultation with service users and carers.
- A formal evaluation of capacity and demand has also been commissioned, with an aim to provide a service that is high quality and makes best use of resources.

For more information on Wakefield Memory Service contact:
Richard.Clibbens@swyt.nhs.uk

Regional Breakdown of the Diagnosis Gap in England



Stigma and discrimination

Although some 21 million people in England know someone with dementia, public awareness remains poor. An Alzheimer's Society Public Awareness survey in May 2009[5] found that 28% of people still thought (wrongly) that dementia was a 'natural process of ageing'. This lack of awareness and stigma, among health and social care staff as well as the public, contributes to negativity about dementia resembling the attitude to cancer in the 1950s[6]

It is further suggested that fear and ignorance of the disease are barriers to people and that unpaid carers approaching their GP about suspected dementia (and the GPs own attitude) could hamper early diagnosis[7]. The advantage of early diagnosis is that people are more likely to receive pharmacological and therapeutic interventions.

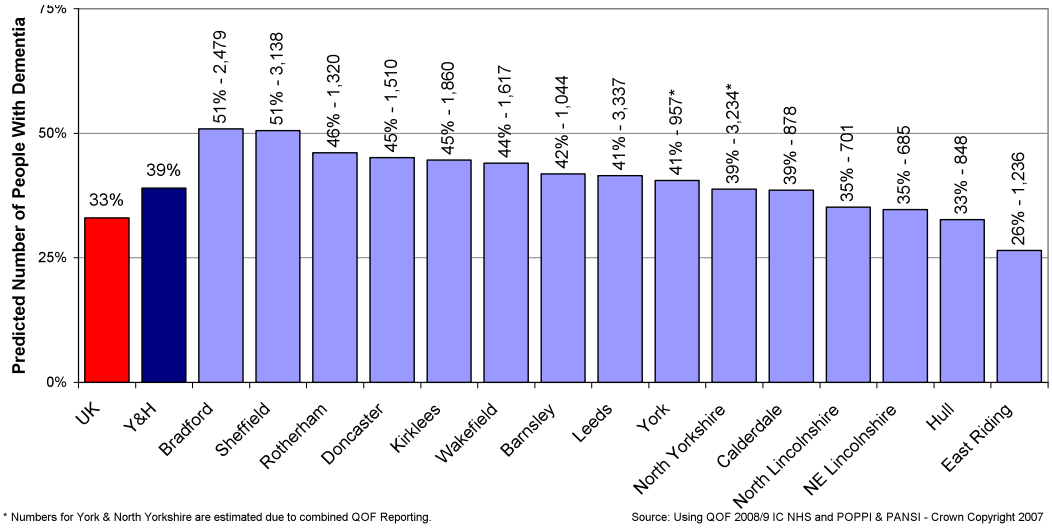
The above report also found that 22% of people thought (wrongly) there was no way to reduce the risk of dementia. Risk factors such as high blood pressure, raised cholesterol, diabetes, smoking, alcohol and cardio vascular disease can lead to vascular dementia. Approximately 50% of all cases of dementia have a vascular component (i.e. vascular dementia or mixed dementia). There is an opportunity to minimise the effects of dementia or prevent it altogether for some people through health promotion messages on diet and lifestyle. Investment is needed in local public

health campaigns to reduce people's risk of developing dementia in later life by encouraging healthy eating, physical activity, mental exercise and social stimulation. What's good for your heart is also good for your head.

Locality reviews

According to the latest Quality Outcomes Framework (QOF)[8] statistics there are 24,844 individuals registered with a clinical diagnosis in Yorkshire and Humber. This figure represents approximately 39% of the number of people estimated to have dementia.

Chart 3: Percentage of people with a clinical diagnosis of Dementia registered with a GP by locality across Yorkshire & Humber 2008/09



* Numbers for York & North Yorkshire are estimated due to combined QOF Reporting.

Source: Using QOF 2008/9 IC NHS and POPPI & PANSI - Crown Copyright 2007

Chart 3 (above) identifies the significant variation in the diagnosis gap[9]. All localities in the region are at or above the national rate of 33% apart from the East Riding.

The importance of a diagnosis was third on the list of priorities documented in the Yorkshire and Humber 'Listening to You'[10] report. During the consultation people with dementia were asked what an early diagnosis meant to them:

"It took 3 years of tests before I was diagnosed by a consultant with frontal lobe dementia. Because I was so young it was worrying."

"Early diagnosis, increased public awareness and talking about it to take away the stigma are really important. Everyone talks about cancer these days but they didn't used to, so they should talk about Alzheimer's and understand what it feels like".

Positive Practice Example:
Doncaster – Dementia Timeline Pathways to Diagnosis

A research project in Doncaster explored the journey that people follow from first developing concerns to actually being seen in a Memory Clinic. The hypothesis was that this is likely to be a varied and often poor experience for people.

This project interviewed 80 patients and carers at the point of arriving at a Memory Clinic. People were asked simple questions about the time that elapsed between first noticing problems to actually seeking help. The key time points that were used were the time of initial recognition of symptoms, the time the person first spoke to a loved one of their concerns, the time they first spoke to a health professional, the time a referral was made to the Memory Clinic and the time of arrival at the Memory Clinic. The interviews also explored some of the detail of their experience. It is intended to use this work to influence commissioning intentions to improve the experience for people with dementia and their carers.

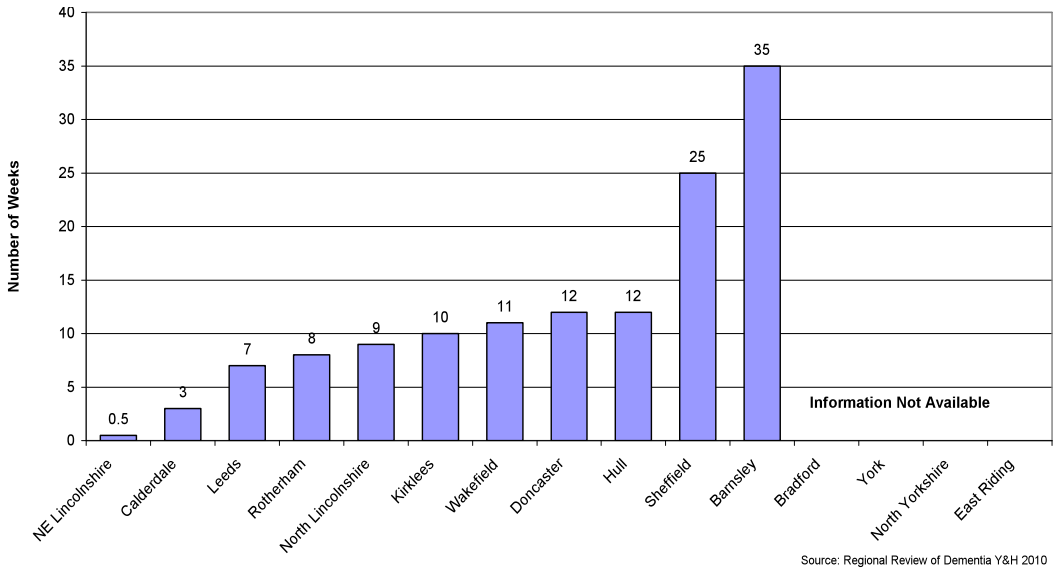
The average time between initial recognition of symptoms and first speaking to a loved one was found to be one year. The average time between this and seeking professional help was slightly over a year. The average time between seeking help and a referral being made to Memory Services was around 4 weeks, and the time between the referral being made and the individual being seen by Memory Services was a further five weeks. So, for the people in this study, on the average, the journey time from when a person first thinks that something may be amiss to the time when they arrive at the Memory Clinic for a formal diagnosis is around 3 years. Across the case studies, the delay appears to be linked strongly to the alertness, awareness and recognition within the family support network of the symptoms of dementia. The implication is that one area for improving early diagnosis rates is to raise the awareness of, and alertness to, the potential symptoms of dementia among the general population.

In addition, the case studies found that once the individual has sought professional help, there are several factors that can help or hinder their progress within the system. These are the presence other medical conditions that can cloud the diagnostic process, the strength of personal support networks, having supportive professionals in key roles, conversely professional beliefs or systems that can slow the referral process and the presence of communication and trust between healthcare professionals, and between the person with dementia and their carer and the professionals. The implication of this is that by giving attention to these factors, the time from seeking help to being seen in Memory Services can be further reduced.

Further information www.arcresearch.co.uk or please contact arc@breakfast.solis.co.uk

There is also a significant variation in the average wait time between receipt of referral to the Memory Assessment Service initial face-to-face contact.

Chart 4: Average wait time from receipt of referral to first face-to-face contact with Memory Services by locality across Yorkshire & Humber 2008/09



Source: Regional Review of Dementia Y&H 2010

Waiting times ranged from 3-5 days (Chart 4) in North East Lincolnshire to 35 weeks in Barnsley. The majority of locality waiting times were between 7 to 12 weeks. However all localities did report that the figures submitted included the non-urgent cases and that priority was given to urgent cases that were seen more promptly.

The variation in wait times could also be the result of service configurations. North East Lincolnshire operated a single point of access to the Specialist Mental Health Services including a triage initial assessment from the Community Mental Health Team.

A pilot in Barnsley enabling comprehensive care navigation demonstrated:

- A reduction in caseload for memory staff.
- Greater and timelier support is given by navigators, allowing memory staff to focus on early detection, diagnosis and treatment.
- A reduction in crisis whilst awaiting initial assessment for diagnosis/treatment.
- A reduction in the amount of inappropriate referrals made from GP practices.
- 55% increase in referrals to navigators in 6 months.
- Contact time with GPs was halved in 50% of cases.
- 20% reduction in admissions to the dementia assessment ward.
- Earlier discharge from the dementia assessment ward with care navigator involvement.
- Improved partnership working between health and social care agencies.
- Better identification of gaps in service provision.

Potential Efficiencies

Early diagnosis and intervention improves the quality of people's lives through enabling them to access suitable support services and to delay or prevent unnecessary admissions into hospitals or care homes.

The Department of Health impact assessment of the NDS[11] suggested that early intervention can be cost effective and improve the quality of life for people with dementia and their families and the available evidence suggests that:

- Carer support and counselling at diagnosis can reduce care home placement by 28%.
- Early provision of support at home can decrease institutionalisation by 22%.
- Even in complex cases, active case management can reduce admissions to care homes by 6%.

An increasing body of evidence exists that demonstrates how investing in a large range of preventative approaches helps maintain older people's independence and wellbeing and contributes to greater efficiencies within the local health and social care system.[12]

Bradford's 'Health in Mind' POPP programme identified:

- 26% of people were prevented from care home admission.
- A further 13% of admissions were prevented or delayed.
- 15% were supported to be discharged earlier than would have been the case.
- 29% reduction in the number of homecare hours immediately after intervention

When operating to full capacity the intensive support teams are expected to produce net savings of £550,000 per year.

In addition many of the community capacity building initiatives that have emerged through LinkAge Plus and POPPs pilots provide the essential foundations required for personal budgets and support planning to really work well with and for older people. Knowing what is available and having good support networks within local neighbourhoods, as well as through formal agencies, is crucial to making all of this work well. This will allow older people to remain connected and in control of their lives.[13]

3.2 Improved Community Personal Support Services

National Dementia Strategy Objective: 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 and take account of their broader family circumstances. Accessible to people living alone or with carers, people who pay for their care privately, through personal budgets, or through local authority-arranged services.

National Context

The majority of people, with or without a formal diagnosis of dementia, live in their own homes. Dementia UK estimated that 63%, (approximately 400,000 people) with dementia live in private households.

The most important service that supports people with dementia in their own homes is good quality home care. This contributes significantly to maintaining people's independence, reducing social isolation, and providing support for carers.

Home care reablement services provide personal care, help with activities of daily living and other practical tasks for a time-limited period. This enables people with dementia to develop both the confidence and practical skills to carry out these activities themselves. Reablement can be described as an 'approach' or a 'philosophy' within home care services – one which aims to help people 'do things for themselves', rather than 'having things done for them'.

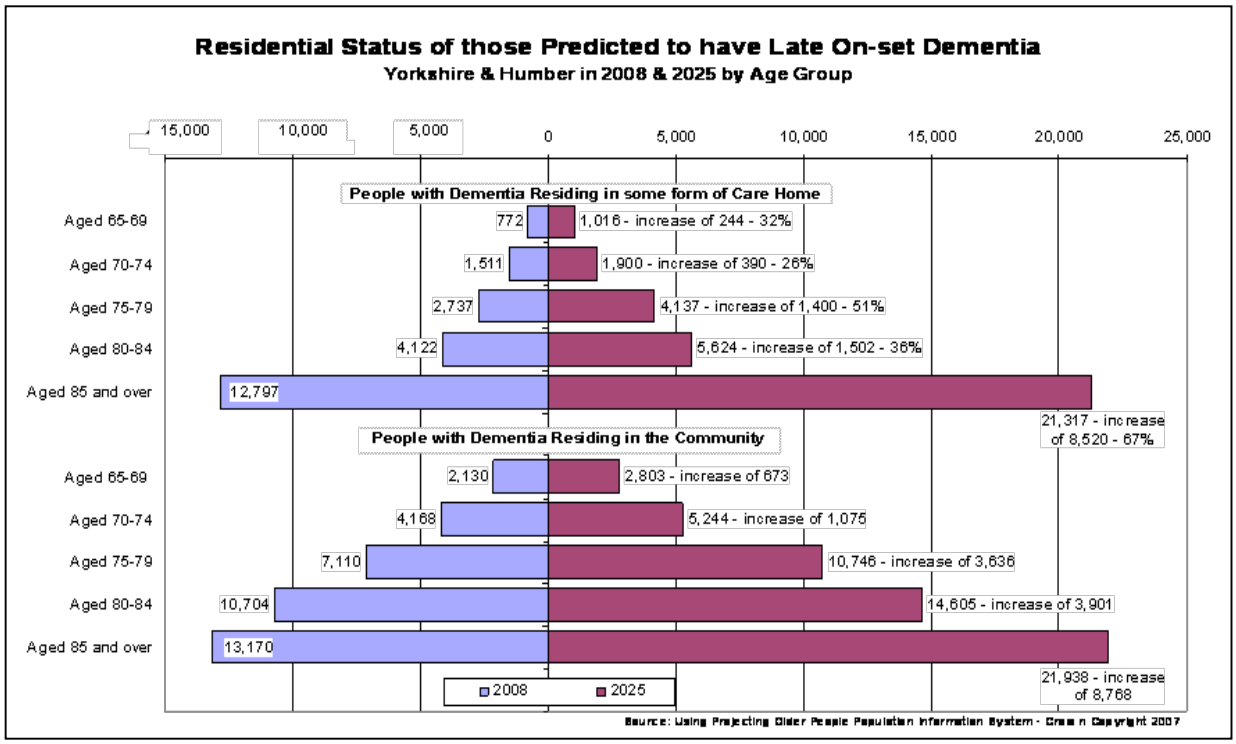
Consistency of care personnel is essential when delivering home based services for people with dementia. Existing home care services are often rotated resulting in staff who are less skilled in observing the small changes in behaviour and cognition that would indicate an increasing level of need.

In addition to home care the development of services such as crisis intervention, supported housing and intermediate care alongside GPs (who are cognisant of available options) may reduce admissions and support people with dementia to live at home[14]. Access to direct payments, individual budgets and the appropriate use of assistive technology may also help to support the person with dementia in their own community.

In the recent Audit Commission report 'Under Pressure'[15] Michael O'Higgins, Chairman of the Audit Commission, said:
"Older people don't want to become dependant. Most older people live at home, not in care homes. The longer they do, the happier they are and the less they cost the taxpayer. Innovative, personalised services mean older people stay independent longer, saving public money".

Locality reviews

The demographic changes of the ageing Yorkshire and Humber population, described earlier, will place greater demand on community services. The chart below illustrates the growth in number of those over 85 in particular who will need to be supported to live at home.



The locality reviews found that two thirds of home care provision was within mainstream services. Although in Kirklees and Wakefield staff do receive specific dementia training. Rotherham, Doncaster, Leeds and York provide specialist home care services for people with dementia.

Bradford has replaced their traditional home care service with a 6 week intensive support package, which is provided prior to any possible onward referral to mainstream home care.

Sheffield reported a number of specific initiatives including an Accelerated Discharge Dementia Team providing specialist support enabling people with dementia or those with symptoms to be discharged more promptly. In addition they have a Rehabilitation Service that has a 15-bed unit for older people with dementia.

Community Support Service – Leeds

There is growing evidence that shows that specialist dementia home care services are more beneficial to people with dementia and their carers, improving the independence for the person with dementia through a person centred approach, whilst reducing stress and the risk of carer crisis.

In Leeds, general home care teams recognised that task based work allocation methods were preventing them from being able to deliver care to people with dementia in a person centred way. A desire to take a rehabilitation and re-ablement approach with these service users to optimise their abilities coupled with recognition that complimentary roles between other services could be exploited to benefit service users; has led to the development of the Community Support Team (CST).

The Community Support Team offers time limited, intensive enabling support to people with dementia in their own home, to facilitate an in-depth assessment of ability to manage tasks of daily living, to sustain and reinforce people's existing abilities with the aim of maximising independence, and to support informal carers through a crisis. There is a strong rehabilitation focus within the service with all work being planned around meeting people's needs not carrying out tasks.

The service is provided by community support assistants employed by Social Services who have all undertaken mental health training. The service is co located with health services, where there is a pattern of joint working which mainly involves follow on enabling assistance, extending the model of crisis intervention to encompass skills reinforcement in the context of daily life routines.

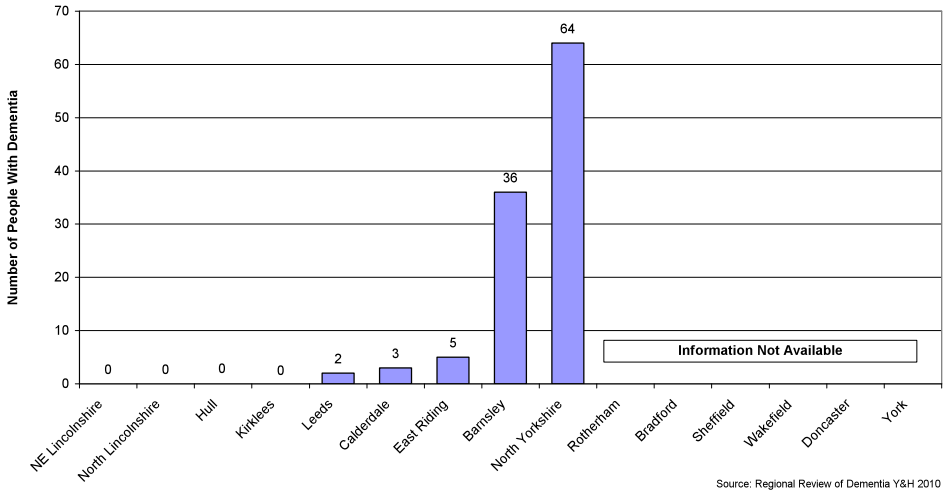
- Qualitative data suggest that staff have developed a creative and user-centred approach to engage with individuals.
- On discharge from the service, nearly three-quarters of people remained in their own home during a period of evaluation.
- Co location and co working between services has allowed teams to become more efficient and effective, reducing hand offs in process

For more information about the initiative please contact jacqueline.wright.HMC.@leeds.gov.uk

As part of the transformation of adult social care, local authorities are required to develop a resource allocation system (RAS) for those eligible for social care including people with dementia. This allows costings to be made for individual packages of care which can be taken as an individual budget if the person chooses to do so.

Currently there are 5 localities in the region (see chart 5 p17) who have a scheme in place to support people with dementia to access individual budgets.

Chart 5: Number of people with dementia currently in receipt of Individual Budgets by locality across Yorkshire & Humber 2008/09



Source: Regional Review of Dementia Y&H 2010

Telecare was used across most of the region but localities were unsure how much was used specifically for those with dementia. 'Under Pressure' identified that North Yorkshire had particular success using telecare to maintain independence and estimate savings of £1 million a year. The council now has a target of including telecare in 15% of service packages, with the average package paying for itself within 6 months. They recently avoided a person with dementia going into residential care utilising a package costing under £700 – equivalent to less than 1 month of an average care package, which costs about £800. (See case study page 18).

There are a number of examples of where extra care housing has been successful for people with dementia. Most localities are planning to provide this as an option. North Yorkshire is focussing specifically on extra care housing in rural communities.

Bradford Dementia Group identified that over half of people with dementia living in extra care housing are transferred elsewhere during the first 2 years due to challenging behaviour, distress and conflicts with staff and other residents. In order to address this they developed the 'Enriched Opportunities Programme'[16] and have employed a staff member with specialist mental health training and expert support to provide leadership and engage with residents, relatives and health and social care teams.

Case study

North Yorkshire's support for carers keeps the family in business

Marj has dementia and lives in a farmhouse with her daughter and son-in-law. Her family have been concerned about leaving her on her own in the house, while they are working out of doors.

As an alternative to moving Marj to a residential care home, the council equipped the farmhouse with a property exit sensor, flood detector, and pager. Now the family is alerted by the pager if Marj goes outside the house, or leaves taps running. They can go back to the house when they need to, but don't have to stay indoors all day. This approach has allowed Marj and her family to live life as they prefer, and to keep the family business going.

The equipment package cost just under £700 – equivalent to less than one month of an average care package, which costs about £800.

Source: North Yorkshire County Council

Potential Efficiencies

It is recognised that actually releasing or re-directing resources from secondary to primary care or from NHS to social care is likely to be difficult to achieve in the short to medium term.

In this context Total Place is a Treasury led initiative that looks at how a "whole area" approach to public services can lead to better services at less cost. It seeks to identify and avoid overlap / duplication between organisations; focusing on service improvement and efficiency at a local level.

Bradford – Total Place Project

Work already ongoing in Bradford has highlighted that the transition for people with mental health difficulties out of acute hospitals is often problematic. Older people with mental health problems often have difficulty recovering from an acute physical condition. A lack of co-ordinated health and social care support services for older people with complex multiple needs often means that they experience longer stays in hospital and have a greater likelihood of admission into long term care.

To begin to address this problem Bradford District Partnership has focused one of the sub themes of their Total Place Pilot on older people with mental health needs leaving acute hospital settings; people with dementia feature prominently in this work.

This pilot has given Bradford the opportunity to raise the profile of issues for older people who have mental health problems. By working together across the district it aims to identify what the priorities are and how they can bring about changes in practice that are needed. It is hoped that this pilot work will lead to an improvement in the quality of care of those in hospital, joint discharge planning and access to appropriate services in the community, whilst avoiding unnecessary admissions into long term care.

By providing improved, inclusive and integrated discharge planning and providing more appropriate support in the community Total Place can reduce the number of Bradford people being discharged directly into long term residential care by an estimated 50%. This estimate is based on bringing Bradford in line with the average figures for the region. Of the 451 patients with mental health problems that were discharged directly to long term Care Homes during 2008/09 the Total Place would enable 216 of them to return home with an appropriate care package. The potential efficiencies from this would be around £1.8m.

The proposed changes are also intended to reduce readmissions amongst the target patient group. Although the range of reasons for readmission will vary an average ‘cost of stay’ is £2384. This equates to an overall cost of £772k. If re-admissions were reduced by 25% efficiency gains of £193,104 could be achieved. This gain in available bed space should also help to ease waiting lists for acute beds.

For more information on Bradford’s Total Place Project see www.yhip.org.uk/totalplace

Mental Health Rapid Response Intermediate Care Team – Leeds

The focus of the Partnerships for Older People Projects (POPPs) has been to test out and evaluate different models of services for older people; aiming to move resources away from hospital based crisis care towards earlier interventions for older people within their homes or communities.

In Leeds POPPs grant funding has been used to develop a Mental Health Rapid Response Intermediate Care Team for older people with mental health problems including dementia.

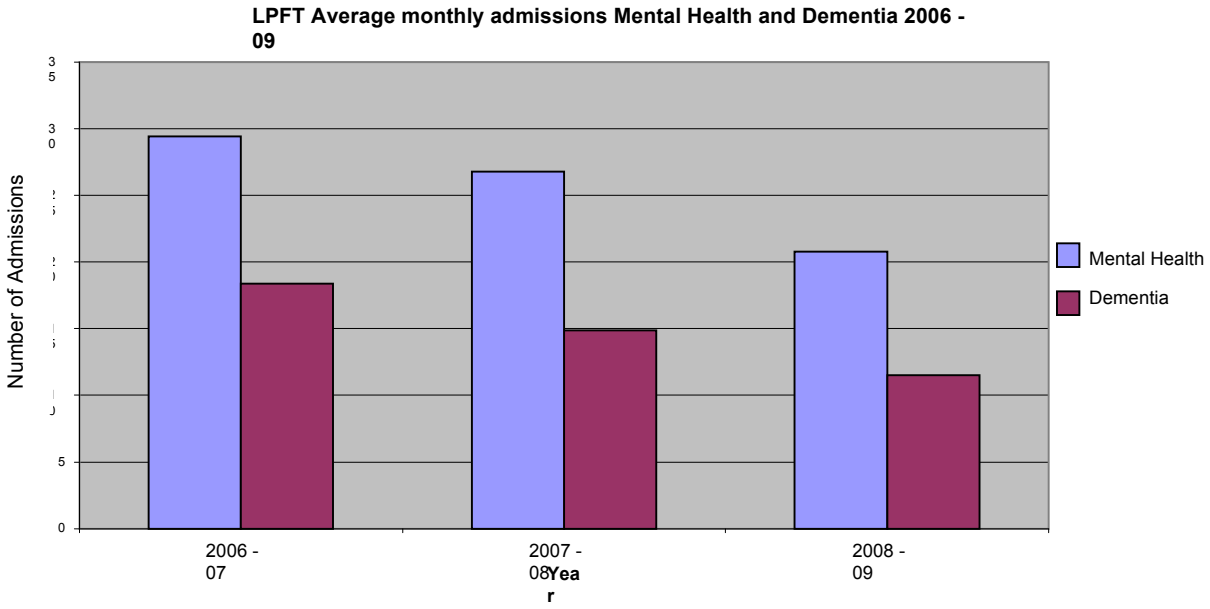
Through close partnership working with other provider services and commissioners; this initiative has developed treatment at home options to prevent unnecessary admissions to both acute and mental health hospitals and to reduce lengths of stay.

The development of this team means that older People with mental health problems living in Leeds now have the choice to remain at home to receive treatment and rehabilitation services from specialist teams. The team believe that an opportunity for home treatment and rehabilitation is a right for people with dementia and that recovery to an optimal state of well being is possible.

Over the 3 years of the POPPs programme there has been a reduction in admissions to mental health service beds, (see chart one below). The length of stay in acute general hospital has reduced by an average of 4 days per admission for people with primary and subsidiary diagnoses of dementia.

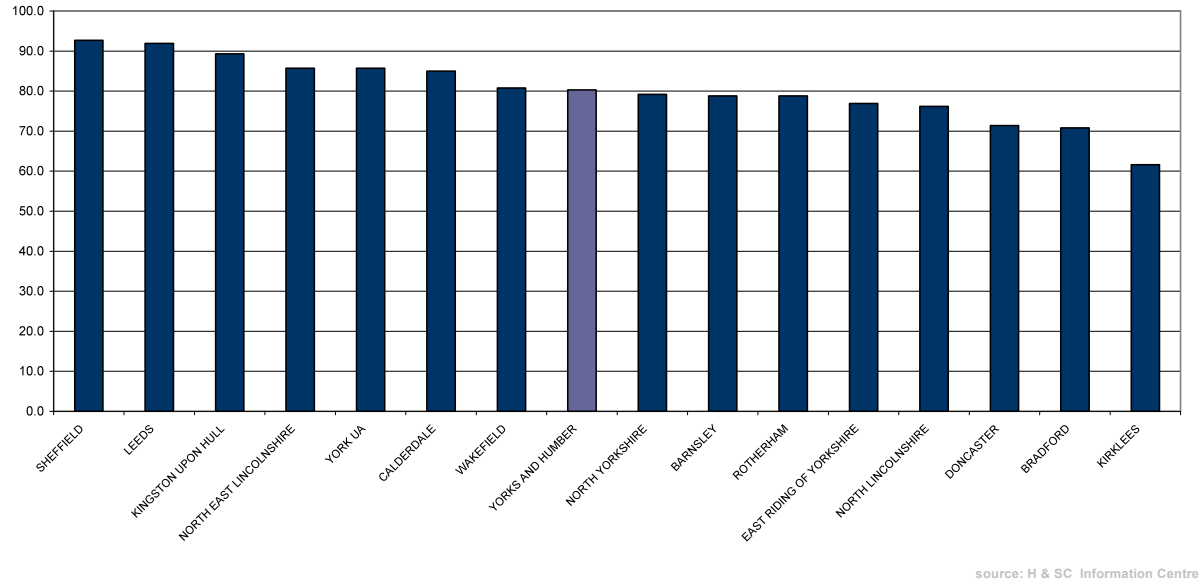
The number of admissions to care homes has reduced with those who need to enter care doing so at a much later stage and for a shorter period. The reduction in admissions and bed days saved have allowed Leeds to reinvest resources into more community based treatment and care.

For more information about the Mental Health Rapid Response Intermediate Care Team contact rachel.richings@leedspft.nhs.uk



The 'Short-term Outcomes and Costs of Reablement Services'[17] study identified that 50% of older people who were offered a short-term package of reablement based care did not require further social care support at the end of their treatment following medical intervention, consistent with the Use of Resources in Adult Social Care[18] report that suggested the most effective way of reducing costs is to reduce the number of people requiring support to live at home.

The graph below illustrates the proportion of people aged 65+ in 2008-09 discharged from hospital to intermediate care/rehabilitation/reablement who are still living 'at home' three months after discharge. This varies from 92.7% in Sheffield to 61.6% in Kirklees.



source: H & SC Information Centre

Intermediate Care has in the past not been widely available for many people with dementia. The indicative timeframe of 6 weeks in the National Service Framework (NSF) for Older People[19] has often meant that those with dementia have been seen as inappropriate for intermediate care. Halfway Home, (DH 2009)[20] states that people with dementia should no longer automatically be excluded from intermediate care.

Recent Care Services Efficiencies Delivery (CSED) studies[21] have shown that people receiving reablement showed a significant short-term improvement in perceived health, quality of life and social care outcomes between the pre and post intervention time points.

The NAO interim report analysed the 'Enriched Opportunities Programme' for people in extra care housing led by Bradford Dementia Group and concluded that "if it was rolled out to all existing extra-care settings in England, over a 2 year period, the net savings to the public through reduced hospital stays and reduced use of nursing homes could be £21m, shared between Local Authorities and the NHS, or a net present value of £89m over 10 years".

3.3 Carers of People with Dementia

National Dementia Strategy Objective: Implementing the Carer's Strategy
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 breaks. Action should also be taken to strengthen support for children who are in caring roles, ensuring that their particular needs as children are protected.

National Context

The National Carers' Strategy[22] sets out a clear vision of carers being acknowledged as a fundamental part of strong families and stable communities. It provides a commitment that support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen.

The NDS evidenced that most people wish to stay in their own homes for as long as possible and most family carers want to be able to provide support to help the person with dementia stay at home, but they sometimes need more assistance than is currently routinely available.

Locality Reviews

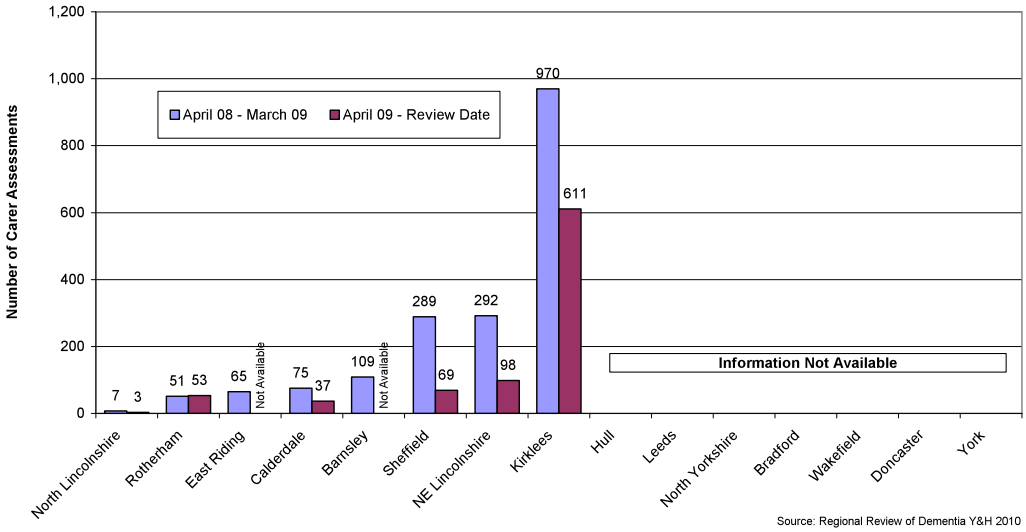
The locality review focused on:

- The number of carers' assessments carried out for carers of people with dementia.
- The number of people with dementia in receipt of short breaks.
- The perception of carers and people with dementia of their local service in order to triangulate analysis.

The pre-planned Carer Emergency card system enables carer contingency plans to be established that include contact names and numbers of the relevant support teams and can also include familiarisation with a Care Home setting for the person with dementia. This is available across half of the region. The provision of short break services is variable, although some level of service is available across the entire region.

Despite the importance of the role of carers, the figures for the number of assessments carried out across the region was unclear (as illustrated in Chart 6).

Chart 6: Number of Carer Assessments carried out for carers of people with dementia by locality across Yorkshire & Humber



Source: Regional Review of Dementia Y&H 2010

Nearly 50% of localities were unable to provide data on the numbers of carer assessments specific to those caring for people with dementia and of those that were, there was a large variation. Figures ranged from 3 carers in North Lincolnshire to 611 in Kirklees for the current financial year. In the previous financial year 1,858 assessments were reported to have taken place in the region, with over 50% attributed to the Kirklees.

Findings suggest that since April 2008 over 2,200 carers have received a carer assessment (70% of which are in the Kirklees locality). However to put this in context, across the region, there are over 24,000 people with a clinical diagnosis of dementia, many who live in their own home and the vast majority dependent on a carer.

'Listening to You' reported the sharing of information between staff, service users and carers and the input of both paid and informal carers was vital. Diagnosis can be complex and people felt it was important to use the correct terminology and give a clear explanation to the person and their family. Also, needs differed between people with dementia and carers and in some cases, it is the carer who wants the diagnosis but not the person with dementia.

Several carers emphasised that they want to be more respected and listened to by professionals, particularly GPs. They also felt their concerns were not acted upon in a timely manner eg referral to memory services. This increased the stress they experienced. Carers can play an important role in providing information for assessment and their knowledge and experience should be valued.

Another reoccurring theme in this report was carers felt they should receive assessment and support in their own right and that staff needed more training on positive partnership working with them to identify and support their individual fears and needs. Many carers preferred to deal with voluntary organisations rather than statutory services.

There was a particular emphasis on both carers and people with dementia having access to post diagnostic counselling. Carers' education programmes were highlighted as good practice post-diagnosis e.g. "Caring and Coping" course run by the Alzheimer's Society in York.

There was also a suggestion that other formats should be used for carers such as distance learning packages eg the Memory Activity and Self Help (MASH) programme run jointly by the Alzheimer's Society and the Older People's Mental Health (OPMH) service in Ripon and Harrogate.

Stigma and social isolation can impact hugely on those with dementia and their families. Dementia Cafés offer much needed social and community activities for people with dementia and their carers and can be a real source of refuge providing information, support and a sense of 'normality'. Prior to the publication of the NDS, YHIP commissioned a regional mapping exercise which identified 38 cafés with various models ranging from the Alzheimer's Café model to community based voluntary run projects. Most cafés are run on small budgets using grants and donations (rather than formal contracts) to meet small direct costs. Comments from carers included:

"It's not about what any professional can do or say – you come here and realise you are not unique in what you are dealing with."

"This is one of the few places we come where I don't have to worry about what he does or says because no one will bat an eyelid."

"It makes me feel less isolated as a carer."

The POPPs project in Bradford established 12 'Wellbeing Cafés across the district with a great deal of success in engaging south Asian and other minority communities; with a consequent increase in the number of referrals of people with dementia.

Admiral nurses are registered mental health nurses specialising in dementia care working alongside NHS and other professions. They provide specialist skilled support to carers and families of people living with dementia, as well as advice and information to other staff working in the field. The Admiral Nurse service is part of the 'for dementia' charity and has been in existence across the UK for a number of years NE Lincolnshire and more recently Kirklees have employed Admiral nurses. 'for dementia' also offers access to a free helpline for carers of people with dementia on 0845 257 9406 or email direct@fordementia.org.uk

Gateway to Care / Carers Gateway – A partnership approach in Kirklees

In Kirklees carers' needs are being address through a partnership approach. Carers Gateway sits inside the Assessment & Support Team at the Gateway to Care. Access and Support are a multi-disciplinary department with a preventative approach to stop carers and customers from rising up the tariff of care by early intervention and timely support. This department believes that Carers should be recognised, respected, understood and supported as 'expert care partners' not only by staff within Kirklees Adult Services but by all other partner organisations. The team has a diverse make up to ensure that the majority of customers cultures and backgrounds are represented aiding to reduce barriers.

The following services are available for carers including carers for people with dementia:

- Access to services from a choice of locations, offering the choice and control for carers.
- A dedicated telephone number for carers support – a listening ear to reduce carer stress and an early intervention to prevent carer breakdown
- Carer's emergency support plan (CESS)
- Action for Carers into Employment (ACE) – support into employment, short courses to enhance skills and boost confidence, help arrange and pay for child care/care cover giving practical help.
- Looking after me - a 6 week course across different venues in Kirklees. The course delivers sessions in English, Urdu and Punjabi and looks at accessing support and services, improving communication with Health and Social Professionals, coping with depression, healthy eating, exercise, planning for the future, Power of Attorneys and joining other health and social support groups after completion with guest speakers, information, activities and support for the group.
- Kirklees Active Leisure pass - to help carers maintain and increase their health and feelings of wellbeing.
- Front door on the High Street - a drop in service with a range of readily available information relevant to the carer. We have the overall responsibility to identify the carers need, problem solve, establish a solution, course of action/service implement this course of action to support the carers who may be in a crisis situation or to prevent a crisis situation or needing support information or advice.

For more information about this service please contact: Dawn Eastwood, on: dawn.eastwood@kirklees.gov.uk

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Potential Efficiencies

The annual overall economic contribution of unpaid carers is approximately £7 billion. Unless we support carers more efficiently and effectively the consequent break down of care will increase costs as people with dementia will be admitted to the acute or care home sector prematurely. The costs and outcomes of this are detailed in subsequent chapters.

Carers under stress are more likely to suffer physical and mental illness. We have a duty of care to support carers and it makes economic sense to work with and support unpaid carers.

Department of Health - Demonstrator Sites

Bradford, Kirklees, Leeds and Wakefield are NDS Demonstrator Sites. The key objective is to test out the effectiveness of two service models proposed within the NDS, namely the Dementia Advisor Service and Peer Support Service Networks.

In Wakefield - a collaboration of local services and agencies is aims to develop Peer Support Service Networks with a focus on helping people with dementia and their carers remain actives member of their community. This is building on Wakefield's successful Integrated Networks Project.

Progress so far - A Peer Support Network Coordinator has been appointed and an initial involvement workshop has helped identify current gaps in support across the locality. The project now plans to test out several peer support networks including an education programme, a campaign group to improve the care of people with dementia in general hospitals and leisure based groups e.g. a gardening allotment group. The project is planning a local evaluation using the Outcome Star as well as contributing to the national evaluation.

3.4 Acute Care

National Dementia Strategy Objective: 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.

National Context

The NDS suggests that pressure to reduce lengths of stay in acute care can mean that people with dementia are rushed into long-term residential care prematurely.

Sampson et al (2009)[23] found that 25% of elderly people with moderate or severe dementia died within two weeks of admission to a hospital with the lowest standardised mortality rate in England.

The quality of the care received by people with dementia in general hospitals is a real and ongoing concern for people with dementia and carers. Counting the Cost[24] report Alzheimer's Society (2009) identified that:

- 68% of respondents were dissatisfied overall with the lack of person centred care. The report cited that communication was one of the major challenges when providing care and that 72% of nursing staff acknowledged that training was needed in this area.
- 47% of carers suggested that being in hospital had had a significant negative effect on the general physical health of the individual.
- Physical effects reported included malnutrition and dehydration, constipation, incontinence, exhaustion, pressure sores, bruising and worsening mobility[25].
- 54% of carers suggested that being in hospital had a significant negative effect on the symptoms of dementia and 25% said they had deteriorated a little. Reported effects include the person becoming more confused, less independent and more distressed which resulted in the worsening of behavioural and psychological symptoms.
- The commissioning of specialist older people's mental health liaison services to facilitate the management and care of people with dementia and to ensure general hospitals are encouraged to develop an informed and effective workforce.
- The need for clinical leadership in hospitals to improve the quality of care provided.

The NAO report Improving Dementia Services in England[26] re-iterates the need for clinical leadership in acute trusts by recommending that by 31st March 2010:

- Every acute hospital should have an identified clinical lead for dementia care.
- Every Primary Care Trust should have a lead commissioner for dementia care and through contract monitoring, should require evidence that acute hospitals and other providers have a lead person with the responsibility for improving dementia care.

Locality Review

The locality review considered 3 areas in relation to the care and support of people with dementia in Acute Care:

- The level of development of liaison services across the region.
- The identification of dementia leadership in general hospitals.
- The identification of innovation that improves the experience of people with dementia in general hospitals.

Liaison
80% of localities have developed liaison services. Where these are in place they provide a combination of specialist assessment for complex cases, as well as provision of advice and support for clinical staff in the detection and care of people with mental health needs. There was no universal definition of liaison identified and each locality is working to their own model. Future work is planned to address this.

Leadership
The review identified named clinical leads in 80% of general hospitals across the region. The NDS does not identify a clinical lead job description, clear development pathway nor make reference to specific training needs. The NAO reports/reaffirms that clinical leads should be identified and every primary care Trust should have a lead commissioner for dementia.

This role appeared to be very much dependent on local interpretation and how localities chose to address this in their jointly owned local action plan.

The issue of the care of people with dementia in acute hospitals has been identified as a major priority by senior leaders across the region. A project has been established to look at the numbers of those in acute beds with dementia, their average length of stay and the additional cost to the whole system. The project will also examine the evidence for best clinical practice and how improvements can be made.

Innovation
5 examples of innovative practice were identified and 2 are cited in this report. The Leeds Specialist Liaison Older People's Mental Health Team (page 29) has reduced the length of stay for people with dementia by an average of 4 days, increased early detection and speed of referral for those with dementia as a primary and secondary diagnosis for those in general wards.

Incontinence in people with dementia is often seen as the gateway to full time care. The Wakefield Continence advice has reduced PCT spend on continence products and 46% of people with dementia referred to the service gained full continence following advice.(page 32)

The remaining examples of innovation can be found in the Innovations Directory.

Specialist Liaison Older People's Mental Health Team – Leeds

In Leeds a Specialist Liaison Older People's Mental Health Team is providing rapid high-quality specialist assessment and input into care planning for those with possible mental health needs admitted to general hospitals. The service works as a multi disciplinary team within the general hospital setting offering consultation, assessment, care planning, treatment and discharge planning. The service has a strong workforce development philosophy and takes a liaison and partnership approach to the treatment and care of people with dementia. Using Partnerships for Older People Projects (POPPs) grant funding the service has been expanded to offer a more equitable service across the city.

The service has been subjected to evaluation by Leeds University. The following findings highlight the effectiveness of the service in early detection, reduced lengths of stay and related efficiencies.

Reduced length of stay for people with dementia in general hospitals - the length of stay in acute general hospitals in Leeds has reduced by an average of four days per admission of people with a diagnosis of primary and subsidiary dementia.

The expansion of the Liaison Service and the impact on the length of stay for people with dementia in general hospitals – figures from 2004/2005 indicate that the average length of stay for a person with dementia in Leeds General Infirmary, where a small Liaison Service was available; was between 20-25.5 days. At St James Hospital where no Liaison Service was available; the length of stay for people with dementia was higher with an average stay being between 31-34 days. With the expansion of the Liaison Service across the general hospital sites the average length of stay has reduced by 3.2 days for all admissions with an HRG code of dementia over the period 2006-09. This equates to 873 occupied bed days (OBD) per year (2.4 beds).

An increase in the detection of mental health problems in older people in general hospitals and referral on to appropriate services - In 2008/09 47% (689) of all patients seen by Specialist Liaison Older People's Mental Health Team were transferred rapidly on to mental health pathways. Of these approximately half (344) had no previous connection or involvement with mental health services indicating the importance of the liaison team in the detection of mental illness and referral on to appropriate services for treatment. Of those transferred to Leeds Partnerships Foundation Trust (LPFT) services, 14% required psychiatric admission and 79% were transferred to community based services. 34% of all patients seen are discharged back to their GP**.**

An increase in earlier detection of dementia as a secondary diagnosis for people admitted to general hospitals – The impact of the Specialist Liaison Older People's Mental Health Team can also be seen through an increase in early detection of dementia as a secondary diagnosis in general hospitals in Leeds. Such episodes have increased from 645 in 2006/07 to 1036 in 2008/09. There has also been a reduction in length of stay amongst this group of patients from an average of 11.5 days in 2006/07 to 7.53 days in 2008/09 (source: SUS – Health Informatics). Had the Liaison Team not had an impact on length of stay over the period then in 2008/9 there would have been 4106 additional bed days for the patients in this group. This equates to 11.2 beds.

For further information about this service please contact Julie.budd@leedspft.nhs.uk

Potential Efficiencies

Yorkshire and Humber have 13,104 general and acute beds (excluding mental health) and spend over £700m on emergency admissions. A significant proportion of these people are over 75 and many of these have more than one stay.

'Counting the Cost' 2009 identified:

- People with dementia over 65 years of age occupy up to a quarter of general hospital beds at any one time.
- 42% of individuals aged over 70 years with unplanned admission to a general hospital have dementia, rising to 48%in those aged over 80 years.
- The longer people with dementia are in hospital, the worse the effect on the symptoms of dementia and physical health.
- Discharge to a care home becomes more likely and antipsychotic drugs are more likely to be used.
- Additional financial pressure is being placed on the NHS by people with dementia staying in hospital longer than expected.

The Alzheimer's Society research found that 42% of hospital admissions for people with dementia were *following a fall*, *broken hip or hip replacement*, *urine infection* or *stroke/minor stroke* and that people with dementia have an extended length of stay in hospital compared to the median for all hospital admissions for the same reasons. The extended duration of hospital stay for people with dementia is illustrated in Table 1 on page 31.

Falls in particular present a significant risk to the health and independence of older people, with up to 33% of people over 65 and 42% of people over 75 each year being affected. It is estimated that 30% of falls could be prevented[27]. 14% of hospital admissions for people with dementia are following a fall.

Supporting people with dementia to leave hospital one week sooner than they currently do can result in savings of at least £80 million (nationally) from only four Hospital Episode Statistics (HES) data codes.

A reduction in the length of stay for people with dementia in hospitals by 1 week would potentially generate efficiencies across these 4 areas and is estimated to be approximately **£4.7m** per year (see Table 2 page 31). Extrapolated across the whole of the Yorkshire & Humber region, efficiencies across these 4 areas could amount to over £10m per year.

Table 1 – Length of hospital stay (LOS) of people with dementia by reason for admission		
Diagnosis / Operation	**Hospital Episode Statistic (HES) median length of admission**	**Proportion of people with dementia staying longer than HES median**
Fracture	16 days	34% staying 1 month or more
Total hip replacement	6 days	85% staying 1 weeks or more
		57% staying 2 weeks or more
		34% staying 1 month or more
Urinary infection	5 days	86% staying 1 week or more
		53% staying 1 week or more
		30% staying 1 month or more
Transient Ischemic Attack (mini stroke)	1 day	73% staying 1 week or more
		57% staying 2 weeks or more
		35% staying 1 month or more
**Source: 'Counting the Cost' – Alzheimer's Society 2009 and based on the DEMHOS Research*		

Table 2: **Estimated Savings in Yorkshire and Humber by the reduction in LOS by one week for people with dementia**			
Diagnosis / Operation	**Estimated number of admitted cases with dementia**	**Excess day tariff**	**Estimated savings in Y&H in 1 year**
Fracture of femur	1,850	£216	£951,048
Total hip replacement	820	£248	£811,406
Urinary infection	3,080	£176	£2,547,776
Transient Ischemic Attack (mini stroke)	480	£178	£422,928
All of above			£4,733,158
**Data from 'Counting the Cost' – Alzheimer's Society 2009/Y&H Demographic Report*			

Specialist Continence Advisor – Wakefield

In Wakefield audits of referrals and ward admission rates highlighted that incontinence was often seen as an inevitable problem for older people with mental health problems, and particularly for people with dementia. Incontinence was often accepted by clinicians as part of the person's presentation and the idea that the person with dementia might be able to regain their continence was not understood. Incontinence in people who have dementia is often a gateway into full time care and is frequently the determining factor in carers deciding they can no longer cope.

These findings have led to the development of a Specialist Continence Advisor post within the older people mental health services in Wakefield. Jane Spencer offers specialist continence advice to people with dementia and their carers. The older people's mental health services comprehensive assessment process includes the Essence of Care trigger question "Does your bladder or bowel ever cause you problems?" A positive response always leads to a referral to the specialist continence advisor and a continence assessment.

The assessment involves the use of bladder and bowel diaries, urine sample analysis and bladder scans. Individuals are given care plans to promote continence, which include diet and lifestyle advice, prompted voiding regimes and the use of orientation cues. Where necessary, people are given prescriptions for products that are suitable to meet their personal needs. Product trials are carried out to make sure that the product manages the individual's needs and have the right capacity to ensure that each person's needs are met with dignity. A Continence Care Support Worker works with Jane to implement care plans for community clients following assessment and all community clients are reviewed on a three-monthly basis or more frequently if requested.

Learning and evaluation to date:

An audit looking at referrals to the service from 2004 – 2005 found that:

- 73 referrals had been made to the service
- Only 13% of service users were advised to use disposable continence aids whilst 46% of service users who were visited and given advice regained their continence.

More recently the service has found that a high proportion of people who are offered advice on the management of continence problems find that they can eliminate incontinence and the number of people who actually need continence products is lower than might have been expected. This has represented a cost saving for the local Primary Care Trust. Significant improvements have also been seen in people with dementia through the use of diet and lifestyle advice, prompting regions, carer education and the use of pictorial signs as orientation clues.

For further information about the Specialist Continence Advisor Service contact Jane.spencer@swyt.nhs.uk

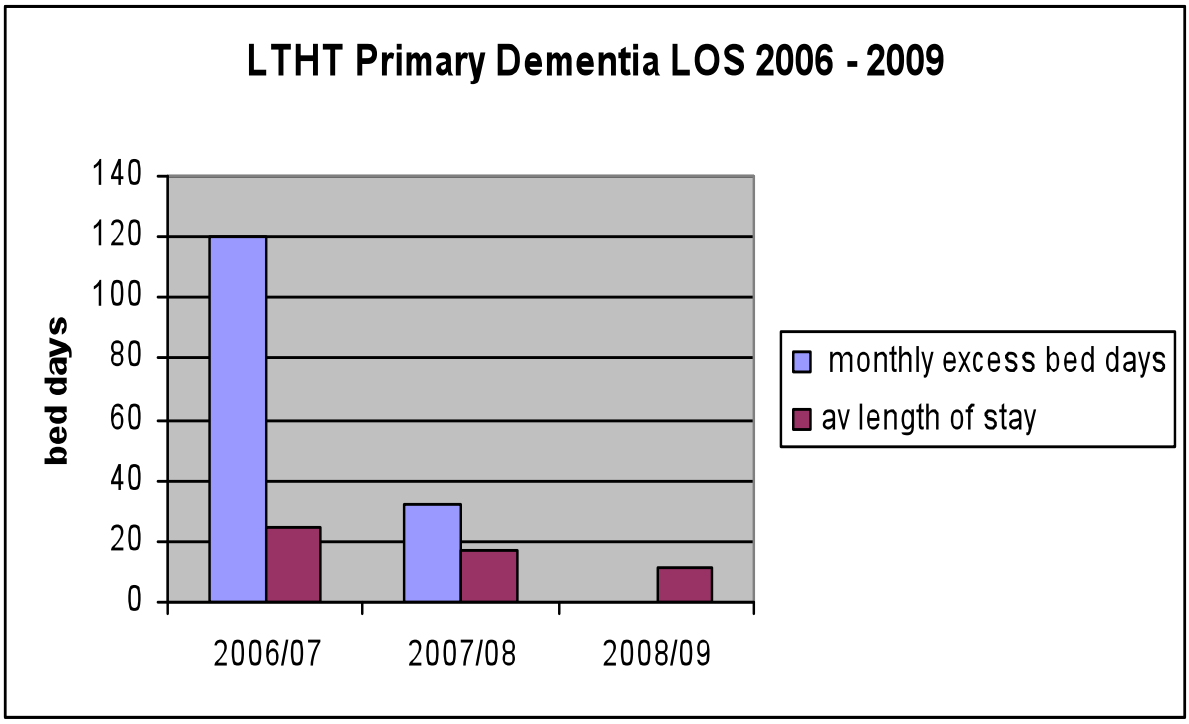
The Partnership for Older People Projects (POPP)[28] evaluation 2010 identifies the reduction in hospital emergency bed days resulted in considerable savings, to the extent that for every extra £1 spent on the POPP services, there has been approximately a £1.20 additional benefit in savings on emergency bed days. An example in this region is the work in Leeds.

In Leeds, a 2008 review of the dementia care pathway led local health bodies to further develop their existing Psychiatric Liaison Service in the acute hospital to include a rapid response community mental health team, specialist short term mental health home care and dementia-specific intermediate care beds. Initial funding of £4.2 million from POPPs led to an average reduction in hospital length of stay of four days per admission, for people with dementia over three years. This released beds to achieve other targets, such as the 18-week wait. The absence of a national tariff for mental health services has made it difficult so far to estimate the savings.

The Leeds project was successful in reducing length of stay from 30 days in 2003/04 progressively down to 10.1 days in 2009/09.

Where dementia was a primary diagnosis (see chart below) there was a reduction in length of stay by 88 bed days per month, 1056 bed days per year between year 1 and 2. In year 3 there were no excess bed days.

Where dementia was a subsidiary diagnosis LOS was reduced by 252 bed days per month, 3024 bed days per year between year 1 and 2. In year 3 there were no excess bed days.



*LTHT = Leeds Teaching Hospital Trust

'Counting the Cost' identified an increased likelihood of being discharged to a care home following a hospital stay. It found that 60% of people with dementia entered hospital from their own home and only 36% returned home. There also appears to be a correlation between this and length of stay. This can be seen in the table below.

Proportion of total number of people with dementia discharged to care home and own home according to length of stay as reported by carer respondents

Where the person with dementia is discharged to	Total number of people discharged to care setting as reported by carer respondent	Proportion of total number of people with dementia discharged to care setting according to length of stay				
		Up to one week	Up to two weeks	Up to one month	Between one and two months	Over two months
Care home	42%	38%	44%	37%	45%	52%
Own home	36%	48%	39%	37%	26%	17%
Other	6%	6%	6%	7%	7%	6%
Not applicable	9%	4%	8%	11%	10%	15%

Admission to residential care from acute hospitals is not the only problem as Sampson et al (2009) also found in their study; 43% of those admitted from care homes to the acute hospital could have been treated in the community with appropriate support.

There appears to be a strong correlation between admission to acute wards, length of stay and subsequent admission to residential care as evidenced further in the following chapter.

3.5 Care Homes

National Dementia Strategy Objective: Living well with dementia in care homes. Improved quality of care for people with dementia in Care Homes through the development of explicit leadership for dementia care within Care Homes, defining the care pathway there, the commissioning of specialist in-reach services from community mental health teams, and through inspection regimes.

National Context

Whilst for some with dementia admission to a care home is both appropriate and necessary, people can be inappropriately placed in residential care because there may be no alternative to meet their care needs in the community[29].

Dementia should not be seen in isolation. It is a complex syndrome often masked by depression and exacerbated by delirium.

- Two-thirds of people with dementia live in their own homes.
- One-third live in care homes.
- At least two-thirds of those in care homes have dementia[30].
- Around 40% of care homes residents will have depression[31]
- 20% of care homes residents will have delirium[32]

The NDS stated that the quality of mental health care for residents could be improved by:

- A detailed specialist assessment of mental health needs following admission.
- Regular mental health reviews in conjunction with the individual's GP and Care Home staff.
- The provision of specialist advice to staff for problems arising between reviews.

Locality Review

The locality review exercise in relation to dementia in Care Homes was focused on two main areas:

- The provision of a local Care Home Liaison service providing specialist support
- Input to care homes; contract monitoring, incentive payments and failing homes improvement mechanisms.

Over half of all localities in the region currently have a Care Home Liaison service, with a joint service across hospitals and care homes in Doncaster, North Lincolnshire, Rotherham and Kirklees.

In Wakefield a robust approach to contract monitoring is being used. 3 components of the contracts are investigated:

- Contract governance.
- Performance.
- Relationship management.

The recent YHIP 'Let's Respect' report recommended that resources should be made available for dedicated Care Home Liaison Services to provide clinical support and education to care homes. The report explored the concerns of people who worked in the care homes and found that:

- Staff felt under huge pressure to deliver high quality care, but often against a back drop of low wages.
- There was little opportunity for career progression and workforce development issues.
- There was poor staff retention.
- They were frequently left to manage complex situations without support.
- There was insufficient information and guidance around alternative strategies to deal with behavioural problems.
- There was insufficient information about resident's condition post discharge.
- They were often expected to support the resident's family with little or no guidance or training.
- They felt "let down" by other professionals including GPs.

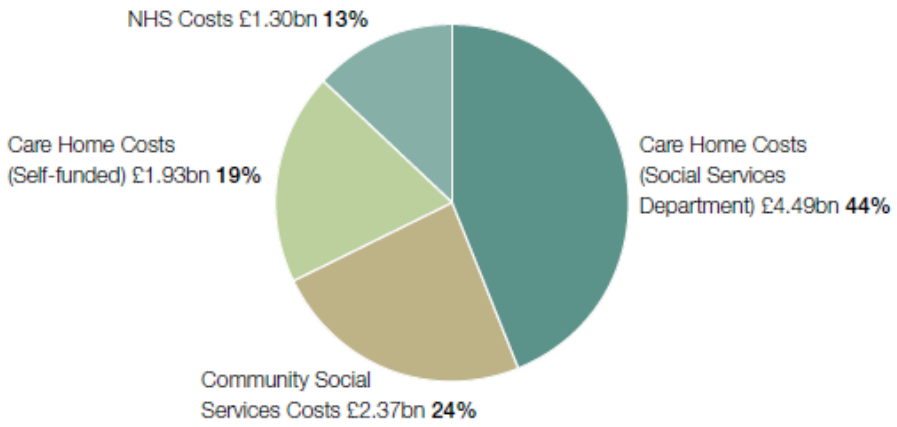
'Listening to You' reported that care homes should provide greater stimulation through purposeful activity, with opportunities to engage with the wider local community. Reviews of assessment of need should be more regular and care plans revised to reflect this.

Yorkshire & Humber currently has an overall low CQC rating for care home quality. There are issues relating to standards, consistency and a shortage of supply. In addition there are consequences relating to recent new guidance for poorer care homes and re-registration.

Improving the quality of care in care homes was the focus of discussion in many of the locality reviews.

Potential Efficiencies

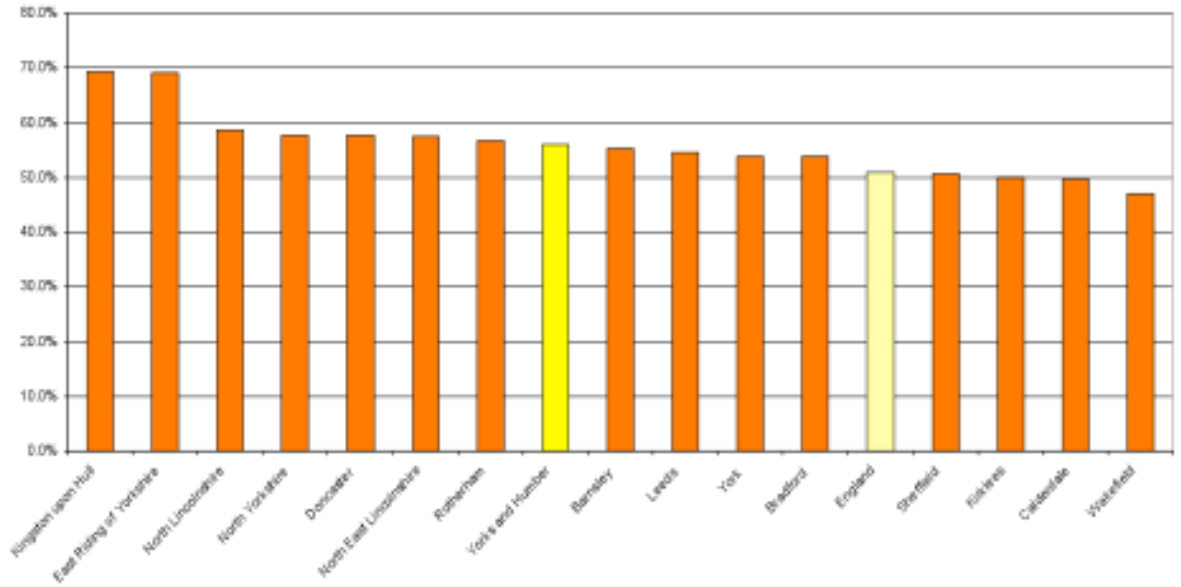
The total estimated direct cost of dementia in 2009 is £10.1 billion, the bulk of which relates to the cost of care home provision.[33]



Local authorities in England collectively spend over £3.3bn[34] on residential care for those over 65 years old providing essential care and support, however the more cost effective community based options enabling people to stay in their own homes are not receiving sufficient investment[35].

It is estimated that £567m per annum is spent in the region on residential care accounting for 57% of the total budget for social care for older people compared to 52% nationally.

Percentage of older people spend in residential homes 2008/09[36].



Patterns of spend vary considerably across the region. Local Authorities might have a high proportion of its money in residential care due to:

- High costs being paid for a number of people.
- Large numbers being admitted.
- Tight eligibility criteria only supporting people with high care needs
- Supply available that needs filling (e.g. an in-house contract that guarantees full occupancy.

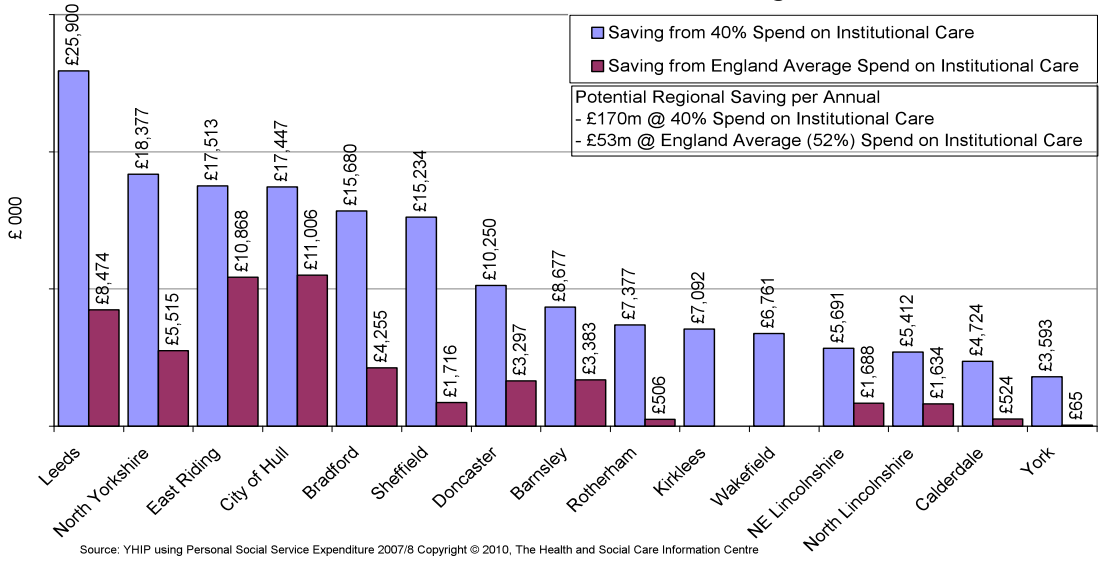
There is substantial variation in the percentage of total spend across the region. Some of the lowest are Kirklees at 49% and Wakefield 51%. The remaining localities are above the national average with Hull and East Riding localities highest at a minimum of 69% on residential care.

The Use of Resources in Adult Social Care[37] report identifies:

- Reducing the proportion of money currently spent on residential care can release money for investment in new service developments.
- A measurement of progress toward investing in preventative and early intervention services is that funding for residential care should be approx. 40% of the total social care budget for older people.

Achieving a target of 40% for spend on residential care,[38] the region could realise an efficiency saving of approximately £170m. These figures clearly relate to spend on older people, not just those with dementia and as such, should be treated with some caution. However, they do appear to correlate with the pie chart on the previous page which shows large amount of investment for people with dementia in residential care.

Chart 4: Potential Efficiency Saving From the Re-allocation of Investment in Institutional Care in the Yorkshire & Humber Region 2007/8



Source: YHIP using Personal Social Service Expenditure 2007/8 Copyright © 2010, The Health and Social Care Information Centre

An interim target for the majority of local authorities in the region would be to match the spending profile to the England average of 52% (2007/8). In achieving this level

of spend of the social care budget for older people on residential care, local authorities across the region could potentially release up to £53m for re-investment.

The Department of Health set out a range of factors to consider in understanding and potentially reducing residential care spend these include:

- The unit cost for residential care.
- The volumes admitted and supply availability.
- Eligibility criteria on supporting those with high needs.
- A high number of self funders who later become the responsibility of the local authority.

They will also be impacted by:

- Emergency admissions to hospital.
- Options for post hospital care.
- Hospital discharge arrangements.
- Availability of intermediate and reablement services, community nursing, domiciliary support, therapists, falls services, podiatry and foot care services, emergency and rapid response services.
- Availability of suitable housing options.
- Utilisation of assistive technologies.

In addition the following initiatives are considered to have potential in realising efficiency savings:

- The Institute of Public Care at Oxford Brookes University reports that joint health and social care investment in dental care, podiatry services, incontinence, dehydration monitoring, falls prevention and stroke recovery services has a positive impact on admissions to residential care[39].
- The Health and Social Care Modelling Group[40] at the University of Westminster concluded that up to 25% of new admissions to care homes can be avoided and the NAO[41] identified that annual savings could be made of £130m by delaying entry of individuals to care homes through early diagnosis and intervention.
- The use of antipsychotic medication for people with dementia: Time for action'[42] (DH 2009) report recommends that primary care trusts should commission from local specialists an in-reach service that supports primary care in its work in care homes with the capacity to work routinely in all care homes.
- Evidence is emerging that Life Story work can have an impact on a person with dementia's MMSE (Mini Mental State Examination) score. In Wakefield a person with dementia's score was 10/30 2½ years ago and after 3 months of life story work this had increased from 10 to 20/30 making him eligible for the anti-dementia drugs as recommended by National Institute Clinical Effectiveness (NICE) guidance[43]. Two years on, his score is only reduced to 16 or 17/30 and his wellbeing is much improved. The Life Story work is also used as a therapeutic tool for intervention when he is agitated or disorientated.

Rotherham Doncaster and South Humber Mental Health NHS Foundation Trust – Care Home Liaison Service

One of the objectives of the National Dementia Strategy is to improve the quality of care for people with dementia in care homes. Evidence suggests that many care homes are not providing optimal care for people with dementia and there is often an absence of a clearly defined care pathway.
In Rotherham Doncaster and South Humber the Care Home Liaison Service provide rapid access to specialist services for older people with mental health difficulties living in care homes.

This service was established in August 2006 following a successful six month pilot, which was conducted in response to national best practice guidance.
The overall aims of the service are to improve the quality of care for people with mental health difficulties living within care homes and prevent hospital admission.

The Service objectives are to:

- Provide comprehensive mental health assessments for older people in care homes and formulate person – centred care plans.
- Work in collaboration with partnership agencies and care homes to enhance evidence based person centred care.
- Support patients admitted to 24- hour care from inpatient settings and prevent readmission.
- Support, educate and train care home staff in managing and caring for older people with mental health problems.

Evaluation of the service is ongoing; data collected so far indicates the following:

- The service receives an average of 500 referrals from care homes each year.
- Numbers of care staff who have completed training in now in excess of 1200.
- There has been a reduction in the length of stay on mental health wards for people being discharged to a care home.
- There has been a reduction in the use of anti psychotic medication in care homes.
- There are fewer hospital readmissions due to placement breakdown.
- There is evidence of spread across the region with other localities expressing an interest in modelling this service
- There as been a marked reduction in hospital admissions from care homes

3.6 Workforce

National Dementia Strategy Objective: 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 necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia.

National Context

The NAO report identified that workforce capacity and capability was a serious concern in 2007 and the subsequent interim report in 2009 confirms that this continues to be the case. Almost every health professional comes into contact with people with dementia, yet there is no required basic training in how to understand and support them.

Workforce development and a need to improve staff training is a priority that runs across all the themes in the NDS. The strategy consultation process highlighted two major concerns from people with dementia and their carers that professionals:

- Did not always have the skills and knowledge required to help them get a diagnosis.
- Failed to understand the specific needs of people with dementia and were often unable or unwilling to adapt their practice to meet these needs.

These criticisms were mirrored in 'Listening to You' where increasing the knowledge and skills of staff caring for people with dementia was identified as a priority action.

The 'Counting the Cost' report suggested that 97% of general nurses work with people with dementia[44] and yet they have no formal training. Consequently, staff lack awareness, confidence and the training required to offer alternative non-pharmacological person centred interventions for people with dementia with complex needs which can lead to the inappropriate use of anti psychotic medication[45].

The report recommends that hospitals need to look at staff capacity for the delivery of high quality dementia care and prioritise workforce development budgets for dementia training. A lack of skills and training amongst general hospital staff has been linked to poor quality of care of people with dementia in general hospitals.[46]

Further problems with staff recruitment and retention impact on the effectiveness of staff working with people with dementia. Stigma attached to dementia gives care work a low status in society which can often lead to low morale and motivation amongst staff and have a negative impact on recruitment.

The Department of Health has commissioned Skills for Care and Skills for Health to map the training needs of the workforce and the training currently available across all sectors, identifying the gaps. The mapping exercise is expected to conclude in March 2010 and make recommendations to inform the DH Workforce Development Action Plan. The NAO interim report has recommended that this includes a timetable for incorporating dementia awareness and care into medical and nursing training. In addition by the end of 2010 there should be an accreditation scheme for dementia training for healthcare professionals allowing accredited training to count towards their professional development.

Locality Review

Locality review findings indicated that two thirds of the localities in the region reported delivery of training to workforce via Care Home Liaison Services, with a joint service across both the hospital and Care Home environments being operated in the Doncaster, North Lincolnshire, Rotherham and Kirklees localities.

The locality review identified an extensive range of dementia courses available across the region ranging from basic awareness courses to modules in a Masters degree. Not all courses were free of charge and a number of individuals within localities stated that courses were self-funded. A number of the staff groups e.g. liaison services, memory clinics and community mental health teams reported that they provided training on dementia and dementia care to other staff groups including care homes and for home care staff.

However there appeared to be very little evidence of co-ordinated training plans/resources within localities other than individual organisations and no evidence of a co-ordinated approach across localities.

Data relating to the number of training courses available and numbers of staff accessing such courses has not been presented due to the complexity of the data collection process.

The ‘Lets Respect’ care homes report highlights that good quality training is crucial to drive up the standard of care in care homes and recommends that good quality training should be provided jointly between the Local Authority and NHS trusts.

The regional ‘Let’s Respect’ work stream focused on the adaptation of training materials specifically for care homes used in the National Campaign, Let’s Respect (DH 2006). The campaign has been used extensively across the Yorkshire and Humber region, the UK and internationally. It provides a toolkit and other accessible and innovative resources including presentations and podcasts, highlighting the mental health needs of older people in hospital.

These resources can be accessed via: www.mentalhealthequalities.org.uk/our-work/later-life/lets-respect/.

North East Lincolnshire – Dementia Academy Project

As part of their initial work to look at the implementation of the National Dementia Strategy, North East Lincolnshire has chosen to focus on providing dementia training, information and advice across the health and social care community. This work will be carried out through the development of a Dementia Academy.

The project consists of three elements:

- A Dementia Care Mapping Team – this team is already established and consists of twenty two Bradford Dementia Group trained mappers who operate across the locality. The team also provides intensive support and training to areas following mapping exercises.
- Training, Support and Workforce Development – this training, support and information service is planned for anybody who provides care for a person with dementia in any setting. This service will provide accredited and quality assured training by pooling resources across the health and social care community and developing a robust local training team and modular flexible training programme for all. This service will aim to drive up standards and remove inequalities.
- Person Centred Care Advisory Team – this team will be headed by a qualified lead and staffed by a group of trained volunteers. The team will follow up training and Dementia Care Mapping by working within an establishment or a person's home; demonstrating Person Centred Care and developing an appropriate programme for implementation. The team will also assist in developing operating procedures, protocols and associated guidelines reflective of best practice

The team will support the work of community based primary care teams by providing specialist dementia input and training and assist the hospital liaison team in delivering training and support into general acute wards and A&E.

For further details about the Dementia Academy please contact Jeanette.Logan@nelctp.nhs.uk

Potential Efficiencies

The NAO Report found that 28% of GPs interviewed were not confident in their dementia diagnosis and 42% were not confident in advising patients on dementia management.

Providing education, support and training for GPs, care home and general hospital staff can lead to a reduction in the use of anti psychotics, medication costs and reduce the risks associated with use of such medication (for example falls). Recent research[47] reveals that 70% of care homes residents experience drug errors caused by poor staff training. There are approximately 180,000 people with dementia being treated with anti psychotic drugs at any one time, and whilst it is recognised that there is no doubt that they can help some people with dementia, evidence suggests that they are being used too often[48].

A project in Kirklees providing education and support to care homes has seen a significant reduction in the use of anti-psychotic medication for people in care homes. Medication costs for the PCT have been reduced by £31,584 in one year. The quality of care for people with dementia has also improved with an increase in person centred activities. Further emerging evidence suggests that the impact of such teams can reduce the reliance on other mental health teams and unnecessary hospital admissions[49]

Building staff capability through training and development is likely to improve the social status of working with people with dementia and ease recruitment and retention problems. The Old Vicarage care home in Dorset spends 8% of its turnover on staff training, which includes an apprenticeship scheme to recruit staff, induction, mandatory training, NVQ and additional units of training. Staff turn over has reduced to 4% whilst the quality of care is now such that residents are cared for from admission to end of life with no requirement to move into hospital due to lack of skills and training.[50]

The good management of mental health problems can make significant contributions to the effectiveness and efficiency of acute hospitals and improve outcomes for patients[51]. Evidence suggests that the education and support provided to general hospital staff by specialist mental health liaison teams can lead to an increase in the early detection of dementia and a reduction in the length of stay for people with dementia; with cost savings from a reduction in bed days. The impact of a Specialist Liaison Team in Leeds has seen the average length of stay for a person with dementia in an acute hospital reduced by an average of 4 days.

3.7 Commissioning and Performance

National Dementia Strategy Objective: 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 how best to meet these needs. Those commissioning plans should be informed by World Class Commissioning guidance for dementia developed to support this strategy'

National Context

People with dementia often live with their condition for a number of years and their care needs change over time, as do their need for health and social care services. It is therefore important that commissioners consider providing services in a coherent joined-up approach.

The NDS Joint Commissioning Framework[52] provides supplementary information identifying some of the levers available to commissioners to deliver the Strategy. However the NAO interim report identified that 'the lack of strong levers for improving dementia care means that there is a risk that the NHS and Social Care delivery organisations will not give it the priority status expected by the Committee and the general public, and service improvements will lag behind the desired pace'.

The Department of Health made £150 million of funding available over two years to support implementation (£60 million available in 2009/10 and £90 million in 2010/11). The growth in allocations is new money and will go into the NHS baseline.

PCT allocations are deliberately not ring-fenced and broken down into funding for individual policy streams. It is for PCTs to decide locally how best to deliver the national requirements and local priorities which were set out in High Quality Care for All, the NHS Operating Framework 2009/10 over the next 12 months.[53]

The recent Public Accounts Committee (PAC) hearing asked Sir David Nicholson to identify how specifically this money had been spent on implementing the NDS. The result was agreement to audit each PCT and report findings at the next PAC hearing

The NAO report is specific in requesting:

- PCTs commission sufficient memory services.
- The next performance indicators focus on outcomes.
- An assessment is made of the potential of new quality levers such as Patient Reported Outcome Measures to apply to NHS dementia care.
- DH should work with the Care Quality Commission to ensure that the system for assessing care homes includes evidence about user experience such as direct measures of the quality of life of people with dementia.

- PCTs use their commissioning framework and contracts with Acute and Foundation Trusts to ensure full participation in the National Clinical Audit of Dementia Services from 2010.
- The DH should, by 30 April 2010, provide an open online database of local performance information by publishing the agreed dementia metrics on the Dementia Portal, and allowing localities to upload their data, benchmark their performance and provide accountability to the public and partners.

It also found that care home managers lacked awareness of the Strategy and did not have a 'co-production' relationship with local commissioners.

The report concluded that 'joined-up working remains patchy and as a result people with dementia are still being unnecessarily admitted to hospital, have longer lengths of stay and enter residential care prematurely. Whilst we found examples of good practice, these were not adopted widely'.

Locality Review

The locality review focused on:

- The local arrangements for the strategy.
- The level of consultation that had been undertaken with people with dementia and their carers.
- Investment sources for the new service developments.

Many localities included dementia within their Joint Strategic Needs Assessment (JSNA). A good example is Kirklees which contains detailed work on dementia, trends and modelling with fact sheets for providers.

The extent of Joint Commissioning varies across the region, but joint commissioning for improved outcomes for dementia is not yet evident and is recognised as a complex area. The locality review identified this as a priority area for development. This has already been developed in Lancashire where a framework has been developed to provide a clear set of outcomes to ensure that delivery of the NDS across Lancashire is firmly rooted in the expectations and aspirations of local people who are affected by dementia. The document is available here: www.yhip.org.uk/dementia.

In Doncaster a commissioning forum has been meeting for the last 18 months, resulting in a more joined-up approach. In Sheffield[54] a plan has been in existence since 2007 and a multi-agency group has now been established to oversee the implementation of the service transformation.

Commissioners reported that consultation exercises with people with dementia and carers had taken place on the development of the commissioning plan for dementia services in 6 localities across the region. An example of positive practice was found in Doncaster (see below).

In just over half of the region's localities commissioners have redesigned services to provide more support in the detection and care of people with dementia. These

service developments include Memory Clinics, enhanced Community Mental Health Teams, Acute Care / Care Home Liaison services and Crisis at Home teams. Barnsley and North Lincolnshire have reconfigured local authority Home Care services into reablement services.

Bradford, Rotherham and Wakefield reported funding for new services had been identified through the reduction in surplus capacity in mental health inpatient facilities and in North Lincolnshire the reduction in surplus residential care capacity has funded the new developments in the Home Care service.

Doncaster – A world class commissioning initiative for people with dementia and their carers

In Doncaster a wide and varied consultation initiative has aimed to ensure that people with dementia and carers are meaningfully engaged in the design and delivery of services. This consultation has included a focus on BME and co morbidity (stroke). This initiative has produced a cooperative framework for involvement where by people with dementia and their carers are involved throughout the governance of the commissioning process.

Collective action is symbolised locally by the PROP (People Relying on People) group, a patient and carer group that lobby to ensure the development and improvement of dementia services for all age groups; particularly younger people with dementia. Collective action has also produced recent partnership working resulting in interagency and cross border commissioning of Dementia Cafés.

Research findings linked to this approach have demonstrated co learning, with one study focusing on patients and carers experiences of involvement and another study commissioned and performed by ARC Research and Consultancy Limited; involved measuring patients and carers' journey and experiences up to receiving a dementia diagnosis.

For further information please contact: Wayne.Goddard@doncasterpct.nhs.uk

The 'Listening to You' report is available at www.yhip.org.uk

Potential Efficiencies

The potential efficiencies and positive practice examples for each part of the dementia pathway have been identified in the preceding chapters.

The NDS is clear that implementation is to be funded largely through efficiency savings (reducing unnecessary use of acute hospital beds) and re-direction to other areas of the pathway (early diagnosis and intervention in people's own homes). The Impact Assessment identified annual savings of £130m from 2013-14 (a net saving of £533m over 10 years), based on delayed entry to care homes through early diagnosis. The NAO interim report case studies identified a further efficiency savings of at least £234m a year that could be identified now. This is, however, dependent on widespread adoption of good practice and being able to release funding from the acute sector to other health and social care settings, which has historically been difficult to achieve.

Dementia does not feature in NHS Operating Framework against which performance is monitored. As such, PCTs may not see this as a 'must do'. In the absence of this steer, improvements could still be driven by local effective leadership, joined up commissioning with quality incentives and comprehensive performance information. Guidance from the National Institute for Health and Clinical Excellence provides evidence based, cost effective national recommendations that can be used to support local decision making.

Current monitoring of dementia services is based largely on input and output measures such as:

- Inclusion in GP registers.
- Hours worked.
- Number of tasks of daily living completed by care workers in people's homes.

The locality reviews confirmed that Commissioners only have limited data on the effectiveness of services to improve the quality of life for people with dementia. There is a lack of robust information which makes it more difficult to make a case for new services or changes to existing ones.

4. Conclusion

The locality reviews across Yorkshire and Humber found that the quality and availability of services for people with dementia and their carers varied enormously. There were many examples of positive practice, some included in this report and expanded upon in the Innovations Directory. However, the consequence of this variation is that the support for people with dementia is neither consistent nor universally available.

This report evidences the fact that the range and breadth of services required is complex and that the interconnection between different parts of the health, social care and wider system is critical to success. In the light of this, the joint commissioning of a clearly defined outcome focused pathway is central to improving services.

A coherent approach to improvement is required across the region and will include:

- Co ordination of a single regional programme of improvement under the direction of the Mental Health Pathway Leadership Group to address common areas of challenge and barriers to implementation.
- Ensuring that different funding streams for improvement are effectively aligned.
- Providing support to localities with implementation of action plans specific to issues in their own area.
- Ensuring that learning and best practice are spread.
- Improvement plans that are informed by the views of people with dementia and their carers.
- Optimising the role of Council members to lead and shape the agenda
- Strengthening the relationship between this programme and other regional initiatives, (particularly the Joint Improvement Partnership) in areas such as commissioning, personalisation, workforce and safeguarding.
- Facilitating effective joint working with other regional partners such as the Care Quality Commission, Universities and Local Government Yorkshire and Humber.

A regional programme of improvement needs to be agreed by the Mental Health Leadership Group taking account of the headline messages in this report:

Early Diagnosis: Although the detection of dementia in this region is higher than the national average, there are still more people with dementia not in touch with services than those that are. There is also an issue around capacity planning evidenced by variation in waiting times. The role and impact of navigators/advisors also needs to be better understood.

Community and Personal Support: Some localities have achieved significant success with community based initiatives developed under the POPP pilots, which have reduced reliance on more intensive services. Other areas have made rapid progress with individual budgets, telecare and extra care housing. However the overall optimum mix of community supports required is not clear. Further work

is required to understand the impact of reablement and how the role of generic health and social care teams needs to change to reduce admissions to acute hospitals.

Carers: This section provided perhaps the greatest level of variation. Data specific to assessments and support for carers of people with dementia was often not available or not routinely collected.

Acute Care: A more detailed analysis of the issues in acute hospitals is underway in this region but it is clearly desirable to achieve a reduction in admissions, reduced length of stays and improvement in the care of those that are admitted. The care of people with dementia is a high priority for regional leaders.

Care Homes: The spend on residential care for older people in this region is higher than the national average. The nature of the relationship between admission to acute hospitals and care home settings (and back again) needs to be better understood as does the optimum provision of services to reduce use of this sector.

Workforce: The availability of data on workforce development was limited. There was recognition that a high percentage of health and social care staff come into contact with people with dementia across the system but there was little evidence of coordinated cross organisation training initiatives. The experience of staff and need for training was a particular concern in acute hospitals and care homes.

Commissioning: Entering a period of no economic growth with rising prevalence and demand for services requires commissioners to effectively redesign their local systems. The report highlights the need for better understanding of total spend on dementia, availability of data, the movement of resources across a system and the development of a consistent pathway of care.

In summary, this report makes the clear case for change and clarifies the need to agree the scope and focus of that change in the year 2010/11.

5. Acknowledgements

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- **Michael Jackson** - Freelance researcher.

For Further Information

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Please Note

The analysis in this report is based on the material collected during the review process, with notes taken during the visit appraised by the Local Dementia Lead and supplied to the report authors. The submissions to the authors are taken on face value as being materially factual and correct.

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The National Dementia Strategy
Where are we now?
Where do we want to be?

Judith Knapton
Head of Commissioning
(Services for Vulnerable People)
NHS North Yorkshire & York

'Local' discussions

- Craven
- Harrogate / Ripon
- Hambleton & Richmondshire
- Scarborough, Whitby & Ryedale
- Selby
- York
- LD Teams

Results

Area	Objective												
	1	2	3	4	5	6	7	8	9	10	11	12	13
Craven	√	√					√	√					√
Harrogate/ Ripon		√				√		√			√		√
Ham & Rich		√				√		√	√		√		
SWR		√						√			√		√
Selby		√				√	√	√			√		
York		√					√	√	√				
LD							√	√				√	

Priorities:

- **Good quality early diagnosis and intervention for all.**
- **Improved community personal support services**
- **Implementation of the Carers Strategy.**
- **Improved quality of care for people with dementia in general hospitals**
- **Living well with dementia in care homes.**
- **Informed and effective workforce**
- **Improved end of life care** (LD)

YHIP Peer Review

What is going well:

- Commitment to improve services for people
- Once in the system people get a good service
- Involvement of the third sector

What needs improving:

- Whole system care pathway needed / greater integration
- Inequity of provision across the county

Where do we want to be?

The aim for North Yorkshire and York is to develop services for people with dementia that:

- Are sensitive to each persons individual circumstances
- support people to live independent, productive, fulfilling and active lives for as long as possible
- encourages people and their carers to be actively involved in the decisions made about their care.
- Support people in negotiating along the care pathway as and when they choose as appropriate
- Provide information in a way that is understood and helps to support the person and their carers in the options available from diagnosis to end of life.
- Are in line with best practice and wherever possible good evidence based practice and are cost effective.

Structures to support implementation

- Long term joint planning and commissioning
- Links to other developments - Workforce / Estates
- Effective & Informed Workforce
- Regional dementia group
- North Yorkshire & York Dementia Network
- Map of Medicine (care pathway)

DRAFT 2 June 2010.

North Yorkshire & York Dementia Network
Terms of Reference

August 2010

1. Aim:
The Network aims to promote collaborative working across agencies, professional groups, users and carers and the voluntary and independent sectors.
The network will inform and actively support the implementation of the North Yorkshire and York dementia strategy.

The network will:

- Obtain agreement between network members and recommend to commissioners the overarching care pathway for people suspected of and with dementia
- Gain agreement between members and put forward recommendations for the standards of care that should be expected throughout the pathway
- Agree measurable outcomes expected from services
- Monitor the localization of the care pathway to take account of local circumstances whilst achieving the same outcomes
- Raise awareness of dementia and reduce stigma associated with it
- Act as a body of expertise to inform the commissioning of services
- Share good practice and arrange process for show casing good practice and learning.
- Provide a mechanism for improving communications between agencies / organsiations
- Identify efficiencies that can be made in the care pathway that benefits people with dementia and their carers.

2. Principles and Values:

The network will promote:

- A partnership approach, based on respect between statutory and voluntary organisations, and people and their carers in receipt of services.
- An integrated approach to care to provide seamless services.
- An holistic approach in the planning and delivery of services
- Service users and the general publics involvement and engagement (being able to demonstrate how this takes place particularly if there are no service users and carers attending the network)
- Equity, equality and diversity in care provision
- Efficiency and the best use of time and resource

- Quality information, advice and access to evidence and effective interventions and outcomes.
- An open policy of sharing information, unless particular documents are marked otherwise.

3. Key Objectives:

- Create a positive 'sharing and learning' network that leads and establishes standards of practice and promotes methods of working that enhance the user and carer experience. It promotes self help, access to appropriate skills and advice closer to home, consistency and continuity over prolonged periods of time.

- Work collaboratively to support the creation of initiatives and implementation of new ways of working through specific workstreams to achieve the desired outcomes identified in the North Yorkshire & York Dementia Strategy.

- Monitor progress towards the objectives in the National Dementia Strategy and contribute to a report for the commissioners of health and social care on a quarterly / 6 monthly basis and to a NY&Y Dementia bulletin.

Membership:

Service Users and carers
Health service provider services – front line staff and management

- GPs / Practice Nurses
- Community and Mental Health Teams
- Intermediate Care / Fast response staff
- District Nursing
- Community Matrons
- Case Managers
- Health Care Assistants
- Therapy services
- Acute Trust

Social care staff – front line staff and management

- Care Workers
- Home care staff
- Therapists
- Care assistants
- Assessment staff

Housing staff
Voluntary sector organsiations

Independent care providers
Care home providers
NHS North Yorkshire & York – Commissioners
City of York Council – Commissioners
North Yorkshire County Council – Commissioners
Practice Based Commissioning Groups
LINKS (Local Involvement Networks)

Other staff will be invited to attend as and when it is relevant to do so for example Workforce Development / Public Health
All sectors are welcome to join if they are committed to the aims, objectives, principles and values of the Network, however it is not mandatory.

Sub-groups

Sub groups will be set up to progress identified workstreams. Relevant expertise will be asked to contribute to the workstream but must be led by a member of the Network. All subgroups will report back to the network on a regular basis either via a dementia Bulletin or presenting at the network meetings themselves.

Frequency of Meetings:

Meetings will be held three times a year from approximately 1.30 to 4.30pm on agreed dates.

Accountability / Reporting mechanism

Each individual member will be responsible for feeding back to their staff / teams / colleagues and feeding their colleagues views in to the network.

The Network will provide a report to the Mental Health Modernisation and Partnership Boards for York and North Yorkshire.

The network will provide reports for the NHS North Yorkshire & York; City of York Council and North Yorkshire County Councils respective commissioning Boards.

Ensure that the Adult Strategic Partnerships are aware of the challenges, opportunities and potential solutions in supporting people with dementia, emphasising the value of partnership working

July 2010

North Yorkshire & York Dementia Network
Galtres Centre, Easingwold
Held on 16th June 2010

Present:	John Bettridge	JB	York (MH Modernisation & Partnership Board)
	Brian Carter	BC	NYCC (Telecare)
	John Clare	JCl	NHS NYY (CMHT)
	Jan Cleary	JC	NYCC
	Emma Day	ED	Scarborough Hospital Trust
	Tony Hall	TH	NYCC
	John Kelly	JKe	CMHT
	Judith Knapton	JK	NHS NYY
	Judith Lambert	JL	NYCC
	Helen Mackley	HM	NHS NYY (CMHT)
	Catherine McGovern	CMc	City of York Council
	Jan Mclauchlan	JMc	Scarborough,Whitby Ryedale
	Kath Murray	KM	North Yorkshire LINK
	Cursty Pepper	CP	Harrogate DFT
	Kevin Pratt	KP	NHS NYY (CMHT)
	Jill Quinn	JQ	Alzheimers Society
	Phil Richardson	PR	Hambleton & Richmondshire (NYCC)
	Olympio D'Souza	ODS	Scarborough Hospital Trust
	Tania Stephenson	TS	City of York Council (Specialist Home Care)
	Norma Sutton	NS	NYCC
	Jackie Tonkin	JT	Scarborough,Whitby Ryedale
	Keren Wilson	KW	Independent Care Group

		For Note Action
1	**Terms of Reference**	
	Agreed to add LINKs to membership and Recognise it is open for all sectors to attend, but not mandatory.	JK
	4th aim: CYC suggest change 'monitor' to review (its was previously 'ensure') – after discussion decision made to keep 'Monitor'	
	With change to membership all agreed TOF are now final. But to be reviewed in the future.	
2	**Draft Strategy**	
	Judith working on next draft after consultation. Agreed: the lack of an integrated care pathway and integrated teams, need to be highlighted or nothing will change. Discussions with NYCC on pathway have begun and to be arranged with CYC	JK
	Regional Feedback by Judith	
3	Stressed need to link all developments to outcomes and savings.	
	SCIE – Excellent training booklets www.scie.org.uk also at Socialcare TV – Part	

		For Note Action
	of scie (Social Care Institute for Excellence) Request made for update on progress from the demonstrator sites	JK
4	**Workstreams –update:** **Objective 13: Effective Workforce** (Jan Cleary /Jan Mclauchlan) - One meeting held and another arranged for next week – Only acute trusts missing (+ CYC omitted in error). Membership includes: PCT provider and workforce development, Tees Esk & Wear Valley (Provider of MH services in the Scarborough Whitby and Ryedale area), Alzheimers Society, North Yorkshire County Council /Workforce Development Unit. It was a very positive start. Dementia e-learning package (made up of 4 modules) being tested for CAFWD (Care Alliance for Workforce Development) with different staff groups including Libraries. 50 Packs are available for use in small organisations and then the Alliance will seek to tailor the use of the 4 modules for different staff groups for induction and professional training in dementia and roll out across all the workforce similar to the approach used in safeguarding training. The modules can be phased to suit individuals and used as they gain experience.	
	The second meeting will consider a draft competency framework. There is money available for these developments. Could we move to a position of standardising the training delivered across the network? The alliance has 40 packages paid for, anything else would need funding – is training the trainer approach the only way. E-learning not the only method.	JC
	- Talking Mats – New communication tool (uses picture cards). Kerin Wilson to enquire who is using it. Phil Richardson might consider using them in a care home.	KW PR
	Objective 6: Personal Support/Advocacy (Jan Cleary/ Norma Sutton / Judith Knapton) -Dementia advocacy notes + literature search to be sent again with notes. (sent 17/6/10). It was agreed that Norma Sutton and Jacki Tonkin would work together to ensure that the dementia requirements be developed and fed in to the discussions between the PCT / NYCC / CYC and the advocacy services. All contributions welcome. Please send to norma.sutton@northyorks.gov.uk NYCC + PCT and PCT + CYC are reconsidering their approach to advocacy across the board within current budgets. Key issues for dementia: - Must focus on the user specifically (Not just take account of what carer	JC/NS/ JK

	For Note Action
says). - Harrogate advocacy have put a costed proposal together. Jill Quinn to circulate to network	Jill Quinn
Personal Support (Obj 6 continued): - Dementia training is planned for all reablement staff - CYC: Re-tendering for contracts for home care. - Recognised that one of the 4 modules above is about communication skills and this will be vital for all staff whatever the client group. Needs to be in contracts and performance managed and logged.	JC CMc
Objective 8 General Hospital One meeting held. Second to be arranged. All present except Scarborough. The network welcomed the new matron for Scarborough General Hospital as a member who will be the representative on the group. Issues discussed: - Training and development: Acknowledged it is a challenge to release staff for training but is essential in gaining a greater understanding by staff in how to treat and care for those in the care of the hospital. - Systems, Processes and protocols: various tools available to support the person with dementia, their carer and staff. - Support for Carers: recommendations within the Association of Directors of Social Services (ADASS) report on carers in general hospital to be included in the discharge policies. - Liaison services: not available everywhere but plans to develop this service in all hospitals. PCT expects to see a commitment from each acute trust they are training staff and putting other measures in place to support people with dementia and their carers before the liaison service is commissioned. Mapping of current + future plans to be done. In Scarb the hospital discharge liaison nurse attends locality meetings and new SGH medical matron was present at this network meeting. P/T consultant in psychiatry is piloting care home liaison in Scarborough.	
Workforce group and Gen hosp group to meet together.	JC/JK
In Harrogate the scheme which identifies patients with dementia using a butterfly, was to be matched with training dementia nurses who would wear a butterfly. Reported that may have been overtaken by designated link nurse on each ward and the increased use of ‘All about me’ documentation for patients.	

	For Note Action
PCT is also in discussion with providers about developing a liaison services into care homes.	
Other issues	
– Appropriate and timely info sharing. CMHT identify people that have eventually come to them and found that they have had a scan for another condition which has highlighted signs of dementia but the person has not been referred to them.	JK to raise with group
- Appropriate discharge practice	JK
- Anti psychotic medication: CMHT noted that patients are being discharged from hospital having been prescribed anti psychotics. Usually only prescribed as a last resort and a feeling some patients are put on it without considering other options first. Is prescribing monitored by drug type/prescriber/client group in all hospitals. Would we need a benchmark as to acceptable use/or is it all case by case/ or should it only be used by a specialist service after holistic risk assessment?	
- In care homes, issue of some GPs who prescribe and do not review.	
- General hospitals, not just care homes need to be included .in any audit.	
- Also wide variations in dementia drugs use across PCT area – Could this be included in the audit?	
Obj 12 End of Life Care:	
End of Life strategy is for all but needs to be 'Dementia Proofed' and appropriate.	
Liz Vickerstaff is PCT lead and next county meeting 1st July – Judith or deputy to attend. Strategy being subsumed in PCT key themes.	JK
Pet Fowler Watts, ex-matron from Lister House might provide some expertise if needed Jill Quinn has contact	
Recent work has focused on 'Do not resuscitate practice'.	
Kerin Wilson, Independent care Group(ICG) is standing member of the End of Life group	
Obj 2 Early support services	
The development of an early assessment and diagnosis service across NY and Y is being linked to the 'Transforming Community Mental Health Services' (process for the split of provider services from the Commissioning side of the PCT).	JK
Intermediate Care: Aim will be that all staff involved should be trained in dementia and OP Mental Health and we are not seeking to establish separate services.	JK

		For Note Action
	-CMHT reported that some GPs charging the service for use of surgery premises to see and support the practices own patients.	
	- 3 GPs have been identified to lead the dementia work for their PBCs (and are included on this network)	
	-PCT Mental Health provider have developed a strategic business plan for integrated mental health and community health services, but could be an 'in principle' model for full integration at later point with wider inclusion of partners. John Clare to forward the plan to JK for circulation to the network.	JC /JK
	- Meeting next week to discuss integrated Care pathways – Seamus Breen, Kevin Pratt, John Clare, Paul Hyde, Judith Knapton and others from ACS Ops.	JK
8	**Minutes of Last Meeting:**	
	- Pathways to be shared TEWV, York	JMc/ JK
	- Discussion held regarding links to Housing and Housing strategies – to invite Juliette Daniel, Strategic Manager Accommodation with Support + Heather Burden from CYC	JK/JC/ NS / CMc
	- To consider invitation to chief housing officers or attending their meeting to promote dementia. Avril Hunter of NYCC is a member.	JK
	- Brain Carter will promote dementia in the Telecare forum	BC
	- CYC has same principles for housing authorities when considering social care needs – Kathy Clarke to be asked to share this	CMc / K.Clarke
	Alzheimers Awareness Week – Craven Focusing on Schools in June. 5-18 year olds – Harrogate Psychology service will link with AzS and Library service	
	Impact of National Awareness raising : - 10% increase in referrals in TEWV - Spike in referrals in Ham and Rich - Steady increase in York - Ham and Rich have higher numbers of younger people being treated than prevalence figures would indicate NYCC mobile Libraries are taking new dementia books out with them	
	Map of Medicine – Care Pathway - National 'map' for dementia available on the internet. Link : http://eng.mapofmedicine.com/evidence/map/dementia1.html	

		For Note Action
	- Map with local amendments, has been circulated to those involved from the Ham/Richmondshire and York/Selby areas for comment or amendments. - Further work needed to ensure gives a holistic care pathway and not just medical elements of care. - JK to circulate it to all on the network.	JK
7	**Other Issues Raised:** a) One of the other priority areas is Objective 11 Living Well with Dementia in Care Homes. Care Quality Commission (CQC) have suspended the ratings system for care homes. It will be replaced by something else. Lack of confidence in the old rating system. Agreed we need to ensure good standards in all homes. Some are very good others need a great deal of improvement. A sub group of the network (utilising the Scarborough group already in existence for some time) to be tasked with: - producing a draft set of standards for care homes (to be in line with requirements of CQC standards) - producing information for people who are self funders for when they are choosing a home that will give a good standard of care for those with dementia (taking into consideration the information already available eg from AzS and the councils) - How to engage with service users and carers of Care Homes to establish their views (without them having any fear of any comeback if they complain) -	JT/NS JT and Group
8	**Any Other Business:** a) Life Story work – An event – new toolkit: Regen Centre, Riccall – 21st September b) NYCC Care and Independence Overview & Scrutiny Committee workshop on Thurs 2nd Sept – an event to engage new and 'old' councillors in the dementia strategy (Councillor Tony Hall , Chair) The focus will be on what local and national progress has been made 2 years on and is the position adopted in Jan 2009 still relevant. The Chair is particularly keen to know whether services have improved on the ground. Gill Ayling from the Department of Health has been invited to attend. Members of network to be invited and need to celebrate what we have achieved. Kevin P' to seek clinical input. Please note: after the workshop, it was confirmed that this event will be in the morning of 2nd September. The network representation to be agreed to provide input. The network meeting will be separate to this.	Kevin Pratt TH / JK

		For Note Action
9	**<u>Next Time:</u>** Any topic suggestions welcome To include: - Housing and dementia - Updates from subgroups on ● Workforce ● General Hospitals, ● Advocacy.Care ● Care Homes **<u>Date and Time of Next meeting</u> of the Dementia Network** **Thursday 2nd September Start at 1.30pm – 4pm** **Galtres Centre, Easingwold.**	