Notice of meeting of
Decision Session - Cabinet Member for Health, Housing and Adult Social Services

To: Councillor Simpson-Laing

Date: Tuesday, 22 November 2011

Time: 4.30 pm

Venue: The Guildhall, York

A G E N D A

Notice to Members – Calling In

Members are reminded that should they wish to call in any item on this agenda notice must be given to Democracy Support Group by:

10:00am on Monday 21 November 2011 if an item is called in before a decision is taken, or

4:00pm on Thursday 24 November 2011 if an item is called in after a decision has been taken.

Items called in will be considered by the Scrutiny Management Committee.

Written representations in respect of items on this agenda should be submitted to Democratic Services by **5:00pm on Friday 18 November 2011.**

1. Minutes (Pages 3 - 4)

To approve and sign the minutes of the meeting held on Tuesday 25 October 2011.

2. Declarations of Interest

At this point Members are asked to declare any personal or prejudicial interest they may have in the business on this agenda.

3. Public Participation

At this point in the meeting members of the public who have registered their wish to speak at the meeting can do so. The deadline for registering is **5:00pm on Monday 21 November 2011**.

Members of the public may register to speak on:-

- an item on the agenda;
- an issue within the Cabinet Member's remit;
- an item that has been published on the Information Log since the last session. Information reports are listed at the end of the agenda.

4. Annual Update on the Carers Strategy (Pages 5 - 86)

This report provides the Cabinet Member for Health, Housing & Adult Social Services with an annual update of the Carers Review 2010/11.

5. Dementia Strategy and Action Plan (Pages 87 - 178)

This report asks the Cabinet Member to approve the North Yorkshire and York Dementia Strategy, and the local plan to deliver the Strategy in York. It also seeks agreement to sign up to the Dementia Declaration.

6. Urgent Business

Any other business which the Chair considers urgent under the Local Government Act 1972.

Information Reports

No information only reports have been published on the Information Log for this session.

Democracy Officers:

Catherine Clarke and Louise Cook (job-share)
Tel: (01904) 551031
E-mail: catherine.clarke@york.gov.uk and louise.cook@york.gov.uk

For more information about any of the following please contact the Democracy Officer responsible for servicing this meeting Catherine Clarke or Louise Cook Democracy Officers

- Registering to speak
- Written Representations
- Business of the meeting
- Any special arrangements
- Copies of reports

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Agenda Annex

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If you would, you will need to:

- register by contacting the Democracy Officer (whose name and contact details can be found on the agenda for the meeting) **no later than** 5.00 pm on the last working day before the meeting;
- ensure that what you want to say speak relates to an item of business on the agenda or an issue which the committee has power to consider (speak to the Democracy Officer for advice on this);
- find out about the rules for public speaking from the Democracy Officer.

A leaflet on public participation is available on the Council's website or from Democratic Services by telephoning York (01904) 551088.

All the reports which Members will be considering are available for viewing online on the Council's website. Alternatively, copies of individual reports or the full agenda are available from Democratic Services. Contact the Democracy Officer whose name and contact details are given on the agenda for the meeting. **Please note a small charge may be made for full copies of the agenda requested to cover administration costs.**

Access Arrangements
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Holding the Cabinet to Account

The majority of councillors are not appointed to the Cabinet (39 out of 47). Any 3 non-Cabinet councillors can 'call-in' an item of business from a published Cabinet (or Cabinet Member Decision Session) agenda. The Cabinet will still discuss the 'called in' business on the published date and will set out its views for consideration by a specially convened Scrutiny Management Committee (SMC). That SMC meeting will then make its recommendations to the next scheduled Cabinet meeting in the following week, where a final decision on the 'called-in' business will be made.

Scrutiny Committees

The purpose of all scrutiny and ad-hoc scrutiny committees appointed by the Council is to:

- Monitor the performance and effectiveness of services;
- Review existing policies and assist in the development of new ones, as necessary; and
- Monitor best value continuous service improvement plans

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City of York Council	Committee Minutes
MEETING	DECISION SESSION - CABINET MEMBER FOR HEALTH, HOUSING AND ADULT SOCIAL SERVICES
DATE	25 OCTOBER 2011
PRESENT	COUNCILLOR SIMPSON-LAING

18. DECLARATIONS OF INTEREST

The Cabinet Member was invited to declare at this point in the meeting any personal or prejudicial interests she might have in the business on the agenda.

No interests were declared.

19. MINUTES

RESOLVED: That the minutes of the last Decision Session of the Cabinet Member for Health, Housing and Adult Social Services, held on 27 September 2011, be approved and signed as a correct record.

20. PUBLIC PARTICIPATION

It was reported that there had been no registrations to speak at the meeting under the Council's Public Participation Scheme.

21. PUBLIC CONSULTATION ON A NEW MANDATORY POWER OF POSSESSION FOR ANTI-SOCIAL BEHAVIOUR

The Cabinet Member considered a report which set out details of consultations being undertaken by the government on proposals to strengthen the sanction social landlords' had to evict tenants who had committed serious anti-social behaviour (ASB).

It was reported that the main changes proposed were:

- Courts could grant possession where a tenant or member of their household had been convicted of violence against property, violence against persons at a scene of violent disorder or theft linked to violent disorder. There would be no requirement that the offence had been committed within the locality of the dwelling house.
- Power to evict for serious, housing related anti-social behaviour proven by another court.
- Powers limiting the court to suspend a possession order.

Officers confirmed that the most controversial element of the proposals were the widening of existing powers to apply for repossession on issues of ASB and criminality that had not necessarily happened in the locality of the tenants residence. Officers pointed out that, although these powers were a welcome addition, they would only be used as a final resort with less punitive measures being used to try and resolve problems.

The Cabinet Member confirmed that she welcomed the new powers but requested that any action taken should be proportional and take account of its impact on families.

Following further discussion it was

RESOLVED: That the Cabinet Member endorses the response at Annex 1 of the report to the consultation document on the new mandatory power of possession for anti-social behaviour.
1.

REASON: To offer City of York Council's views on the consultation paper.

Action Required
1. Forward consultation response. TB

Cllr Simpson-Laing, Cabinet Member
[The meeting started at 4.30 pm and finished at 4.40 pm].

Decision Session - Cabinet Member for Health, Housing and Adult Social Services **22 November 2011**

Report of the Carers Strategy Manager, Adults Children & Education on behalf of the Carers Strategy Group

Annual Update on the Carers Strategy

Summary

1. The Health Overview Scrutiny Committee (HOSC) completed a Carer's Review in 2010/11. The Committee recommended that the Cabinet Member for Health, Housing & Adult Social Services should receive an annual report updating the Carers Strategy and that the same report should be submitted to the Health Overview & Scrutiny Committee.

2. This report's purpose is to provide the annual update for the Cabinet Member.

Background

3. In November 2010 the HOSC appointed a Task Group of three members. The task group worked with Adult Children & Education (ACE) officers: Head of Commissioning and Partnerships and Carers Strategy Manager. Informal and formal meetings were held, as well as a public event to gather evidence.

4. The Review agreed the following aim and objectives:

Aim: To promote the valuable work done by carers and to improve the way City of York Council and its key partners identify carers and ensure they have access to information and the support available.

Key objectives:

i to raise awareness of carers

ii to improve access to information for carers

5. The review was completed in April 2011.

6. The summary of the Final Report of HOSC's Carers Review is attached as Annex 1.

7. The Carers Strategy Group is a partnership of statutory and voluntary agencies and carer representatives which oversees the implementation of York Strategy for Carers. The Strategy has been refreshed in 2011, incorporating the recommendations of the Carer's Review. The Strategy (Annex 2) was agreed by ACE DMT on 6 October and includes a summary of progress 2009–2011 and an action plan for 2011–15.

Consultation

8. The HOSC Carer's Review included a consultation event in January 2011 and in total 34 people contributed their views.

9. York Strategy for Carers 2011–15 was developed by the multi-agency partnership and includes a summary of information from a number of consultations with carers during 2010–11 (see Annex 3).

10. These included a meeting held with carers in August 2010 in order to respond to the refresh of the National Strategy. In addition, in September 2010 York LINks held a Public Information and Awareness Event on Carers Rights, and in January 2011 York Carers Centre received 183 responses to its user survey.

11. Some of the key messages from carers are as follows:

- "protect the carers and the cared for is protected"
- the importance of supporting the carer's physical health and mental wellbeing
- the importance of short breaks
- given that people do not always identify themselves as a carer it is important that key professionals, especially GPs are able to identify carers
- 95% of carers consulted by York Carers Centre felt that leaflets in the Carers Information Pack were useful and relevant
- young carers need specialist support in schools and further education

Carers Strategy Update

12. York Strategy for Carers 2011-2015 includes a summary of progress (p21–27) which is attached as Annex 4. A significant number of achievements have been made in working to support carers in York. There is also a range of work that still needs to be done which is summarised in the Action Plan 2011-2015 (p28-33) attached as Annex 5.

13. Some of the achievements and outstanding work are listed below.

Achievements

- The Carers Information Pack is annually updated and additional fact sheets developed as needed.
- York Carers Centre is established as an independent organisation and focal point for information provision and signposting.
- York Carers Centre led the development of two e-learning carer awareness training tools which were launched in June 2011.
- York now has three active and well established carer led forums: York Carers Forum (adult carers); CANDI (parent carers); Young Carers Revolution (young carers).
- City of York Council's Library Service worked actively with York Carers Centre during Carers Week 2011 to distribute information and raise carer awareness.
- The Flexible Carer Support Scheme continued to provide an increased number of direct payments to support and sustain carers in their caring role, with 680 carers being supported in 2010/11.
- York Carers Centre's Employment Education and Training service provides a specialist service supporting carers with training, work and related issues.
- NHS North Yorkshire and York included carers issues in the principles for the Admissions and Discharge Policies for all Acute Trusts to follow.
- York Carers Centre has contacted all GPs surgeries in York distributing information and organised 13 awareness raising sessions.

- York Carers Centre's Young Carers Service continues to work with York schools to raise awareness and increase the school based support available for young carers.
- Young Carers Revolution (the young carers forum) has produced a DVD which is recognised as an excellent awareness raising tool and has been promoted locally and nationally.

What still needs to be done:

- Effectively provide information in public places which is accessible to people who may not recognise themselves as carers.
- Reduce the length of the waiting list for Carers Assessments of Need.
- Roll out information about carers employment rights to employees and employers in York.
- Engage with the new NHS commissioning bodies as they develop, to promote carers issues.
- Set up a Young Carers task group.
- Implement the Common Assessment Framework (CAF) as the assessment tool for young carers.

Analysis

14. As this report is for information, no further analysis or options are needed.

Corporate Objectives

15. Carers are York residents, or are supporting York residents and as such are affected by all the five key priorities in The Council Plan 2011–15. However, the actions and projects under 'protect vulnerable people' are of particular significance in providing services and support to sustain carers in their caring role.

Implications

Financial

16. All of the actions will be accommodated within existing budgets.

Equalities

18. An Equalities Impact Assessment has been completed for York Strategy for Carers 2011-15.

19. The actions arising are:

- Continue to improve accessibility of information for carers and key workers and improve identification of 'hidden' carers.
- Ensure information about carers ethnicity is appropriately recorded by City of York Council, York Carers Centre and all Carers Strategy partner organisations to inform future service planning.
- Use existing contact mechanisms with BME, multi-faith and multi-cultural groups to identify the numbers of carers from BME communities and take appropriate action.
- Monitor the progress City of York Council makes in implementing the 'Carer Friendly Employer Chartermark' Action Plan.

Other

20. There are no implications relating to Human Resources, Legal, Crime and Disorder, Information Technology or Property arising from this report.

Risk Management

21. As the report is for information, no risks arise directly from this report. In a broader sense, however, failure to recognise the importance of carers could lead to the Council failing to comply with its statutory duties under the Equalities legislation, and to additional costs falling on social care budgets.

Recommendations

22. The Cabinet Member is invited to receive the report, note its contents, and comment as appropriate.

    Reason: To comply with the recommendations of the Health Overview and Scrutiny Committee and to highlight the importance of the work of Carers in accordance with the council's Corporate Strategy.

Contact Details

Author:
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Chief Officer Responsible for the report:
Paul Murphy
Assistant Director (Integrated Commissioning)
Adults, Children and Education

Report Approved ✓ **Date** *7 November 2011*

Pete Dwyer
Director of Adults, Children and Education

Report Approved ✓ **Date** *7 November 2011*

Specialist Implications Officer(s)

Wards Affected: **All** ✓

For further information please contact the author of the report

Background Papers:

Annexes:

Annex 1: Carer's Scrutiny Review Final Report March 2011

Annex 2: York Strategy for Carers 2011-15

Annex 3: What Carers in York have told us

Annex 4: Summary of Progress July 2011

Annex 5: York Carers Strategy Action Plan 2011–2015

Carer's Scrutiny Review

Final Report

March 2011

COMMITTEE MEMBERSHIP

The Heath Overview & Scrutiny Committee established a Task Group to carry out this review on their behalf. The Task Group was made up of the following three members:

- Councillor Barbara Boyce (Chair)
- Councillor Tom Holvey
- Councillor Siân Wiseman

ACKNOWLEDGEMENTS

The Task Group would like to thank all those that took part in the review including officers at the Council, representatives from the voluntary organisations and the members of the public who attended the event at the Monk Bar Hotel.

FOR FURTHER INFORMATION

Please contact:

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CHAIR'S FOREWORD

As I type this foreword the spellchecker doesn't recognise the word "carer" - I get the zigzag red line to say the word isn't in its dictionary. A fitting metaphor for a role which is often unseen, unrecognised and unappreciated.

There are thousands of carers across York, often female and middle-aged, but they can be of any age or gender and any educational or occupational background. What they share is commitment, hard work and worry. For many these are accompanied by exhaustion, struggle and ill-health.

In purely economic terms these unpaid carers give incredible value, but if they are to be relied upon to continue they need a little bit of care themselves. Some of them have never had their work acknowledged in any way by anybody, they ask for nothing and that is exactly what they receive.

Members of the Task Group found the research for this report an enlightening and humbling experience. We are now asking for a little support for our recommendations which would make such a difference to those who work tirelessly to support their spouses, parents, relatives or friends who are in need of their care.

Councillor Barbara Boyce, Chair

OBJECTIVES

At the start of the review the Committee agreed the following overall aim and key objectives for the review:

Aim

To promote the valuable work done by carers and to improve the way City of York Council and its key partners identify carers and ensure they have access to information and the support available.

Key Objectives

i. To raise awareness of carers
ii. To improve access to information for carers

CORPORATE STRATEGY

This review was closely linked to the 'Healthy City' element of the Corporate Strategy 2009/2012:

'We want to be a city where residents enjoy long, healthy and independent lives. For this to happen we will make sure that people are supported to make healthier lifestyle choices and that health and social care services are quick to respond to those that need them.'

RECOMMENDATIONS

The Carer's Review Task Group have made the following recommendations which were subsequently approved by the Health Overview & Scrutiny Committee:

Recommendations arising under Key Objective (i)

a. That health commissioners and providers ensure that there is greater consistency around how carers are identified and once identified their needs addressed. This would need to include:
   - Training in carer awareness for all health professionals and allied staff
   - That the hospital looks at extending the innovative approaches they have been piloting and embedding these into standard practices for all admissions and discharges
   - That a written report be provided to the Health Overview & Scrutiny Committee on a six monthly basis in relation to quality indicators that are being monitored in respect of carers.

b. That the Multi-Agency Carer's Strategy Group identifies where it would be helpful to provide public information about what it means to be a carer and how to access support to enable carers to identify themselves earlier.
   - Where places are identified carer awareness training should be made available for key workers.

RECOMMENDATIONS Continued

c. That City of York Council reviews its Equalities Framework to ensure that carers become an integral part of all equality and inclusion work and this to include:
   - Inviting a carer representative to become a member of the Equalities Advisory Group

Recommendations arising under Key Objective (ii)

d. That health commissioners ensure that all care pathways provide guidance on the information and advice carers will need regarding specific medical conditions as well as sign-posting them to support and advice. This will need to address what the impact might be on:
   - The carer
   - The family as a whole
   - The cared for person

e. That Adult Social Services develop a clear pathway, which provides an integrated approach to assessment for the whole family whilst recognising the individual needs within the family and the impact of caring on the carer

f. To continue to promote carer awareness an annual update on the Carers Strategy for York be presented to the Health Overview & Scrutiny Committee and thereafter to the Executive Member for Health & Adult Social Services

METHODOLOGY

The review took place between November 2010 and February 2011. The Task Group held both informal and formal meetings as well as a public event to gather evidence.

Meeting one: This was an informal meeting to scope and timetable the review and included setting the remit that the Task Group worked to. The remit, scope and timetable were subsequently agreed by the Health Overview & Scrutiny Committee.
Meeting two: This was a formal meeting to look at good practice examples, carer awareness raising, information provision in other areas, current practice in York, the York Strategy for Carer's document and information relating to key partners.
Meeting three: An informal meeting to put together questionnaires to gather evidence and plan the public event.
Meeting four: A public event was held to enable the Task Group to talk in person with carers and care workers
Meetings five & six: Discussion of the evidence gathered through the public event and returned questionnaires
Meeting seven: Consideration of the evidence received during the course of the review and formulation of the recommendations arising from the review.

NATIONAL & LOCAL POLICY CONTEXT

The Government's recently refreshed Carer's Strategy 'Recognised, Valued & Supported: Next Steps for the Carer's Strategy was published on 25th November 2010. One of its key messages echoes the overall aim of this review:

'Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of the contribution and involving them from the outset both in designing local care provision and in planning individual care packages.'

The key messages contained within the refreshed national policy do not significantly change the priorities within the current York strategy for carers, however this will be refreshed over the next 12 months.

KEY FACTS

For further information and reference sources on information within the Key Facts section of this report please refer to the full final report considered by the Health Overview & Scrutiny Committee at their meeting on 2nd March 2011. This can be found at: http://modgov.york.gov.uk/ieListDocuments.aspx?CId=671&MId=5633&Ver=4

Profile of Caring Nationally & Locally

* Carers are of all ages and come from all walks of life
* Three in five people will become carers at some point in their lives
* In 2009/10 City of York Council completed assessments or reviews for 1473 carers and York Carers centre had 1959 carers registered on its database.
* It is estimated that 37% of the caring population start caring and a similar proportion cease caring every year in the UK, which means over 6, 000 new carers in York annually
* In a survey undertaken by Carers UK for a report in 2006, 65% of carers did not identify themselves as a carer in the first year of caring
* Many carers are sustained in their role through natural support from their communities

KEY FACTS continued

Profile of Caring Nationally & Locally continued

* The 2001 census records 17, 009 carers in York and 342 young carers aged 8 to 17. Since then the population of York has risen and gives rise to an estimate in carer numbers of 18, 676 in 2010.
* York's older population is likely to increase by 32.7% within the next 20 years. The rise in the ageing population will mean a rise in the numbers of carers and a rise in the number of older carers.
* There are various services in York that support carers & both the City of York Council and third sector organisations provide these.
* A multi-agency Carers Strategy Group meets on a quarterly basis and there is an agreed 'York Strategy for Carers 2009-2011' (extended to 2012) and a Carers Strategy Action Plan. The York Carers Centre is also commissioned to provide a range of support for carers in York.

KEY FACTS continued

Economic Importance of Carers

* In 2007 Leeds University published 'Valuing Carers: Calculating the Value of Unpaid Carers' which stated that
'The true value of the care and support provided by carers cannot be quantified, as caring is also an expression of love, respect, duty and affection for another person. However it is important to recognise the true scale of carers' support provided to frail, disabled and ill people. Our estimates here seek to highlight the importance of the contribution carers make, unpaid, in relation to the amount of money spent annually on health and social services.'

* The report indicated that unpaid carers in York alone are saving local health and social care systems approximately £223 million per annum.

Performance & Funding

* Funding for carers support is currently provided primarily through the Carer's Grant which has traditionally been paid to the local authority as part of the Area Based Grant, but which will, from next tear, form part of the overall grant settlement.

KEY FACTS continued

Performance & Funding continued

* The Government gave Primary Care Trusts additional funding to support more carer breaks, this funding was part of their base budget. It was understood by the Task Group that the Primary Care Trust had not been able to release funding from base budget to increase services for carers. The multi-agency Carer's Strategy Group for York were advised that there was no specific funding allocated in the Primary Care Trust's budget for 2010/11 for carer's breaks.
* Currently City of York Council is performing against its targets; however it is struggling to keep pace with the demand for assessments and there are currently waiting lists for new carer assessments.

OTHER INFORMATION GATHERED

Identification of Carers by York Hospital

The Chair of the Task Group wrote to York Teaching Hospital NHS Foundation Trust to ask them about their procedures for identifying carers who may be supporting patients at the Hospital. The following response was received from the assistant Chief Nurse:

OTHER INFORMATION GATHERED continued

Response from York Hospital

'We are piloting a health passport in neurology and this would be a useful way to identify carers formally and ensure robust communication with them. The Learning Disability Liaison Nurse works with all patients with learning disabilities who attend the hospital an d she routinely identifies and involves carers as part of her role. Her input includes asking carers for feedback on their experience. In more general terms when a patient is admitted to hospital our routine information gathering is expected to identify who is a carer. In some instances this would be to ensure that there is not a 'cared for' person at home who requires urgent input as a consequence of an emergency admission of their carer for example and the converse to ensure we know who to communicate with if the 'cared for' person is admitted to hospital. Carers needs are considered in discharge planning, more specifically for complex discharges rather than routine hospital discharge and their needs are taken into consideration or indeed carers would be invited to a discharge planning meeting.'

The Task Group were encouraged by the new ways of working to identify carers & wanted the Hospital to embed these approaches into all hospital admissions and discharges.

OTHER INFORMATION GATHERED continued

Information Received at the Public Event & Via Completed Questionnaires

The Task Group were particularly interested in hearing first hand from carers and care workers and held a public event on 7th January 2011 at the Monk Bar Hotel, York. This took the form of a drop in session and ran from 2pm until 6.30pm. Approximately 20 people (both carers and care workers) attended the event to give their views to the Task Group.

In addition to this two questionnaires were devised and these were e-mailed to carer's organisations, condition groups, voluntary sector organisations, care workers and key partners. One questionnaire was targeted at carers and another at care workers. In total 34 of these were completed and returned.

The information received at the public event and that contained within the questionnaires was subsequently collated and attached as annexes to the final report arising from this review. This can be found at :
http://modgov.york.gov.uk/ieListDocuments.aspx?CId=671&MId=5633&Ver=4
or by contacting the Scrutiny Officer at City of York Council

FINDINGS

This section sets out a brief summary of the review's findings after consideration of all the information gathered. This formed the basis of the recommendations arising from the review and the following key themes were discussed:

The Importance of Early Identification of Carers

The NHS is undergoing significant change with new legislation aiming to pass the responsibility of Public Health to local authorities and commissioning to newly formed GP Consortia. It was therefore vitally important that key professionals, especially GPs were aware of carers from an early stage and identified them as soon as possible. GPs were often the first point of contact for carers who frequently accompanied the person they cared for to GP appointments.

There had been an incident reported in one of the returned questionnaires where a GP had refused to talk to a carer and not wanted them present with the patient for the appointment. However, overall the responses given were mixed in relation to how carer aware GPs were. There were strong indications that the way GPs behaved in relation to carers was variable. Other comments suggested

FINDINGS continued

the GP would be the best person to hand out information to carers in the first instance. Care workers who attended the public event believed that GPS should keep a register of carers.

Having noted the variability of the information received the Task Group asked York Health Group and NHS North Yorkshire & York the following questions:

Question 1 What is being done by NHS North Yorkshire & York and York Health Group to raise GP's awareness of carers and the role that carers undertake?

Question 2 Are NHS North Yorkshire & York and York Health Group currently undertaking any work to close the 'gaps in service' indicated by the variable comments received?

In summary the Task Group received the following responses:

From the York Health Group
York Health Group is very aware of the needs of carers and would like to raise their profile. There is not a specific plan to do this at present but it is an aspiration to be handed on to the new GP commissioning consortium. GP practices are

FINDINGS continued

The Importance of Early Identification of Carers continued

encouraged to hold a carer list and identify patients who are carers and offer them support and contact with York Carer Centre. York Health Group is in the process of commissioning a memory advisor whose role will include provision of information, guidance and support for carers.

From NHS North Yorkshire & York (the PCT)
The PCT chairs the York Carers Health Group that has an action plan with the aim of improving the health and well being of the carers. This includes the promotion of a self-assessment tool for carers to complete and then discuss with their GPs. The PCT also commissions the Carers Centre to promote carer's issues with practices, including how to identify carers and how to provide them with the relevant support.
As part of the Quality & Outcomes Framework (QOF) GP practices are expected to have a protocol in place to identify carers and a mechanism for referral to social services for assessment. There are no further requirements as part of their contract to do any more than this. However many GP practices have carer registers and some are more proactive than others in supporting carers. QOF visits are undertaken and questions are asked in relation to the support offered to carers.

FINDINGS continued

The Task Group appreciated that there was a willingness within both York Health Group and NHS North Yorkshire & York to address issues around carer identification. However it was unclear how the quality checks detailed in the responses would lead to a clear action plan and a clearer understanding by GPs of the impact caring can have on a carer's health.

On balance and having taken all the evidence into consideration, the Task Group believed that this was an area where there was room for ongoing improvement. There was further scope for some GPs and GP practices to be more carer aware and a need to establish consistent practice across all GP surgeries, ensuring all GPs and practice staff were able to identify carers and offer appropriate support and services. GPs also needed to work more proactively to recognise a carer's own needs as well as those of the person they were caring for. Recent changes to the NHS and the introduction of GP consortia made this a prime time to encourage GPs to undertake some work in this area.

Some GPs had been highly praised for their attitude towards carers and the help and support they had given and the Task Group did not want this to be forgotten.

FINDINGS continued

Recognising you are a Carer

Responses to the questionnaires and at the public event indicated that most people did not immediately recognise themselves as a carer with many feeling that they were 'just looking after my mother/child/spouse' or 'just doing my duty'. From the comments received recognising that you were a carer was often a gradual process, however it often became very clear at a point of crisis, such as hospital admission or diagnosis of a particular condition.

In some cases it was friends or health professionals that were the first people to recognise that someone was a carer. The Task Group felt that steps needed to be taken to encourage early carer self-identification so that the right information could be provided at the right time.

The multi-agency Carer's Strategy Group could undertake work to identify the key places where information can be made available, so that people can be encouraged to identify themselves as a carer at an early stage.

FINDINGS continued

Provision of Information

From responses received it became apparent that not all carers wanted or needed the same level of support as others. Information needed to be proportionate to the needs of each individual carer.

Some carers said that they preferred written information whilst others would prefer to talk with someone face to face. It was also important who gave information to carers, as they needed to be able to have confidence and respect for the person or organisation providing it. In the first instance the Task Group identified, through the comments received as part of this review, that this was about providing the right advice on the cared for person's medical condition.

It was important that a carer was able to understand the impact a particular condition would have on both the cared for person and the carer. In the second place it was important to have clear and up to date information and advice on rights for both the cared for and the carer and the support available to them. All Health professionals needed to think about the information they were giving and the impact it might have on the carer.

FINDINGS continued

A Carer's Own Needs

Some comments received identified that often more emphasis was placed on the needs of the cared for than on the needs of the carer. This meant that the carer's health often suffered as a consequence. Carers didn't always get enough time to spend on their own needs, especially if they were caring for more than one person. One person said directly that *'the impact caring has on carer's lives is not always recognised.'* However, other people commented on this point in different ways such as identifying the need for day care, respite care and help with non-personal matters such as organising housing or utility repairs. One commenter said that employers did not always afford the same consideration to carers as they would to parents for example.

In a recent case reported in the national media a child's parents spoke about the situation that many carers faced as well as a lack of available respite care:
'Caring for my daughter is relentless. She needs someone 24 hours a day. Caring takes over your whole life. Carers across the country are struggling the same way. It's not a new thing. It's been going on for years.'

FINDINGS continued

The public event and questionnaire responses highlighted the fact that some carers did not feel they received an holistic or integrated assessment. In York a carer's needs should be identified through the carer assessment process, however it was understood that this did not always happen in tandem with the assessment of the cared for. If the carer's needs had not been appropriately identified then the care package in place should be checked to ensure that it was providing the relevant help.

The Task Group asked the Assistant Director (Assessment & Personalisation (Adults)) at the City of York Council the following:

Question 1 How are carer and 'cared for' assessments currently undertaken and are there any plans to change this. Do you think there are any ways the assessments could be undertaken in a more holistic/integrated way?
Summary of Response *Assessments for the cared for person start with the Social Care Assessment following a referral to Adult services. The Care Manager undertaking the assessment would ask the Carer if they also wanted to undertake a Carer's Assessment. When there is a need to look at longer term support for the cared for person carers are asked what level of support they are able to give so that this can be taken into consideration.*

FINDINGS continued

A Carer's Own Needs continued

Question 2 Are there any reasons why both assessments could not take place at the same time/in parallel to each other?
Summary of response *There is no reason why an assessment can not take place at the same time. The difficulty for the carer could be that they may not be able to express their needs in front of the cared for person. Older people can sometimes underestimate their needs as a cared for person thus the Care Manager will have to support the family in making positive choices that do not diminish their independence.*

Many of the challenges facing carers and their families are understood by Care Management but the Task Group were not confident that there was an agreed way forward that would address the needs of a family as a whole as well as the needs of each individual within that family.

Apart from the benefits to both carer and cared for of having an appropriate care package in place there are also economic benefits that should be acknowledged. If carers are not fully supported they will be more likely to give up their caring role and the responsibility for and cost of care would most likely need to be borne by the public sector.

FINDINGS continued

Carer Awareness Raising & The Cheshire Carers Link Model

The Task Group considered the 'Cheshire Carers Link Model' which was developed through a multi-agency strategy group identifying 'carer link workers' or champions across health and social care teams. The carer link workers take on additional responsibilities and are a pivotal point of contact to provide advice, information and support to colleagues. Workers are provided with training and a toolkit to help them in their role. The Task Group did not look into the model in any detail but did recognise that it would not be difficult or expensive to build a carers element into the already existing Equalities Champion role at the Council.

The Task Group asked the Corporate Equality & Inclusion Manager at City of York Council for her views on this and she was of the opinion that this should be championed by the Executive portfolio holder for inclusion. She also suggested that it would be timely to consider amending the membership of the Equality Advisory Group to include a carer representative.

The Task Group were keen to encourage the Corporate Equalities agenda to support the changes brought in by the Equalities Act 2010, which gives carers greater recognition.

CONCLUSION

The Task Group were of the opinion that reviewing this topic was a significant milestone in itself towards raising the profile of carers within the city. The review had highlighted many positive aspects of the services available, in particular the 'Caring & Coping' course run by the Alzheimer's Society. This had been mentioned many times by carers at the public event and in responses to the questionnaires. In addition the Task Group recognised that several professional individuals had been named during the review in relation to the outstanding care and services they had provided to carers.

The Task Group also wished to acknowledge the valuable and unpaid work undertaken by carers. Carers saved the local economy a substantial sum every annum and in the hope that they would continue to do this it was important that, whenever and wherever possible, they could receive support and assistance.

The Task Group appreciated that in the current time of financial restraint there was a need to obtain the best results for the budget we currently had. However, if any additional monies were to become available the Task Group hoped that consideration could be given to fund respite care in order that carers could take some well-earned breaks.

SCRUTINY'S ROLE

For each completed scrutiny review, the Overview & Scrutiny Committee produces a final report containing their proposed recommendations for the Executive's consideration.

In most cases, the Executive will approve all of the recommendations made and will instruct officers to proceed with the actions required in order to implement them.

The Overview & Scrutiny Committee is responsible for monitoring the progress of implementation and receives regular update reports from the Scrutiny Officer. Once they are confident that a recommendation has been fully implemented they will agree to sign it off.

In addition, each year Scrutiny Services produces an Annual Report which includes an assessment of the successful outcomes from each completed scrutiny review.

Equality In Accessing Information

The aim of City of York Council is to ensure the public is always given appropriate access to information. On request, we can provide this final report in large print, electronically (by computer disk or by email), in Braille or on audio tape.

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For a full guide to the Overview & Scrutiny function in York, go to:

http://democracy.york.gov.uk/ecSDDisplay.aspx?NAME=Guide%20to%20Overview%20%26%20Scrutiny%20in%20York

NHS
North Yorkshire and York

CITY OF YORK COUNCIL

York Strategy for Carers

2011 – 2015

York Carers Centre

YORK CARERS FORUM
yorkcarersforum@tiscali.co.uk

CANDI

Young Carers Revolution

YORK STRATEGY FOR CARERS 2011 - 2015

Contents

Appendices

1. Why carers matter

Many of us will be carers at some point in our lives. It is a role that can creep up gradually and for some it can be a life long role. For others it can come unexpectedly and suddenly following a crisis. Supporting carers is in all our interests.

Who are carers?
'A carer is someone who, unpaid, looks after or supports a relative, friend or neighbour who is ill, disabled, frail or in need of emotional support'.

Facts

- There are 6 million carers in the UK.
- Over 1 million carers provide more than 50 hours care per week.
- An estimated 37% of these carers are new to caring every year.
- 58% of carers are women and 42% men.
- Women have a 50% chance of becoming a carer before they are 59.

'Facts about carers' Carers UK, June 2009.

The impact of caring

Carers make a significant contribution in providing health and community care to relatives, friends and neighbours. The impact of caring varies depending on individual circumstances, however it is known that those caring for long hours each week are more likely **not** to be in good health. Caring can also have a financial impact and one in eight workers in the UK combine work with caring responsibilities. [1]

Carers are from all walks of life and all backgrounds. Some carers can face particular disadvantage and we may know little about them. These carers are often called 'hidden carers'. They can be 'hidden' due to the circumstances of the person they care for, or their cultural background. For example, carers of people with mental ill health or substance misuse can find it hard to access support.

Equality and social inclusion

Some carers may be less likely to access appropriate information and support. The City of York Council's 'Equality Action Group' provided feedback about the Carers Strategy in 2010 [2] identifying carers who need specific support:

- People with sensory impairments
- Carers with learning disabilities
- Carers from black and minority ethnic communities
- Lesbian, gay, bisexual and transgender (LGBT) carers
- Travellers
- Carers with mental health problems
- Older carers

[1] Carers UK (June 2009) *Fact about carers*
[2] City of York Council, Equality Action Group (February 2010) *Help us get it right day: feedback report.*

In order to achieve greater equality i ll carers, specific approaches should be adopted to reach carers who are currently unknown.

2. National Picture

All public bodies are engaged in a time of major and unprecedented change in responding to the challenges following the Comprehensive Spending Review of 2010, and the new legislative requirements affecting health, social care and many other aspects of local government.

Carers Strategy

'*Recognised, valued and supported: next steps for the Carers Strategy'* was published by the Coalition Government in November 2010 to outline current priorities for the ten year vision set out in the Carers Strategy of 2008. [3]

Social care

The Coalition Programme committed the Government to reforming the system of social care in England. *A Vision for Adult Social Care: Capable Communities and Active Citizens*[4] was published in 2010 and is one a number of key documents[5] which sets out principles and required actions. The Government plans to publish the Social Care Reform Bill in spring 2012. This follows the Law Commission's review of adult social care legislation and the Dilnot Commission's work on the funding of care and support.

Health

The Health and Social Care Bill was published in January 2011. The Bill provides for significant changes to the health service. This includes the abolition of Strategic Health Authorities and Primary Care Trusts, the transfer of commissioning responsibilities to GPs and the transfer of responsibilities for public health to local authorities.

Performance framework

The national requirements for health and social care are in a process of change. The government describes a vision moving away from top-down performance management, to sector-led improvement and local accountability. New outcomes frameworks for both health and social care have been published in 2010/11, however these have not yet been implemented.

Equality Act 2010

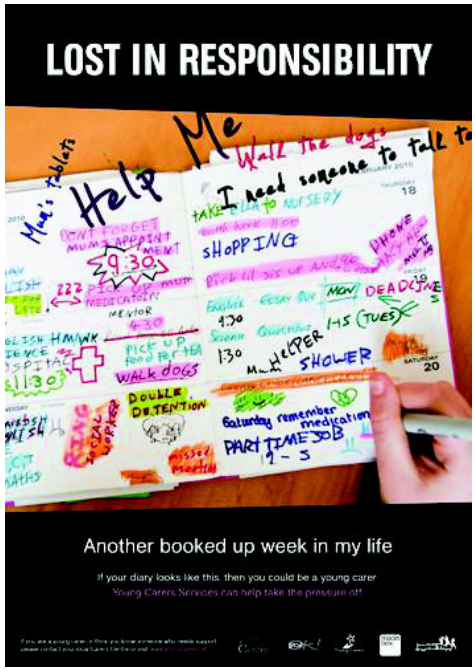
This Act introduces nine 'protected characteristics' replacing what were known as the six equality strands:

- Age
- Disability
- Gender reassignments

[3] HM Government (2010) *Recognised, valued and supported: next steps for the Carers Strategy;* HM Government (2008) *Carers at the heart of 21st-century families and communities: A caring system on your side, a life of your own.*
[4] Department of Health (2010) *A Vision for Adult Social Care*
[5] Department of Health (2010)*Think Local, Act Personal ;* Department of Health (2010) *Transparency in Outcomes :a framework for quality in adult social cares*

- Race
- Religion or belief
- Sex
- Sexual orientation
- Marriage and civil partnership
- Pregnancy and maternity

The Act also strengthens the protection of carers against harassment and discrimination at work and in the provision of goods and services. This is because a carer is now counted as being 'associated' with someone who is already protected by the law because of their age or disability.[6]



(Campaign Images produced by Young Carers Revolution 2010)

[6] Government Equalities Office leaflet (2010) *Equality Act 2010: What do I need to know as a carer?*

3. Local picture

Carers in York

Carers in York (2001)	Numbers	%
Total population	181,094	100%
Total population of unpaid carers	17,009	9%

[7]

Carers make up over 9% of the population in York. The 2001 census records 342 young carers aged 8 –17 years in York, which is likely to be an underestimate, as other research suggests there are as many as 1,600.

An estimate based on the increase in population suggests there were 18,676 adult carers in York in 2010.

Hours of care provided by carers (2001)	Numbers	%
Total population of unpaid carers	17,009	100%
Care provided 1 - 19 hours per week	12,478	73%
care provided 20 - 49 hours per week	1,520	9%
Care provided over 50 hours per week	3,011	18%

[8]

Analysis of the 2001 census indicates that 21% of carers caring for 50 hours a week are likely to be in poor health. This is double the percentage of people who are not caring. [9]

Population and demographic change

York's population is rising. A total population of 181,094 was recorded in the 2001 census. The population is predicted to be 202,400 in 2011. A total of 89% of York's population is 'White British', with the BME population rising from 4.9% in 2001 to 11% in 2009. [10]

[7] 2001 Census
[8] 2001 Census
[9] Carers UK, (2004) *In Poor Health: the impact of caring on health.*
[10] City of York Council, Business Intelligence Hub Highlight Report July 2011

Older people

There is a significant growth in the population of older people. The Council reported in 2006 an expected 31% growth in the population of older people over 65 in the following 15 years and an estimated 700 additional older people with dementia.[11] This highlights the associated increase in mental health and physical and sensory needs as the population ages. It is expected that there will be an increase in both the number of older people being supported by carers, as well as the number of older carers. It is likely that more people will become 'mutual carers' where two or more people, each experiencing ill health or disability, will care for each other.

Strategic planning

Without Walls is the name of a group of people who have worked together since 2003 to jointly develop a shared vision for the city. The Partnership is made up of representatives of public, voluntary and business organisations in York. They have developed a '*Strategy for York'*, which sets out the long-term vision for the local area based on what matters most to people. In addition, they have also developed a '*City Plan*' that focuses on a small number of priorities that are critical to address in the next four years to secure York's future.

Partners of the Without Walls Partnership all agreed to include the ambitions of the 'Strategy for York' and 'City Plan' into their own plans and strategies. City of York Council have produced a plan for 2011 – 2015 describing priorities and actions that will be taken to deliver our contribution towards the 'Strategy for York' and 'City Plan'.

Joint Strategic Needs Assessment

This aims to provide a comprehensive analysis of current and future needs in relation to the health and wellbeing of children and adults in the City and to inform future planning and commissioning decisions. The 2010 Assessment included a section about carers which referenced the Carers Strategy Action Plan. The production of a revised Assessment is underway, overseen by the Shadow Health and Wellbeing Board.

Carers Strategy Group

The Carers Strategy Group is a partnership of people from statutory and voluntary organisations as well as carer representatives from the carer led forums. The group meets every three months to monitor progress with the Carers Strategy Action Plan. The group is coordinated by City of York Council's Adults, Children and Education directorate and is working towards increasing carer awareness at all levels of strategic planning.

[11] City of York Council (2007) *City of York Commissioning Strategy for Older People 2006 - 2021*

Funding

York Carers Strategy Group supports partnership working between health and social care agencies in the commissioning and provision of services.

City of York Council dedicates funding from the Area Based Grant and NHS North Yorkshire and York uses funding from its core budget to support carers in the following ways:

- Strategic support and direct payments for carers.
- Services commissioned specifically for carers.
- Respite and sitting services.
- Through support provided to the cared for person which allows carers to take a break.
- Specialist services for example Community Mental Health Services that provide advice and support to carers.

As part of the National Strategy refresh the government announced that it is including £400m over four years in PCT allocations and potentially GP consortia subsequently, to spend on supporting carers. This funding is an indicative amount and is included in the PCTs baseline budget and in many cases is already committed against the current service provision. Therefore there is no new separate allocation specifically for Carers on top of the 'core' funding for PCTs.

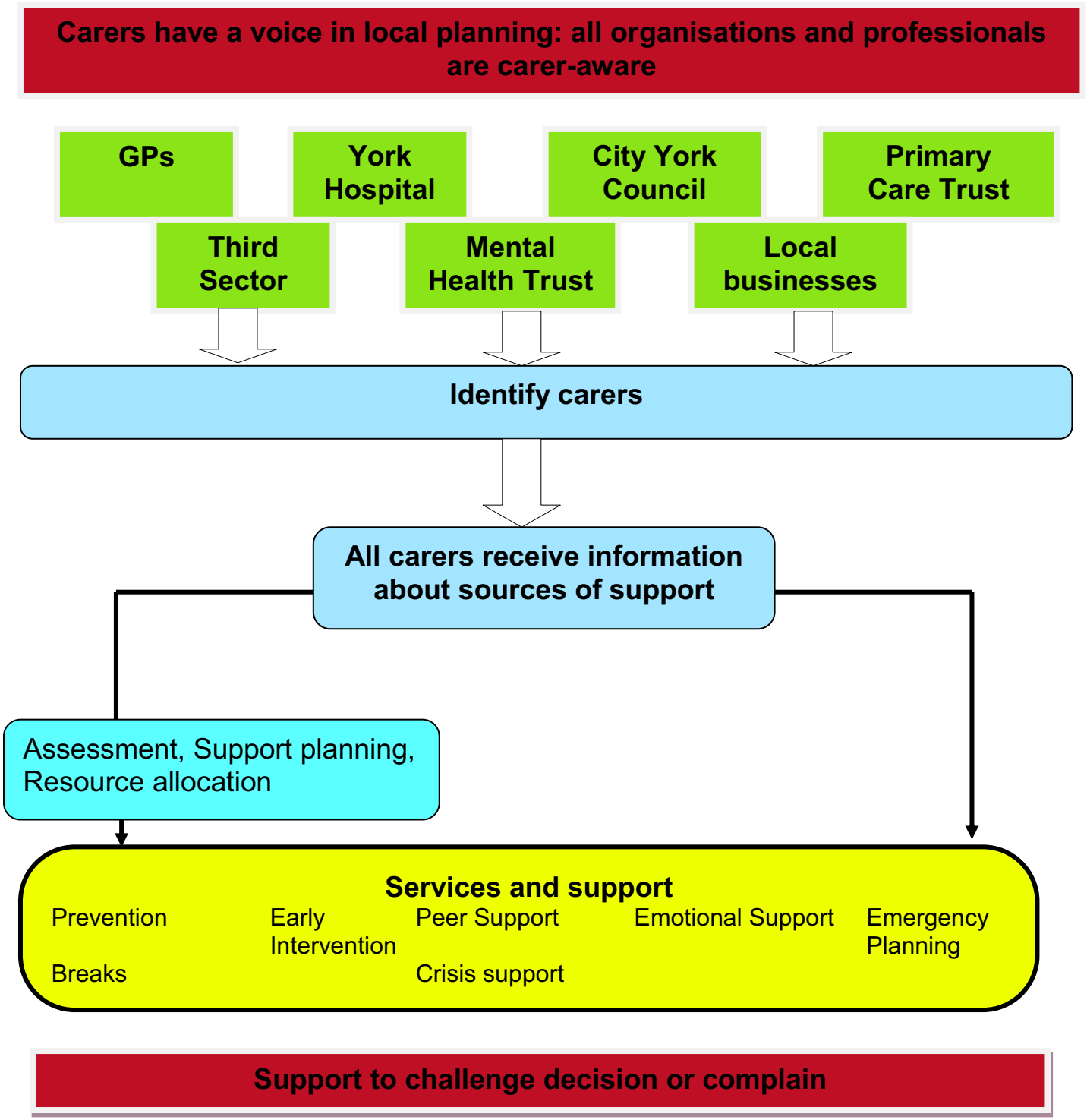
4. Vision and Outcomes Framewo

Our vision in York is to work towards developing a local community where carers' needs are identified and supported by all public services and other organisations in the City. In short: 'Carers are everybody's business'.

Carers should be respected and acknowledged. Each carer has a unique perspective, alongside skills and knowledge gained through the experience of caring.

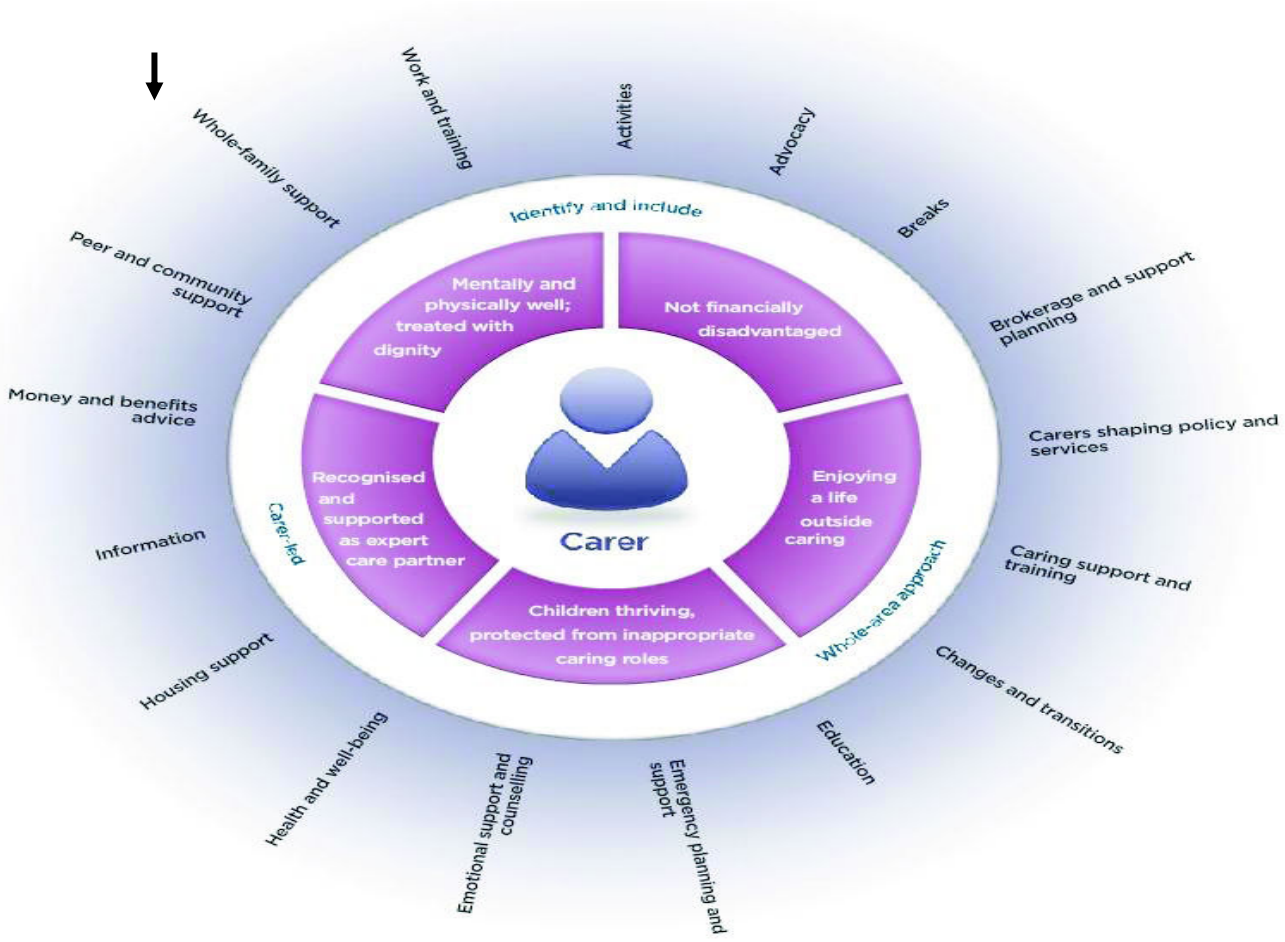
Care pathway for carers support

This has been drafted as a guide for all agencies. The chart below shows how we can work towards making sure carers are always recognised and directed to sources of support .



Outcomes framework

The 'Carers Hub' [12] is a resource developed by the Princess Royal Trust for Carers. It is a model of comprehensive carer support based on the outcomes of the refreshed National Strategy.



The carer is at the centre of the hub. The five outcomes are in the inner section and are universal ambitions for carers. These ambitions underpin the work of York Strategy for Carers.

The middle band states the overarching values:

- 'Identify and include' – we must make sure we reach all carers including those most at risk of being overlooked.

- 'Carer-led' – services and support should be individually tailored, and carers should be part of planning and strategic forums.

- 'Whole-area approach' – effective whole area planning is needed to make sure carers' specific needs are met.

We will use the Carers Hub to help us plan work required to implement the carers strategy in the future.

[12] http://www.carershub.org

5. Achievements and what we still

Recognised and supported as expert care partners

What we have achieved

Information
York Carers Centre is now an established local independent charity and a focal point for information and advice.

Carers shaping policy
There are three active carer led forums in York helping to make sure carers voices are heard: CANDI, York Carers Forum and Young Carers Revolution.

Carer Awareness Training
Regionally funded training held for library staff, workers in primary care health settings and those undertaking Carers Assessments of Need.

Carers Assessments
City of York Council's social work teams have skilled Carers Support Workers carrying out carer assessments.

Carer awareness raising
York Carers Centre led the development of the Young Carer and Adult Carer e-learning tools.

Personalisation
Regional conference on personalisation hosted by York Carers Centre, February 2011.

Young adults carers
York Carers Centre successfully provides specialist support to young adult carers aged 18 and over.

Personalisation
York Carers Forum has worked with City of York Council to inform carers about personalisation.

City of York Council Health Overview Scrutiny Committee
Review successfully undertaken2010/11 focussing on carer identification and information.

Integrated services and better coordination
A 'Care Pathway for carers support' has been drafted. Initial discussions have taken place about some of the implications for City of York Council's adult social care services.

York LINk review
Review completed and recommendations made spring 2011.

Development work at York Carers Centre
Lead agency in work to develop services for Young Carers, whole family support and expanded to incorporate a specialist service for carers affected by substance misuse.

What we still need to do

- Ensure all Carers Strategy partners adopt the 'Care Pathway for carers support'.
- Set up a robust system for update and distribution of accessible information for carers.
- Identify and display information for carers in key places in York.
- Provide public information in these 'key places' which is accessible to people who may not recognise themselves as 'carers'.
- Establish the potential 'trigger points' for carer recognition, so carers can be identified earlier.
- Involve GPs in the provision of information to carers.
- Ensure Adult Social Services to provide a coordinated approach to assessment for the 'whole family'.
- Reduce length of waiting list for Carers Assessment of Need.
- Include carer awareness raising in all workforce development strategies.
- Map carer involvement in local health and social care planning networks with attention to the development of Healthwatch.
- Review carer involvement.
- Ensure information about carers ethnicity is appropriately recorded by City of York Council and York Carers Centre to inform future service planning.
- Scope the work needed to identify the numbers of carers from BME communities and assess their needs.
- Ensure City of York Council reviews its equalities framework enabling carers to become part of all equality and inclusion work.

Enjoying a life outside caring

What we have achieved

Carers Discount Card
York Carers Centre launched a free discount card for carers supported by 50 local businesses.

Carers Emergency Card Scheme
Over 400 carers of all ages registered. Launched for Young Carers.

Carers Breaks- York Carers Forum
In response to feedback from carers, new monthly Art and Craft sessions established in addition to monthly social meetings with massages provided; coach trips trialled- enabling carers to take a break with the person they care for; events during carers week.

Flexible Carer Support Scheme
Direct payments received by 600 carers in 2009/10 and 680 carers in 2010/11 to support and sustain caring role.

Young adult carers
York Carers Centre supported 44 young adult carers in 2010/11 with 14 new carers joining. Monthly pub quiz and cinema groups.

Carer Breaks and Promoting Social Networking - York Carers Centre
Art classes, card making, special events and massage sessions support over 200 carers annually aiming to promote well-being and reduce social isolation.

Telecare *
Small pilot scheme offered 3 months free trial of equipment to carers 2010/11.

* see footnote[13]

[13] **"Telecare is the continuous, automatic and remote monitoring of real time emergencies and lifestyle changes over time in order to manage the risks associated with independent living." It can provide people with electronic equipment such as community alarm systems or falls sensors which makes it possible to live independently and also call for help when needed.**

What we still need to do

- Set up a clear framework for provision of breaks for carers which links to self directed support and personalisation.
- Audit existing services and support.
- Agree the concept of what a carers break is.
- Ensure learning from the report of the National Demonstrator Sites is incorporated into future local plans.
- Pursue roll out of Carers Emergency Card to parent carers.
- Ensure telecare services are accessible to carers.

The Carers' Quilt in St Nicholas's Chapel, York Minster

Not financially disadvantaged

What we have achieved

Employment
York Carers Centre Employment Education and Training service supported carers with writing CVs, training, volunteering, becoming 'work ready'. Work with employers to support carers to stay in work.

Benefits uptake
York Carers Centre achieved an increase of £77,000 in welfare benefits uptake during a ten month period in 2011/11.

York Explore training courses
York Carers Centre has established links with York Library Service to help carers access free courses on computer skills and managing finances.

York Carers Centre – laptops
Funding obtained providing 30 carers with laptops enabling access to digital services to reduce social isolation, access job searches and online shopping, and increase networks.

Young adult carers
York Carers Centre supported 2 young carers to volunteer abroad and provided support to others to enable access to higher education.

What we still need to do

- Audit benefits advice services available to carers.
- Improve the availability of financial information and advice to young people aged 16+.
- Ensure carers can access financial advice when the cared for enters residential care and at end of life.
- Ensure City of York Council implements the action plan linked to the 'Carers Friendly Employer' chartermark.
- Develop links and engage with local businesses.
- Ensure information about carers' employment rights is available to employees and employers in York.

Mentally and physically well and t ignity

What we have achieved

GP surgeries
York Carers Centre has contacted all GP surgeries in York and distributed information, organised 13 awareness raising sessions for surgery staff and held 13 advice sessions at one GP surgery.

Back care support and training for carers
Proposal developed for 2 year training package utilising new non recurrent DH funding.

Self health checklist
This has been piloted and the feedback is positive. It supports carers to identify their own health needs and acts as a prompt for discussion with their GP practice.

Admissions and Discharge Policy
NHS North Yorkshire and York included carers issues in the principles for the Admissions and Discharge Policies for all Acute Trusts to follow.

Drug and Alcohol Misuse
NHS North Yorkshire and York arranged for the Carers Centre staff to access training on support for carers of those with Substance misuse and alcohol misuse.

Dementia Care Pathway
Carers issues have been included in to the Dementia Map of Medicine to prompt primary care to consider the needs of carers and supportive mechanisms such as the Emergency Carers Card.

End of life
York Carers Forum has worked with York Hospital to ensure carers are recognised, supported and included in the End of Life Pathway.

What we still need to do

- Health commissioners and providers ensure greater consistency around identifying and addressing the needs of carers.

- Health commissioners monitor work towards ensuring that all care pathways provide guidance on the information and advice carers will need.

- To engage with the new NHS Commissioning bodies (Clinical Commissioning Groups) as they develop, to promote carer issues and build on existing work in Primary, Community and Acute Care.

Children thriving, protected from inappropriate caring roles and supported in their caring roles

What we have achieved

Supporting schools
York Carers Centre's Young Carers Service started dedicated work with schools in 2009.

Whole family working
York Carers Centre secured funding for a specialist one year post 2010/11 offering direct support to families and work to support strategic change.

Strategy
City of York Council has identified a lead officer for young carers. A task group has been established to plan and implement actions.

Carers Assessments for Young Carers
A Task Group has begun work to implement young carer assessments in York using the Common Assessment Framework.

Young Carers Forum
Ongoing meetings of Young Carers Revolution have started, leadership of the group has been established and new members attended a meeting in April 2011. DVD promoted locally and nationally. York MP Julian Sturdy praised work of Forum in speech in House of Commons.

Young Carers Service
Support for 95 young carers in 2010/11 and 38 new carers joined due mainly to increased awareness in schools.

Young Carers Awareness Raising
Young Carers Revolution (YCR) DVD promoted locally and nationally. York MPs attended YCR meetings. YCR received standing ovation at No Wrong Doors Conference 2010. Links made with Youth Parliament. Best Community Project in York and Volunteer award in London received.

Breaks for young carers
Monthly sessions held for 3 different age groups, 286 sessions of one to one support, 50 separate activities and 36 groups sessions provided by Young Carers Service 2010/11.

Good practice in schools
Staff at Millthorpe School have been supported to run support groups for young carers. Lessons held at All Saints School for year 11 students to raise awareness re young carers. Feedback from Huntington school deputy head confirms that student and teacher awareness about young carers has increased as a result of work by Young Carers Service.

What we still need to do

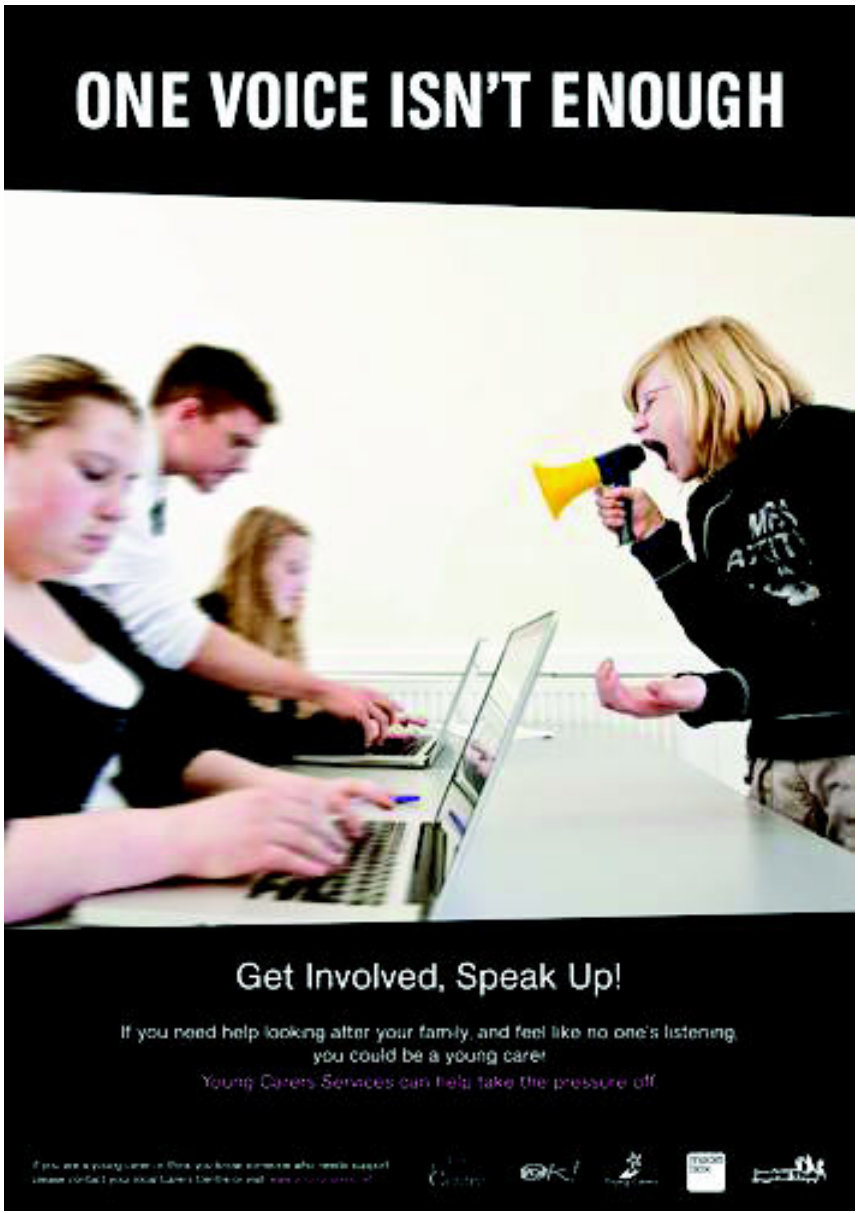
- Support the development of the Young Carers task group and action plan.

- Implement the Common Assessment Framework (CAF) as the assessment tool for Young Carers Assessment.

- Ensure all adult services assessment processes and paperwork includes identification of young carers.

- Develop work in schools which identifies the support needs of young carers and ensures this support is made available.

- Young Carers Task Group to consider York LINk report (March 2011) recommendation: 'Young carers should be given help to get home access to computers'.



6. Priorities

The Carers Strategy Group agreed the following priorities for the renewed Strategy Action Plan at its meeting in July 2011:

- **Develop work with partner agencies which reaches unknown carers and provides appropriate responses.**
- **Increase access to information for carers and key workers in 'key places'.**
- **Raise carer awareness amongst GPs and all workers in health settings.**
- **Engage with the Clinical Commissioning Group for Vale of York to raise awareness of the support needs of carers.**
- **Ensure the need to provide support for carers is included in all work at a strategic level.**
- **Implement the young carers assessment of need.**

York Carers Forum outing to Yorkshire Lavender (Terrington) – 7th July 2011

APPENDIX 1

Progress summary July 2011
York Carers Strategy Action Plan - Key priorities and targets 2009 - 2011

National Strategic Outcome One ***Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role.***			
	Outcome	**Local priority**	**Achievements: July 2011**
1A	**Information**: Carers will have easy access to accurate information and advice	• Provision of easily accessible information and signposting	• Carers Information Pack produced and annually updated • York Carers Centre developing as focal point for information • York Carers Centre, CANDI, York Carers Forum, Young Carers Revolution and City of York Council websites provide information for carers
1B	**Carer identification:** Carers will be recognised and valued for their unique role in supporting the cared for person	• Increase identification of carers in Primary Care (see 4C)	• York Carers Centre contacted all GP surgeries and distributed information in 2010/11 • City of York Council Health Overview Scrutiny Committee completed a carer review in spring 2011 focussing on carer identification
1C	**Young Adult Carers:** Carers will have easy access to accurate information and advice	• Establishment of support for young adult carers aged 18 years + by York Carers Centre	• York Carers Centre provides regular ongoing support to 44 young adults (July 2011)

1D	**Integrated services:** Services and information will be provided in a coordinated way across and within agencies	• Closer joint working and partnerships between health, social care and the third sector • Awareness raising for professionals	• Draft 'Care Pathway for Carers Support' presented to Carers Strategy Group April 2011 • E learning carer awareness raising tools re 'Young Carers' and 'Adult Carers' launched May/June 2011
1E	**Personalised services:** Carers will have access to a range of flexible services that meet their individual needs	• Carer Assessment of Need • Common Assessment Framework *(NB not implemented for adults in York)* • Personal budgets	• Continued increase in numbers of separate carer assessment and review completed (673 in 09/10 and 857 in 10/11) • Carer's role acknowledged in assessment questionnaire for cared for person's personal budget
1F	**Carer involvement:** Carers will be involved in planning and monitoring the services they receive	• Training for carers – Living for Learning • Carer involvement	• One Living for Learning course held in 2009 • Three active carer led forums established and offered ongoing support

National Strategic Outcome Two ***Carers will be able to have a life of their own alongside their caring role***			
	Outcome	**Local priority**	**Achievements**
2A	**Break provision:** Carers should have access to a range of flexible breaks	• Joint plans with NYYPCT re new money for breaks • Review current breaks provision • Personal budgets to enable carers to take breaks	• Breaks review presented to Carers Strategy Group April 2010 • Continued increase in numbers of carers benefiting from Flexible Carer Support Scheme (600 in 09/10 and 680 in 10/11)
2B	**Emergency Card Scheme:** Carers should be better equipped to deal with a crisis and have peace of mind	• Emergency Card Scheme	• Card scheme well established for adults, now includes young carers
2C	**Technology:** Carers should have access to a range of services and support	• Telecare	• Small scheme to promote benefits of telecare for carers completed in 10/11
2D	**Housing, Leisure and Transport:** Carers should have access to a range of services and support	• Discount card scheme	• Carers with Carers Emergency Card and those in receipt of Carers Allowance can access discounts at City of York Council leisure classes and swimming pools • York Carers Centre launched a discount card for carers in December 2010 involving 50 local businesses

National Strategic Outcome Three ***Carers will be financially supported so that they are not forced into financial hardship by their caring role***			
	Outcome	**Local priority**	**Acheivements**
3A	**Income:** Carers should have access to benefits advice	• Welfare benefits advice	• York Carers Centre continues to increase uptake of benefits for carers.
3B	**Employment:** Carers should have access to employment support and vocational training	• Ensure carers in employment are supported • Encourage carer aware employment practice • Make local links with new 'care partnership managers' at Jobcentre Plus	• York Carers Centre Employment Education and Training service established. • York Carers Centre works with employers • City of York Council awarded a Carer Friendly Employer charter mark • Care Partnership Manager a member of Carers Strategy Group

National Strategic Outcome Four ***Carers will be supported to stay mentally and physically well and treated with dignity***			
	Outcome	**Local priority**	**Achievements**
4A	**Prevention:** Carers should have access to appropriate medical advice, and support about their own health needs	• Self-health checklist distribution and evaluation	• Check list piloted and distributed • Business case for back care support for carers compiled and short term development work planned • Need to give advice to carers on moving and handling included in principles for Admissions and Discharge policies circulated to Acute Trusts
4B	**NHS:** Carers needs should be addressed in hospital admission and discharge procedures		• NHS North Yorkshire and York included carers issues in the principles for the Admissions and Discharge Policies for all Acute Trusts • Health passport piloted for Neurology patients includes pages about carers. • York Carers Forum worked with York Hospital to ensure carer recognition at End of Life Pathway
4C	**Primary Care and GPs:** Primary care professionals should identify carers ensuring appropriate support, signposting and referrals	• Update GP resource pack (*Decision made not continue with pack)* • Develop work to improve carer identification and signposting in primary care settings	• York Carers Centre contacted all GP surgeries in York and distributed promotional information • Carer issues included in Dementia Map of Medicine to prompt support of carers

4D	**Emotional Support:** Carers should have support to maintain their well being and reduce stress		

National Strategic Outcome Five ***Children and young people will be protected from inappropriate caring and have the support they need to learn, develop, and thrive, to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes*.** *(Every Child Matters outcomes: be healthy, stay safe, enjoy and achieve, make a positive contribution, achieve economic well-being)*			
	Outcome	**Local priority**	
5A	**Universal services:** Children will have the support they need to learn develop and thrive	• Support schools in York to support young carers	• York Carers Centre began dedicated work with York Schools in 2009 • Young Carers Revolution produced and publicised a range of carer awareness raising tools
5B	**Targeted support for young carers:** Young carers will be able to make a positive contribution and have their views respected	• Set up a Young Carers Forum	• Young Carers Revolution established as York's carer led forum for young care
5C	**Whole family support:** Children and young people will be protected from inappropriate caring		• York Carers Centre secured funding fo a specialist one year post 2010/11 offering direct support to families and work to support strategic change which enabled the development of the e learning carer awareness raising tools.

York Carers Strategy Action Plan 2011 - 2015

Appendix 2

National Strategic Outcome One ***Recognised and supported as expert care partners***		
	Outcome	**What we need to do**
	Information: Carers will have wider access to accurate information and advice available through a range of communication methods	• Set up a robust system for update and distribution of accessible information for carers, including electronic distribution methods • Decide which are the 'key places' in York where carers information should be available • Develop and distribute public information which is accessible to people who may not recognise themselves as 'carers' • Involve GPs in the provision of information to carers
	Carer identification: Carers will be recognised and valued for their unique role in supporting the cared for person	• Enable professionals to effectively identify carers. • Include carer awareness raising in all workforce development strategies
	Integrated services: Services and information will be provided in a coordinated way across and within agencies	• Ensure all Carers Strategy partners adopt the 'Care Pathway for carers support'

	Personalised services: Carers will have access to a range of flexible services that meet their individual needs	• Adult and Children's Social Services to provide a coordinated approach to assessment for the 'whole family' • City of York Council will reduce length of waiting list for Carers Assessment of Need
	Carer involvement: Carers will be involved in planning and monitoring the services they receive	• Review and increase carer involvement and take appropriate action • Map carer involvement in local health and social care planning networks with attention to the development of Healthwatch
	Equality and social inclusion: All carers will be able to access services and support.	• Ensure information about carers ethnicity is appropriately recorded by City of York Council, York Carers Centre and all Carers Strategy partner organisations to inform future service planning • Use existing contact mechanisms with BME, multi-faith and multi-cultural groups to identify the numbers of carers from BME communities and take appropriate action • City of York Council to review its equalities framework to ensure carers become part of all equality and inclusion work

National Strategic Outcome Two ***Enjoying a life outside caring***		
	Outcome	**What we need to do**
	Break provision: Ensure carers have access to a range of flexible breaks	• Set up a clear framework for provision of breaks for carers which links to self directed support and personalisation • Audit existing services and support • Agree and promote the concept of what a carers break is • Research and adopt good practice • Roll out the Carers Emergency Card to parent carers
	Technology: Ensure carers have access to a range of services and support	• Provide accessible telecare services to adults

National Strategic Outcome Three ***Not financially disadvantaged***		
	Outcome	**What we need to do**
	Income: Ensure carers have access to benefits and financial advice	• Audit current benefits advice services available to carers • Ensure carers can access financial advice when the cared for enters residential care and at end of life
	Employment: Carers should have access to employment support and vocational training	• Monitor City of York Council's implementation of the action plan linked to the 'Carers Friendly Employer' charter mark • Develop links with local businesses • Roll out information about carers employment rights to employees and employers in York

National Strategic Outcome Four ***Mentally and physically well; treated with dignity***		
	Outcome	**What we need to do**
	Prevention: Carers should have access to appropriate medical advice, and support about their own health needs **NHS:** Carers needs should be addressed in hospital admission and discharge procedures **Primary Care and GPs:** Primary care professionals should identify carers ensuring appropriate support, signposting and referrals **Emotional Support:** Carers should have support to maintain their well being an reduce stress	• Health commissioners and providers ensure greater consistency around identifying and addressing the needs of carers • Health commissioners will work towards ensuring that all care pathways provide guidance on the information and advice carers will need • To engage with the new NHS Commissioning bodies (Clinical Commissioning Groups) as they develop to promote carers issues and build on existing work in Primary, Community and Acute Care

National Strategic Outcome Five ***Children thriving, protected from inappropriate caring roles***		
	Outcome	**What we need to do**
	Universal services: Children have access to the support they need to learn, develop and thrive	• Set up the Young Carers task group and action plan • Ongoing development of the work now established in schools which supports young carers • Task group to consider York LINk report (March 2011) recommendation: 'Young carers should be given help to get home access to computers'
	Whole family support: Children and young people are protected from inappropriate caring. Young adults have access to appropriate advice in relation to their transition into adulthood.	• Implement the Common Assessment Framework (CAF) as the assessment tool for Young Carers Assessment. • Ensure adult services identify young carers in their assessment processes and paperwork • Ensure effective sources of advice are available to young carers aged 16-18+

Appendix 3

What carers in York have told us?

National Strategy refresh session – York 2010
25 people attended a consultation meeting on 16th August 2010.
16 were carers, of whom 4 were young carers. Three other carers returned written responses. Nine workers/professionals attended of whom all had specialist roles to support unpaid carers. Carers discussed what the priorities for services and support to carers should be.

KEY MESSAGES (from final discussion at meeting)

"Don't let money rule it, sometimes have to spend a bit to create a lot."

Do not cut services to carers. Carers save money, and are value for money. Protect the carers, and the cared for is protected.

"These services are our rights."

Personalisation and respite is a complex issue.

Third sector equals value for money.

Short breaks are a priority.

Emergency support at short notice.

Development of personal budgets and support to maintain them.

Identification of carers in schools, GPs, hospital and hospital discharge.

Training by carers in carer awareness for professionals/workers.

Carers Allowance: increase and change the rules.

Young Carers need specialist support and support in schools and Further Education.

Carers own health.

Quotes from carers

Peer Support
"The only things that have worked well for me is when I have spoken to other carers….they were the ones who put me on to things that helped me. I would love to say "serviceland" helped me but I can't."

"Enabling parent/carers to speak to other parent/carers. People listen and learn best from people that know what they mean without having to explain."

Health and Well-being
"One of the most important outcomes of the strategy. If the carer doesn't have support and attention to their physical needs then there would be two people in need of care."

"For me, the most important priority for the carer strategy is to ensure both the mental and physical well-being of the carer…..in the long term, funds targeted at ensuring carers are mentally and physically able to continue in their supporting roles will pay huge dividends by avoiding significant costs when things go wrong."

"Emotional support for carers would be very welcome as it is badly needed. The only emotional support I have ever received in my caring role, has come from other carers. Funding carer led support groups should be a priority."

Health Overview Scrutiny Report 2011
In November 2010 the City of York Council's Health Overview Scrutiny Committee set up a Task Group to carry out a Carer's Scrutiny Review.

Aim: to promote the valuable work done by carers and to improve the way City of York Council and its key partners identify carers and ensure they have access to information and the support available.

Key objectives:
1) To raise awareness of carers
2) To improve access to information for carers

20 carers and 10 care workers contributed information in person or via a questionnaire.

Analysis of information from the Public Event and questionnaires

The importance of early identification of carers
Key professionals, especially GPs need to be aware of carers from an early stage and identify them as soon as possible.

Recognising you are a carer
People do not always immediately recognise themselves as a carer. Steps need to be taken to encourage early carer self-identification so that the right information can be provided at the right time. Carer needs to have access to information immediately that they recognise themselves as a carer.

"Many comments were received (at the public event and in returned questionnaires) that recognising that you are a carer was a gradual process, however it often became very clear at a point of crisis (such as hospital admission or diagnosis or a particular condition.)"

Provision of Information
Information would need to be proportionate to the needs of each individual carer.

Carers own needs
Comments at the public event were backed up by questionnaires that identified that frequently more support is given to patients/customers than to carers. This meant that the carer's health often suffered as a consequence and carer didn't always get enough time to spend on their own needs especially if they were caring for more than one person.

York LINk Report 2011
The LINk Steering Group held a Public Information and Awareness Event on Carers Rights on September 8th 2010. Evidence about services for carers in York was provided by a total of 48 individuals and York Carers Centre staff.

Recommendations from "Report on Carers Rights – March 2011" were made on the following themes:

Young Carers
- City of York Council to help fund York Carers Centre to promote young carers awareness in schools
- Implementation of a Young Carers Card Scheme and funding for York Carers Centre for a young carers event
- GPs should keep a record of young carers
- City of York Council provide support to help young carers to find ways of funding home computers

Employment
- City of York Council organise support and advice to help carers combat discrimination in the workplace
- Local organisations to offer work experiencing placements to carers

Parent carers
- City of York Council should improve access for disabled children to social services
- Jointly commissioned (by NHS North Yorkshire and York and City of York Council) posts to help parent carers liaise with community, social services and health services

City of York Council
- Congratulations to City of York Council for the amount of support provided for carers and carer organisations and request that high standards are maintained.

Carers Assessments
- Increased resources from City of York Council to reduce waiting times for Carers Assessments

GPs
- GP surgeries in York should adopt the model used in Somerset called the Carers Champions Scheme, with training delivered by York Carers Centre and York Carers Forum.

York Carers Centre Survey 2011
In January 2011 York Carers Centre sent out a survey to 650 adult carers registered on its database. In total 183 surveys were returned: a response rate of 28%. The following is a summary of feedback from carers.

To view the full survey results go to:
http://www.yorkcarerscentre.co.uk/content/carers-survey-2011

Current services

- 47% of carers heard about York Carers Centre from a social worker or carer support worker.
- 13% of carers heard about York Carers Centre from their GP surgery.
- 57% of carers responded that one of the reasons they initially contacted the Centre was to find information about services, and 42% to register for the Carers Emergency Card.
- 58% of carers usually contact the Centre by phone.
- 94% of carers felt able to speak to someone at the Centre at a convenient time.
- 95% of carers fed back very positively about all aspects of home visits from Centre workers.
- 88% of carers agreed that information in York Carers Centre newsletter was useful and relevant.
- 95% of carers felt that leaflets in the Carers Information Pack were useful and relevant.
- 79% of carers agreed that York Carers Centre helps them with the stresses of being a carer.

What carers would like to see in the future

- 80% of carers would like to have regular advice surgeries in their local area.
- 74% of carers felt if would be useful to have a telephone helpline for emotional support.

Appendix 4

Carers Scrutiny Review March 2011 – summary of recommendations

City of York Council Health Overview Scrutiny Committee Carers Review Task Group met between December 2010 and March 2011.
For further details and the full final report see:
http://democracy.york.gov.uk/ieListDocuments.aspx?CId=718&MId=6313&Ver=4

Carers Scrutiny Review March 2011 – summary of recommendations

To raise awareness of carers:

- Health commissioners and providers ensure that there is greater consistency around how carers are identified and once identified their needs addressed.
- That the Multi-Agency Carer's Strategy Group identifies where it would be helpful to provide public information about what it means to be a carer and how to access support to enable carers to identify themselves earlier.
- That City of York Council reviews its Equalities Framework to ensure that carers become an integral part of all equality and inclusion work.

To improve access to information for carers

- That health commissioners ensure that all care pathways provide guidance on the information and advice carers will need.
- That Adult Social Services develop a clear pathway, which provides an integrated approach to assessment for the whole family.
- To continue to promote carer awareness an annual update on the Carers Strategy for York be presented to the Heath Overview and Scrutiny Committee and thereafter to the Executive Member for Health and Adult Social Services.

York Strategy for Carers

Compiled and agreed by York Carers Strategy Group August 2011.

For more information contact:

Frances Perry
Carers Strategy Manager
City of York Council

Phone **01904 554188**
Email **frances.perry@york.gov.uk**

Acknowledgements

Thanks to Young Carers Revolution for the campaign images page 5 and 19, to see their campaign please visit www.youngcarersrevolution.wordpress.com

Thanks to York Carers Forum for photos page 14 and 20.

Other photos from local and national library sources.

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Annex 4

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3A	**Income:** Carers should have access to benefits advice	• Welfare benefits advice	• York Carers Centre continues to increase uptake of benefits for carers.
3B	**Employment:** Carers should have access to employment support and vocational training	• Ensure carers in employment are supported • Encourage carer aware employment practice • Make local links with new 'care partnership managers' at Jobcentre Plus	• York Carers Centre Employment Education and Training service established. • York Carers Centre works with employers • City of York Council awarded a Carer Friendly Employer charter mark • Care Partnership Manager a member of Carers Strategy Group

National Strategic Outcome Four ***Carers will be supported to stay mentally and physically well and treated with dignity***			
	Outcome	**Local priority**	**Achievements**
4A	**Prevention:** Carers should have access to appropriate medical advice, and support about their own health needs	• Self-health checklist distribution and evaluation	• Check list piloted and distributed • Business case for back care support for carers compiled and short term development work planned • Need to give advice to carers on moving and handling included in principles for Admissions and Discharge policies circulated to Acute Trusts
4B	**NHS:** Carers needs should be addressed in hospital admission and discharge procedures		• NHS North Yorkshire and York included carers issues in the principles for the Admissions and Discharge Policies for all Acute Trusts • Health passport piloted for Neurology patients includes pages about carers. • York Carers Forum worked with York Hospital to ensure carer recognition at End of Life Pathway

4C	**Primary Care and GPs:** Primary care professionals should identify carers ensuring appropriate support, signposting and referrals	• Update GP resource pack (*Decision made not continue with pack)* • Develop work to improve carer identification and signposting in primary care settings	• York Carers Centre contacted all GP surgeries in York and distributed promotional information • Carer issues included in Dementia Map of Medicine to prompt support of carers
4D	**Emotional Support:** Carers should have support to maintain their well being and reduce stress		

National Strategic Outcome Five ***Children and young people will be protected from inappropriate caring and have the support they need to learn, develop, and thrive, to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes*.** *(Every Child Matters outcomes: be healthy, stay safe, enjoy and achieve, make a positive contribution, achieve economic well-being)*			
	Outcome	**Local priority**	
5A	**Universal services:** Children will have the support they need to learn develop and thrive	• Support schools in York to support young carers	• York Carers Centre began dedicated work with York Schools in 2009 • Young Carers Revolution produced and publicised a range of carer awareness raising tools
5B	**Targeted support for young carers:** Young carers will be able to make a positive contribution and have their views respected	• Set up a Young Carers Forum	• Young Carers Revolution established as York's carer led forum for young carers

5C	**Whole family support:** Children and young people will be protected from inappropriate caring		• York Carers Centre secured funding for a specialist one year post 2010/11 offering direct support to families and work to support strategic change which enabled the development of the e learning carer awareness raising tools.

Annex 5

York Carers Strategy Action Plan 2011 - 2015

National Strategic Outcome One ***Recognised and supported as expert care partners***		
	Outcome	**What we need to do**
	Information: Carers will have wider access to accurate information and advice available through a range of communication methods	• Set up a robust system for update and distribution of accessible information for carers, including electronic distribution methods • Decide which are the 'key places' in York where carers information should be available • Develop and distribute public information which is accessible to people who may not recognise themselves as 'carers' • Involve GPs in the provision of information to carers
	Carer identification: Carers will be recognised and valued for their unique role in supporting the cared for person	• Enable professionals to effectively identify carers. • Include carer awareness raising in all workforce development strategies
	Integrated services: Services and information will be provided in a coordinated way across and within agencies	• Ensure all Carers Strategy partners adopt the 'Care Pathway for carers support'

	Personalised services: Carers will have access to a range of flexible services that meet their individual needs	• Adult and Children's Social Services to provide a coordinated approach to assessment for the 'whole family' • City of York Council will reduce length of waiting list for Carers Assessment of Need
	Carer involvement: Carers will be involved in planning and monitoring the services they receive	• Review and increase carer involvement and take appropriate action • Map carer involvement in local health and social care planning networks with attention to the development of Healthwatch
	Equality and social inclusion: All carers will be able to access services and support.	• Ensure information about carers ethnicity is appropriately recorded by City of York Council, York Carers Centre and all Carers Strategy partner organisations to inform future service planning • Use existing contact mechanisms with BME, multi-faith and multi-cultural groups to identify the numbers of carers from BME communities and take appropriate action • City of York Council to review its equalities framework to ensure carers become part of all equality and inclusion work

National Strategic Outcome Two ***Enjoying a life outside caring***		
	Outcome	**What we need to do**
	Break provision: Ensure carers have access to a range of flexible breaks	• Set up a clear framework for provision of breaks for carers which links to self directed support and personalisation • Audit existing services and support • Agree and promote the concept of what a carers break is • Research and adopt good practice • Roll out the Carers Emergency Card to parent carers
	Technology: Ensure carers have access to a range of services and support	• Provide accessible telecare services to adults

National Strategic Outcome Three ***Not financially disadvantaged***		
	Outcome	**What we need to do**
	Income: Ensure carers have access to benefits and financial advice	• Audit current benefits advice services available to carers • Ensure carers can access financial advice when the cared for enters residential care and at end of life
	Employment: Carers should have access to employment support and vocational training	• Monitor City of York Council's implementation of the action plan linked to the 'Carers Friendly Employer' charter mark • Develop links with local businesses • Roll out information about carers employment rights to employees and employers in York

National Strategic Outcome Four ***Mentally and physically well; treated with dignity***		
	Outcome	**What we need to do**
	Prevention: Carers should have access to appropriate medical advice, and support about their own health needs **NHS:** Carers needs should be addressed in hospital admission and discharge procedures **Primary Care and GPs:** Primary care professionals should identify carers ensuring appropriate support, signposting and referrals **Emotional Support:** Carers should have support to maintain their well being an reduce stress	• Health commissioners and providers ensure greater consistency around identifying and addressing the needs of carers • Health commissioners will work towards ensuring that all care pathways provide guidance on the information and advice carers will need • To engage with the new NHS Commissioning bodies (Clinical Commissioning Groups) as they develop to promote carers issues and build on existing work in Primary, Community and Acute Care

National Strategic Outcome Five ***Children thriving, protected from inappropriate caring roles***		
	Outcome	**What we need to do**
	Universal services: Children have access to the support they need to learn, develop and thrive	• Set up the Young Carers task group and action plan • Ongoing development of the work now established in schools which supports young carers • Task group to consider York LINk report (March 2011) recommendation: 'Young carers should be given help to get home access to computers'
	Whole family support: Children and young people are protected from inappropriate caring. Young adults have access to appropriate advice in relation to their transition into adulthood.	• Implement the Common Assessment Framework (CAF) as the assessment tool for Young Carers Assessment. • Ensure adult services identify young carers in their assessment processes and paperwork • Ensure effective sources of advice are available to young carers aged 16-18+

Decision Session - Cabinet Member for Health, Housing and Adult Social Services **22 November 2011**

Report of the Assistant Director (Adult Assessment and Safeguarding)

Dementia Strategy and Action Plan

Summary

1. This report asks the Cabinet Member to approve the North Yorkshire and York Dementia Strategy, and the local plan to deliver the Strategy in York. It also seeks agreement to sign up to the Dementia Declaration

Background

2. The National Dementia Strategy for England was published on 3 February 2009.

3. It identified 17 key objectives which, when implemented, should result in a significant improvement in the quality of services and promote a greater understanding of the causes and consequences of dementia.

4. In 2010 the Department of Health produced an updated implementation plan 'Quality Outcomes for people with dementia; building on the work of the National Dementia Strategy'. It identified four priority outcomes:

   - good quality early diagnosis and support
   - improved care in hospital
   - living well with dementia in care homes
   - reducing the use of anti-psychotic drugs

5. North Yorkshire and York Primary Care Trust have been leading work since 2009, to develop a joint local dementia strategy, covering both City of York Council and North Yorkshire County Council.

6. In York a working group has been looking at the strategy, on behalf of the York Mental Health and Modernisation Partnership Board, since early 2010. The working group has identified the priorities for York from the National Strategy, and produced suggestions for a plan to address these priorities.

7. 45 national organisations launched the 'Dementia Declaration' and invited wider sign up to the declaration as a way of committing organisations to the delivery of the outcomes within the Quality Outcomes.

Consultation

8. The national strategy was developed following extensive consultation with a wide range of stakeholders, including significant input from people living with dementia, and their carers.

9. The North Yorkshire and York Strategy used information from Overview and Scrutiny Committee reviews in both North Yorkshire and York, and undertook local mapping exercises involving a wide range of key stakeholders. Separate discussions were held with groups of people with dementia and their carers to gain their views on the current services and what they felt could be improved to provide better treatment and care. The main issues raised were:

   - not knowing who to turn to for support when symptoms cause concern
   - not being listened to particularly in the early stages and particularly by primary care
   - carers not being listened to when the cared for person is having tests or treatment for the dementia or another condition
   - lack of respite for the carers

10. The York Dementia Working Group has involved a wide range of stakeholders including service providers from health, the independent sector and the Council, the voluntary sector and service users and carers.

11. Further work is in progress within the city, led by the Joseph Rowntree Foundation, to engage more actively with people living with dementia to give them a stronger voice in the development of services, as the strategy is implemented. 'Dementia Without

Walls' is a 12 month project to support people living with dementia to suggest how a city can become more dementia friendly.

Options

Option 1

12: (a) To approve the North Yorkshire and York Dementia Strategy attached at Annex A

(b) To note the Executive Summary of the report of the York Dementia Working Group (Annex B)

(c) To sign up to the Dementia Declaration (Annex C)

(d) To agree the action plan proposed in Annex D

Option 2

13. To propose changes to the North Yorkshire and York Dementia Strategy, and/or the York Action Plan.

Analysis

Option 1

14. (a) The North Yorkshire and York Strategy (Annex A) outlines the high level information about dementia services in the whole of the Primary Care Trust (PCT) area, and provides an outline framework for action to address the objectives of the original National Dementia Strategy. The principles and direction of travel are consistent with the national strategy, and the subsequent four priority outcomes, but because of its overarching nature it does not give a strong sense of the priorities and action proposed in York. Within North Yorkshire County Council and the PCT there is a commitment to the Dementia Network driving the actions within the county. The Network was set up, in part, as a result of a North Yorkshire County Council Health Overview and Scrutiny review. On its own the county wide strategy is unlikely to provide a strong focus for action in York, and reliance solely on the Dementia Network could mean that specific York issues are lost. There are, however, strong advantages to maintaining contact with the Network to ensure learning and good practice is shared widely.

15. (b) The report of the York Working Group (Annex B) provides a more detailed review of the services for people living with

Dementia in York. During the development of the report progress has already been made with the city in respect of the objectives of the National Strategy, with work on a local pathway led by local GPs, and the commissioning of a new memory advisor service by the previous GP commissioning group in York. Care home providers have started to share good practice, across the independent sector and council providers, and social care commissioners have begun to work more closely with care homes to assure and improve quality. Our review of residential care homes and the proposal to develop more community based care and improve the quality of care homes will also contribute to the delivery of the strategy and action plan. The Working Group's report gives a good sense of where, collectively, providers and commissioners believe the priorities lie in York.

16. (c) The Dementia Declaration (Annex C) was signed by 45 organisations in October 2010. Created in partnership with people with dementia and their carers, the declaration explains the huge challenges presented to our society by dementia and some of the outcomes we are seeking to achieve for people with dementia and their carers. Outcomes range from ensuring people with dementia have choice and control over decisions about their lives, to feeling a valued part of family, community and civic life. Commitment to the declaration requires publication of and action plan setting out what we will do to secure these outcomes and improve the quality of life of people with dementia by 2014.

17. (d) The Action Plan, (Annex D) is a response from the council to the York Dementia Working Group report, and shows what can be achieved within the resources currently available to the council. It also addresses the commitment requested through the Dementia Declaration.

Corporate Priorities

18. The proposals within this report support the Council Plan and priorities in respect of ensuring those who are most vulnerable are protected.

Implications

Financial

19. There are no financial implications to the recommendations in this report. The proposals within the action plan would be delivered within existing resources.

Human Resources (HR*)*

20. There are no immediate HR implications to this report. The action plan does, however, include the further development of the York Workforce Development Strategy, in conjunction with our partners.

Equalities

21. The issues addressed within this report have implications for the following equality strands: age; disability; gender; carers. None of the recommendations would disadvantage people within these groups – the purpose of the strategy is to improve access to services and support, and the quality of life for people within these strands.

Other

22. There are no implications relating to Legal, Crime and Disorder, Information Technology or Property arising from this report.

Risk Management

23. There are no risks associated with the recommendations in this report that need to be considered for active management.

Recommendations

24. That the Cabinet Member approves the recommendations in Option A to:

    (a) approve the North Yorkshire and York Dementia Strategy attached at Annex A

    (b) note the report of the York Dementia Working Group (Annex B)

    (c) sign up to the Dementia Declaration (Annex C)

    (d) agree the action plan proposed in Annex D

Reason: To improve the quality of life for those living with dementia

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Report Approved ✓ **Date** 7 November 2011

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Wards Affected: **All** ✓

For further information please contact the author of the report

Annexes

Annex A: North Yorkshire and York Dementia Strategy

Annex B: Report of the York Dementia Working Group

Annex C: Dementia Declaration

Annex D: CYC Dementia Strategy Action Plan

North Yorkshire and York Dementia Strategy

2011 - 2013

Judith Knapton
(Head of Commissioning Adult and Community Services)
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Pete Dwyer
Director
City of York Council

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North Yorkshire County Council

Forward

Dementia affects more and more people each year. Many of us already know the impact that dementia can have on the individual and their families. In North Yorkshire and York we have an above average older population and face the demographic challenges of an aging population and with that an increase in the number of people with dementia.

In order to respond to this challenge it is imperative that health and social care, in partnership with other services have a clear strategy to support people with dementia and their carers, now and in the future.

Staff working in statutory, voluntary and independent sector services and people with dementia and their carers were asked for their views on the current services. They told us of the need to improve the early assessment and diagnosis of those with dementia, better support for those with dementia when they have to go in to General Hospitals and better support for their carers. This strategy acknowledges those views and describes our joint approach to improve services and ensure more personalised services and support to help people 'live well' with their dementia.

The publication of the NHS White Paper in July 2010 and the Comprehensive Spending Review means a radical change in health and social care services. This strategy sets out a clear vision underpinned by a commitment to its implementation as these changes take place and beyond.

We would like to thank all those individuals, groups and organisations who have given their views and helped to shape this strategy. By working together on its implementation it will drive forward the changes needed to improve the care and quality of life of people with dementia, their families and carers.

Jayne Brown
Chief Executive NHS North Yorkshire and York
August 2011

Working in partnership:

Pete Dwyer
Director
City of York Council

Seamus Breen
(Assistant Director Health, Reform and Development)
North Yorkshire County Council

1. Introduction and purpose of this document.

The national dementia strategy for England 'Living Well with Dementia' was released on 3rd February 2009.
It identifies 17 key objectives which when implemented should result in a significant improvement in the quality of services and promote a greater understanding of the causes and consequences of dementia.

The purpose of the strategy is to:

- Provide a strategic quality framework within which services can deliver quality improvements to dementia services and address health inequalities relating to dementia;
- Provide advice, guidance and support for health and social care commissioners, SHA's (*Strategic Health Authorities)*, local authorities, acute trusts, mental health trusts, PCTs *(Primary Care Trusts),* independent providers and the third sector, and PBC's *(Practice Based Commissioners)*, in the planning, development and monitoring of services,
- And provide a guide to the content of high quality health and social care services for dementia to inform the expectations of those affected by dementia and their families.

The purpose of this local strategy is to outline how partners in North Yorkshire & York have responded to this, describe what we aim to achieve and how we intend to develop services to meet local needs, taking into account the particular characteristics of each locality.

The case for focussing on dementia and the impact dementia has on the person, their families and friends, local health and social care community and the economy are not covered in this document. This has been well documented within the national strategy and many other documents including:

- Everybody's Business. Department of Health 2005.
- Dementia UK Alzheimer's Society 2007
- Dementia: Out of the Shadows. Alzheimer's Society 2008
- Improving Services and Support for People with Dementia. House of Commons Committee of Public Accounts 2008.
- Listening to You – National Dementia Strategy Yorkshire & Humber Listening & Engagement Events Feedback 2008.
- Healthy Ambitions. Department of Health 2008
- My Generation – The Journey of Life (Report on Access to Dementia Services in North Yorkshire. NYCC Care and Independence Overview and Scrutiny Committee. 2009
- North Yorkshire's Joint Commissioning Framework for Dementia NYCC ACS/NHS NY&Y 2009.
- North Yorkshire and York Mental Health Commissioning Strategy 2010 – 2015 (Draft) 2010.
- The Operating Framework for the NHS in England 2011/12, Department of Health.

The Operating Framework for England 2011/12 expects NHS organisations to make progress on the National Dementia Strategy, including the four priority areas of:

- Good quality early diagnosis and intervention for all
- Improved quality of care in general hospitals

- Living well with dementia in care homes
- Reduced use of antipsychotic medication.

2. Aim

The strategic aim is by working with service users and carers and other agencies NHS North Yorkshire and York, City of York Council and North Yorkshire County Council will 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.

The strategy is intended to secure better mental health for those both under and over the age of 65 who are suspected of having or have a diagnosis of dementia and live within the boundaries of North Yorkshire and York and will also consider those primarily over the age of 65 who have a functional mental health problems (such as depression, anxiety, psychosis).
It should be noted however that older people should be entitled to services irrespective of age and this strategy aims to ensure that the best and most effective mental health care is available to everyone.

3. Dementia in NY&Y

A demographic profile of dementia across the Yorkshire & Humber region commissioned by the Yorkshire & Humber Improvement Partnership showed that for NY&Y the levels of dementia are predicted as:

	2008	Predicted for 2025
Early onset dementia	175	200
Late onset dementia	8,264	13,876

The numbers predicted to have late onset dementia by sub-type within NY&Y

Alzheimer's	5,196
Vascular dementia	1,382
Vascular and Alzheimer's	855
Lewy bodies	333
Fronotemporal	111
Parkinsons dementia	139
Other	248

Source: Dementia UK & POPPI

There are 1344 adults with a Learning Disability known to care management and health services in North Yorkshire and over 550 in York.
Consistent with the national prevalence of the population with Down's syndrome and dementia, the large majority of people with Down's in Yorkshire & Humber region have early on set dementia with 64% aged between 55 and 64 years old and 32% being between 45 to 54 years. This is set to change by 2025 to 67% for 55 to 64 ages while the 45 to 54 years group will increase in absolute terms, the overall proportion will decrease by 2025 to 29%.
(Dementia in Y&H: A demographic profile July 2009)

The Joint Strategic Needs Assessments for York and for North Yorkshire have identified dementia as a priority and concern for the future.

The Independent Review of Health Services in North Yorkshire and York was set up to make recommendations for the future commissioning of services within a sustainable financial framework to ensure future financial balance. The report highlighted a key development being the forecast of the significant increase in the older population. This population makes significant use of health and social care services and states that one of the key priorities should be the care of the growing numbers of people with dementia.

4. Local services

North Yorkshire and York the Community Mental Health services have recently undergone the national process of Transforming Community Services. The new providers of Older Peoples Mental Health services are:

Leeds Partnership NHS Foundation Trust has been awarded a three year contract to provide services in York, Selby and Tadcaster.
The proposed date of transfer of services to Leeds Partnership NHS Foundation Trust has been agreed as 1 October 2011.

Tees Esk and Wear Valleys NHS Foundation Trust has been awarded a three year contract to provide services in Harrogate district with outreach in to Craven where appropriate; Hambleton and Richmondshire, Scarborough, Whitby and Ryedale.
The proposed date of transfer of services has been agreed as 1 June 2011.

There are two Councils with Social Services responsibilities - North Yorkshire County Council and City of York Council and seven District Councils. Social Care staff in North Yorkshire were previously integrated in with Community and Mental Health Teams however this is no longer the case. Services have not historically been integrated in the York area.

There are five main district hospitals:
Airedale NHS Trust (covers the Craven area)
Harrogate District Foundation Trust (covers the Harrogate, Knaresborough Ripon and district)
South Tees Hospital (covers the Hambleton and Richmondshire area)
Scarborough Hospital (Covers Scarborough, Whitby and Ryedale)
And York (covers Selby and York).

There are a variety of voluntary sector and independent organisations that provide a range of primary and secondary prevention services that play an important role in supporting people with dementia and their carers. Investment in many of these organisations has been made by City of York Council (CYC), North Yorkshire County Council (NYCC) and NHS North Yorkshire and York. However the commissioning of these services is inequitable across the area.

NHS North Yorkshire currently have joint commissioning arrangements with both City of York Council (CYC) and North Yorkshire County Council (NYCC) and see dementia and the implementation of the new strategy as a priority area of work.

A mapping exercise was carried out to review the existing services against the objectives in the National Strategy. The discussions took place with key stakeholders in each geographical area and they were asked what they felt the priorities should be for that area (appendix 3). The areas were:

- Craven
- Harrogate, Ripon and Nidderdale
- Hambleton & Richmondshire
- Scarborough, Whitby and Ryedale
- Selby
- York

As would be expected there are many similarities across the different geographical areas but it also shows the gaps in service that relate specifically to an area.

5. Mapping of services and Peer Review

5.1 Mapping of services against the national strategy.

The table below shows the objectives from the national strategy, each area identified as a priority (those ticked) for the people they provide services for.
All areas identified objective 2 Early diagnosis and treatment and Objective 8 Care in General Hospitals as priorities.

Area	Objective												
	1 Raise awareness	**2 Early diagnosis**	**3 Infor-mation**	**4 Access to care after diagnosis**	**5 Peer support**	**6 Community Personal support**	**7 Carers strategy**	**8 General Hospitals**	**9 Inter-mediate care**	**10. Housing support**	**11 Care homes**	**12 End of life**	**13 Workforce**
Craven	√	√					√	√					√
Harrogate / Ripon		√				√		√			√		√
Ham & Rich		√				√		√	√		√		
SWR		√						√			√		√
Selby		√				√	√	√	√		√		
York		√					√	√	√				
Learning Disabilities							√	√				√	

5. Mapping of services and Peer Review - continued

The mapping exercise identified two objectives all areas felt are priorities for action:

- Objective 2 Good quality early diagnosis and intervention for all

There was felt to be a lack of support for people in the early stages of dementia and in particular the period between first raising concerns with services and eventually confirming a diagnosis. It is acknowledged that it can be very difficult in the early stages to make a diagnosis but more needs to be done in providing support to people at this time.
The importance of a multi disciplinary integrated approach was stressed by all and a need to ensure services are personalised.

- Objective 9 Improved quality of care for people with dementia in general hospitals

Real concerns were expressed by staff and service users and carers about the experiences of people in general hospitals who have dementia and their carers.
Issues raised include:

- Lack of knowledge and understanding by staff for those with dementia
- Lack of dignity and respect for patients and their carers
- Lack of systems in place to facilitate effective flow through the hospital and appropriate discharge to the appropriate place

Both of these objectives have been identified for early action in the implementation of the strategy.
Other issues raised as major concerns in all areas were:

- The lack of an integrated care pathway. Staff and services users and carers commented on the impact removal of social care staff has had on service delivery.
- Inconsistent and inequitable provision by the third sector in providing services for people with dementia and their carers.
- Capacity of services to deal with the increase in numbers of people with dementia as the elderly population grows at a time when the funding of public sector services is being reduced.

An issue that was raised in all areas was the benefits of different agencies and service users and carers coming together to share ideas and listen to each other. Many felt the previous Dementia Collaborative (a national initiative that came to an end in 2007) had many benefits and staff stated they would welcome something similar being set up.

5.2 The Yorkshire and Humber Health Improvement Partnership (YHIP) Peer Review.

YHIP carried out two Peer Reviews. One for North Yorkshire services and one for York services. This involved a small team (including health and social care commissioners and providers; Alzheimers Society Representatives and Strategic Health Authority representatives) visiting the area and meeting staff (commissioners and providers), service users and carers and a visit to a service. Set questions were asked that relate to the objectives in the national strategy.

Feedback from the review teams highlighted the following:

What is working well?

- Commitment from stakeholders to improve services for people with dementia and their carers

  In each (sub) locality there are many individuals and organisations committed to improving the experience of those suspected of and having dementia. The partnership working in this initial planning phase was considered very positive.

- Once in the 'system' people generally get a good service

  The services provided by the Community Mental Health Teams in particular were considered to be working well for those with moderate to severe dementia, with good links to other services.

- Involvement of the third sector
  The range of services provided across the North Yorkshire and York was seen as very positive. However the provision is not consistent across the area.

What needs improving?

- A whole system care pathway is needed with greater integration

  The Peer Review team commented that social care staff integrated within community mental health teams is considered to be good practice. However this is not the situation within North Yorkshire or York.

  The role of the third sector also needs to be clarified and supported to provide services that are equitable.

- Inequity of provision across North Yorkshire and York

  The current provision of services is largely based on historic commissioning of services when there were four Primary Care Trusts. This has resulted in inequity across the Trust in what and how services are provided and not necessarily addressing health inequalities.

6. Areas of Good Practice

The mapping exercise and the Peer Review both highlighted areas of good practice across North Yorkshire and York. These include:

Example of good practice	Benefits
Craven Information packs are given out to each person newly diagnosed with dementia. The pack is tailored to the persons specific stage and circumstances.	The person and their carer get supporting information for them to look at their leisure that is specific to their circumstances. Information that backs up the discussions with staff that is enough to help them understand the condition and issues to consider for them, as well as other support available. But not too much to overwhelm them.
Harrogate A Memory And Self Help group (MASH), patients (with carers) work with professionals over 12 weeks. Learn to cope, tips & techniques. Feedback from those who have attended is very positive. Input from Alzheimer's Society, Physiotherapy, Occupational Therapy and Community Mental Health	Supports the person with dementia and the carer to self manage the condition and the impact it has on their lives. It helps them plan for the future and provides peer support.
Hambleton & Richmondshire Completion of the Memory Service National Accreditation Programme by the Older Peoples Mental Health Service	This drives up the standards and quality of care given to people with memory problems, involves service users and carers in the process and identifies areas for improvement.
Scarborough, Whitby & Ryedale Day assessment and support for people with dementia. Community based staff work proactively and collaboratively with assessment colleagues to provide tailored support to people with dementia	The proactive approach helps to reduce social isolation and challenges attitudes that lead to people withdrawing from or being excluded from community based activities, whilst being able to access ongoing medical reviews when required.
York Extended hours of service for Community Mental Health Team to 8pm during the week and from 9am to 5pm at the weekends and Bank Holidays.	The teams are able to step up their support when necessary to enable people to stay at home when their needs increase and prevent the distress of an avoidable admission to acute care.
Selby Use of Assistive Technology to support people with dementia and their carers	Enables people to stay in their homes for longer. Reduces the need for home care and can reduce the anxiety levels of the person with dementia and their carers.

7. Learning Disabilities and Dementia

Within North Yorkshire and York the treatment and care of those with Learning Disabilities (LD) and Dementia is generally managed by the Learning Disability Teams with support from CMHT.
Staff within the LD Teams were consulted to establish what they felt were the issues and areas for improvement.
The results of these discussions highlighted the following:

- Issue of end of life care being provided out of area. Consideration needs to be given to the development of a North Yorkshire & York service for end of life.
- The importance of carers in maintaining people at home and the support needed by them in order to continue providing a caring role, particularly respite, both planned and unplanned.
- Reports of poor experiences by people in general hospitals. Training and education is needed for staff to raise awareness of the issues for those with dementia and LD.

8. Consultation and service user and carer involvement

Both the Overview and Scrutiny Committee reviews and the mapping exercise involved a wide range of key stakeholders including: Members from the Health Scrutiny committees; Adult services from North Yorkshire County Council and City of York Council (both commissioning and providers); PCT commissioners and providers from community, primary and secondary care services; the voluntary and independent sectors and people who have dementia and their carers.

Separate discussions were held with groups of people with dementia and their carers to gain their views on the current services and what they felt could be improved to provide better treatment and care.
The main issues raised were:

- Not knowing who to turn to for support when symptoms cause concern
- Not being listened to particularly in the early stages and particularly by primary care
- Carers not being listened to when the cared for person is having tests or treatment for the dementia or another condition.
- Lack of respite for the carers

9. Services for all

Information on who uses our services is mixed. In North Yorkshire and York the numbers of people from Black and Minority Ethnic (BME) is small compared to the national average.
It is expected that the number of older people with a sensory impairment will increase substantially. Commissioners need to ensure that people from all backgrounds and lifestyles have equal access to services and the services are responsive to their needs. This will have implications for service delivery. For example older people whose first language is not English may revert to speaking their first language as the dementia develops.

10. Values & Principles

During the discussions held for the Health Scrutiny reviews and the mapping against the national strategy a consensus emerged for the values and principles that would underpin good dementia services:

- There should be sufficient capacity within the system, including the third sector for services to respond effectively.
- Service design, planning and delivery should be transparent in the data provided to inform decisions and the process in which decisions are made.
- Services should where ever possible be based in the community and governed by minimum standards that are evidence based and in line with best practice.
- Services should be integrated to ensure close working between the different strands of care.
- Services should be available and easily accessible at every stage of the persons condition without unnecessary delays or repeated referrals to the same service.
- Services should be personalised to meet the individuals needs and circumstances.
- People and their carers should be informed and active partners in the decisions made about their care at all stages of the illness.
- The role of carers should be acknowledged and included as active partners in the care of those with dementia.

The Dementia Declaration was launched in October 2010 by the Dementia Action Alliance. It calls on families, communities and organisations to work together to transform the quality of life of millions of people affected by dementia.
NHS NYY, NYCC and CYC are all signed up to the principles of this declaration to:

- Ensure the work is planned and informed by the views of people with dementia and their carers and evidence this.
- Be an ambassador for the National Dementia Declaration
- Report publicly on progress against the plan to support the delivery of the declaration
- Work in partnership with others to share knowledge about best practice in dementia
- Improve understanding about dementia.

(www.dementiaaction.org.uk, 2010)

11. Prevention

Although the national strategy does not specifically address the issue of prevention it is one that has been raised by a number of people.
There is growing evidence indicating that certain medical conditions - such as high blood pressure, diabetes and obesity - may increase the risk of dementia whereas a healthy lifestyle may reduce the risk.
The dementia strategy will link to the wider public health agenda to promote a healthy lifestyle by the population.
A range of research projects looking at the causes and treatments of dementia are underway nationally. The North Yorkshire and York strategy will take account of any emerging findings and make any amendments that are felt to be advantageous to those at risk of and with dementia.

For those with dementia it is well recoqnised that activities such as individualised exercise programmes help to maintain the individual's health, independent function and delay the progression of the effects of the condition. (Larson et al 2006).
Secondary prevention methods will be considered to reduce the speed of decline and maintain independence.

12. Action Plan & Future Commissioning

The difficult economic climate and changing demographic profile, means that commissioning new services or new ways of working will become increasingly challenging for all.
The Governments white paper 'Liberating the NHS' (July 2010) sets out the government's long term vision for the future of the NHS. It means that there will be further changes to organisations, management structures and performance measures in the coming months.

The engagement of GPs, as they take on the responsibilities of commissioning services will be vital in ensuring dementia is seen as a priority area of work and ensure high quality and cost effective services are commissioned.
The following Clinical Commissioning Groups will be developed:

- Hambleton, Richmondshire and Whitby
- Vale of York (including Easingwold, Selby, Tadcaster, Kirbynoorside and Pocklington)
- Harrogate Rural and District
- Scarborough (not Rillington)
- Ryedale (including Rillington, Pickering, Malton, Amplforth and Helmsley)
- Craven are to join Airedale and Wharfedale Alliance
- Bentham to join South Lakes Commissioning Group

Public Health functions will transfer to Local Authorities and Health and Wellbeing Boards will be established to increase public engagement.
Primary Care Trusts are due to cease from 2013 and Commissioning Support Units may provide some of the commissioning functions.

Despite these changes, there is agreement from local stakeholders that the work needed to improve services for people with dementia and their carers must continue while these changes take place.

The assessment of services against the objectives in the national strategy has resulted in the attached action plan for implementation over the next three to five years that will inform the commissioning of services.

It highlights those areas seen as a priority by staff and service users and carers and also indicates the activity that relates to the other objectives in the national strategy.

The Action Plan will be delivered through local area based action plans that will focus on specific priorities for the local area. For example:

- York currently has a Dementia Working Group which is a sub group of the Mental Health Modernisation and Partnership Board for the City.

- Scarborough, Whitby and Ryedale have a Planning and Implementation Group for Older Peoples Mental Health that have been developing and improving local services for people with dementia for many years.

Where required, business cases for the redesign and/or resources needed to implement the strategy will be submitted to the relevant decision making bodies for approval.

13. Sharing learning

Staff across North Yorkshire and York raised the benefits of the previous Dementia Collaborative. This was a national initiative to bring staff, users and carers together to look at improving services. The methodology used was 'Plan, Do, Study, Act' cycle.

Staff felt that it would be useful to set up a network to share learning, prevent duplication, improve communication and understanding between organisations and have a vehicle to engage with commissioners in the planning of services. Staff and other key stakeholders were also keen to play an active role in finding solutions and supporting the implementation of the strategy.

As a result of this, NHS North Yorkshire and York in Partnership with North Yorkshire County Council have set up the North Yorkshire and York Dementia Network. Over one hundred and thirty individuals and groups are on the membership list and three or four meetings are held each year. The feedback has been very positive and the attendances at the meetings are good.

14. Accountability

The implementation of this strategy links directly to the Quality, Innovation, Productivity and Prevention (QIPP) plans for North Yorkshire including 'Shifting Settings of Care and Urgent Care' and 'Best Practice Care pathways for Long Term Conditions'. These will be monitored and progress will be reported to each of the CCG area Locality Programme Boards (which includes PCT/CCG; Local Authorities; Acute Trusts and others). The Locality Programme Boards are supported by the Central Programme Board.

The two Mental Health and Modernisation Partnership Boards for York and North Yorkshire will also monitor progress. In York this group currently reports to the Adult Commissioning Group for the City (Locality Programme Board). In North Yorkshire the Board will report and make recommendations to North Yorkshire County Council Executive Members. In both cases they also report to NHS North Yorkshire Transition and Reform Programme Board.

Where appropriate information on progress will also be put before; both Scrutiny Committees, the Clinical Commissioning Groups via the Transition and Reform Programme Board, and third sector providers via the third sector liaison groups.
Regular updates on progress will also be shared with all who are part of the North Yorkshire and York Dementia Network.

NY&Y Dementia Strategy Action Plan 2011 – 2013

NHS NYY = NHS North Yorkshire and York
CCG = Clinical Commissioning Group
CYC = City of York Council
NYCC = North Yorkshire County Council

To note - Local areas eg York have agreed specific action plans to address local issues.

Objective	**Commissioning Action**	**Lead** Other partners and agencies involved	**Timescales**	**Notes** **Resources / Risks**
1 - 13	1. To describe an integrated care pathway for dementia and the expected outcomes. To incorporate dementia in to the development of the levels of care initiative to develop more integrated health and social care services.	NHS NY&Y All CCG NYCC	December 2011 From April 2011 onwards.	
1-13	2. To develop the relevant service specifications to include the qualitative and quantitative performance measures that will demonstrate the desired outcomes. To reflect the integrated health and social care pathway once approved linked to the Transforming Community Mental Health Services.	NHS NY&Y All CCG CYC NYCC	Ongoing as required.	
1-13	3. To develop robust and effective commissioning of the third sector in order to support the implementation of the care pathway effectively and addresses inequity of provision	NHS NY&Y All CCG NYCC	April – October 2011 and as required	Cuts to public sector spend may impact on third sector provision.
1 – 13	4. To maintain and develop the North Yorkshire and York Dementia Network.	NHS NY&Y NYCC	Meetings held quarterly or as required. Sub groups to meet as required	Capacity to co-ordinate and maintain the network.

Action Plan continued…

Objective	Commissioning Action	Lead Other partners and agencies involved	Timescales	Notes Resources / Risks
1. Improving public & professional awareness and understanding	- Support National Agenda on raising awareness. - Using local media and websites to market messages on on-going basis - Develop wider public / community engagement. Support for Joseph Rowntree Foundation initiative in York and roll out of learning from it.	**NHS NY&Y** All CCG **NYCC** **CYC**	April 2011and ongoing	Network to consider and recommend approach and co-ordination of improving awareness and understanding – in line with national campaign. Local groups to consider implementation at the local level, including support within York for JRF project.

Objective	Commissioning Action	Lead Other partners and agencies involved	Timescales	Notes Resources / Risks
2. Good quality early diagnosis and intervention for all.	Describe a community model for early diagnosis and intervention that incorporate health, social care and the voluntary sector to: - provide a memory assessment service - Provision of Care plans - Reablement - Sign posting and - Point of contact / advisor role That is accessible to all including those with Young Onset dementia and LD. - post diagnosis care to be in line with NICE guidance and include therapies such as cognitive stimulation, cognitive behaviour therapy and others. - telecare to be offered as part of care pathway - services to be available outside usual working hours and at weekends.	**NHS NYY** CCG NYCC CYC Vol sector	Model described by October 2011. Evaluation of care navigator role March 2012.	Seen as a priority in all of the 6 areas. Risk - Identification of resources to enable service development and sustainability. Risk of cuts to public sector funding effecting implementation. Risk – lack of consistent agreement from CCG.
	- Negotiate implementation of early diagnosis pathway with providers.	**NHSNYY** CCG CMH Providers	Sign up to pathway by December 2011.	
	To increase the level of 'undiagnosed' dementia through activity such as: - engagement with CCG - use of QOF registers - awareness raising reducing stigma - better co-ordination between diagnosis for other conditions and dementia services.	Network NHS NYY CCG Acute Trusts		
	To promote good practice guidance to primary care for the care and treatment of those with dementia and their carers	NHS NYY CCG		

	To reduce / prevent inappropriate use of antipsychotic drugs to older people with mental health problems: - GP's to challenge and reduce repeat prescriptions for anti psychotics - Hospitals to have a policy in place for the use of anti-psychotics and monitor their use. - Undertake antipsychotic audit and assess results	NHS NYY CCG General Hospital Trusts		

Objective	Commissioning Action	Lead responsibility Other partners and agencies involved	Time-scales	Notes Resources / Risks
3. Good quality information for those with diagnosed dementia and their carers.	Review of information given to service users and carers and recommend information for each stage of the persons condition and individual situation to provide consistent, accurate, high quality information and advice based on the latest evidence and good practice.	**NHS NYY** via Dementia Network		

Objective	Commissioning Action	Lead Other partners and agencies involved	Time-scales	Notes Resources / Risks
4. Enabling easy access to care, support and advice following diagnosis.	To consider the role of the dementia advisor as part of the community model for early diagnosis - see objective 2	**NHS NYY** CCG NYCC CYC		

Objective	Commissioning Action	Lead Other partners and agencies involved	Time-scales	Notes Resources / Risks
5. Development of structured peer support and learning networks	Review current provision against care pathway and commissioning of third sector. Develop effective and robust commissioning of the third sector to support the implementation of the care pathway including the provision of peer support and learning networks.	NHS NY&Y NYCC All CCG CYC		Risk – resources to commission sufficient peer support that provides a personalised service and that is sustainable.

Objective	Commissioning Action	Lead responsibility Other partners and agencies involved	Time-scales	Notes Resources / Risks
6 Improved community personal support services	To incorporate the necessity for staff to have basic dementia training as part of the contract requirement for home care services. To commission services that respond to need rather than work to time slots.	NYCC		
	To review the contract agreement with advocacy services to ensure a consistent level of service is provided across NY&Y. To engage with Healthwatch and Advocacy providers in York to develop a sustainable service for older people	NYCC NHS NYY		Risk – available resources to commission advocacy services in York for Older

				People.
	Ensure the use of assistive technology and telehealth are built in to the care pathway and linked to development of equipment services and housing support.	CYC NYCC NHS NYY		
	To review the provision of flexible and responsive respite and breaks.	NYCC NHS NYY		
	To promote good practice in the review of patients physical health needs to include sight and hearing as part of the annual review by GP practices.	NHS NYY All CCG		
	To consider the needs of those with early onset dementia and develop support mechanisms to meet those needs.	NHS NYY CYC NYCC		Risk – available resources
	To explore feasibility of residential support for women with challenging behaviour	NHS NYY		Risk – resources to develop the service.

Objective	Commissioning Action	Lead responsibility	Time-scales	Notes Resources / Risks
7. Implementing the Carers Strategy.	Refresh both York and North Yorkshire Carers strategies in the light of the changes to the national strategy. Sign off both the Joint strategies between the PCT and CYC and NYCC and other key stakeholders. Implementation of the both action plans.	CYC NYCC NHS NYY	York - Sign off by Nov 2011 NY – Sign off by Feb 2012	

Objective	Commissioning Action	Lead Other partners and agencies involved	Time-scales	Notes Resources / Risks
8. Improved quality of care for people with dementia in general hospitals	a) Identify a lead for dementia in each acute Trust. b) Identify responsibilities of acute care providers in the care of those with dementia in secondary care settings and incorporate it into the contracting process.	a) All acute trusts / NHS NYY CCG b) NHS NYY CCG Acute Trusts	a)April 2011 b) March 2012	Seen as a priority in all of the 6 areas.
	To review the use of anti psychotic drugs in secondary care	Acute Trusts NHS NYY		
	Develop a service specification for liaison services to A&E and the wards within acute care settings and commission service accordingly – to include the submission of a business case to the Transformation and Reform Programme Board as required.	NHS NYY CCG	Draft spec by Sept 2011	Lack of available resources to cover costs

Objective	Commissioning Action	Lead Other partners and agencies involved	Timescales	Notes Resources / Risks
9. Improved intermediate care for people with dementia	Ensure that the care pathway and discharge planning for people with dementia includes intermediate care and reablement. To utilise the reablement monies to support training of staff in dementia care. To include this as part Transforming Community Services. Ensure that staff providing reablement services and intermediate care have the skills and competencies for supporting people with dementia. Ensure that all elements of the intermediate care system work together in an integrated way.	NHS NYY Acute Trusts All CCG NYCC CYC	April 2011 To March 2012	

Objective	Commissioning Action	Lead Other partners and agencies involved	Timescales	Notes Resources / Risks
10. Considering the potential for housing support, housing related services and telecare to support people with dementia and their carers.	To engage with housing support providers and ensure the needs of those with dementia are considered within the current provision. York – Deliver the Older Peoples Housing Strategy	NYCC NHS NYY CYC		
	To ensure assistive technologies, telecare and telehealth are built in as part of the care pathway for people with dementia at the different stages of the condition.	CYC NYCC NHS NYY	Ongoing	
	To ensure that the design of future extra care housing takes account of the needs of people with dementia, and influence the design of general housing to ensure the needs of those with dementia are considered.	Housing providers NYCC NHS NYY	Ongoing	

Objective	Commissioning Action	Lead Other partners and agencies involved	Timescales	Notes Resources / Risks
11. Living well with dementia in care homes	To agree and promote standards of good care and guidance for care homes including: - identified named dementia lead in the care homes - appropriate use of medication including antipsychotics - tools and policies that supports people with dementia to undertake meaningful activities	NHS NYY Network to draft CYC NYCC	Draft by Nov 2011	
	To produce guidance on choosing a home for the general public aimed at self funders	Network to draft	Draft by Nov 2011	
	To consider the development of in reach services to care homes including a liaison service to care homes in the treatment and care of those with dementia. To discuss with providers.	NHS NYY	Nov 2011.	Risk - Lack of available resources
	To monitor the use of anti psychotic drugs given to those with dementia in care homes.	NHS NYY	Ongoing	
	To monitor the number of admissions to hospital from care homes and work with homes who have repeated high levels of admissions to develop an action plan to address the causes.	NHS NYY NYCC CYC	Ongoing	

Objective	Commissioning Action	Lead responsibility Other partners and agencies involved	Timescales	Notes Resources / Risks
12. Improved end of life care	To ensure end of life / advanced directives training is incorporated in to staff training programmes for dementia particularly for health, social care, care home and voluntary sector staff.	All partners Network		

	To support care homes to manage end of life for their residents who have dementia and are dying.	NYCC CYC Network / Independent Care Group		
	To explore feasibility of an in area service for those with LD and dementia.	NHS NYY CCG		Available resources / provider

Objective	Commissioning Action	Lead Other partners and agencies involved	Timescales	Notes Resources / Risks
13. An informed and effective workforce for people with dementia.	a) Commission a training programme for staff in North Yorkshire involved in the Enhanced Community Teams that is specific to their role utilising the winter pressures/reablement funding. b) Agree competencies required for level and responsibilities of staff c) Commission a general dementia training programme for the wider health and social care community d) Introduce skills and competencies within service specifications and agreements with commissioned services including health, social care, the voluntary and independent sectors.	a) NHS NYY NYCC b) Network c) NHSNYY NYCC c) NYCC NHS NYY and Provider services.		a) Use of reablement monies to support this.

Objective	Commissioning Action	Lead Other partners and agencies involved	Timescales	Notes Resources / Risks
14. A joint commissioning strategy	To draft the Joint strategy with key partners and send out to key stakeholders for comments before amending and producing the final version.	NHS NYY CYC NYCC	Draft by Feb 2010. Sign off by: NHS NYY / CCG	

			CYC NYCC by December 2011.	

Objective	Commissioning Action	Lead Other partners and agencies involved	Timescales	Notes Resources / Risks
15. Improved assessment and regulation of health and social care services and of how systems are working for people with dementia and their carers.	Work with Providers to ensure they understand that commissioners only wish to commission good or excellent services for people with dementia. 'Adequate' or 'Poor' will not be acceptable. Ensure quality of services are built in to commissioning of services and the appropriate evidence to ensure outcomes are met.	NYCC NHS NYY		

Objective	Commissioning Action	Lead Other partners and agencies involved	Timescales	Notes Resources / Risks
16. A clear picture of research evidence and needs.	a) To look for opportunities for carrying out research to inform best practice. b) To ensure a good evidence base informs service development and commissioning.	All	Ongoing	

Objective	Commissioning Action	Lead Other partners and agencies involved	Timescales	Notes Resources / Risks
17. Effective national and regional support for implementation of the strategy.	a) Attend the Regional Dementia Leads Group and events to share good practice and learning and ensure communication and transfer of information between national, regional and local levels. b) To access any available support from regional or national level and to inform region and national level of progress and any examples of good practice from NY&Y and lessons learnt.	a) NHS NYY b) NHS NYY NYCC	a) Ongoing b) Ongoing	

Appendices

1. Mapping exercise summary by area.
2. Summary of findings from York Overview & Scrutiny Committee.
3. Summary of North Yorkshire Report
4. References

Appendix 1: Results of mapping exercise by area.

1. Priorities for York

CYC Health Scrutiny Committee carried out a review of dementia within secondary care. This highlighted several areas for further work including:

- The role and needs of carers
- Improving overall communication between staff and relatives including written patient information
- The development of a liaison service in partnership between CYC, NYYPCT and YDFT.
- Awareness and training for staff on dementia.

The York Health Group (Practice Based Commissioning Group) were involved in the mapping exercise and highlighted dementia as one of their priorities for service development. The initial group that undertook the mapping exercise have formed in to the York Dementia Working Group and is a sub group of the York Mental Health Modernisation and Partnership Board.

The mapping exercise resulted in the following areas being seen as a priority:

- **Objective 2: Good quality early diagnosis and intervention for all.**

Elements of a diagnosis service exist but it was felt that it needed to be improved to provide a more co-ordinated, user friendly and efficient service.
The option of a multidisciplinary 'One Stop Shop' was considered. This would be based in the community linked to practices that would provide:

  - Rapid access to early diagnosis
  - Relevant information and support appropriate to the individuals circumstances
  - Signposting to other support and information including voluntary / independent sector support for both the carer and cared for person.

- **Objective 7: Implementation of the Carers Strategy.**

Support to carers is a crucial element of supporting those with dementia.
Breaks for carers are seen as inadequate.
Education that provides practical tips on coping with daily living and self management was seen as important. There are several different programmes available and the benefits of each will need to be explored.

- **Objective 8: Improved quality of care for people with dementia in general hospitals**

The main acute provider is York District Foundation Trust.
A recent report by the York Health Scrutiny Committee on the dementia and accessing secondary care highlighted several areas of concern.
The training and education of staff needs to be prioritized and the responsibilities of secondary care need to be made explicit.

The development of a liaison service was identified as a major gap that has existed for some time.

- **Objective 9: Improved intermediate care for people with dementia –** There is currently no dedicated intermediate care service accessible to people with dementia. Currently it is unknown how often someone with dementia is offered the service or offered rehabilitation on discharge from hospital.

2. Priorities for North Yorkshire

The NYCC Care and Independence Overview and Scrutiny Committee also decided to focus on Dementia and carried out a review of services. This has resulted in a report that includes 18 proposals that outline what people feel a good dementia service should look like (appendix 2)
One area all agreed would be useful is the establishment of a Dementia network. This network will:

- provide leadership to the implementation of this local strategy and action plan
- improve communication and co-ordination between agencies
- devise, co-ordinate and ensure common standards and competencies in training and service provision
- ensure the people who use services and their carers are involved in the development, implementation and monitoring of the action plan.

The mapping against the national strategy objectives highlighted the following as priorities for each area:

2.1 Craven:

The main acute provider is Airedale District Hospital. However some patients in the north of the area use Lancaster Acute Trust. The mental health services are provided by Bradford and Airedale Community Mental Health Trust

- **Objective 1: Improving public and professional awareness and understanding**

Some members of the group felt it was important to support people in identifying symptoms and seeking support at an earlier stage. To reduce the stigma of dementia to enable people to feel more comfortable about discussing concerns and seeking help with the confidence they will be listened to and treated with respect.

- **Objective 2: Good quality early diagnosis and intervention for all.**

The group discussed the need for greater integration between services particularly mental heath and primary care; health and social care and the role of the voluntary sector. This is to reduce duplication of assessment reduce delays and provide more rapid and personalized services. Services should be based in the community linked to practices that would provide:

  - Rapid access to early diagnosis
  - A point of contact for people with dementia and their carers
  - Relevant information and support appropriate to the individuals circumstances

- Signposting to other support and information including voluntary / independent sector support for both the carer and cared for person.

- **Objective 7: Implementation of the Carers Strategy.**

Support to carers is a crucial element of supporting those with dementia.
Breaks for carers are seen as inadequate.
Education that provides practical tips on coping with daily living and self management needs to be developed.

- **Objective 8: Improved quality of care for people with dementia in general hospitals**

The training and education of staff needs to be prioritized and the responsibilities of secondary care need to be made explicit.
A specialist nurse liaison is commissioned to provide the service but no other staff / resources are commissioned. The development of a more robust liaison service was identified as a priority.

- **Objective 13 – informed and effective workforce** – to develop a learning network to provide opportunities for training and education for staff from all agencies.

2.2 Harrogate, Ripon and Nidderdale:

The main acute provider is Harrogate District Foundation Trust.

- **Objective 2: Good quality early diagnosis and intervention for all.**

The group discussed the option of a multidisciplinary service based in the community linked to practices that would provide:

- A case finding function to detect dementia at an earlier stage
- Integrated team with health and social care
- Rapid access to early diagnosis
- Relevant information and support appropriate to the individuals circumstances
- Signposting to other support and information including voluntary / independent sector support for both the carer and cared for person.
- To provide a dementia advisor/Admiral nurse function to provide a point of contact, advice and signposting for people through their journey from diagnosis to end of life (including support to carers after death of the cared for person)

- **Objective 6 Improved community personal support services**

The home care support available to people with dementia needs to be improved. There are also gaps in the provision of day activities particularly in the Ripon area.

- **Objective 8 improved quality of care for people with dementia in general hospitals**

Gap in knowledge and skills of ward staff in supporting those with dementia. Training identified as a need. Development of the current nurse led liaison service highlighted as

a priority to provide links between primary/community and secondary care. Important to have both social care and therapy input.

- **Objective 11 Living well with dementia in care homes.**

There are some examples of good practice within the Harrogate & Ripon areas, however there are some that need improvement. Some support is given to care homes currently by CMHT but needs to be improved particularly regarding provision and monitoring of medication. The development of a liaison service to care homes with links to the hospital liaison service would improve both the care for people with dementia and support for the staff.

- **Objective13 An informed and effective workforce for people with dementia.**

The training of staff in a range of settings is needed to improve the care and quality of life for people with dementia and their carers.

2.3 Hambleton & Richmondshire:

The main acute Trust Provider is South Tees Acute Trust.

- **Objective 2 Good quality early diagnosis and intervention for all.**

The group identified the need for greater integration between services particularly mental heath and primary care; health and social care and the role of the voluntary sector. This is to reduce duplication of assessment, reduce delays and provide more rapid and personalized services. Services should be based in the community linked to practices that would provide:

  - Rapid access to early diagnosis
  - A point of contact for people with dementia and their carers
  - Relevant information and support appropriate to the individuals circumstances
  - Signposting to other support and information including voluntary / independent sector support for both the carer and cared for person.

- **Objective 6 Improved community personal support services**

Concerns were expressed at the level of training of staff, reliability and lack of flexibility of personal home care services. This section of the strategy includes a range of home care support and was seen as a priority to raise standards and improve peoples quality of life. The role of the voluntary sector in providing day opportunities was acknowledged as an important part of the care pathway.

- **Objective 8 Improved quality of care for people with dementia in general hospitals**

The main general hospital services are provided by South Tees Acute Trust from the Friarage Hospital site or in Middlesbrough. Services are also provided at the Lambert and Richmond Friary Hospitals.

Gap in knowledge and skills of ward staff in supporting those with dementia. Training identified as a need.
Although the current nurse led liaison service is functioning well it is highlighted as a priority to develop the service to provide greater links between primary/community and secondary care.

- **Objective 9 Improved intermediate care for people with dementia**

There is no intermediate care service that meets the needs of people with dementia. This should link to the development of the Liaison service between secondary care and the community.

- **Objective11 Living well with dementia in Care Homes.**

There is no specific liaison service to care homes provided by CMHT. Support is provided by CMHT usually in response to behaviour disturbance or deterioration. A liaison service would greatly improve the quality of life of many of those with dementia in care homes and provide support to staff.

2.4 Scarborough, Whitby and Ryedale:

The main acute trust provider is Scarborough Hospital Trust. The mental health services provider is Tees Esk and Wear Valleys NHS Trust.

- **Objective 2 Good quality early diagnosis and intervention for all.**

Elements of a diagnosis service exist but it was felt that it needed to be improved to provide a more co-ordinated, user friendly and efficient service. Proactive **Case Finding** would identify people sooner and provide the support they need in the early stages of the condition.
The development of a multi agency memory service based in the community that could provide:

  - Support to staff to proactively case find
  - Rapid access to early diagnosis
  - Relevant information and support appropriate to the individuals circumstances
  - Signposting to other support and information including voluntary / independent sector support for both the carer and cared for person.

- **Objective 8 Improved quality of care for people with dementia in general hospitals**

The main general hospital is Scarborough, however some patients also use South Tees Acute Trust in Middlesbrough.
Gap in knowledge and skills of ward staff in supporting those with dementia. Training identified as a need. Development of the current nurse led liaison service highlighted as a priority to provide links between primary/community and secondary care.

- **Objective 11 Living well with dementia in care homes.**

There is no specific liaison service to care homes provided by CMHT. Support is provided by CMHT usually in response to behaviour disturbance or deterioration. A liaison service would greatly improve the quality of life of many of those with dementia in care homes and provide support to staff.

- **Objective13 Informed and effective workforce**

The training of staff in a range of settings is needed to improve the care and quality of life for people with dementia and their carers

2.5 Selby:

The main acute trust provider is York District Foundation Trust.

- **Objective 2: Good quality early diagnosis and intervention for all.**

The group discussed the option of a multidisciplinary based in the community that would provide:

  - Rapid access to early diagnosis
  - Relevant information and support appropriate to the individuals circumstances
  - Signposting to other support and information including voluntary / independent sector support for both the carer and cared for person.
  - To provide a dementia advisor/Admiral nurse function to provide a point of contact, advice and signposting for people through their journey from diagnosis to end of life (including support to carers after death of the cared for person)

- **Objective 5,6,7,: Prevention of Crisis: This has links with 5 – Structured Peer support / 6: Improved community personal support / 7: Implementation of the Carers Strategy.**

It was felt that a combination of improved respite for both the person with dementia and the carer is an important element in preventing crisis. Breaks for carers tend to be provided in a crisis – inadequate planned respite available.

The provision of structured peer support that is specific to that individual also limited. Plus no access to crisis team from York for Dementia (can access for functional mental health).
If OOH service required – often no one goes out to the person and they are admitted. General view that staff do not understand the needs of those with dementia.

- **Objective 8: Improved quality of care for people with dementia in general hospitals**

A recent report by the health Scrutiny Committee on the dementia and accessing secondary care highlighted several areas of concern.
The training and education of staff needs to be prioritized and the responsibilities of secondary care need to be made explicit.
The development of a liaison service was identified as a major gap that has existed for some time.

- **Objective 11: Living well with dementia in Care Homes.**
  There is no specific liaison service to care homes provided by CMHT. Support is provided by CMHT usually in response to behaviour disturbance or deterioration. A liaison service would greatly improve the quality of life of many of those with dementia in care homes and provide support to staff.

Appendix 2.
Issues highlighted in the York Health Scrutiny Committee Dementia Review regarding care given at YDFT

- Carers and relatives recounted stories of negative experiences in relation to staff attitudes, clinical care and the level of dementia awareness training of staff. There was a recurrent theme of lack of involvement of carers and relatives and the difficult balance between privacy, dignity and confidentiality and the need to support the patient through involvement of a carer.

- Flexibility at meal times and visiting times was raised as carers felt that they were prevented from supporting the patient and should be able to visit outside of normal visiting times.

- Clinic appointments posed problems as clinic staff may not have enough time to realise that the patient has memory problems and often patients presented fairly well but could not remember what they had been told with regard to medication or future treatment plans.

- A consistent theme was an apparent lack of communication between staff with regard to the needs of the patient and poor communication with relatives and carers resulting in lack of continuity.

- Lack of patient information was also highlighted. The Alzheimer's Society have produced a leaflet entitled `This is Me ` which would provide individual information on a patient and they are hoping to introduce this into the hospital

- Lack of progress on the Essence of Care benchmark in relation to mental health was highlighted by hospital staff during the committee visit.

- The need for a psychiatric liaison service was outlined by hospital, NYYPCT and local authority staff. Acknowledgment was given to the work previously carried out to identify the need for the service.

Appendix 3
Recommendations from the North Yorkshire Care and Independence Overview and Scrutiny Committee report on Dementia

Proposal 1, Values and Principles. A consensus emerged from the people The Committee spoke to, on the values and principles that might underpin a good dementia service.

Proposal 2, A Dementia Network. Development of an organised network to provide leadership, drive and enthusiasm should be established to make this good dementia service a reality. Partners are therefore invited to re-commission what was known as the Dementia Collaborative on a substantive rather than short term basis.

Proposal 3, National Dementia Strategy. The National Dementia Strategy aims, in a short period, to transform the way people with the illness are cared for. It should be adopted as a strategic framework so that partners can then commit to delivering its aims.

Proposal 4, Education Programme Only by tackling the low level of public and professional 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

Proposal 5, Community Engagement. 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

Proposal 6, Training Programme 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.

Proposal 7. Diagnosis. Most of the people Members spoke to believe 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.

Proposal 8. Care Pathways. 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. This exercise is best carried out by the newly created Dementia Network proposed earlier.

Proposal 9. Data Collection. 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.
Proposal 10. Telecare and Assistive Technology. People like the idea of Telecare and Assistive Technology devices as an enabler, helping people with dementia to live independently in the community.

Proposal 11, Single Focus for Referrals 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.

Proposal 12, Information People with dementia and their carers should be provided with good-quality information linked to Care Pathways.

Proposal 13, Support and Advice. Continuous support and advice ought to be provided to help people understand and accept the diagnosis.

Proposal 14, Improving Care and Support. 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.

Proposal 15, Home Care Services. 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.

Proposal 16, Short Breaks and Respite. Short breaks and respite help support families in the caring role in the community. This emerged as a priority in the Committee's consultation. 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.

Proposal 17, Joint Commissioning. Joint Commissioning and planning mechanisms should be established to determine the services needed for people with dementia and their carers, and how best to meet their needs.
The report offers comments on the remaining aspects of the strategy which address care in residential settings but Members recognised these were for further study by others.

Proposal 18, Delivering the Strategy. Any action taken by the council in 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.

Proposal 19, One Stop Shop. 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.

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Annex B

THE YORK MENTAL HEALTH PARTNERSHIP AND MODERNISATION BOARD

Implementing the National Dementia Strategy in York

A Report by the Board's Dementia Working Group

July 2011(v2)

CONTENTS

SECTION 1: EXECUTIVE SUMMARY

This is a report by York's multi-disciplinary Working Group on Dementia. The Group became a standing working group of the York Mental Health Partnership and Modernisation Board in 2010, and was tasked with recommending how the National Dementia Strategy (NDS) "Living well with Dementia" 2009 should be implemented in York.

The Group consulted York-based statutory, voluntary and independent service providers (including managers and staff from City of York Council (CYC) and independent care homes) and other organisations which work with older people.

The group considered each of the 17 objectives in the Strategy and identified the dementia services and dementia-related activities in York, identifying where local provision fell below the requirements of the NDS. From this, recommendations have been made against each objective and suggested priorities for future action.

The report outlines services that were already in place, and new developments that have been stimulated as the Group undertook the mapping exercises. The report highlights the progress that is being made by many of the organisations involved in providing care and that improving dementia care is not only about big commissioning decisions - the introduction of many small improvements across a wide range of activities can together make a significant difference to those receiving care.

It identifies further work needed as priority actions (for commissioning and administrative action) within three bandings:

Priority one actions include:

- Commissioning a Psychiatric Liaison Service at York Hospital.
- Providing a specialist in-reach service for care homes in order to reduce hospital admissions.
- Identifying investment opportunities to increase the support available to carers including carers' breaks.
- Providing an annual report on the monitoring of dementia services by CYC.

Priority two actions include:

- Ensuring that intermediate care services are open to people with dementia.
- Making better use of support networks by reviewing the local Voluntary and Community Sector (VCS) services including dementia support groups and learning networks, using learning from national demonstrator sites.

Priority three actions include:

- Supporting York and Selby Alzheimer's Society in its work to raise awareness of dementia and funding the Society periodically to arrange local activities in support of national campaigns.
- Providing education for GPs on dementia to include dealing with patients at the various stages of dementia and the importance of effective signposting to appropriate services.
- Issuing guidance to care homes on avoiding the inappropriate use of antipsychotic medication.

The report calls for a detailed action plan which addresses the major gaps in our service provision and looks to the PCT and CYC to work with the two new health organisations in York – the new commissioning consortium and Leeds Mental Health Partnerships NHS Foundation Trust to develop a plan which establishes the desired outcomes for particular activities and identifies targets, lead responsibilities and costs.

The Working Group was not charged with looking at how York could (and should) prepare to deal with the big expansion in the numbers of people likely to need dementia care in the future, but identifies this as a key challenge.

Finally, the report concludes on the importance of empowering service users and carers to play a leading part in shaping and developing services, and highlights a new project, commissioned by the Joseph Rowntree Foundation, to enlist the help of people with dementia in identifying the factors that determine whether York is, or can become, a dementia-friendly city. The project called "Dementia Without Walls" aims to raise the aspirations of people with dementia and their carers, as well as those of providers and commissioners, about what services in York could become.

INTRODUCTION

The Working Group was originally set up by the PCT's Local Implementation Team but in early 2010 became a standing working group of the York Mental Health Partnership and Modernisation Board. The Group was tasked with recommending how the National Dementia Strategy (NDS) "Living well with Dementia" 2009 should be implemented in York. When the NDS was launched, it was expected that implementation would be spread over a five year period.

The NDS focuses on the following areas: the awareness of dementia both by members of the public and by professionals working with older people; the need for earlier specialist diagnosis and intervention through memory services; and higher quality health and social care for people with dementia. It makes a convincing case for improvements in all these areas. and this point was reinforced by the Audit Commission which said that, nationally, dementia care did not represent value for money.

No money was ring-fenced for implementing the Strategy and it was clear from the start that improvements in care would either have to be made by doing things differently within existing budgets or funded from efficiency savings or other reductions in the budgets of CYC, the PCT and other commissioners. The latter will be extremely difficult at a time when all budgets are under considerable pressure. However, as our work progressed, we found that a significant number of improvements could be made at little cost, for example, better training for staff involved in delivering care, adopting good practice from elsewhere and through better leadership in care homes and hospitals.

The profound negative effect of the illness on those with dementia and their families is brought out very clearly in the NDS and need not be rehearsed here. The high costs of treating dementia both now and in the future are also acknowledged.

Having assembled a multi-disciplinary team with appropriate experience (the members are listed on page 26), we approached our task as follows:

- First, we looked at the numbers of people with dementia in York and the predictions over the next 20 years. Details are at page 25.
- Next, we considered each of the 17 objectives in the Strategy and identified the dementia services and dementia-related activities in York.
- We then identified against each objective where local provision fell below the requirements of the NDS. We made recommendations against each objective and suggested priorities. Details are set out in Section 2.
- Our recommendation for an action plan for York which includes both commissioning and administrative action is at Section 3 (page 19).

This is a time of enormous change in local health and social care arrangements. Changes include: the transfer of community and mental health services to Leeds Mental Health Partnerships NHS Foundation Trust; the setting up of the new Vale of

York Commissioning Consortium; new organisations such as The Health and Wellbeing Board and HealthWatch; the transfer of public health functions to CYC; and the wider use of personalised budgets. With no ring-fenced money and so many changes in hand, this is clearly not an easy time to recommend a detailed and costed plan for implementing the NDS in York. We have not produced such a plan but we have made considerable progress towards doing so and details are set out in Sections 2 and 3. We believe that some of the changes set out above will provide opportunities to improve dementia care and this is something that needs monitoring in the coming months.

In September 2010 the Department of Health (DH) published a paper "Quality Outcomes for People with Dementia: building on the work of the National Dementia Strategy". This paper confirms that the Coalition Government intends to see the NDS implemented and it sets out four priority objectives: good quality early diagnosis and intervention for all, improved quality of care in general hospitals, living well with dementia in care homes and reduced use of antipsychotic medication. The paper states that "local organisations are expected to publish how they are delivering quality outcomes so that local people can hold them to account". We believe that our Report could help meet this requirement.

In the course of our work we consulted York-based statutory, voluntary and independent service providers (including managers and staff from CYC and independent care homes) and other organisations which work with older people. Our members included a representative from LINks and we have kept in touch with the York Health Overview and Scrutiny Committee. We intend to work closely with all these organisations as our work continues.

Since our work began there have been a number of new developments and initiatives. The PCT, which has the lead in dementia across the whole PCT area, has set up a North Yorkshire and York Dementia Network which is proving to be useful in undertaking work which is common to all localities and details are included at Section 3 on page 22. Nationally, a number of demonstrator sites have been set up in order to inform the local implementation of the NDS and details are on page 23.

We have covered a large number of subjects in preparing our report but a lack of money and resources have meant that there are many important issues that we have not tackled. We return to these issues in Section 4 (Further Work and Conclusions).

And finally, I am grateful to Working Group members for their time and contributions and to the many others who have helped in our work.

John Bettridge CBE
Chair

28th July 2011

SECTION 2: NOTES ON YORK'S DEMENTIA SERVICES AND THE GROUP'S COMMENTS AND RECOMMENDATIONS

The National Dementia Strategy (NDS) sets out key opportunities for transforming dementia care under the following four themes: raising awareness and understanding; early diagnosis and support; living well with dementia: and making the change. The Strategy contains 17 objectives, which are listed below.

	Initial findings on dementia services and related activities in York	Recent progress and the Group's comments, recommendations and priorities
RAISING AWARENESS AND UNDERSTANDING		
1	**A public information campaign to improve public understanding about dementia**	
1a	A national dementia awareness campaign on TV, radio and in the press took place in March 2010. The York branch of the Alzheimer's Society has a range of good material which it uses to raise general awareness about dementia. There have been no recent dementia awareness initiatives run by the Alzheimer's Society or the statutory services in York.	We recommend that the Alzheimer's Society is supported to continue its work to raise awareness locally. We recommend that the focus of this work should be on people who already have dementia, together with their carers and families. **Priority 3** The possibility of arranging local awareness initiatives to coincide with future national campaigns should be considered by CYC. **Priority 3** The Dementia Action Alliance has over 40 organisations committed to transforming the quality of life for people living with dementia in the UK and the millions of people who care for them. Members of the Alliance have signed up to a National Dementia Declaration and have published their own action plans setting out what each will do to secure these outcomes and improve the quality of life of people with dementia by 2014. The PCT has signed up to the Declaration and we recommend that CYC also signs. **Priority 3**

Initial findings on dementia services and related activities in York		Recent progress and the Group's comments, recommendations and priorities
EARLY DIAGNOSIS AND SUPPORT		
2	**Good quality early diagnosis and intervention for all** (all people with dementia to have access to a pathway of care that delivers a rapid and competent specialist assessment, an accurate diagnosis sensitively communicated to the person with dementia and their carers and 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)	
2a 2b 2c	The Strategy makes the case for commissioning a specific service for the early diagnosis of dementia and intervention. There is no such service in York – instead, this is undertaken by CMHTs and GPs. GPs have guidance on specialist assessments and early diagnosis of dementia and this is also available on the internet. Assessments take time to do properly and GPs do not always have the time to do them. GPs often identify cases and refer them to services. CMHTs provide a specialist memory service but not through memory clinics. Assessments are sometimes made at a person's home. There are no dedicated dementia advisers or care navigators but some elements of this work are provided by CMHTs and some voluntary sector organisations such as Age UK and the Alzheimer's Society. Feedback from carers suggests that some GPs could conduct consultations with patients experiencing the early symptoms of dementia more sensitively. Some carers felt that they should be more involved when assessments were being made. We also noted that some people find it difficult to accept a diagnosis of dementia.	Setting up a specific service (as described opposite) is not a priority at present. Further discussion on this should await the completion of the transfer of services to the new provider. Setting up a new service would also need to be co-ordinated carefully with other improvements in dementia care in order to avoid raising expectations which could not be met. **Priority 3** Memory advisers play a very useful role in supporting patients and carers and they can provide information and advice and help "signpost" patients to further support. In June 2011 York Health Group (GP Commissioning) and the PCT jointly funded a memory adviser post in York / Selby which is being filled by the Alzheimer's Society. The service will be evaluated after a year. A new, local care pathway for dementia has been prepared and this will become part of the Map of Medicine. The "map" is a computer-based tool for clinicians and health professionals. It includes details of local statutory and voluntary sector services available at different stages of the care pathway. We recommend provision of education about dementia for GPs as part of their continuing professional development to include dealing with patients at the various stages of dementia and the importance of effective signposting to appropriate services. However, before this can be delivered, more work needs to be done to redefine appropriate pathways and guidance for GPs. **Priority 3**

	Initial findings on dementia services and related activities in York	Recent progress and the Group's comments, recommendations and priorities
EARLY DIAGNOSIS AND SUPPORT		
3	**Good quality information for those diagnosed with dementia and their carers** (providing people with dementia and their carers with good quality information on the illness and the services available, both at diagnosis and throughout their care)	
3a	No specific information packs are available but staff are able to put together appropriate packs from information they have on procedures for diagnosis, local dementia services, and care after diagnosis etc. The Alzheimer's Society has produced a local directory of services available. Feedback from carers suggests that patients do not always get the timely information they need.	We recommend that a review is carried out to determine if this system is satisfactory or if new information packs are required. Where national information material is used it is important that it is complemented by adequate local information. We note that the Hospital Dementia Strategy Group is also reviewing this topic. A good way of tackling this would be to ask people with dementia and their carers what they think – see page 20. **Priority 3**
4	**Enabling easy access to care, support and advice following diagnosis** (one of the strongest messages from people with dementia and carers in the consultation on the Strategy was that people want a single local named contact (a dementia adviser) to advise them about dementia and where they can get help)	
4a 4b	York has no dementia advisers but members of the CMHTs carry out part of this function. CMHTs are not integrated with social care staff as they are in many areas; this needs to be explored as part of the work on integrating health and social care.	We support the idea of dementia advisers. We note that a number of national voluntary sector organisations provide a similar service. We also note that Bradford / Kirklees is one of the national demonstrator sites for dementia advisers; we intend to monitor the lessons from this and similar sites when they are available. **Priority 3**
5	**Development of structured peer support and learning networks** (people with dementia and carers have said that they draw significant benefit from being able to meet other people with dementia and carers to share practical tips about how to live and cope with dementia. Some of these networks already exist across the country as dementia cafes or support groups. These networks will also enable people with dementia and their carers to take a more active role in the development and prioritisation of services)	
5a	In York, a number of dementia support groups and networks are provided by the voluntary sector and part-funded by the PCT and CYC. Providers include the Alzheimer's Society, Age UK, Our Celebration / Mind and the York Carers' Forum. These services, in various ways, offer practical and emotional support and help overcome problems of isolation.	We believe that support and learning networks have a very important role to play in helping people with dementia and their carers cope with the illness. They also play an important part in helping people with dementia take control of their own lives and care for themselves as much as possible. We recommend that a study is carried out jointly with the organisations providing these networks to: identify the different local models, evaluate their outcomes and report on their capacity to meet the need. **Priority 2**

Initial findings on dementia services and related activities in York		Recent progress and the Group's comments, recommendations and priorities
LIVING WELL WITH DEMENTIA		
6	**Improved community personal support services** (two thirds of people with dementia live in their own homes either on their own or with a carer. The Strategy proposes the provision of an appropriate range of services to support people with dementia to remain more independent. It stresses the need for access to flexible and reliable services ranging from early intervention to specialist home care services)	
6a	Services provided, funded or part-funded by CYC and the PCT include the following: • Three multi-disciplinary community mental health teams (CMHTs). • Specialist home care teams. • Primary care mental health workers (these work with people of all ages and deal mostly with common mental health issues). • Memory groups – these are not the same as the memory service described in paragraph 2b. These groups are less formal groups and are run by occupational therapists providing courses of about eight sessions offering strategies to cope with failing memory. • Peer support services – dementia cafes, day clubs, and support groups (see also serial 5a, page 9). The York Vision for Older People sets out important outcomes and guidance for services funded by health and social care. The Dementia Network has carried out work into the availability of advocacy services for people with dementia. No advocacy services have been commissioned by the PCT or CYC in York. There have been discussions between the PCT and CYC on developing a generic advocacy service for all ages but these have been put on hold until there is more clarity on the role of HealthWatch	York has a wide range of community personal support services. However, we believe that the following are gaps (or deficiencies) in services which need to be addressed: • There is considerable anecdotal evidence which suggest that there are insufficient places at supported day activities for people with dementia. **Priority 2** • There is a specialist care service at weekends but this is only for people who are already known to the CMHTs. The service needs increased capacity in order to manage new referrals and prevent unnecessary hospital admissions. **Priority 2** • We are concerned that the needs of people with early onset dementia are not being met. Younger people with early onset dementia are at present being treated by the older people's services. This means that it is often difficult to put together an appropriate package of care for people in this category. • The York / Selby Alzheimer's Society runs a support group for younger people with dementia; the outcomes of this group should be monitored. • The service for "more challenging" individuals has a men-only service. There is no women-only service. An equivalent women-only service is needed. **All above Priority 3**

Initial findings on dementia services and related activities in York		Recent progress and the Group's comments, recommendations and priorities
LIVING WELL WITH DEMENTIA		
7	**Implementing the carers' strategy for people with dementia** (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. Carers have a right to an assessment of their needs and also to support – this will include good quality personalised breaks. Action should be taken to strengthen support for children in caring roles ensuring that their particular needs as children, are protected)	
7a 7b 7c 7d 7e	There is a national carers' strategy and also a carers' strategy which has been agreed by the PCT and CYC. Carers (including those caring for people with dementia) have been involved in developing this strategy. Our Celebration/Mind provides a specialist counselling service for carers. Carers' grant funding is used to support short breaks for carers including a home sitting service. There is no new ring-fenced money for carers' breaks and feedback from carers suggests that the demand for carers' breaks is not being met. Although some care homes provide good information, anecdotal evidence suggests that people paying for their own care often find it difficult to get appropriate information.	The strategy correctly emphasises the importance of short breaks for people with dementia and their carers. We see this as a high priority area and it is one which will increasingly be influenced by "personalisation". Our comments/recommendations are as follows: 1. The York Carers' Strategy Group currently reviews its progress in implementing the Strategy quarterly. The Group has been tasked with setting up a clear framework for the provision of breaks which links to self directed support and "personalisation". Once this has been done the cost of meeting any shortfall should be identified. **Priority 1** 2. The Carers' Strategy is currently being "refreshed" in the light of new national guidelines and local consultations by LINks and the Health Overview and Scrutiny Committee. 3. We note that the need to support young carers and protect them from inappropriate caring is included in the priorities set out in the York Strategy for Carers 2009-2011. The Carers' Centre has been working with young carers – this work has included: the development of a Young Carers' Forum; production of an awareness raising DVD; and work with schools. 4. Better information needs to be provided for people funding their own care. **Priority 3**

Initial findings on dementia services and related activities in York		Recent progress and the Group's comments, recommendations and priorities
LIVING WELL WITH DEMENTIA		
8	**Improved quality of care for people with dementia in general hospitals** (identifying leadership for dementia in general hospitals, defining the care pathway for dementia there and commissioning of specialist liaison older people's mental health teams to work in general hospitals. The impact of these proposals will be to: make hospital environments more dementia-friendly, ensure that dementia is identified and managed alongside other conditions, provide better care and allow quicker and more effective discharge from hospital into the community with less recourse to long-term care)	
8a	Dr Sandeep Kesavan is the dementia lead at York Hospital.	1. A Hospital Dementia Strategy Group has been set up to oversee and monitor improvements in dementia care. The Group is working on an end of life care pathway – a draft has been prepared. The pathway will recognise the importance of the role and needs of carers.
8b	There is not an agreed care pathway for people with dementia in the hospital.	
8c	The hospital does not have a specialist liaison older people's mental health team. Setting up a Psychiatric Liaison service at York Hospital was a key recommendation of the Health Scrutiny Committee Report on dementia care in 2008.	2. It has been decided (May 2011) to commission a Psychiatric Liaison Service. 3. The hospital has participated in the National Audit of Dementia which looked at clinical and organisational issues at the Hospital. A report was published in 2011 and a follow up action plan is now being prepared.
8d	Feedback from carers suggests that clinicians and nursing staff often exclude carers at critical stages, including when patients are assessed. The Dementia Network has a workstream on improving care for people with dementia in General Hospitals. This has identified 4 main areas for improvement: staff training; care pathway policies and procedures; support for carers; and use of antipsychotic medication.	4. The hospital has carried out some dementia awareness raising training. A dementia nurse has been identified on each elderly ward. This person will take the lead on dementia-related training (see also Objective 13 on page 16). 5. We note that action is in hand to ensure that people admitted to hospital for reasons other than dementia but who subsequently show symptoms of the illness, are identified and referred appropriately. We strongly support this 6. The PCT has included the following in its guidance on Admissions and Discharges: the requirement for staff training in dementia; actively including carers in the care and treatment of people with dementia (with the consent of the cared for person); and providing advice and support for carers in their caring role after discharge.

Initial findings on dementia services and related activities in York		Recent progress and the Group's comments, recommendations and priorities
LIVING WELL WITH DEMENTIA		
9	**Improved intermediate care for people with dementia** (intermediate care which is accessible to people with dementia and which meets their needs)	
9a	DH is developing new guidance on intermediate care for people with dementia to make clear that intermediate care services should be accessible for people with dementia. Providing better access to appropriate intermediate care (e.g. rehabilitation services) will ensure that people with dementia would be more likely to remain in their own homes for longer. In York, there is an agreement that intermediate care services will be open to people with dementia.	Setting up a Psychiatric Liaison Service at York Hospital (see 8b above), will help people with dementia who are discharged from hospital access intermediate care services. We note the agreement that intermediate care services will be open to people with dementia. We recommend that use of these services by people with dementia be monitored. **Priority 1**
10	**Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers** (the needs of people with dementia and their carers should be included in the development of housing options, assisted technology and telecare. As evidence emerges, commissioners should consider the provision of options to prolong independent living and delay reliance on more intensive services)	
10a	The Strategy suggests tackling this in three ways: 1. Monitoring the development of models of housing, including extra care housing, to meet the needs of the people with dementia and their carers. **This is done in York.** 2. Staff working in housing-related services to develop the skills needed to provide the best quality care. **In York, home care staff (who also provide support in Extra Care Housing) are only trained in basic dementia awareness. There is no specific training for generalist housing support workers.** 3. A watching brief over the emerging evidence based on assistive technology and telecare to support the needs of people with dementia and their carers. **CYC does this**.	York has 4 Council run extra care schemes and 2 run by social landlords. Supporting People contracts for housing-related support in extra care housing require 10% to be available to people with dementia – these include mild and moderate cases and (where it is safe to do so) those with severe needs. The requirement to improve levels of training of staff in housing-related services should be included in the work on training recommended under Objective 13 (see page 16). CYC is to conduct a review of its elderly persons homes; the consultation period for this is July – October 2011. The Working Group plans to contribute to this. **Priority 2**

Initial findings on dementia services and related activities in York		Recent progress and the Group's comments, recommendations and priorities
LIVING WELL WITH DEMENTIA		
11	**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 times and through inspection regimes)	
11a	The Strategy suggests this can be delivered by the following actions:	A big gap in service provision is the lack of a specialist in-reach service for care homes (see 11c opposite). In our view, a good in-reach service could reduce emergency admissions to hospital and is a high commissioning priority. **Priority 1** A particular concern for some of our members was the question of inappropriate use of antipsychotic medication for people with dementia. Our recommendations on this are in Section 3 (page 20). **Priority 2** As a Working Group we are keen to stress the importance of good leadership, staff training and person-centred care all of which contribute to the creation of a stimulating environment in a care home. We note that CYC give these issues a high priority in their contracting decisions. In our discussions with care home managers and staff we were struck by the readiness to share good practice and consider new ideas. Our meetings have been useful in this respect and we have compiled a list of "good practice" ideas that is being shared. An example of this is that maintaining a daily activity sheet for each client can show that people have enough to do and, where it is appropriate, help with administrative tasks around the care home. We believe that CYC's inspections and liaison visits are also proving useful in sharing good practice in care homes. We recommend that in all care homes run or used by CYC: a. Written guidance is readily available for staff on best practice in dementia care. b. There is clear guidance to all care homes on the need to avoid the inappropriate use of antipsychotic medication. c. Breaches of safeguarding standards in care homes are monitored together with the action taken to prevent further breaches – a,b,c, above – **Priority 2**.
11b	Appointment of a senior staff member to take the lead for quality improvement in dementia care in the care home. **In York this happens where a home is registered to provide dementia care. In other homes this is not always the case.**	
11c	The commissioning of specialist in-reach services from older people's CMHTs to work in care homes. Also the commissioning of other in-reach services e.g. primary care and dentistry. **In York there is no dedicated specialist in-reach service for homes but where a resident is an active patient of the CMHT, support will be provided. Some care homes provide the other in-reach services described above.**	
11d	Readily available guidance for care home staff on best practice in dementia care. **In York there is no agreed standard guidance on this but most homes have prepared their own material.**	
11e	Only appropriate use of antipsychotic medication for people with dementia**. More work is needed on this in York.**	
11f	Contracting for quality of care in care homes. **In York, the importance of this is understood and CYC has introduced a new monitoring system which will help inform commissioning decisions.**	

Initial findings on dementia services and related activities in York		Recent progress and the Group's comments, recommendations and priorities
LIVING WELL WITH DEMENTIA		
12	**Improved end of life care** (people with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the DH End of Life Care (EoL) Strategy. Local work on the EoL Care Strategy to consider dementia)	
12a	The Strategy recognises that end of life care for people with dementia is often limited. It emphasises that the principles and priorities outlined in the DH End of Life Strategy and also best practice in mental capacity and palliative care need to apply to care for people with dementia.	In May 2011 the role, terms of reference (TOR), membership, and priorities of the York / Selby Locality EoL Care Locality Group were reviewed. As indicated opposite (12c), the Group deals with all EoL issues regardless of age or illness – it is not feasible to have a separate care pathway for each illness. The locality group plans to engage with the new Vale of York Commissioning Consortium and will identify local priorities. The Group reports to the PCT EoL Care Strategy Group, (but the locality groups will be reporting to the various commissioning consortia once the TOR have been revised). Our Working Group plans to keep abreast of the work of the Locality Group through its Chair. We believe that the following requirements of the NDS are not yet being addressed: a. That people with dementia and their carers should be involved in planning EoL care (i.e. services and pathways). b. That the special EoL needs of people with dementia will be met. c. That EoL care pathways are consistent with the Gold Standard Framework (see 12b opposite. **Priority 2** We note that the training of care staff involved in delivering EoL for people with dementia in all care settings is particularly important – see also Objective 13 on page 16.
12b	The NDS recommends that local EoL Care pathways are consistent with the Gold Standard Framework identified in the DH EoL Care Strategy.	
12c	In York, there is an EoL Care Locality Group (run jointly with Selby), which follows the PCT's EoL Strategy. An end of life pathway exists but it is a general pathway and does not address the particular needs of people with dementia.	
12d	York has a Palliative Care Team and good pain relief and nursing support in community units for the elderly	

Initial findings on dementia services and related activities in York		Recent progress and the Group's comments, recommendations and priorities
MAKING THE CHANGE		
13	**An informed and effective workforce for people with dementia** (all health and social care staff involved in the care of people who may have dementia to have the 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)	
13a 13b 13c	People with dementia and their carers need to be supported and cared for by a trained workforce with the right knowledge skills and understanding of dementia to offer the best quality care and support. The need for improved training is a priority that runs across all the NDS themes. The NDS calls for the Department of Health to work with representatives of all bodies involved in professional and vocational training in order to reach agreement on the core competencies required in dementia care. Locally, we identified a number of effective training schemes but the approach to training has been somewhat piecemeal.	In York a Workforce Development Unit was set up in April 2010 and is preparing an Adult Social Care Training and Development Strategy; the work on dementia training in York will form part of this Strategy. The Dementia Network has a workstream on Workforce Development which has: • evaluated a number of E-learning schemes, the results of which have been encouraging; • developed dementia competencies for staff; • begun preparing a Dementia Workforce Development Action Plan. York is participating in this work which is drawing on the results of the work at national level (see opposite). Deciding who needs training and to what level is a complex matter bearing in mind the large number of organisations and agencies involved; setting standards and arranging monitoring systems to ensure that training is carried out are also important. However, once this work is complete, commissioners will be able to specify the training required by staff of service providers and also the dementia training required by other staff whose work involves dealing with older people. There is a need to monitor all the above. **Priority 3**

Initial findings on dementia services and related activities in York		Recent progress and the Group's comments, recommendations and priorities
MAKING THE CHANGE		
14	**A joint commissioning strategy for dementia** (local commissioning and planning mechanisms to be established to determine the services needed for people with dementia and their carers and how to best meet these needs. These should be informed by World Class Commissioning guidance)	
14a	The NDS emphasises the importance of joint local planning on dementia to improve access to quality dementia services. This is particularly important given the complexity of the dementia pathway and the need of a wide range staff in many services that need to understand dementia. A draft overarching dementia strategy has been prepared by the PCT and this is expected to be agreed by NYCC, and CYC shortly.	The draft strategy (see opposite) is due to be signed off by all parties by the Autumn 2011. As part of its work, the Working Group has consulted local statutory, voluntary and independent sector organisations which work with older people. It has informed the York Health Overview and Scrutiny Committee of its progress and has kept in touch with York LINk through its representative on the Group. The CYC Transition Board is preparing new arrangements for commissioning and these will include dementia care. The new structures will include the new local commissioning consortium and new boards and organisations such as York's Health & Wellbeing Board. The transfer of mental health services to Leeds Partnerships NHS Foundation Trust by November 2011 is another important development which will affect local planning.
15	**Improved assessment and regulation of health and social care services and of how systems are working for people with dementia and their carers** (inspection regimes for care homes and other services that will ensure better quality of dementia care)	
15a	We noted that the Care Quality Commission, which is responsible for inspecting care homes, is changing its current ratings system following reports of a lack of confidence in the system. We also note that the Dementia Network has a workstream which is working on a revised set of standards for care homes.	We believe that this objective is particularly important, bearing in mind that at least two thirds of people in care homes have dementia. See also our comments on Objective 11, page 14. CYC has introduced additional quality monitoring for residential homes and other services for which it is responsible and this includes input from service users and carers. We welcome this initiative and recommend that this scheme is kept under review - see also Objective 11 on page 14. **Priority 1**

Initial findings on dementia services and related activities in York		Recent progress and the Group's comments, recommendations and priorities
MAKING THE CHANGE		
16	**Dementia Research. A clear picture of research evidence and needs** (DH has committed to work with the Medical Research Council and research funders across the public, private and voluntary sectors to develop a plan for the future of dementia research in the UK)	
		We have noted the national programme of research into the assessment, treatment and care of people with dementia.
17	**Effective national and regional support for implementation of the Strategy** (appropriate national and regional support to be available to advise and assist local implementation of the Strategy. Good quality information to be available on the development of dementia services including information from evaluations and demonstrator sites)	
		The evaluations from the national demonstrator sites will be particularly important. We expect to get these and examples of good practice in dementia care from across the Region through the Dementia Network.

SECTION 3: RECOMMENDATIONS FOR A YORK ACTION PLAN

Part a: Action by Commissioners. We have set out below the key commissioning issues we have identified.

Serial	Sec 2 Table	Action	Notes
1	8c	Commission a Psychiatric Liaison Service at York Hospital. **Priority 1**	A decision has been made to proceed with this but funding has not yet been agreed
2	11	Provide a specialist in-reach service for care homes in order to reduce avoidable hospital admissions. **Priority 1**	
3	7	A recent CYC review of carers' breaks along with contract monitoring and anecdotal evidence, suggests that support for carers (including carers' breaks) does not meet demand. **Priority 1**	Once the Carers' Strategy Group has completed its review (see page 11) the cost of meeting any shortfall should be identified.
4	9A	PCT and CYC to ensure that intermediate care services are open to people with dementia. **Priority 2**	This is included in the "Levels of Care Project" signed up to by the PCT, the Vale of York Commissioning Consortium, CYC and York Foundation Trust
5	2	Commission an early assessment and diagnosis service. **Priority 3**	Consideration of this should await the transfer of mental health services to Leeds Partnerships NHS Foundation Trust. Setting up a new service would need to be co-ordinated carefully with other improvements in dementia care (see page 8).
6	1a	Provide funding support to the York and Selby Alzheimer's Society in their work to raise awareness of dementia. **Priority 3**	This funding should be sufficient to enable the Society to arrange local activities in support of national campaigns.
7	2	Provide education for GPs on dementia as part of their continuing professional development. This should include dealing with patients at the various stages of dementia and signposting to appropriate services. **Priority 3**	Before this can be delivered more work needs to be done to redefine appropriate pathways and guidance for GPs.

Part b: action (other than commissioning) by service providers, the PCT (including acute trusts), CYC and the VCS. Some of the serials may require commissioning action in due course.

Serial	Sec 2 Table	Action	Notes
1	11a and 15	CYC has an updated monitoring scheme for its care homes and other homes which it helps fund. CYC undertakes to keep this scheme under review – this should also include breaches of safeguarding standards. **Priority 1**	CYC has agreed to provide a report annually in October on this and on its dementia services and arrangements in general.
2	5	Review local VCS dementia support groups and learning networks. **Priority 2**	We recommend asking people with dementia and their carers for their views. This may be something that the "Dementia Without Walls" project would wish to address (see page 24).
3	3	Review the information packs on dementia which are currently in use to determine if the material is satisfactory. **Priority 3**	As above
4	6a	Review the availability of places at supported day services to determine if these meet the need **Priority 2**	See notes at serials 2 and 3 above
5	6a	Increase the capacity of the specialist care service to provide cover at week ends to manage new referrals and prevent unnecessary hospital admissions **Priority 2**	
6	11	Issue guidance to care homes run or used by CYC on best practice in dementia care. **Priority 2**	The Dementia Network has a workstream looking at similar issues
7	11	Issue guidance to care homes either run by or used by CYC on avoiding the inappropriate use of antipsychotic medication**.** **Priority 2**	This is a matter common to all localities It is being addressed by the Dementia Network in Autumn 2011. We also note that the PCT is co-ordinating an audit on this in 2011.
8	12	End of Life (EoL) care. People with dementia and their carers should be involved in planning services and pathways. Action is required to ensure that the special EoL needs of people with dementia are met. EoL pathways should be consistent with the Gold Standard Framework as recommended by the NDS. **Priority 2**	The Working Group plans to keep in touch with the work of the EoL Care Locality Group through its Chair. The Dementia Network intends to provide feedback from the PCT EoL Care Strategy Group.

9	12a	The dementia care pathway needs to make it clear that people with dementia have the same access to services as everyone else covered by the End of Life Strategy. The pathway should also provide guidance about "advanced decisions" and preferred future treatment. **Priority 3**	As in serial 8 above
10	4a	Dementia advisers - monitor the results of the national demonstrator sites. **Priority 3**	The Working Group expects to work with the Dementia Network on this.
11	6a	Anecdotal evidence suggests that the needs of people with early onset dementia are not being met. This should be examined further. **Priority 3**	The Working Group to discuss this with the PCT and the new service provider.
12	6a	Monitor the Alzheimer's Society local support group for younger people with dementia to determine if this approach could be used more widely. **Priority 3**	Action by the Working Group.
13	6a	Provide a women-only service for more challenging individuals. **Priority 3**	At present there is a men-only service. A women-only service is under consideration by the PCT.
14	7	Better information needs to be provided for those funding their own care. **Priority 3**	The Dementia Network is working on this topic.
15	13	The work of the York Workforce Development Unit and the other measures described on page 14 which are designed to ensure an informed and effective workforce, need to be monitored. **Priority 3**	To be included in CYC's annual report (see serial 1 above). This should include progress in improving the training of staff that come into contact with people with dementia across a wide range of care settings.
16	1	CYC should consider signing up to the National Dementia Declaration. **Priority 3**	
17	10a	CYC's is to review its elderly persons homes – the consultation period is July – October 2011. **Priority 2**	The Working Group to advise the Partnership Board on the line to take – bearing in mind the implications for people with dementia.

Part c: The North Yorkshire and York Dementia Network Workstreams. The Network has set up a number of workstreams which are looking at particular areas of work indentified in the NDS. These are areas where common approaches could apply to localities throughout the PCT area.

Serial	Sec 2 Table	Action	Notes – additional measures being taken in York to meet local priorities
12	4	**Workforce Training** The network has set up a group to work on this and recommend standards of training and learning for staff who deliver dementia care. Lead is Jan Cleary of NYCC	York's Workforce Development Unit is participating in this workstream and is preparing a Social Care Training and Development Strategy which will include dementia training
13	6	**Personal Support/Advocacy** The network has a workstream on personal support and advocacy provision.	In York, CYC and the PCT are reviewing these topics. The lead for York is Catherine McGovern.
14	8	**Dementia Care in General Hospitals** Dignity and older people's champions have been identified in each Acute Trust. Ongoing work includes: staff training, discharge policy, liaison services and advice on prescribing anti-psychotic medication. Lead is Judith Knapton.	
15	11	**Living Well with Dementia in Care Homes** This workstream is led by Jacki Tonkin. The Group intends to circulate an information pack shortly with the results of its work including: what people expect from care homes, information in lay language for care home staff and residents, information for self-funders and details of Care Quality Commission inspections.	The Working Group has established useful contacts with managers and front line staff from local care homes (see page 14).
16	12	**Improved End of Life Care** Feedback from the End of Life Strategy Group will be provided to the Network. Subjects under review include: resuscitation, "advanced decisions" and the use of "do not resuscitate forms"	
17		**Involvement of people with dementia and their carers** The Alzheimer's Society has a number of service user groups which have become sub-groups of the Network. These groups will provide feedback on services and plans. Lead is Jill Quinn (Alzheimer's Society).	In York, we expect to learn from the Dementia Without Walls project about engaging with people with dementia and their carers and how they can be empowered to play a leading part in shaping and delivering services.

Part d: The National Demonstrator Site Programme. About 40 sites have been set up – 20 have been funded for each of the following themes. The funding covers two years and the programmes will be completed in 2011.

Serial	Sec 2 Table	Action	Notes
17	4	Enabling easy access to care, support and advice following diagnosis.	A dementia adviser to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers.
18	5	Development of structured peer support and learning networks.	The establishment and maintenance of such networks will provide direct local peer support for people with dementia and their carers. It will also enable people with dementia and their carers to take an active role in the development and prioritisation of local services.

SECTION 4: FURTHER WORK AND CONCLUSIONS

Our remit has been to recommend how the NDS should be implemented in York. Our work so far has prompted a number of service providers to make improvements in dementia care. We have identified in this Report the progress which is being made by the PCT, CYC, the Vale of York Commissioning Consortium and statutory, voluntary and independent sector care providers. We believe that improving dementia care is not only about big commissioning decisions but also about making many small improvements across a wide range of activities which, together, can make a significant difference to those receiving care.

In this Report we have set out our recommendations for an action plan for York. Ideally a detailed action plan is needed which sets out how the gaps in local services and other shortcomings in dementia-related activities are to be addressed. The plan should list the desired quality outcomes for particular activities and identify targets, lead responsibilities and costs. A local plan on these lines can only be made by commissioners from the PCT, CYC, and the new commissioning consortium, working together with the new provider of services. We believe that making a detailed plan will have to wait until the new provider of services and the new commissioning consortium have settled into their new roles and the changes being considered by the Transition Board have been put in place.

Because our task has been to recommend how the NDS should be implemented in York, our work has been directed at short and medium term improvements. We have not addressed how York could (and should) prepare to deal with the big expansion in the numbers of people likely to need dementia care in the future – a problem which Paul Burstow MP, Minister for Care Services has described nationally as “the greatest health and social crisis of the century”. Another big problem which needs to be addressed is how people with dementia and their carers can be empowered to play a leading part in shaping and developing services. We know this should be done but, if it is to be done thoroughly, it will need considerable resources.

With these last two points in mind, we believe that The Joseph Rowntree Foundation’s (JRF) York dementia project (Dementia Without Walls) which began last month is an exciting development for everyone working to improve dementia care in the City. In writing recently about the project, John Kennedy (Director of Care Services JRF Housing Trust) explained that "the aim of the project is to enlist the help of people with dementia in identifying the factors that determine whether York is, or can become, a dementia-friendly city and, in drawing from their engagement, make recommendations about how barriers to achieving this can be overcome. The project aims to raise the aspirations of people with dementia and their carers, as well as those of providers and commissioners, about what services in York could become by identifying practical exemplars locally, nationally and internationally. This project has been commissioned by JRF as a key part of our new programme Dementia and Society http://www.jrf.org.uk/work/workarea/dementia-and-society

ANNEX A: DEMENTIA PREDICTIONS – YORK

People in York aged 65 and over predicted to have dementia by age band (65-69, 70-74, 75-79, 80-84 and 85 and over) projected to 2030.

Dementia – All People	**2009**	**2015**	**2020**	**2025**	**2030**
People aged 65-69 predicted to have dementia	105	138	123	132	149
People aged 70-74 predicted to have dementia	212	224	284	257	276
People aged 75-79 predicted to have dementia	382	417	433	561	508
People aged 80-84 predicted to have dementia	603	647	714	761	986
People aged 85 and over predicted to have dementia	1002	1282	1481	1750	2045
Total people 65 and over predicted to have dementia	**2304**	**2708**	**3035**	**3461**	**3964**

Source: Institute of Public Care 2008

ANNEX B: MEMBERS OF THE WORKING GROUP

John Bettridge	Carer and Chair
Sheila Barry	Service User and Carer
Sue Beckett	Directorate Manager Elderly Medicine, York Hospital
John Burgess	Chair Voluntary Sector Mental Health Forum and Trustee of Our Celebration / Mind and OCAY
Judith Knapton	Head of Commissioning (Adult and Community Services) NHS NY&Y
Dr Kate Langridge	GP and dementia lead for York Health Group (GP practice-based commissioning); this Group has since been disbanded
Veronica Mackley	Service Manager for the Elderly – Bootham Park Hospital
Catherine McGovern	Commissioning Manager – Commissioning and Partnerships CYC
Dr Lance Middleton	Consultant Psychiatrist
Gill Myers	Support Services Manager York and Selby Alzheimer's Society
Dr Cath Snape	GP, Vice Chair Vale of York Commissioning Consortium and lead for mental health
Katie Smith	York Carers' Forum
Robin McIlroy	York LINks

We have also been grateful for advice from a number of specialists from the statutory services and from managers and frontline staff from local care homes. The latter group has included: Keren Wilson Chief Executive Independent Care Group; Janice MacDonald Operations Manager for Barchester based at Mulberry Court; Elaine Pollard Manager Morrel House (CYC); Val Sutton Group Manager Adult Services at CYC with responsibility for Elderly Persons' Homes and Learning Disabilities Day Services; and Karen Cox Head of Unit, Dementia Care, South Park Care Home

ANNEX C: SOME OF THE RELEVANT POLICY DOCUMENTS AND PAPERS WE HAVE CONSULTED

1. Living well with Dementia – National Dementia Strategy 2009

2. Department of Health (DH) – Quality outcomes of people with dementia: building on the work of the National Dementia Strategy, September 2010

3. DH Mental Health Strategy – No health without mental health, February 2011

4. North Yorkshire & York End of Life and Palliative Care Commissioning Strategy 2008-2011, September 2008

5. North Yorkshire & York Mental Health Commissioning Strategy, 2010-2015

6. A Review of Services for People with Dementia, the case for Change Across Yorkshire and Humber – Yorkshire and Humber Improvement Partnership (undated)

7. Inspiring Innovation in Dementia – Regional Directory for Yorkshire and the Humber 2010

8. North Yorkshire & York Dementia Strategy (third draft)

9. Improving Dementia Services in England – an Interim Report – National Audit Office, January 2010

10. Dementia Review (Accessing Secondary Care) – Report of the CYC Health Scrutiny Committee, November 2008

11. York Strategy for Carers 2009-2011

12. The Vision of Older People's Health and Well Being in York 2010-2015, May 2010

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National Dementia Declaration for England

DAA Dementia Action Alliance

www.dementiaaction.org.uk

National Dementia Declaration for England

A call to action

Dementia is one of the greatest challenges facing our ageing society. There has been major progress in recent years in securing public and political commitment to responding more effectively to dementia. We now need to ensure that this commitment is turned into concerted action. With the publication of this National Dementia Declaration we announce the launch of a Dementia Action Alliance and a major plan of action to change the experience of living with dementia in England for good. The organisations signed up to this Declaration call on all families, communities and organisations to work with us to transform quality of life for the millions of people affected by dementia.

The scale of the challenge

There are 750,000 people living with dementia in the UK now and by 2025 there will be over one million. Dementia is an incurable condition caused by diseases of the brain which over time seriously impairs the ability of someone with dementia to live independently. Symptoms can include severe memory loss, mood and personality changes and behaviour that challenges others such as serious confusion, agitation and aggression. Many people with dementia also have other medical conditions or develop them during the course of their illness.

Families currently provide the majority of care and support for people with dementia and this can be both tiring and stressful – physically, emotionally and financially. A large number of people with dementia also live alone and can be at particular risk of isolation or abuse. However, if people with dementia are diagnosed early, and they and their families receive help, they can continue to live a good quality of life.

The financial cost of dementia in the UK is £20 billion a year and rising. Two thirds of people with dementia live in their own homes and one third live in care homes. One in four people in hospital have dementia and two thirds of people in care homes have dementia.

This National Dementia Declaration has been created by people with dementia, carers of people with dementia and a large number of organisations who seek radical change in the way that our society responds to dementia. We seek a similar level of change as has been seen in our society's response to cancer over recent decades.

All organisations that are signatories to this National Dementia Declaration are setting out publicly what they intend to do by 2014 to transform quality of life for people with dementia and their family carers.

In 2011 the Dementia Action Alliance will seek support from partners in civic organisations, businesses and professions to deliver dementia supportive communities. For more information visit www.dementiaaction.org.uk

Why is there a need for a National Dementia Declaration?

- Public awareness of dementia is high but understanding about it is still very poor. Fear of dementia also remains high; there is a reluctance to seek help and few people understand that it is possible to live well with dementia. In addition there is limited understanding of the fact that dementia can affect people in many different age groups.
- NHS and social care systems have not historically developed to reflect the fact that people with dementia are now a key group using many services.
- Only one third of people with dementia receive a specialist diagnosis and many are receiving that diagnosis late. GPs often report being reluctant to diagnose dementia either because they lack the knowledge to do so, do not see the benefits of early diagnosis or because they are aware of the lack of specialist support and services available for people after a diagnosis.
- Following diagnosis many people with dementia and carers report receiving no information about their condition or about what support might be available.
- Reports from regulator the Care Quality Commission (CQC) and its predecessor the Commission for Social Care Inspection (CSCI) show that although there are examples of excellent dementia care in care homes, many providers are struggling to deliver quality of life for people in the later stages of the condition.
- Equally, some people with dementia struggle for too long in their own homes without the help they need when better person-centred care or a good care home could provide a more stimulating and supportive environment.
- The All-Party Parliamentary Group on Dementia and Professor Banerjee have both produced reports revealing people with dementia are being inappropriately prescribed or over-prescribed antipsychotic drugs which increase risk of death and reduce quality of life.
- Health and social care staff routinely report that they have not received training in how to treat or care for people with dementia, despite the fact that they are now increasingly in contact with people with dementia.
- The National Audit Office and Parliamentary Public Accounts Committee have found that there is very ineffective use of current resources to deliver quality of life for people with dementia. For example the NAO has highlighted the potential for the NHS to identify savings of at least £284 million per year through improving dementia care. In addition to the costs borne by public services people with dementia and carers face high costs for care.
- UK spending from all sources on dementia research is low compared to other disease groups and by international standards.

Government action on dementia

In 2009 the then government in England published a five-year National Dementia Strategy. As part of this work, strategies on end of life care and carers are also in place. NICE/SCIE guideline 2006 and Dementia Quality Standards describe what good dementia care should look like.

The coalition government has stated its commitment to implement the National Dementia Strategy; however, it can only do so much. The Department of Health, as a signatory to the Declaration, will set out what it intends to do to help improve the lives of people with dementia. However, radical and sustainable change will only come about through the action of individuals and organisations working together locally and nationally to challenge what is wrong and to do things better.

Desired outcomes for people with dementia and their carers

People with dementia and their family carers have described seven outcomes they would like to see in their lives.

There is overlap between these outcomes and the draft outcomes in the Department of Health's National Dementia Strategy Implementation Plan. Both the Department of Health's draft outcomes and those described below will need to be developed further. In addition work will need to be done to better understand how to measure these outcomes.

1 I have personal choice and control or influence over decisions about me

I have control over my life and support to do the things that matter to me.

I have received an early diagnosis which was sensitively communicated.

I have access to adequate resources (private and public) that enable me to choose where and how I live.

I can make decisions now about the care I want in my later life.

I will die free from pain, fear and with dignity, cared for by people who are trained and supported in high quality palliative care.

2 I know that services are designed around me and my needs

I feel supported and understood by my GP and get a physical checkup regularly without asking for it.

There are a range of services that support me with any aspect of daily living and enable me to stay at home and in my community, enjoying the best quality of life for as long as possible.

I am treated with dignity and respect whenever I need support from services.

I only go into hospital when I need to and when I get there staff understand how I can receive the best treatment so that I can leave as soon as possible.

Care home staff understand a lot about me and my disability and know what helps me cope and enjoy the best quality of life every day.

My carer can access respite care if and when they want it, along with other services that can help support them in their role.

3 I have support that helps me live my life

I can choose what support suits me best, so that I don't feel a burden.

I can access a wide range of options and opportunities for support that suits me and my needs.

I know how to get this support and I am confident it will help me.

I have information and support and I can have fun with a network of others, including people in a similar position to me.

My carer also has their own support network that suits their own needs.

4 I have the knowledge and know-how to get what I need

It's not a problem getting information and advice, including information about the range of benefits I can access to help me afford and cope with living at home.

I know where I can get the information I need when I need it, and I can digest and re-digest it in a way that suits me.

I have enough information and advice to make decisions about managing, now and in the future, as my dementia progresses.

My carer has access to further information relevant to them, and understands which benefits they are also entitled to.

5 I live in an enabling and supportive environment where I feel valued and understood

I had a diagnosis very early on and, if I work, an understanding employer which means I can still work and stay connected to people in my life.

I am making a contribution which makes me feel valued and valuable.

My neighbours, friends, family and GP keep in touch and are pleased to see me.

I am listened to and have my views considered, from the point I was first worried about my memory.

The importance of helping me to sustain relationships with others is well recognised.

If I develop behaviour that challenges others, people will take time to understand why I am acting in this way and help me to try to avoid it.

My carer's role is respected and supported. They also feel valued and valuable, and neither of us feel alone.

6 I have a sense of belonging and of being a valued part of family, community and civic life

I feel safe and supported in my home and in my community, which includes shops and pubs, sporting and cultural opportunities.

Neither I nor my family feel ashamed or discriminated against because I have dementia. People with whom we come into contact are helpful and supportive.

My carer and I continue to have the opportunity to develop new interests and new social networks.

It is easy for me to continue to live in my own home and I and my carer will both have the support needed for me to do this.

7 I know there is research going on which delivers a better life for me now and hope for the future

I regularly read and hear about new developments in research.

I am confident that there is an increasing investment in dementia research in the UK. I understand the growing evidence about prevention and risk reduction of dementia.

As a person living with dementia, I am asked if I want to take part in suitable clinical trials or participate in research in other ways.

I believe that research is key to improving the care I'm receiving now.

I believe that more research will mean that my children and I can look forward to a range of treatments when I need it and there will be more treatments available for their generation.

I know that with a diagnosis of dementia comes support to live well through assistive technologies as well as more traditional treatment types.

DAA Dementia Action Alliance

What do organisations signing up to the National Dementia Declaration commit to?

Separate to this Declaration, each signatory organisation will be setting out what it intends to do by 2014 (the date when the current National Dementia Strategy comes to an end) in order to deliver better quality of life for people living with dementia and their carers. These plans are being published separately. Each organisation is committed to the following principles:

- Ensuring that the work they do is planned and informed by the views of people with dementia and their carers and showing evidence for this
- Being an ambassador for the National Dementia Declaration and securing commitment from partners for the second phase of the Declaration
- Reporting publicly on their progress against the plan they have set out to support delivery of the National Dementia Declaration
- Working in partnership with other organisations to share knowledge about best practice in dementia
- Improving understanding about dementia.

How will the Declaration be tracked and monitored?

Organisations signed up to the National Dementia Declaration commit to making public the information about what they are doing to deliver better quality of life for people with dementia. They will be expected to publicise their contribution to the Declaration widely, especially to people with dementia, carers and the organisations representing them. In that way organisations can be held to account, particularly by their local population, to ensure they deliver what they have signed up to. There will be quarterly reporting on the outcomes and an annual report so it is possible to see what progress there has been.

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Annex D CYC Dementia Strategy Action Plan

Objective	Issues identified by York Working Group	Working Group priority	CYC Action	When	Lead and resources	Progress
1**. Improving public & professional awareness and understanding**	Support Alzheimer's work. Focus on those who already have dementia and their families Local initiatives to coincide with future national campaigns Sign up to National Dementia Declaration	Priority 3	Funding for Alzheimer's Society protected 2011-12 Support local awareness initiatives Dementia Declaration addressed in report to Cabinet Member	Achieved Nov 2011	AD Integrated Commissioning Work with voluntary sector	
2 **Good quality early diagnosis and**	Discussion on setting up a specific service should await the	Priority 3	Engagement in discussions with new MH provider	Post Nov 2011	AD Assessment and	

intervention for all	completion of the transfer of services to the new provider. Memory advisors play a very useful role. YHG and the PCT have jointly funded a temporary memory advisor post in York / Selby		on integrated pathway Work with GPCC to monitor impact of proposed memory advisor service and explore ways to continue the service	April 2012	Safeguarding AD Integrated Commissioning	
3. **Good quality information for those with diagnosed dementia and their carers**	Review information available on procedures for diagnosis, local dementia services, care after diagnosis and consider developing new packs, depending on user and carer feedback	Priority 3	Health will need to lead on review of information Ensure CYC staff access the same information available to health teams		AD Assessment and Safeguarding	
4. Enabling	Review evidence on	Priority	Consider	TBC	AD Integrated	

easy access to care, support and advice following diagnosis.	new national demonstrator sites for dementia adviser service	3	evidence when it is available		Commissioning	
5 **Development of structured peer support and learning networks**	Evaluate the local models offered by Alzheimer's, Age UK, Our Celebration/Mind and York Carers' Forum regarding outcomes and capacity	Priority 2	Encourage collaborative working by voluntary sector Learn from JRF Dementia Without Walls project Review issues through routine contract monitoring	Ongoing March 2012 April 2012 - 13	AD Integrated Commissioning	
6 Improved community personal support services	Gaps in day activities for people with dementia (anecdotal evidence). Limited weekend	Priority 2	We are already considering day care and supported activities as part of the review of	April 2012	AD Integrated Commissioning	

	service Needs of those with early onset dementia not met adequately Challenging behaviour service for women needed	 Priority 3 Priority 3	residential care Other elements to be considered with health partners			
7 **Implementing the carers' strategy for people with dementia**	We note that the York Carers' Strategy Group has been tasked with monitoring carers' breaks and identifying any unmet need. 2. We note the need to support young carers and protect them from inappropriate caring is included in the priorities set out in the York Strategy for Carers 2009-2011. 3. Better information	Priority 1 Priority	Ensure carers issues are addressed in personalisation work Ensure care assessments 'think family' and address issues for young carers New web based information system (My Life	April – Dec 11	Carers Strategy Manager and AD Assessment and Safeguarding	

	needs to be provided for people funding their own care	3	My Choice) is in development	Dec 2011	AD Assessment and Safeguarding	
8 **Improved quality of care for people with dementia in general hospitals**	A Hospital Dementia Strategy Group has been set up to oversee and monitor improvements in dementia care.		Hospital lead			
9. Improved intermediate care for people with dementia	Ensure Intermediate care services are open to people with dementia Monitor use of Intermediate care services by those with dementia.	Priority 1 Priority 1	'Levels of care' work with health partners will increase and improve intermediate care	Dec 11 (phase 1)	AD Integrated Commissioning and AD Assessment and Safeguarding	

	Better liaison for hospital discharges with psychiatry services, and commissioning a Psychiatric Liaison Service at the acute hospital	Priority 1	Health lead			
10. Considering the potential for housing support, housing related services and telecare to support people with dementia and their carers	Include housing related support staff in workforce development plans on dementia care	Priority 3	Workforce strategy will highlight dementia as area of priority and will include housing based support Delivery of Older People's Housing Strategy Telecare to be integral part of new intensive	Dec 11 Ongoing Nov 11	AD Integrated Commissioning Communities and Neighbourhood Directorate AD Assessment and	Acheived

			assessment approach		Safeguarding, and AD Service Delivery	
11 **Living well with dementia in care homes**	A big gap in service provision is the lack of a specialist in-reach service for non specialist care homes A particular concern for some of our members was the question of inappropriate use of anti-psychotic medication for people with dementia. (link to objective 3) As a Working Group we are keen to stress the importance of good leadership, staff training and person-	Priority 1 Priority 2 Priority 2	Health lead Promoting and share good practice via the ICG , contract monitoring and quality assurance work. This to include joint work with health to promote guidance to all care homes on the need to avoid the inappropriate use of anti-	On going	AD Integrated Commissioning	

	centred care We recommend that in all care homes run or used by CYC: a. Written guidance is readily available for staff on best practice in dementia care. b. There is clear guidance to all care homes on the need to avoid the inappropriate use of anti-psychotic medication.	Priority 2	psychotic medication. Highlight need for leadership training in workforce strategy Work with Dementia Network and Integrated Care Group to develop and disseminate good practice guidance	Nov 11	AD Integrated Commissioning AD Integrated Commissioning	
12 **Improved end of life care**	That people with dementia and their carers should be involved in planning EoL care (i.e. services and pathways). b. That current	Priority 2	CYC workforce development plan to support care providers to deliver good end of life care for those with	Nov 11	AD Integrated Commissioning	

	arrangements will ensure that the particular EoL needs of people with dementia will be met. c. That EoL care pathways are consistent with the Gold Standard Framework.		dementia			
13 **An informed and effective workforce for people with dementia**	We believe that improving workforce training is a key factor in improving dementia care.	Priority 2	Dementia will be a key priority in the new Workforce Strategy We will work with all providers to agree what level of training is needed by which staff. We will share learning from the	Nov 11 Nov 11 onwards	AD Integrated Commissioning AD Integrated Commissioning	

			national strategy, and with and from the NYY Dementia Workforce group			
14 **A joint commissioning strategy for dementia**	The CYC Transition Board is preparing new arrangements for commissioning which will include dementia care. These arrangements will take account of the new GP Commissioning Consortium and new boards such as Health & Wellbeing. The imminent transfer of mental health services to Leeds Partnerships NHS Foundation Trust is another important development which will affect local planning		NYY Joint Strategy to be considered by Cabinet Member Shadow Health and Wellbeing Board to be established Joint Commissioning plans agreed through Adult Commissioning Group – Dementia agreed as a priority and on the agenda of Sept 11	Oct 11 Oct 11	AD Integrated Commissioning AD Integrated Commissioning	

15 **Improved assessment and regulation of health and social care services and of how systems are working for people with dementia and their carers**	We believe that this objective is particularly important, bearing in mind that at least two thirds of people in care homes have dementia. It is closely related to objective 11 (living well with dementia in care homes) CYC have introduced additional quality monitoring for residential homes and other services for which they are responsible and this includes input from service users and carers. We welcome this initiative and recommend that this scheme is kept under review	Priority 1	We will continue to monitor customer /carer feedback via our contract monitoring process. And will work with JRF Dementia Without Walls project to listen to people with dementia over the coming year	Ongoing July11-12	AD Integrated Commissioning AD Integrated Commissioning	