



Annual Report

2009/10

**Supporting your right to
the best health and social**

York LINK Annual Report 2009/10

Contents

1. Introduction	page 1
2. Information about the LINK	page 3
3. How we included people	page 5
4. Involvement with stakeholders	page 7
5. Training	page 9
6. What we did during 2009/10	page 10
7. LINK reports	
• Neurological services	page 11
• Mental Health services	page 25
• End of Life Care services	page 35
• Dignity & Respect in services	page 37
8. Further Information Requests	page 40
9. Enter & View visits	Page 42
10. Summaries	page 51
11. Financial Statement	page 52
Appendix 1.	List of events organised by LINK
Appendix 2.	LINK Report Writing Protocol
Appendix 3.	List of Steering Group members

1. Introduction

I am delighted to introduce York LINK's Annual Report for 2009/2010. During the year, we used several methods to recruit members such as attending local events; editorials, letters and advertisements in 'The Press' newspaper; and advertisements in the 'Your Local Link' magazine and on the local 'First York' buses. We have also raised awareness of the work of the LINK by holding a series of Roadshows. These started with an event in the Guildhall then continued in various areas outside the city centre. Steering Group members and volunteers also attended many other meetings to gain information, and find out what people thought about services. Public Awareness and Consultation Events (PACE) were held for aspects of the LINK work plan (see appendix 1 for a list of these events; a full list of publicity, events and meetings with dates is available from the LINK office on request).

The LINK Steering Group looked at the issues that were voted onto the work plan at the last AGM. They were neurological services; mental health services; end of life care services; dignity and respect in services and the 'personalisation' agenda. We produced two reports in 2009 on neurological services and mental health services and had significant success in achieving the implementation of most of the recommendations. Further information on these publications is available on page 11 and 25 of this report. The development of a Health Passport for people with neurological conditions is a major development that has come from the report and we look forward to reading the results of the pilot scheme taking place shortly in York Hospital. The recommendation to improve training for Home Care staff and the process developed by the LINK to achieve this is another success and has been put forward as an example of how LINKs can improve services by the Department of Health, see page 23. However, there have also been challenges as some statutory authorities were unhappy with the process we used to agree the reports. In order to overcome these difficulties we have now agreed a 'Report Writing Protocol' which has been agreed by all statutory partners (see appendix 2) and hope to develop a Strategic Partnership Group with stakeholders such as NHS North Yorkshire and York, York Foundation Hospital Trust and City of York Council Social Services.

We also had the challenge of finding new office space for the LINK as the premises on Shipton Road were no longer available. We moved to premises nearer to the city centre on Holgate Road. This has the benefit that people are now more able to drop in, speak to staff and/or give or receive information. Our next challenge is to look into the areas that have been voted on for this year's work plan which will be announced at the AGM. We will be concentrating on gaining information and planning events for these areas at the first Steering Group meeting on 5 May 2010.

If you would like to be regularly informed about our work by receiving our newsletter or if you would like to get directly involved (in any way that suits you) please let us know either via letter, phone or email. If your organisation would like to hear more about the LINK, via a presentation or by attendance at one of your events, we would be delighted to hear from you to arrange a date and time.

We are delighted that the Archbishop of York, Dr John Sentamu agreed to be a Patron for the LINK. We are aware that he is a busy person and are grateful to him for his support.

Finally, I would like to thank the LINK Steering Group and the rest of the hard working LINK volunteers who have helped to make a difference to health and social care services on behalf of our community. As the LINK is more established, we hope to as well, if not better, this year.

Andrew Kent

Chair of York LINK

2. Information about the LINK

The LINK office is now based at Holgate Villa, 22 Holgate Road, York YO24 4AB, 01904 621631 admin@yorklink.org.uk.

The LINK Host organisation is North Bank Forum, 94 Alfred Gelder Street, Hull HU1 2AN, 01482 472458 admin@nbf.org.uk

Membership of the LINK is open to any resident living within the boundary of the City of York Council, over the age of sixteen years old, or any voluntary organisation that is interested in working with the LINK.

The LINK is governed by an elected Steering Group consisting of a maximum of seven Community Representatives who liaise directly with the people of York and a further seven Steering Group members representing various York voluntary groups. The role of a Steering Group member is to make decisions on behalf of the LINK, meet with groups, visit Health and Social care establishments and get to know the needs of people living in York. They also provide information regarding LINK activities to the community, undertake surveys and collate the opinions of residents. Steering Group members are supported by LINK Ward Representatives.

Steering Group meetings now take place on the first Wednesday of each month except January and August. Robin McIlroy was elected to be Chair of the LINK by the Steering Group members on 6 May 2009. However, due to personal circumstances Robin decided to stand down from the position in September. At the Steering Group meeting on 7 October, Andrew Kent was elected as Chair. The LINK agreed to have two vice-chairs therefore Lesley Pratt was elected as Vice-chair along with Kath Briers.

A list of the people who have been Steering Group members since the last AGM with the dates for the people who have joined since the event is available at appendix 3. There have been vacancies, but due to the outstanding work done by the LINK volunteers and extensive local publicity only one vacancy exists this year. Unfortunately we have been unable to find a member to represent the BME community.

As well as those on the Steering Group, the work during the past year has been assisted by a number of Ward Representatives, and other volunteers who have helped when they were able. Without the assistance of the outreach work that has been done by these people, the work the LINK has produced would not have been as rich and we hope that others will volunteer their services as Ward Representatives this year.

A pool of LINK Experts have been trained to undertake the 'Enter and View' role (visit and gather evidence from service providers) for the LINK. These people have also been trained to facilitate discussions and interview people to obtain knowledge of a situation. The first 'Enter & View' visit was to the Wheelchair Centre on 23 March 2010.

The LINK Readers Panel read publications to ensure they can be easily understood by members of the community. Members of the Readers Panel have been busy this year and were asked to comment on the list of documents; this list is available on request from the LINK office. The Steering Group members are pleased that this service has been adopted predominantly by the PCT. However, we are confident that City of York Council and other statutory bodies will eventually see the benefit of lay readers commenting on publications. To enable the work to increase we distributed nomination forms to recruit people to the Readers Panel with notices for the AGM and gained more people interested in the role.

Task and Finish work groups, such as the York Neurology Group, led by a LINK Steering Group member can include any member who has an interest in the subject. This group has been instrumental in improving training for Home Care workers and producing a 'Health Passport' to pilot in York Hospital; more information about this is available on page 24. It is planned to have more work groups as the need arises.

The LINK has adopted Governance documents including a Code of Conduct for members that outline the principles of equality and diversity. To date the LINK has 193 individual members, 45 associate members and 323 group members. Many of the voluntary sector groups that are actively involved with the LINK have over 300 members who are regularly kept up to date with developments. We plan to employ a Membership Development Officer during the next year to help recruit more individuals and groups.

3. How we included people

There are 193,300 people living within the boundary of City of York Council. In the 2001 Census, 95% of the York population classified themselves as White British compared to 5% non white. However, new research has discovered that the ethnic population in the city has almost doubled. It is estimated that 70 different languages are spoken and 800 migrant workers are currently employed in the city. The largest BME populations by ward estimated at that time were Heslington, Fishergate and Guildhall. The obvious link to the University of York impacts on the ethnic mix in Heslington ward. There were around 350 Gypsy and Traveller households in the City of York in 2001. In 2007/8 there were 1,720 national insurance registrations for non-UK nationals in York indicating there has been an increase in the number of people who would not classify themselves as White British living in the area.

In the 2001 Census 16% of people in York area said that they had a limiting long-term illness/disability. A breakdown of these figures by age group showed that rates were particularly low in men and women under 65, compared to national figures. The number of older people who received home care services in York in 08/09 was 3,095. However, the population over 65 is predicted to grow by 31% over the next 15 years. This would indicate that by 2020 an additional 1300 people will need services due to having physical disabilities.

In March 2007 there were 1,140 people registered as deaf or hard of hearing in York. Of these 895 were registered as hard of hearing with 115 in the 18-64 year old age band and 130 65-74 and 650 over 75. In the same year 25 people were newly registered as blind or partially sighted.

The health of people in the area is generally better than average however, inequalities exist mainly related to the area in the city where people live. Overall York's levels of deprivation are decreasing. In the 2007, (based on data from 2005) York was ranked 242 out of 354 compared to a position of 219 in 2004. In 2007 there were eight areas in the City estimated to be in the most deprived 20% in the country compared to eleven in 2004. Nevertheless, 60% of the population in York live in areas that are in the best 40% nationally. The number of areas in the most deprived fifth of the country has reduced from 3 to 2 but one area, Westfield, has remained consistently in the most deprived 10% in the country.

It is estimated that one in eight of the population in York is a carer therefore there are 22,000 carers in York. Of these 3,290 could spend up to 50 hours per week caring and 6,675 spend at least 20 hours per week.

The LINK recognises the need to involve people who represent specific communities and has recruited people to represent those who have caring responsibilities, learning disabilities, physical disabilities and long term neurological conditions onto the Steering Group. These representatives are all involved with local groups and liaise with a large number of people e.g. the representative for people with neurological conditions has regular contact with 300 or more people and the Carers representative has regular contact with approximately 300 people. Some of the individuals involved with these groups informed the LINK that they were unable to attend events due to their condition and their Carers stated that they were too busy caring to attend therefore they are obviously hard to reach people.

The LINK also had a vacancy on the Steering Group for someone to represent people from the BME community in York. A representative from this community was a member of the Interim Steering Group for the LINK but unfortunately had to give up the position due to personal circumstances. However, we are hopeful that another representative can be recruited this year.

The LINK has some members in the wards identified as being deprived areas in York. However, it is widely recognised that only parts of these wards are deprived and other areas are affluent therefore numbers alone are unhelpful. In order to reach people within the different wards the LINK has attended several Ward Committee meetings during the year.

The LINK Roadshows that were held in areas outside the City centre were poorly attended therefore it has been suggested that we try to contact people via information stands in various public places such as supermarkets during the next year.

Presentations were also given to several local voluntary groups and information was gained on the perceived value of services by users as well as informing them about the LINK.

The York LINK newsletter, LINKed In, is published bi-monthly and sent to all individuals and groups on our mailing list either by e mail or paper copy. The newsletter is designed and printed by Our Celebration, a local organisation which supports recovery from mental ill health.

A new York LINK website (www.yorklink.org.uk) was developed, and launched in January 2010. The new site will be developed further during the coming year. It aims to provide a resource for LINK members, and a source of health and social care information for the whole community.

4. LINK Involvement with Stakeholders

LINK Representatives are now members of the Healthy City Board and the Inclusive York Forum which are sub-groups of the City of York Local Strategic Partnership (Without Walls). Although it is early days to make a great contribution to the work of these groups the information gained has been helpful and positive relationships are developing.

The LINK is delighted to be asked to externally quality assure the City of York Council's 'Safeguarding' procedures which will start with an extensive information session on the scheme in May 2010.

The LINK was asked to help gain information for the Joint Strategic Needs Assessment for 2010/11 by the Chair of the Healthy City Board who is also the Locality Manager for the York area at NHS North Yorkshire & York. A copy of the questionnaire was distributed to all LINK members with the December edition of the LINKed-in newsletter.

The LINK has established a good relationship with the City of York Council Health Overview & Scrutiny Committee. A LINK Steering Group member attends most OSC meetings and has regular meetings with the Chair and Vice-chair.

Work with York Health Group (Practice based Commissioning Group for GP's) began with a presentation from the Chief Executive Officer about the work of the group. The LINK offered assistance to establish Patients Forums in GP surgeries and is delighted that LINK Representatives have been asked to be members of the Patients Forum that will cover the whole of the York area.

A training event for Steering Group members and LINK volunteers to find out more about how NHS North Yorkshire & York work was held earlier in the year. Since then, regular meetings have been held with members of the Patient Involvement Team. LINK Representatives have also met with the Chair and Chief Executive Officer and a healthy working relationship has been established. The Chair also offered to take part in the LINK AGM.

Members of the LINK Steering Group met with the Chief Executive Officer and the Chief Nurse of York Foundation Hospital. A meeting with some Hospital Governors was also held. A LINK Information Day was held in the hospital and plans to pilot a Health Passport document in some Wards have also helped to develop a positive relationship with staff and managers.

LINK Representatives have attended a variety of voluntary and community organisation meetings and events. The relationship between the LINK and voluntary organisations has developed well over the past year and the LINK welcomes a staff member of York Council for Voluntary organisations as a member of the Steering Group for 2010/11.

The proposal to establish a Statutory Stakeholders Group that was debated at the inaugural AGM in 2009 did not develop. Some statutory agencies appeared to be very willing to work with the LINK but others were reticent and needed time to fully appreciate the legislation around listening to the views of members of the public. However, following specific requests from the City of York Council Health Overview & Scrutiny Committee and the York Health Group, quarterly meetings have been agreed for the next year.

5. Training

Members of the LINK Steering Group are either individuals or belong to a variety of organisations. In order that everyone understood the legislation around the working of the LINK, an induction day was held on 23 April which was attended by 10 people. Further inductions for new members were also carried out on an individual basis throughout the year.

A training scheme for the LINK Experts who can be authorised to undertake 'Enter & view' visits was also designed. This training was delivered in 3 stages and followed the national guidelines on 'Enter & View'. Sessions on safeguarding and equality and diversity were also included.

- Seven people attended on 13 May for stage 1. The session was also repeated for people who could not attend on 13 May.
- Stage 2 was held on 8 June
- Stage 3 on 16 June.

LINK Experts were also required to undertake CRB checks and so far a total of 7 people have completed all the training and checks. The first 'Enter & View' visit took place on 23 March; please see report on Enter and View. LINK Experts also visited local nursing homes etc to gain information about how services are delivered.

Other information sessions for Steering Group members and volunteers were delivered throughout the year as follows:

- 19 June – Personalisation Agenda & New Complaints Procedures for healthcare
- 14 July – How the PCT works
- 23 July – Home Call - Mobile Warden Service
- 2 September - York Health Group (Commissioning group for GP's)
- 4 September - Altogether Better project
- 4 November – York Hospital Pharmacy
- 5 December – JSNA
- 13 January 2010 – media training

6. What we did during 2009/10

Where did the issues for the LINK work plan come from?

Following extensive publicity, most people gave evidence to the LINK via phone, letter, on our information leaflet or via Interim Steering Group members and volunteers. All evidence that was given by letter or leaflet was followed up by either a phone call or a meeting with the person to gain further insight into the problem. In addition some people gave evidence to Steering Group members at ward committee meetings, the LINK Roadshows that were organised in various areas around York, following presentations that were made to voluntary groups, at Public Awareness and Information Events (PACE) and other public events.

To ensure that as many people as possible had the opportunity to provide evidence for the work plan for 2010/11 a notification was placed in the local media and in the LINKed In newsletter, which goes to most voluntary and community groups in York, asking for people to contribute issues.

How did the LINK decide which issues to make enquiries about during the year?

The Steering Group decided that people in the York community should be able to vote on the issues for the work plan. Last year the issues were debated and voted on during the inaugural AGM and the work plan was announced some time after the event. In order to be able let people know as soon as possible the issues that the LINK will be making enquiries into this year the Steering Group agreed that voting should take place prior to the AGM. To facilitate this, after the published cut off date to refer issues, a log of the issues was produced and collated into an 'Issue Voting Form'.

How did people vote on issues for the work plan?

The 'Issue Voting Form' was checked by Steering Group members and posted to all members eligible to vote. It was to be returned to the LINK office by a date prior to the AGM. The forms were then counted and checked by Steering Group members and the ones with the highest number of votes incorporated into the work plan which will be announced at the AGM. The work plan will also be communicated to other members via the LINKed In newsletter and posted on the LINK website. To promote transparency, all voting papers will be retained by the LINK until at least the next AGM.

7. York LINK Reports

Neurological services

Various problems experienced by people with neurological conditions were referred to the LINK and the issue gained the highest number of votes for the work plan 2009/10.

Individuals and groups informed the LINK that the beds for patients with neurological conditions that had been based on one ward in York Hospital were now reduced and moved to another location and this was the cause of many of the problems. It was rumoured that the PCT had cut the funding for the beds. LINK Steering Group members questioned NHS North Yorkshire and York about this and were subsequently informed by the PCT Commissioner that the funding had not been cut. The LINK was also informed that people requiring neurological care, in the main, are assisted by community services but may need to be cared for in a medical facility during times of crisis and possibly at the end of their life. Anecdotal information about problems around 'end of life care' related to the reduction of the neurological beds in one area had also been given to the LINK.

The LINK was informed by patients and their carers that when the neurological beds had been based on Ward 38 the staff gained an insight into the different neurological conditions, thus patients stated they received an extremely good service. Neurology is a specialised area, and every person who has a neurological condition has individual symptoms therefore it is very difficult to train every member of staff on all wards on all conditions. Personalised care plans for people with long term conditions, such as neurological conditions, are scheduled to be implemented in 2010. New guidance has also been issued to help NHS and Social Services staff to ensure that people who have long term conditions are more involved in decisions about their illness and treatment, including their treatment in hospital. It is widely recognised that people with long term conditions require a great many health and social services and often find difficulty in accessing the services they need at the correct time due to the variability of their condition. NHS guidance states that a care plan must be agreed between the person with the condition, their family or carer, the NHS and social services staff. This care plan must be accessible for all to read so there is no mistake in what has been agreed (National Service Framework for Long Term Conditions now renamed National Service Framework for Long Term Neurological Conditions).

During the first meeting with York Foundation Hospital Chief Executive and members of the LINK Steering Group it was discovered that three wards had been closed because the hospital had received a reduction in funding from

the PCT. The hospital had applied for Foundation Trust status and one of the conditions is the need to show the organisation is financially sound, meaning the services they intend to provide meet with the amount of funding they will receive. In order to balance the books, a decision was made to reduce the number of wards. Thus the 14 beds specifically for people with neurological conditions that were based on Ward 38 were reduced to 8 and moved to the Cardiology ward. Some staff were transferred with the patients but many took early retirement or moved to work in another part of the hospital. When the 8 beds on the Cardiology ward are occupied, patients with neurological conditions are allocated a bed within another ward thus patients with neurological conditions are scattered throughout the hospital. Also, staff on the Cardiology ward could not possibly gain the knowledge and experience required to nurse people with long term conditions in a short time so patients experienced an inferior service. When asked, York Hospital Patient Advice Liaison Service (PALS) stated that no complaints had been received either before or after the neurological beds were moved, bringing into question why people complained to the LINK and not PALS.

The LINK was informed that beds for people with neurological conditions would eventually be reallocated to the Stroke Unit. Stroke is classed as a neurological condition therefore the staff should have more of an insight into the nursing skills required on this ward than others. However subsequent information emerged that the Stroke Unit is permanently full and could not accommodate further patients so the future of the neurological beds would come under a 'Bed Review' that was being undertaken by the Hospital. There appeared to be much confusion on what was happening with beds provided for people with neurological conditions in the hospital therefore the LINK formally requested to have copies of the minutes of all meetings regarding the 'Bed Review' and the time-table for this piece of work. However, a written reply was eventually received stating that the 'Bed Review' was being undertaken by a manager in NHS North Yorkshire and York employment. The LINK formally requested information regarding this and discovered that no-one working for NHS North Yorkshire & York was involved.

In order to progress matters and discover more evidence, the LINK Steering Group agreed to hold a Public Awareness and Consultation Event (PACE) on services for people with neurological conditions. Speakers from five neurological charities (MS, PD Society, York Epilepsy branch, Stroke Association and York Against MND) were invited to speak followed by a general discussion on what is good and bad with the services available. Invitations were sent to individuals and groups involved with neurological conditions and statutory services.

Information requested

Date	Person	Request
15 June	Marilyn Thirlway, Patient Experience Manager, York Foundation Hospital	Following conflicting information regarding beds allocated for patients with neurological conditions, request for copies of minutes of meetings where the 'Bed Review' was discussed
		Reply
22 July		NHS North Yorkshire & York are undertaking the 'bed review'

Date	Person	Request
3 Aug	Pat Sloss, NHS North Yorkshire & York	Following the reply from York Hospital, the name of the person undertaking the 'bed review'
		Reply
20 Oct		After an extensive search no one from this organisation is leading a 'bed review' for beds in York Hospital

Using information gained from the PACE on neurological services and evidence provided by members of the public the following recommendations were made to the relevant statutory authorities on 30 September 2009. Replies received from the organisations are also included as follows:

- 1. York LINK should help to form a 'York Neurology Group' to bring people interested in all neurological conditions together to identify problems, highlight good practice and work with health and social services.**

Reply

Date		
20 Oct	LINK	First meeting of York Neurology Group, 14 people identified as members.
		Regional Officers from national Neurological Charities are building on work done by York Neurology Group and hope to establish a Neurological Alliance in the area. A meeting to discuss this has been booked for 5 July 2010.

2. York LINK recommends to NHS North Yorkshire & York and York Hospital that a ward designated for people with neurological conditions is made available, with the necessary equipment.

People with most neurological conditions have suffered as a result of the designated ward being closed in York Hospital. There are also other ongoing problems such as the lack of recognition given to Carers which could possibly be resolved by implementing the standards contained in the National Service Framework (NSF) for Long Term Neurological Conditions. Staff on the Cardiology Ward, since the report was completed, have increased their knowledge and experience in how to treat people with neurological conditions but these beds are often full so patients are admitted to any ward. The lack of an informed workforce in other wards appears to be the cause of much of the problems experienced by patients at present such as improper use of chairs.

Replies

Date	Person	
23 Oct	Marilyn Thirlway, Patient Experience Manager, York Foundation Hospital	'We are looking at the detail and will contact you again'.
26 Oct	Jayne Brown, Chief Executive, NHS North Yorkshire & York	'We will ensure we are working closely with acute Trust colleagues in developing neurological services further, including taking forward these recommendations'.
23 Nov	Marilyn Thirlway, Patient Experience Manager, York Foundation Hospital	'We are continuing to examine your recommendations'.
12 Feb	Patrick Crowley, Chief Executive Officer York Foundation Hospital	'We explained in our letter of 14 August, that we have not closed any services for people with neurological conditions, only the location from which they are delivered. As you will know, providing a designated ward for people with neurological conditions is not a Quality Requirement of the national Service Framework for Long-term Neurological Conditions. We keep the deployment of all beds under review to meet the changing demands on our resources and any opportunity to improve is taken whenever possible'.

3. The LINK should work with the York Neurology Group, York Hospital staff, Social Services and NHS North Yorkshire & York to establish Local Implementation Teams (LITs) for all the NSF for Long Term Neurological Care standards.

Replies

Date	Person	
16 Oct	Bill Hodson, Director of Housing & Adult Social Services, City of York Council	‘Given other priorities that have been identified for joint working between health and social care it is likely to be difficult to commit to this recommendation at present. I would encourage the group when established to make contact with existing, multi-agency partnership groups that have a common interest in this topic’.
23 Oct	Marilyn Thirlway, Patient Experience Manager, York Foundation Hospital	‘We are looking at the detail and will contact you again’.
26 Oct	Jayne Brown, Chief Executive, NHS North Yorkshire & York	‘The PCT is in the process of finalising its 5 year Strategic Plan. This plan includes specific priority concerning reviewing and improving care pathways. As a key part of this work it is intended that neurological services will be the subject of a review in line with NSF standards to identify future commissioning priorities and requirements’.
23 Nov	Marilyn Thirlway, Patient Experience Manager, York Foundation Hospital	‘We are continuing to examine your recommendations’.
12 Feb	Patrick Crowley, Chief Executive Officer York Foundation Hospital	‘I understand the first meeting of York Neurological Group was on 20 October and that Fiona Ronan, Advanced Nurse Specialist for MS, has twice attended on behalf of the Trust. It has been difficult for a nurse to attend at the time the meeting is held because it coincides with our clinic times. However, Karen Cowley, Matron for Medical Specialities, will try to ensure that we have some representation on the group. We have been able and continue to make progress on the implementation of this

		NSF and I enclose an updates report from Mike Harvey, Directorate Manager Medical Specialities. This report summarises our progress against the Quality Requirements for the NSF, outlines any outstanding issues and makes recommendations as necessary. It is supported by an action plan in Appendix 1, which indicates target dates for the actions required. I hope you will find it helpful and reassuring'.
--	--	--

4. York LINK recommends to GP's via the York Health Group that an information event such as the LINK PACE day is made available for GP's to enhance their knowledge of the various neurological conditions.

Reply

Date	Person	
01/04/10	Dr John Lethem, Chair York Health Group	There is already a neurology interest group with the next meeting being about MS in late April. There is also quarterly Protected learning days for GP's with a rolling programme of educational events and I'm sure Neurology can be considered although I am not in charge of the events. I will past this comment on to the appropriate organiser.

5. York LINK also recommends that GP's provide 'information prescriptions' to all patients when necessary.

Many people experience problems being diagnosed with neurological conditions such as epilepsy and ongoing problems due to GP's lack of in-depth knowledge about the conditions. The Darzi review recommended that people are given 'information prescriptions' when they are diagnosed. These prescriptions should contain information about the condition as well as the contact details of local voluntary groups that people can access for ongoing support if they wish.

Reply

Date	Person	
01/04/10	Dr John Lethem, Chair York Health Group	GP's do often give out information as appropriate, either in printed or electronic form as appropriate. Please look at the website: http://www.patient.co.uk which is used by many GP's nationwide as a reputable source of information for

		patients. Please let us know what you think.
--	--	--

6. York LINK recommends to all concerned that the neurological charities work together to provide a programme of training on neurological conditions and this be made available to all hospital and community based staff and student nurses at York University. Particular in-depth training on Epilepsy should be provided to staff working in the A & E department.

Many problems that people with neurological conditions experience are as a result of staff not being aware of their fluctuating condition. Members of the public believe that nurses and care staff are often not given the initial training required to nurse people with specialised conditions and that many nurses and care workers would be horrified to discover that they had treated people inappropriately. However, Hospital and Social Services managers must recognise that this lack of knowledge does impact on the care given to patients/clients.

Replies

Date	Person	
23 Oct	Marilyn Thirlway, Patient Experience Manager, York Foundation Hospital	'We are looking at the detail and will contact you again'.
23 Nov	Marilyn Thirlway, Patient Experience Manager, York Foundation Hospital	'We are continuing to examine your recommendations'.
12 Feb	Patrick Crowley, Chief Executive Officer York Foundation Hospital	'We identify training requirements for our staff from a variety of sources, including training needs analyses, serious untoward incidents, adverse incident reports, Department of health requirements, national guidance, our Corporate Directors, complaints and the Patient Advice and Liaison Service (PALS). We provide training through a range of methods as necessary, depending on requirements. These methods include statutory and mandatory training sessions, and generalist and specialist training within and outside the Trust. Our training is targeted and tailored to ensure that our staff are appropriately trained in

		<p>accordance with their roles and responsibilities.</p> <p>Training on epilepsy is included in the pre-registration education of doctors and nurses in their induction. Guidelines in treatment of epilepsy are available in the Emergency Department (ED) in electronic and paper formats. Where there are specific skill requirements, our staff receive the necessary training to support them according to the different conditions under which they work’.</p>
--	--	--

7. York LINK recommends to statutory services that a ‘Passport’ be used for neurological patients in York Hospital, Primary Care and Social Care services.

Replies

Date	Person	
16 Oct	Bill Hodson, Director of Housing & Adult Social Services, City of York Council	‘The Council has looked at introducing ‘person held records’ already and is in discussion with carers, through the health task group of the Carers Strategy Group, to explore the use of a ‘carers health passport’. The concept of a passport may be similar and we would want to understand more what is intended by this concept. Following discussions with York Carers Forum, Social Services staff and PCT Commissioner for Carers services it is proposed to make this a joint project.
23 Oct	Marilyn Thirlway, Patient Experience Manager, York Foundation Hospital	‘We are looking at the detail and will contact you again’.
26 Oct	Jayne Brown, Chief Executive, NHS North Yorkshire & York	‘The importance of empowering patients to self-care through effective information and an agreed care plan is a key feature of the PCT’s strategy for long term conditions and will be developed considerably in the years ahead. The PCT has already commissioned an Enhanced Services for Multiple Sclerosis care through GP practices, which includes developing care plans and effective co-working between primary and secondary care’.

23 Nov	Marilyn Thirlway, Patient Experience Manager, York Foundation Hospital	'We are continuing to examine your recommendations'.
12 Feb	Patrick Crowley, Chief Executive Officer York Foundation Hospital	'We look forward to continuing our work with the LINK through the York Neurological Group to develop a passport system for neurological patients. Fiona Ronan, Advanced Nurse Specialist for MS, is keen to develop a passport system and we hope to make good progress on it'.

8. York LINK recommends to all statutory services that a 'Carer's Post Bereavement Course' should be jointly funded and made available.

Replies

Date	Person	
16 Oct	Bill Hodson, Director of Housing & Adult Social Services, City of York Council	'We struggle with the concept of a 'course' in this context. The need for bereavement support for family and carers is identified within the End of Life strategy. Funding for any new services will need to be considered alongside other priorities'.
23 Oct	Marilyn Thirlway, Patient Experience Manager, York Foundation Hospital	'We are looking at the detail and will contact you again'.
26 Oct	Jayne Brown, Chief Executive, NHS North Yorkshire & York	'The importance of bereavement support has been recognised by both City of York Council and the PCT through the local End of Life strategy'.
23 Nov	Marilyn Thirlway, Patient Experience Manager, York Foundation Hospital	'We are continuing to examine your recommendations'.
12 Feb	Patrick Crowley, Chief Executive Officer York Foundation Hospital	'We are developing our bereavement services for relatives and carers. Currently we offer support and guidance on how to access support which is not typically provided by hospitals, but signpost to other well equipped groups and organisations'.

9. York LINK recommends that lockers for patient medications should be installed in all wards in York Hospital so specifically patients with PD can self-medicate while an in-patient.

Replies

Date	Person	
23 Oct	Marilyn Thirlway, Patient Experience Manager, York Foundation Hospital	'We are looking at the detail and will contact you again'.
23 Nov	Marilyn Thirlway, Patient Experience Manager, York Foundation Hospital	'We are continuing to examine your recommendations'.
12 Feb	Patrick Crowley, Chief Executive Officer York Foundation Hospital	'I am pleased to say that the Trust has obtained new lockers with a lockable compartment for patients' medications. As part of our medicines management programme we are developing self-medication and one –stop dispensing for all patients assessed as suitable for this. This means that patients who are used to managing their own medicines safely will be able to continue to do this if they are admitted to hospital'.

10. York LINK recommends to NHS North Yorkshire & York that GP's should agree a protocol with pharmacists so patients with epilepsy receive the medications on which they are commenced, whether they are branded or a parallel import.

Reply

Date	Person	
		No response

11. York LINK recommends that a protocol be drawn up between NHS North Yorkshire & York and Social Services to ensure that a fast-track system is in place that meets the needs of people when equipment is required.

Replies

Date	Person	
16 Oct	Bill Hodson, Director of Housing & Adult Social Services, City of York Council	'Our understanding is that the provision of equipment within the community is not a problem area. Our performance indicators suggest that we perform well on this. The report gives examples of where hospital patients have needed access to specialist chairs, which would be the responsibility of the Foundation Trust and would be their responsibility'.
26 Oct	Jayne Brown, Chief Executive, NHS North Yorkshire & York	'The PCT is currently looking into these issues with a view to ensuring that patient's needs are met'.

On 2 December the LINK Steering Group agreed to arrange an 'Enter & View' visit to Wheelchair Centre in New Year to discover what is going on.

12. York LINK recommends that CYC Social Services department looks at the time taken to obtain Disabled Facilities Grants to ensure that no one is kept waiting.

Reply

Date	Person	
16 Oct	Bill Hodson, Director of Housing & Adult Social Services, City of York Council	'We know that there are delays in providing Disabled Facilities Grants. This is something we are exploring, but it will very likely require additional investment.'

13. York Link recommends to CYC Social Services that a programme of intense training including aspects of end of life care is in place for all Home Care Workers.

Reply

Date	Person	
16 Oct	Bill Hodson, Director of Housing & Adult Social Services, City of York Council	'The council would be happy to share information about current training programmes that are made available to home care providers, and to receive input on known needs, for consideration in the development of the next programme'.

14. York LINK recommends to City of York Council Health Overview and Scrutiny Committee that they monitor regular reports on how many members of staff have undergone the differing types of training.

Reply

Date	Person	
5 Oct	Tracy Wallis, City of York Council Health Overview and Scrutiny Officer	'The committee will consider the report back after receiving clarity on the recommendation specifically the type of training required and those who need to be trained'.

15. York LINK should congratulate York Hospital on their acute stroke services.

16. York Link recommends to NHS North Yorkshire & York that they commission rehabilitation services for stroke patients in a more germ-resistant community setting outside a hospital ward.

Reply

Date	Person	
26 Oct	Jayne Brown, Chief Executive, NHS North Yorkshire & York	'The development of community-based services and the effective transition of care between primary and secondary care is a recognized priority for the PCT and we are pleased that this is reinforced in the recommendations of this report. The development of community-based rehabilitation services is a priority within the national Stroke Strategy and this is similarly recognised within the PCT's Strategic Plan'.

Impact of report

Recommendation to City of York Council Health Overview and Scrutiny Committee that they monitor regular reports on how many members of staff have undergone the differing types of training.

The OSC replied to the LINK asking specifically for further clarity on the type of training required and those needed to be trained. It became apparent that the information required to monitor training for all Home Care staff was not available to OSC members therefore the LINK decided to pursue alternative arrangements.

The LINK discovered that all Home Carers, whether they are employed directly by the Council or by Home Care agencies and non nursing staff employed in residential and nursing homes should receive training to meet National Minimum Standards. The standards are part of the Care Quality Commission assessment and include the Common Induction Standards (CIS) that have been developed by Skills for Care. Further statutory standards specifically for first aid, moving and handling, food hygiene, safeguarding and health and safety must also be undertaken and many workers are encouraged to undertake NVQ Level 2 in Health and Social Care for Home Care Workers. However, these standards do not include training on aspects of care for people with a specific condition.

The LINK carried out a small survey of Home Care providers and Care Homes in the York area and discovered that some, but not all, provide additional training for staff on specific conditions. It appears that the biggest barriers to this are the costs and the difficulty in finding organisations to deliver the training.

The LINK has contact with a large number of local voluntary groups and charities and some have stated that they would be willing to provide training free of charge. The LINK wrote to all Home Care providers, Residential and Nursing Homes in the area asking them if a list of free training providers made available via the LINK office would improve matters. This proposal has received a positive response as most providers wish to improve staff performance so the LINK has collated a list of voluntary organisations willing to provide free training. Although this training may not include a great deal of Anatomy and Physiology about conditions it will be in the main provided by the people who have the condition or their Carer so they will be able to give the Home Carers information that they cannot gain from books or formal training courses.

The actual training will need to be agreed between the agencies and voluntary/charitable groups concerned but a record of the numbers of staff who attend as well as an evaluation of how it will improve Staff's

performance at work will be gathered by the LINK. It is hoped that this information will be helpful in the commissioning process for Home Care services and for public information for those who are undertaking personalisation of their care. The scheme has also been recommended as good practice for other areas by the Department of Health that supports LINKs.

Recommendation that a 'Health Passport' be used for neurological patients in York Hospital, Primary Care and Social Care services.

A draft document has been agreed in conjunction with members of York Neurology Group and York Carers Strategy Group. A launch of the Passport supported by the Chief Executive, Chief Nurse and the Chair of the Foundation Trust is planned to take place soon and a pilot scheme is due to commence in the hospital shortly after. An independent evaluation of the usefulness of the document will be undertaken by a student from York St John's University and the results will be published when available.

Recommendation to help establish a York Neurological Alliance

The first meeting for all neurological groups to establish a Neurological Alliance for York and North Yorkshire will be held on 5 July 2010.

Mental Health services

At the time of the LINK inaugural AGM, NHS North Yorkshire & York ran the majority of Mental Health services in York and North Yorkshire. Services in Scarborough are run by a Mental Health Trust based in Teesside and in the Skipton area they are run by a Bradford based Mental Health Trust. This arrangement had developed over a number of years but the role of NHS North Yorkshire & York, in line with Department of Health policy (Transforming Community Services) changed from providing services to finding the best organisation, then contracting for services (commissioning). This meant that it would be difficult to continue to provide mental health services because it would be like contracting with themselves to provide their own goods so a 'transformation' of how mental health services are run was necessary.

NHS North Yorkshire & York established a 'Shadow Board' for the provider services; this is separate to the overall PCT Board. However, ongoing discussions around the type of organisation best placed to provide mental health services, and the types of services required for people with mental health conditions in future was considered. Also considered was the number and type of services that are needed and whether the quality of the present services could be improved.

New standard contracts for health services are governed by strict rules and can last for three years. This may cause problems for smaller voluntary groups who provide services at present and there is a desire to form a Mental Health Consortium to tender for contracts then subcontract with the various smaller groups. The Department of Health (DH) also expects NHS organisations to invest approximately 15% of their overall budget on grants to voluntary and community providers. Although this has not happened in the past due to the financial constraints of NHS North Yorkshire and York it is hoped that this funding would be available in the future.

There is a Mental Health Forum in York run by the local Council for Voluntary Services (York CVS). Members of the Forum presented a list of mental health service needs for the area to the Local Implementation Advisory Group (LIAG) run by NHS North Yorkshire and York. Interestingly, Forum members maintained that the Joint Strategic Needs Assessment devised by the PCT and City of York Council was inadequate to address the problems experienced by people with mental health problems.

Mental health services was voted onto the LINK work plan at the inaugural AGM. In order to discover more about the situation the LINK Steering Group decided to hold a Public Awareness and Consultation Event (PACE) on mental health conditions. Speakers from local charities were asked to give information on the history of mental health services, dementia, the main types

of problems people experience and the services they provide. The Project Manager for the transformation of the mental health services from NHS North Yorkshire and York also agreed to provide an update on progress. Invitations were distributed to individuals and groups involved with services for people with mental health problems and statutory services.

Using information gained from the PACE on mental health services and evidence provided by some voluntary groups the following recommendations were made to the relevant statutory authorities on 30 September 2009. Replies received from the organisations are also included as follows:

- 1. York LINK recommends that NHS North Yorkshire & York must include lay stakeholders in York (mainly York Mental Health Forum) in the commissioning process for a new provider of mental health service at all stages.**

Reply

Date	Person	
30 Oct	Jayne Brown, Chief Executive, NHS North Yorkshire & York	'It is essential for us to engage with all stakeholders to ensure that commissioning decisions are informed by a range of perspectives. An invitation will be made to York Mental Health Forum to nominate a representative to join the Mental Health Partnership & Modernisation Board for York which is to be established this autumn'.

- 2. York Mental Health Forum could consider undertaking a survey to indentify the services required from the new provider.**

Reply

Date	Person	
9 Oct	Sue Bradley, York CVS	'As you know the (Mental Health) Forum undertook a survey relatively recently. It was a significant task for our members in terms of extra energy, and they responded in considerable detail. It was undertaken in order to input through York's LIAG which feeds into the commissioning plans being developed by NHS North Yorkshire & York. I think we would suggest that the

		information from this survey will also form a useful basis of developing effective partnership between members of the Forum for mental health and any new provider’.
--	--	--

3. York LINK recommends that NHS North Yorkshire & York and City of York Council Commissioners provide assistance to local voluntary groups and charities on how to prepare bids for tenders to provide services.

Replies

Date	Person	
16 Oct	Bill Hodson, Director of Housing & Adult Social Services, City of York Council	‘CYC has been working with York CVS who offer advice training and support on bidding for tenders. York CVS have been successful in gaining additional funding through the LSP Delivery Fund to continue this capacity building’.
30 Oct	Jayne Brown, Chief Executive, NHS North Yorkshire & York	We are pleased to report that Melanie Bradley, Assistant Director (Vulnerable People and NHS Funding Continuing Healthcare), has already offered this to North Yorkshire’s Third Sector and advised York CVS that we would undertake an engagement exercise prior to any tenders the Third Sector could apply for so that they are fully informed on how to complete the forms and make their applications’.

4. York LINK recommends that services are commissioned in York using the evidence of need by the population of York.

Commissioning for services in York should be carried out mainly using statistics from the York population which could soften the blow of block contracts.

Reply

Date	Person	
30 Oct	Jayne Brown, Chief Executive, NHS North Yorkshire & York	‘NHS North Yorkshire & York, with York Health Group and City of York Council, aim to commission services based on evidence of need, using available data and

		the expressed needs of the community. It is also important that core services are provided across all areas and that service users can expect the same range and quality of services regardless of postcode’.
--	--	---

5. York LINK recommends that NHS North Yorkshire & York allocates 15% of the budget for the Central Locality area to support local voluntary groups and charities.

If 15% of the overall NHS North Yorkshire and York budget is allocated for the Central Locality (York) and invested in local voluntary groups and charities they will be able to develop more innovative approaches.

Reply

Date	Person	
30 Oct	Jayne Brown, Chief Executive, NHS North Yorkshire & York	‘Community Health Services, would in principle support service developments from the Third Sector where they are best provided. We would question a fixed percentage allocation of 15%; however, as we consider that commissioning decisions should be based on service user need and investment in effective services, rather than a quota system.

6. York LINK recommends that statutory services commission more learning opportunities for people with mental health problems.

Reply

Date	Person	
16 Oct	Bill Hodson, Director of Housing & Adult Social Services, City of York Council	‘It is not clear whether this is suggesting that there needs to be specific learning opportunities for people with Mental Health problems. Our approach would be to seek to support people to access the learning opportunities available to all, with appropriate support’.
30 Oct	Jayne Brown, Chief Executive, NHS North Yorkshire & York	‘Again, we agree in principle. There are already some good examples of investment in learning opportunities in place, such as the partnership with St John’s University and North Yorkshire and York Community and Mental Health Services which has resulted in the

		development of a Theatre Course. This and other such initiatives have been well received and in the future we will be exploring further partnership working to enable more learning opportunities for people with mental health problems’.
--	--	--

7. York LINK recommends that NHS North Yorkshire & York and City of York Council consult members of the Mental Health Forum on an ongoing basis to redress this imbalance in the 2010/11 Joint Strategic Needs Assessment.

Replies

Date	Person	
16 Oct	Bill Hodson, Director of Housing & Adult Social Services, City of York Council	‘CYC and NHS North Yorkshire & York currently consult with the Local Implementation Action Group, and have already received, through this group, the issues raised about gaps in services. It is planned that a new Mental Health Partnership and Modernisation Board for York will be established this autumn. This Board will include representatives from the LIAG. The first JSNA recognised that there was a need for more ‘voice’ and so it is intended that the next refresh will include feedback from users, carers and the voluntary sector’.
30 Oct	Jayne Brown, Chief Executive, NHS North Yorkshire & York	‘While it is recognised that the first JSNA identified gaps in evidence, including in the area of mental health, it is disappointing to see it portrayed negatively in this report. The Local Implementation Action Group (LIAG) Chair was actively involved in developing the mental health section of the JSNA and has written to confirm that he does not consider the LINK report’s content on the JSNA to be a fair reflection. Nevertheless, NHS North Yorkshire & York and City of York Council recognise that the next version of the JSNA should involve more input from patients, service users, their carers and the general public and will take on board the themes identified in this and other LINK reports. In the meantime there is

		ongoing engagement of the LIAG in development of services.
--	--	--

8. York LINK should congratulate the many local voluntary groups and charities on the excellent supportive and preventative work that they provide at present.

9. York LINK recommends that NHS North Yorkshire & York commission more preventative services highlighting the dangers of recreational drugs in young people and early intervention services for people who are going through stressful times.

It is worrying that depression and anxiety affects 1 in 6 people at present and is predicted to rise due to the present financial crisis, also, that young people who use cannabis are more prone to develop mental health problems.

Reply

Date	Person	
30 Oct	Jayne Brown, Chief Executive, NHS North Yorkshire & York	'We have expanded the Early Intervention in Psychosis service which is based in the Cotford Centre at Bootham Park Hospital. The EIP works with 14-35 year old people and their families who are recovering from a first episode of psychosis. The team is multi-disciplinary, made up of psychiatrists, psychologists, occupational therapists, nurses, social workers and support workers. It is also the responsibility of the Drug and Alcohol Team to ensure that appropriate services are put in place for people who are substance misusers and potential misusers. The DAAT service ensures that commissioning decisions are based on an understanding of local need'.

10. York LINK recommends that NHS North Yorkshire & York investigate providing specific services to support young cannabis users.

Reply

Date	Person	
30 Oct	Jayne Brown, Chief Executive, NHS North Yorkshire & York	'Please see response above in relation to the DAAT and EIP service. Please note that nationally it is Local Authorities who are the lead for commissioning drug misuse services for young people'.

11. York LINK recommends that York Health Group members (GP's) are made aware of the benefits of asking people about their feelings and providing time to speak about this.

Missed opportunities for introducing early intervention by GPs who may be too busy to speak to people about their feelings must be redressed.

Reply

Date	Person	
01/04/10	John Lethem, Chair York Health Group	I agree, (as a GP) with your point that statistics should be treated with caution and later on about the difficulties GP's have in terms of time available in consultations.

12. York LINK recommends that statutory services implement a campaign to highlight that people with mental health problems are just as capable as other employees and can effectively contribute to businesses.

Replies

Date	Person	
6 Oct	Bill Hodson, Director of Housing & Adult Social Services, City of York Council	'This will need to be considered as part of the development of our strategy to improve employment opportunities. It may be that a more individualised approach with employers will be more effective than a public campaign. There was a discussion at the last Mental Health Partnership Board about tackling stigma attached to mental health and support for the 'Time to Change' campaign'.

30 Oct	Jayne Brown, Chief Executive, NHS North Yorkshire & York – NHS North Yorkshire & York	‘Community and Mental Health Service strongly endorse local initiatives to support people with mental health problems to remain in employment and to regain employment when they have lost it. Work and education are crucial to well-being and people should not be discriminated against because they have experienced mental health problems. We will continue to work with local partners on this issue’.
--------	---	---

13. York LINK recommends that statutory services work in partnership to support people recovering from mental health problems to prepare for work and improve their access to employment opportunities.

Reply

Date	Person	
6 Oct	Bill Hodson, Director of Housing & Adult Social Services, City of York Council	‘This is a national issue and CYC recognises that more needs to be done to improve employment opportunities and support for many vulnerable groups. We will look to benefit from regional initiatives to take this forward as part of the work on Public Service Agreements 16. The integrated mental health service in York includes a Recovery Service that is active in this area. The opening of the Umbrella Cafe in Bootham Hospital is just one example of new approaches that are being developed in this area’.
30 Oct	Jayne Brown, Chief Executive, NHS North Yorkshire & York – NHS North Yorkshire & York	‘As the LINK will be aware, this is a national issue and we would agree that more needs to be done to improve employment opportunities for all vulnerable people. The Recovery Service which is part of the integrated mental health service in York is active in this area. As the LINK may be aware the Umbrella cafe at Bootham Park Hospital contributes to this work and is an example of new approaches that are being developed’.

14. York LINK recommends that NHS North Yorkshire & York work with the Independent Domestic Abuse Service to commission appropriate services for children from families with a history of domestic violence

It is encouraging that the onset of mental illness in people below the age of 14 can be prevented in many cases. However, services must be available for the most vulnerable such as children and young people from families with a history of domestic violence.

Reply

Date	Person	
30 Oct	Jayne Brown, Chief Executive, NHS North Yorkshire & York – NHS North Yorkshire & York	‘The governments’ draft mental health strategy, New Horizons, addresses this point and many of the others raised in the LINK report. There is also a very active Children’s Partnership Board, YorOK Board which looks specifically at issues relating to children and families. NHS North Yorkshire & York are working with partners to support children and families who are victims of domestic abuse’.

15. York LINK should make contact with people in Askham Grange Women’s prison to ascertain their views on health and social services.

The social visit or gain information about Askham Grange Prison will be on 4 May 2010.

16. York LINK should establish a York Dementia Group that includes both voluntary and statutory stakeholders to implement the 15 recommendations from the National Dementia Strategy that must be delivered within the next five years.

People fear a lack of control over their lives if they experience dementia in old age which is understandable given the number of people with dementia living in residential or nursing homes. There is much more work to be undertaken in the area of investigating services for people with dementia than was included in the PACE.

Replies

Date	Person	
30 Oct	Jayne Brown, Chief Executive, NHS North Yorkshire & York – NHS North Yorkshire &	‘Thank you for the invitation to join the LINKs York Dementia Group. I understand that the group is to be established specifically to ensure local implementation

	York	of the National Dementia Strategy. However, it may be helpful for you to be aware that a substantial amount of work has already taken place via the York Dementia Working Group (a sub group of the York LIAG) and we would suggest that the LINK discuss progress on this work with the Chair or with Judith Knapton who is leading on the implementation of the national dementia strategy and a member of the group.
--	------	---

Impact of report

Recommendation to include lay stakeholders in York (mainly York Mental Health Forum) in the commissioning process for a new provider of mental health service at all stages.

The previous Chair of the York CVS Mental Health Forum is now the Chair of the York Mental Health Partnership Board. Consultation on the transformation of services with members of the public will be held via these groups.

Recommendation that services should be commissioned in York using the evidence of need by the population of York.

It has been agreed that the LINK will provide volunteers to take part in the procurement of all new services in York including Mental health services

Recommendation to consult members of the Mental Health Forum on an ongoing basis to redress the imbalance in the 2010/11 Joint Strategic Needs Assessment.

Ongoing discussions are taking place between both bodies. Also, the LINK was asked to help gain information for the Joint Strategic Needs Assessment for 2010/11. A copy of a questionnaire to discover information was distributed to all LINK members with the December edition of the LINKed In newsletter.

End of Life Care services

The 'provision of end of life care services' was one of the issues with the most votes and so was adopted as part of the LINK work plan for 2009/10.

In July 2008 the Department of Health (DoH) published a national End of Life Care Strategy. This is the first such strategy for the UK and aimed to promote consistently high quality care for all adults at the end of their lives. It acknowledged that, in the past, the profile of end of life care within the NHS and social care services had been relatively low and the quality of care delivered had been variable.

It is envisaged that implementation of this strategy will make a 'step change' in access to high quality care for all people approaching the end of life. High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere.

The strategy stresses the need for Primary Care Trusts (PCTs) to work with local authorities, hospitals, hospices, carers etc to agree and implement ways to promote consistently high quality of care for people as they approach the end of their life.

The Gold Standard Framework (GSF) is an approach which is designed to enable a gold standard of care for all people nearing the end of life. It is concerned with helping people to live well until the end of life and includes care in the final years of life for people with any 'end stage' illness in any setting.

The Department of Health End of Life Care Strategy 2008 says that every organisation involved in providing end of life care will be expected to adopt a co-ordination process, such as the Gold Standards Framework. It is also recommended as best practice by NICE, Royal College of General Practitioners, Royal College of Nurses and other major policy groups.

Local background

In North Yorkshire and York, deaths are attributable to three main areas of illness:

- Heart and circulatory disease 41%
- Cancer 26%
- Respiratory disease 12%

Of the remaining 21% some deaths will be sudden or unexpected, such as road accidents. Other deaths relate to a range of long term illnesses such as

Neurological Disease or Renal Disease. Other deaths relate to frailty and very old age, without a specified diagnosis.

In York, approximately 1,822 people of all ages die each year. Approximately 56% of all deaths take place in hospital, 19% take place in peoples own homes, 5% take place in hospices and 19% take place in nursing and residential homes. (PCT End of Life Review/Healthy Ambitions 2008)

In York, NHS North Yorkshire and York staff were already working with City of York Council Social Services staff to review end of life care services before the National Strategy was published. The work began with issues around cancer services but it was recognised that 'end of life' is a much broader area.

The North Yorkshire and York End of Life and Palliative Care Commissioning Strategy 2008-2011 was published in September 2008 and an End of Life and Palliative Care work plan has been developed to deliver the strategy.

In order to discover more about End of Life Care services in York, the LINK Steering Group decided to hold a Public Awareness and Consultation Event (PACE) on End of Life Care services. The event took place on 28th August 2009. Speakers from City of York Council Social Services, NHS North Yorkshire and York and York Foundation Hospital were asked to give information on the services they provide. To include the support available from the voluntary sector a speaker from MacMillan Cancer Support was also invited. Invitations to the event were sent to individuals, local voluntary and community groups and statutory services.

In order to find out about hospice services in York, the LINK Steering Group also arranged an informal visit to St Leonards Hospice on 15th December 2009.

The report on End of Life Care services has been sent to all statutory partners within York for comments before publication as agreed in the LINK report writing protocol. Unfortunately, the 20 day period does not expire until after the York LINK AGM when this annual report is presented. However, a copy of the End of Life Care Report will be available from the LINK office on request as soon as possible after this date.

Dignity and respect in services

One of the times at which people are most in danger of losing their dignity and self-respect is when they need health or social care services. These services are provided when people are at their most vulnerable and so respect for dignity is particularly important.

Dignity and respect in services was voted onto the 2009/10 LINK work Plan. The Steering Group wanted to find out whether the people of York feel that they are treated with dignity and respect when they receive health and social care services. This includes hospitals, ambulances, clinics, doctors, residential care, day care services, respite care services.

To try to find out about the experiences of people the LINK designed and produced a questionnaire based on a respect and dignity checklist produced by The British Nursing and Midwifery Council (NMC).

From October 2009- February 2010 people visiting the York LINK stand at roadshows and other events were invited to fill in the questionnaire. It was also sent out to groups and organisations on the LINK's mailing list and was available to download from the York LINK website. People were asked to comment on a time within the last year when they or someone they know/care for received a health or social care service in York. The services could include hospitals, ambulances, clinics, doctors, dentists, residential care, day care services, respite care services. In total 90 questionnaires were completed and returned.

The LINK also decided to use Dignity Action Day to raise awareness of the importance of dignity in care with people in York. A display and stand was set up at Morrison's Supermarket, Foss Islands Road on 22nd February and at St Sampson's Centre for older people on 25th February. At both of these events members of the LINK Steering Group talked to shoppers and visitors about the Dignity Campaign and the role everyone can play in promoting dignity and respect in services.

The questionnaire responses were as follows:

Question	Yes	No	Not sure	
Did staff care about you as an individual? – not just care for you?	72	11	7	
Were the staff courteous and respectful?	77	8	5	
Did you feel safe and secure when you were there?	79	7	4	
Were you, or someone who knew what you would want, involved when decisions were made about your care and treatment?	58	15	17	
Were you happy with the treatment you got?	73	8	9	
Were you given information about how to make a compliment or complaint?	29	44	17	
Question	Not applicable	Yes	No	Not sure
If you were given a meal, did it meet your dietary needs?	53	24	7	7
If necessary, were you given help to eat and drink?	10	69	4	7
Did you get pain relief when you needed it?	33	43	7	7
Were your hygiene and continence needs met?	31	50	6	3

A response from 90 people is only a small percentage of the number of people who have used health and social care services in York during the past year. This small sample cannot be used to draw hard and fast conclusions, but it is a useful 'snapshot'.

The majority of people who responded to the questionnaire gave answers which indicate that their dignity was maintained and they were treated with respect.

11 of the respondents used the questionnaire to provide further details about their experiences of services. These have been added to the list of issues which have been referred to York LINK. This list is used to compile the issues voting form for LINK members to decide the next years work plan.

The responses to 2 of the questions indicate that there are some services which would not pass the Dignity Challenge:

- Two thirds of respondents (61) were not given, or were not sure if they were given, information about how to make a compliment or complaint.
- Just over one third (32) of respondents answered 'no' or 'not sure' to the question about whether they (or someone who knew what they would want) were involved when decisions were made about their care and treatment.

Both of these relate to ineffective communication. York LINK is already aware of a number of issues regarding ineffective communication. Carers rights is also an issue on the work plan voting form, and it is hoped a Carers Passport will be introduced in the near future.

Dignity and Respect is not an issue which should stand in isolation or be regarded as another 'flash-in-the-pan' initiative. The York LINK Steering group have pledged to make sure it is a fundamental part of all the LINK's future work plan items and will work to make sure that:

- Issues of dignity are embedded in the commissioning of health and social care.
- Health and social care services in York have policies in place to promote dignity and respect and are able to pass the Dignity Challenge.

To demonstrate their commitment to the Dignity Challenge, in April 2010 the York LINK Steering Group decided that all Steering Group members will sign up to become Dignity Champions.

8. Further requests for information

Following receipt of a promotional brochure from Yorkshire Ambulance Service.

Date	Person	
7 May	Sara Fatchett, Yorkshire Ambulance Service	Request for contact details for Manager for York area.
		Reply
		None to date

Following Homeless Forum meeting where a lack of Health Visitors was discussed.

Date	Person	
7 June	Pat Sloss, NHS North Yorkshire & York	Request for information regarding the numbers of Health Visitors and where they are based
		Reply
10 June		One HV based at Monkgate for homeless people – need a business case to employ more
2 July		5.52 HVs work in SE York, 7.64 HVs work in West York & 7.56 HVs based in NE York

Following receipt of DH document on how LINKs should work with Foundation hospitals.

Date	Person	
2 July	Penny Goff, Membership Manager, York Foundation Hospital	Request for discussions on proposal of LINK member to be Hospital Governor and a Governor to be on LINK Steering Group
		Reply
2 July		Email on 2 July stating this is not appropriate but LINK Steering Group members could put themselves forward to be elected as Public Governors

Following information changes by PCT to Lower Back Pain treatment.

Date	Person	
24 March 2010	Graham Purdy/Pat Sloss NHS North Yorkshire & York	Request for copies of the 'impact assessment' for the change and copies of the other sources of evidence (other than NICE Guidelines) used to make the decision to withdraw the spinal injections.
		Reply
		No response by the time the Annual Report was printed

9. Enter & View

The following LINK members have successfully completed a programme of Learning Workshops and have undergone a satisfactory Criminal Records Bureau check. They have familiarised themselves with, and agreed to abide by, the national Code of Conduct relating to Local Involvement Networks' visits to enter and view services.

- Carolyn Murphy
- Andrew Kent
- Jackie Chapman
- Richard Smith
- Kath Briers
- Lesley Pratt
- Fiona Walker

In the Neurological Services report the LINK recommended that a protocol should be drawn up between NHS North Yorkshire & York and Social Services to ensure that a fast-track system is in place that meets the needs of people when equipment is required.

Problems reported to the LINK mainly related to wheelchairs. The response from NHS North Yorkshire & York was 'the PCT is currently looking into these issues with a view to ensuring that patient's needs are met'.

The LINK Steering Group however, agreed to arrange an 'Enter & View' visit to Wheelchair Centre to discover more about the situation.

On 23 March 2010, Lesley Pratt and Kath Briers undertook the first 'Enter & View' visit on behalf of York LINK and produced the following report which was sent to the Wheelchair Centre on 12 April 2010:

York LINK Enter and View Report	
Enter and View visit to:	York Wheelchair Centre Bluebeck House, Bluebeck Drive Shipton Road York YO30 5SF
Date:	23 rd March 2010
Authorised Enter and View visitors:	Lesley Pratt Kathleen Briers
The Enter and View visitors would like to thank Jane Thurlow and her staff for their courtesy and cooperation during the visit.	
Background	<p>York wheelchair centre covers the York and Selby area and is funded by North Yorkshire and York NHS Trust.</p> <p>The premises are well equipped and suitable for the work of the wheelchair centre. Parking is available on site, and there is a bus service near by. The centre has 4,500 clients and receives around 1500 referrals per year for motorised and standard wheelchairs. 65% of the centre's clients are aged 65+, 7% are children. Centre staff visit special schools in the area where children have buggies or wheelchairs.</p> <p>The centre is currently fully staffed with 19 staff (including part time). The staff includes physiotherapists and occupational therapists, in-house repair staff, and 2 mobile (off site) repair staff. 2 vans are available for mobile repair work.</p> <p>Facilities at the centre include:</p> <ul style="list-style-type: none"> • 2 assessment rooms • Workshops • Storerooms • Large reception/waiting area <p>Tea and coffee is available for clients in the waiting area. There are various pamphlets available including a folder showing what accessories are available e.g. wheelchair gloves,</p>

	rain covers. The centre cannot recommend specific suppliers.
Summary	<p>The LINK visitors were made very welcome and were able to view all areas of the centre. They were able to talk to members of staff and clients, although there were only 2 clients at the centre on the day of the visit. One client was undergoing a training session for using a motorised wheelchair - there is a comprehensive training programme for this. The centre is well situated for the training as there is access to a good range of pavements and roads nearby.</p> <p>Each referral (which has to be endorsed by a Health or Social Care professional) is screened by the wheelchair centre and, if required, clients are individually assessed. Each assessment takes about one hour, but flexibility is key as each client has specific needs and the wheelchair is tailored as required. Some assessments therefore take more than one hour.</p> <p>Referrals are considered to be urgent for the following reasons:</p> <ul style="list-style-type: none"> • Wheelchair required for discharge from hospital • Indication on the referral that the person is in the end stage of a terminal illness <p>Indication of acute, clinical problem that will deteriorate rapidly if equipment is not supplied quickly e.g. pressure sores, high risk of falls.</p> <p>Wheelchair service prescription criteria and agreed policy guidelines say that 'standard attendant push wheelchairs for urgent referrals will be issued as a priority within 5 working days'. The wheelchair centre staff state that they are currently able to meet this target. For urgent referrals with more complex issues, the guidelines do not give a timescale. The average time between the referral and the issue of the wheelchair to the client varies according to the complexity of the need. If a chair has to be ordered, it can take 4-6 weeks after the clinic appointment, depending on the supplier. If this is</p>

the case, the Centre may offer a basic chair as an interim partial solution.

The wheelchair centre buys in equipment from a variety of suppliers throughout the EU and worldwide. A very good stock of wheelchairs and spare parts is kept on site. There is a policy of re-using and re-cycling wheelchairs wherever possible. Some wheelchairs are sent to be re-used in third world countries via a charitable organisation.

It is the clients' responsibility to get to and from the wheelchair centre. The Enter and View visitors were advised that some clients experienced problems when using the ambulance service for transport as they were not given a time for the journey home and this could mean that clients are kept waiting for a long time at the centre. On the day of the visit one client had arrived by ambulance but had no idea what time she would be picked up and taken home.

There is not currently a wheelchair user/focus group but the Enter and View visitors were advised that one was in the process of being re-introduced.

The wheelchair service offers a voucher scheme, which enables clients to enhance the equipment they receive from the wheelchair centre. Clients are able to access models of a higher specification than the standard NHS wheelchair, by paying a top-up towards the cost of the chair. The Enter and View visitors were advised that not many clients took up this option as it meant that they would be responsible for the repairs to the wheelchair.

The wheelchair service is not an emergency service. During weekdays when the Repairs Service is operating, response to an urgent repair request is usually the same or next day. From April 1st 2010, anyone with an emergency breakdown after 4pm or at weekends or Bank Holidays can call the PCT's Fast Response Team. They will assess the situation and if

	<p>necessary provide support to enable the person to perform basic functions until their wheelchair can be repaired.</p>
<p>York Link Recommendations</p>	<ol style="list-style-type: none"> 1. Some wheelchair centre clients experience problems with transport to and from the centre. Although travel arrangements are the clients' own responsibility, the wheelchair centre could provide an information leaflet for clients with details of all the options available. This should include details about bus passes and taxi tokens, contact details for disabled taxis and Dial & Ride buses. York LINK would be able to help in the production of this – we have a Readers Panel which reviews health and social care publications. 2. The voucher scheme should be more widely publicised at the wheelchair centre, using posters, leaflets etc. More clients might make use of the scheme if they were aware of the benefits it could bring. York LINK would be happy to help with the design/production of a poster. 3. Re-introducing a wheelchair user group should be a priority for the centre. In addition to dealing with issues relating directly to the wheelchair centre, the group could feed back any issues which relate to other organisations, such as the Yorkshire Ambulance Service or the City of York Council, to York LINK as appropriate. 4. A client/patient pathway needs to be clearly outlined and communicated. This should include a client/patients charter which sets out standards and response times for all types of wheelchair and all client categories. Where precise response times cannot be given e.g. when a wheelchair is being delivered from a supplier, or needs to be customised, the client should be informed of an estimated delivery date, and regularly updated throughout the waiting period. 5. Alongside the development of the client/patient

	<p>pathway, the wheelchair centre should be audited to ISO quality standards. This would ensure that the centre is able to make the most efficient use of its resources and help make sure that the needs and expectations of the clients are met.</p> <p>6. Although the wheelchair centre is not an emergency service, clients should be provided with contact numbers to be used in case of an emergency breakdown. This information could be attached to the wheelchair so that it is always available, e.g. as a sticker.</p> <p>7. There is a gap in repair service provision at weekends, Bank Holidays and after 4pm. In the event of a wheelchair breakdown, the Fast Response Team would be able to support the person but they would not be able to repair the wheelchair. There should be provision made for an out of hours repair service.</p>
Conclusion	<p>The wheelchair centre is well run with enthusiastic staff, who work well together. The centre is a very welcoming environment and with a few small adjustments could provide an excellent service.</p>

- 1. Recommendation that the wheelchair centre could provide an information leaflet for clients with details of all the options available. This should include details about bus passes and taxi tokens, contact details for disabled taxis and Dial & Ride buses.**

Some of the LINK Steering Group offered to help produce a leaflet on transport and members of the Readers panel could read the final document and give advice on whether the public would understand the contents.

Reply

Date	Person	
15 April	Jane Thurlow, Team leader, York Wheelchair Centre, NHS North Yorkshire & York	'We do have a leaflet but it is not very comprehensive and needs updating, so yes, we would appreciate the help of your Readers Panel.'

- 2. Recommendation that the voucher scheme should be more widely publicised at the wheelchair centre, using posters, leaflets etc. More clients might make use of the scheme if they were aware of the benefits it could bring.**

The LINK offered assistance to produce a poster advertising the voucher scheme

Reply

Date	Person	
15 April	Jane Thurlow, Team leader, York Wheelchair Centre, NHS North Yorkshire & York	'Discussion of the scheme features in every clinical assessment, so everyone who is being prescribed a wheelchair knows that they have a choice. As we said at the visit, we have very little take up as the range of wheelchairs we prescribe is quite wide and covers most clients' needs and wants. Not all NHS chairs are heavy and red! By taking up the voucher scheme the client has the responsibility for all repairs, and most prefer the security of access to our repairs service. The scheme costs the NHS clients more. This is because we pay the cost of the prescribed chair plus 3% to cover repairs costs (even if they never have to spend this). Also, the client pays the retail cost for their chair, rather than the discounted cost available to the Wheelchair Service. So the main difference from what we prescribe, having cost us an extra 3% and them possibly £100 or more. So we feel the benefits are marginal and therefore not worth publicising more widely.

- 3. The recommendation to re-introducing a wheelchair user group as a priority for the centre.**

Reply

Date	Person	
15 April	Jane Thurlow, Team leader, York Wheelchair Centre, NHS North Yorkshire & York	'We absolutely agree that we need a user group and are currently working towards setting one up. This group may well want to feedback to York LINK if appropriate.

- 4. Recommendation that a client/patient pathway needs to be clearly outlined and communicated which includes a client/patients charter which sets out standards and response times for all types of wheelchair and all client categories.**

Reply

Date	Person	
15 April	Jane Thurlow, Team leader, York Wheelchair Centre, NHS North Yorkshire & York	'We are currently taking part in a service development project that is looking at the reporting and improving of wait times and pathways. It may be that this will result in the creation of a leaflet for our clients. In any case we do try to keep our clients informed of how long they are likely to wait at each stage in the process.

- 5. The recommendation to develop a client/patient pathway using ISO quality standards.**

Reply

Date	Person	
15 April	Jane Thurlow, Team leader, York Wheelchair Centre, NHS North Yorkshire & York	'We are not aware of any other NHS wheelchair service being audited to ISO quality standards, and would need much more information on the implications and benefits before we could decide whether this would be a desirable move.

- 6. Recommendation to provide contact numbers to be used in case of an emergency breakdown which could be attached to the wheelchair as a sticker.**

Reply

Date	Person	
15 April	Jane Thurlow, Team leader, York Wheelchair Centre, NHS North Yorkshire & York	'Every wheelchair we have on issue has a yellow sticker showing the phone number of the Wheelchair Centre. The ansaphone gives the repairs number, and every user is given the repairs number in their welcome pack when they are issued with the chair.

7. Recommendation that provision for an out of hours repair service is made.

Reply

Date	Person	
15 April	Jane Thurlow, Team leader, York Wheelchair Centre, NHS North Yorkshire & York	‘Until the end of March 2010 we did offer a service, but the take-up was very low, and most people were able and willing to wait until a repairs engineers could call the next day. This was an expensive service to provide as under NHS conditions of service we had to pay the staff a % uplift on their basic salary. We therefore decided to stop this rarely used service and instead offer the option of clients contacting the PCT’s Fast Response Team if they felt they could not cope. This team can provide essential support if necessary out of hours.

10. Summaries

Requests for information

Total number of requests	6
Number related to health	6
Number related to social care	0
Number received within 20 days	1

Enter & View visits

Total number of visits	1
Number related to health	1 joint
Number related to social care	1 joint
Number that were announced	1
Number that were unannounced	0

Recommendations from reports

Total number of reports	2
Total number of recommendations to York Foundation Trust	6
Number replied with required timescale	0
Number recommendations to NHS North Yorkshire & York	18
Number replied with required timescale	18
Total number of recommendations to City of York Social Services	11
Number replied with required timescale	11
Total number of recommendations to City of York Health OSC	1
Number replied with required timescale	1
Total number of recommendations to York GP's via York Health Group	5
Number replied with required timescale	0
Number of recommendations that have led to changes in services	6

11. Financial statement

Amount allocated to City of York Council by the Department of Health	£108,330
Amount retained by City of York Council for administration	£ 3,330
Amount allocated to LINK NBF (Host) by City of York Council	£105,000
Amount carried over from 2008/9	£ 25,305
Total LINK budget	£130,305
Total spent by NBF	£ 86,471
Total spent by LINK	£ 13,931
Total spend	£100,402
Under-spend	£ 29,903

Income and Expenditure Analysis 2009-2010				
Host	Budget	Expenditure	Variance	
Staff Salaries/NI	£ 50,367	£ 50,645	-£	278
Accommodation	£ 7,221	£ 6,106	£	1,115
Staff Expenses	£ 3,000	£ 2,053	£	947
Overheads	£ 26,511	£ 27,667	-£	1,156
Total	£ 87,099	£ 86,471	£	628
LINK	Budget	Expenditure	Variance	
Participant's Expenses	£ 1,000	£ 818	£	182
Marketing	£ 5,000	£ 4,673	£	327
LINK Activity	£ 37,206	£ 8,440	£	28,766
Total	£ 43,206	£ 13,931	£	29,275
Grand Total	£ 130,305	£ 100,402	£	29,903
Notes:				
Host overheads include: Salaries, Administration, Communications, CRB Checks, Office Supplies and Facilities.				
LINK Activity Costs include: Hospitality, Meeting/Conference Facilities, Postage and Reprographics.				
Budget Allocation not spent (£29,903) is to be carried forward to 2010- 2011 to fund LINK activity.				

Appendix 1.**List of public events organised by the LINK**

Event	Date
Public Awareness & Consultation Event on Neurological Services	25 June '09
Public Awareness & Consultation Event on Mental Health Services	20 July '09
Public Awareness & Consultation Event on End of Life Care services	28 August '09
LINK awareness raising roadshow, Guildhall	1 October '09
LINK awareness raising roadshow, New Earswick	14 October '09
Joint consultation event (Big Care Debate) with York CVS & York Carers Forum	30 October '09
LINK awareness raising roadshow, Haxby	11 November '09
LINK awareness raising roadshow, Dunnington	19 November '09
LINK awareness raising roadshow, Poppleton	8 December '09
LINK awareness raising roadshow, Acomb	13 January '10



Appendix 2.

LINK Report Writing Protocol

Following an inquiry of issues, York LINK will publish a report containing the findings and any recommendations to improve or develop services.

It is important to try to make sure that everyone in the community has a chance to contribute towards the evidence given to the LINK and statutory services have the chance to verify that the LINK has the correct factual information about the services necessary to provide constructive recommendations.

This will be achieved through the following steps:-

Prior to adopting an issue for inquiry

1. Information on how to refer 'issues' for the work plan will be published in the LINK newsletter and posted on the website at least two months prior to the Annual General Meeting (AGM).
2. When all issues have been gathered they will be collated into an 'issues voting form' that will be sent to all members. Members will be asked to complete and return the form at least two weeks before the date of the LINK AGM.
3. The result of the voting will be assessed by at least two members of the Steering Group and the issues collecting the highest number of votes will be adopted to form the LINK the work plan for the following year.
4. The work plan will be announced at the AGM and communicated to other members via the next LINK newsletter and posted on the LINK website.

5. All voting papers will be retained by the LINK until at least the next AGM.

Collecting information

1. Following the AGM the LINK Steering Group will agree dates to begin enquiries into the various issues during the year.
2. Notification of the start of an inquiry will be published via a letter in the 'letters page' or an editorial in the 'Press' newspaper. This will appear at least two weeks prior to the agreed date for an enquiry and will request further information on the relevant issue.
3. The LINK will request information from statutory services, arrange 'enter and view' visits or Public Awareness and Information Events (PACE) to gain further information prior to writing a report.
4. The LINK will cross reference all evidence and information gained from the above actions to the Care Quality Commission Essential Standards of Quality and Safety; all information will be retained and made available to the Care Quality Commission Assessors on request.

Writing a LINK report

1. When Steering Group members are satisfied that all information has been collected a report of the findings will be written in draft form and sent to presenters at PACE events etc as required, for verification.
2. A meeting will be arranged with at least two Steering Group members who will go through the information in the report and agree recommendations that meet the Care Quality Commission Essential Standards.
3. The recommendations including the numbers of people who provided evidence will be written into the draft report which will then be sent to statutory services for initial comment and verification of factual accuracy - within a timescale of twenty working days.

4. The draft report will then be sent to all Steering Group members for final agreement / approval at the following Steering Group meeting. Any responses from statutory services to the draft report will be discussed at that meeting.

Publishing a LINK report

1. When a draft report has been agreed at a LINK Steering Group meeting it will be published within a period of two weeks.
2. The published report and a letter outlining the recommendations will be sent by the LINK to the relevant statutory authority requesting a response within 20 days or a reason why this is unavailable.
3. The expected response should include details of how the relevant statutory authority intends to take forward the recommendations made, or provide an explanation as to why this will not be feasible.
4. A notice will be put in the 'Press' newspaper and the LINK newsletter and posted on the website to inform members and the public that the published report is available via the website, and on request from the LINK office.
5. A copy of the published report will also be sent to all public libraries and as many public gathering places as possible in York with a request to put it on display.
6. A letter will be sent to everyone who provided evidence asking them to inform the LINK office if they would like a copy of the published report.

This protocol has been agreed by the LINK Steering Group and statutory authorities.

Signed:Date.....

Appendix 3.

Community Reps	
1. Kathleen Briers	Individual
2. Robin McIlroy	Ex PPI Forum
3. Carolyn Murphy	Ex PPI Forum
4. Jane Perger	Individual
5. Lesley Pratt	Ex PPI Forum
6. Jackie Chapman	Individual from May 09
7. Vacant	
Voluntary Reps	
1. Andrew Kent	People with Neurological conditions
2. Katie Smith	Carers
3. Fiona Walker	People with Learning Difficulties
4. Chris Edmondson from Nov 09	People with Disabilities
5. Sian Balsom from March 10	York CVS
6. Vacant	Older People
7. Vacant	BME



York Local Involvement Network

Holgate Villa

22 Holgate Road

York

YO24 4AB

Tel: 01904 621631

Fax: 0845 3130271

email: admin@yorklink.org.uk

website: www.yorklink.org.uk

North Bank Forum

2nd Floor

94 Alfred Gelder Street

Hull

HU1 2AN

01482472458

admin@nbforum.org.uk

www.nbforum.org.uk



York LINK is a project hosted by North Bank Forum. The North Bank Forum is registered in England and Wales as a Private Company Limited by Guarantee No. 5206464 and a Registered Charity No. 1107013.