



A Stronger Voice In Health And Social Care Services

Annual Report

1st April 2009 - 31st March 2010



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I have great pleasure in presenting the second Annual Report produced by the Hull LINK.

The focus of this year's work has been around activity and demonstrating the effectiveness of what we do. We have engaged with a large number of people in a range of different ways, highlighted key issues with our membership and produced a series of reports which have made key recommendations around health and social care services in the City. The responses of our health and social care partners have been extremely positive and a number of our recommendations are being carried forward to develop and enhance services.

Through the ongoing commitment, drive and enthusiasm of a dedicated staff team and a diverse and active Steering Group the Hull LINK is now recognised as a model of good practice on a local, regional and national level.

The work of the LINK would not be possible without the activities of its members and I would like to take this opportunity to thank those people who have taken the time to tell us their stories and share their experiences of health and social care services in the City. I hope that the reports we have produced this year reflect what they have told us and show how the recommendations we have made will bring about the change they talked about.

There are a number of challenges ahead over the next year but I prefer to see these as further opportunities to demonstrate the value and impact of what we do. We are committed to ensuring that the views and experiences of patients and the public continue to shape the services we receive not only today but in the future.

**Jason Stamp,
Chair, Hull LINK**



Hull LINK, Chair, Jason Stamp

This is the second Annual Report of Hull LINK covering the period April 2009 to March 2010.

The first Annual Report for 2008/9 focussed on steps to set up and promote the LINK, leading to its formal launch in November 2008. This Report shows how Hull LINK has built on this foundation and demonstrates its influence and impact on health and social care services in the city of Hull.

Key Achievements

Managed by a Steering Group elected by the LINK membership and supported by a staff team employed by Hull CVS as host body, Hull LINK has examined the following issues:

- Dementia services;
- Mental health services for young people;
- Safeguarding of vulnerable adults and personalisation in social care;
- Cancer diagnosis services;
- Hospital discharge procedures and support services for people once discharged (to be published May 2010). This investigation also made use of the LINK's enter and view power.

For each of these issues reports have been written with recommendations on improving the services commissioned and provided. These reports have been submitted to the relevant service commissioners and providers under the legal powers of the LINK.

Responses from service commissioners and providers have been very positive and the recommendations in each of the reports will be adopted to improve these services.

Regular reports on the work of Hull LINK have been presented to Hull City Council's Health and Social Well Being Overview and Scrutiny Committee and a positive relationship established.

Working in Partnership

Working with the City Council Adult Services Department, NHS Trusts and local voluntary and community groups, Hull LINK has also:

- Consulted on the Council's plans to increase the provision of Extra Care Housing in Hull;
- Supported the work of the health sub-group of the Hull Learning Disabilities Partnership;
- Assisted Carers' Centre Hull to promote support services for carers and consultation on a new carers' strategy;
- Supported the work of Hull's sexual health modernisation forum;
- Worked with NHS Hull to examine improvements to the opening times at NHS premises.

Membership and Engagement

Membership of the LINK has increased over the year both from individuals and voluntary/community groups and stood at 547 groups and individuals in March 2010, with a further 180 stakeholders from public sector partners. Formal quarterly members' forums were held throughout the year including the LINK AGM in December 2009, and numbers attending have steadily increased.

Recognising that not all people and groups want to become members, but do want an opportunity to have a say on a particular issue, the LINK has also developed a variety of means to engage more people and groups in its work. These included questionnaires; comment cards; focus groups; and one to one interviews.

Feedback on the work of the LINK and the provision of information is also important. Visits and hits to the LINK website www.hull-link.org.uk and circulation of the LINK newsletter have increased over the year. The LINK has also received increased media coverage both in the local press and on local radio and regionally in the Yorkshire Post.

Looking Ahead

For 2010/11 the LINK will monitor the implementation of recommendations from its 2009/10 reports and begin investigations into new issues covering: alcohol rehabilitation and support services; maternity services; eating disorders; and transport to hospital services.



Low Flying Heroes Event
September 2009

Background to LINKs

Local Involvement Networks or LINKs bring together local individuals and groups and organisations to give the community a stronger voice in improving health and social care services. LINKs were set up across England in 2008 and have legal powers to examine issues of concern.

LINKs' role is to find out what people want from services and recommend improvements to services based on local feedback. All health and social care services paid for by public money can come under the remit of LINKs, whoever provides the service.

LINKs have powers to carry out their role, including: to consult the public; to request information from services and get a response; to make reports and recommendations to services and get a response; and to carry out spot checks to see if services are working well (known as 'enter and view').

Anyone in the local community can get involved in LINKs – residents, service users, patients, carers...everyone's views matter. Groups can also join – community groups, charities, residents' associations. LINKs provide a variety of different ways for the local community to give their views on services.

Hull LINK was set up in July 2008 and covers the local authority area of Kingston upon Hull.

Our Structure and Governance

Membership

- Membership is free and is open to both individuals and voluntary and community groups in Hull.
- LINK members receive information and newsletters, can attend events and vote and stand in elections for the LINK Steering Group. There are lots of opportunities to give your views on issues and services.
- Forums and events are held regularly to enable people to feed in to the work of the LINK and hear about progress with our investigations.
- For more information on categories of membership see page 11.

Hull LINK Steering Group

This is the body that oversees the work of the LINK, decides how the LINK should tackle priority issues identified by the members, and agrees how the LINK's budget should be spent. Elected by the LINK membership, the group has fourteen members – seven individuals and seven group members. One third of the group stands down each year and an election is held to fill the vacancies. Membership of the Steering Group is an unpaid role.

Steering Group Members as at 31 March 2010

Individual Members:

Jason Stamp (Chair)	(elected Chair January 2010) (Interim Chair September to December 2009)
Sally Browne	
Ali Lovelock	
Penny Stephenson	
Andy Train	
Pam Quick	(elected December 2009)
John Lawrence	(elected December 2009)

Group Members:

Humber All Nations Alliance (HANA)	Zia Salik (since September 2009)
Cornerhouse (Yorkshire)	Tish Lamb (re-elected December 2009)
nCompass Hull	Helen Laws (Vice-Chair) (elected Vice Chair January 2010)
Goodwin Development Trust	Sam Bell (since September 2009)
Carers' Centre Hull	Samantha Chaney (since December 2009)
Choices and Rights Disability Coalition	Karen Stretton (re-elected December 2009)
North Bank Forum	Wendy Bennett

Other Steering Group Members 2009-10

Individual Members

Chris Lefevre (Vice Chair, April-December 2009) – stood down December 2009
A further individual place on the group was vacant April - December 2009.

Group Members

Humber All Nations Alliance (HANA) – Gabriel Doherty (LINK Chair April-September 2009). Replaced by Zia Salik, September 2009.

Goodwin Development Trust – Terry Quinn, April-September 2009. Replaced by Sam Bell.

Carers' Centre Hull – Greg Harman, April-December 2009. Judy May, March-April 2009. Replaced by Sam Chaney.

Task and Finish Groups and Sub Groups

- Task and Finish Groups are set up by the Steering Group to work on specific issues and pieces of work. This year Task and Finish Groups were formed to work on: Mental Health Services for Young People; Cancer services; and Hospital Discharge.
- Groups can draw on a wide range of people and call on specialist help where necessary.
- Sub Groups are created by the Steering Group to focus on ongoing areas of work. Currently there is a Finance Sub Group and a Communications Sub Group.

The Host

Hull Community and Voluntary Services Ltd (Hull CVS) was contracted to provide host services for Hull LINK in July 2008. The contract runs until March 2011. As host Hull CVS provides support to the LINK Steering Group, promotes the LINK, holds its budget and helps the LINK find out people's views on health and care services. A registered charity, Hull CVS has over 25 years experience of supporting voluntary and community groups in Hull. Its services cover information, funding advice, volunteering and training.

Staff Team

The following staff were employed by Hull CVS to support the LINK as at 31 March 2010:

- Jonathan Appleton, LINK Team Leader
- Helen Blanchard, LINK Engagement Worker
- George Campbell, LINK Membership Engagement Officer
- Barbara Langdale, LINK Administrator

In September 2009 we used savings in our budget to enable our host to employ our Membership Engagement Officer, a new post dedicated to ensuring greater involvement in the LINK among the community. The post boosts the original staff team of three and the role involves raising awareness of our work, boosting recruitment to the LINK, encouraging people and groups to get involved and connecting the work of the LINK with the wider community.



Hull LINK Staff Team (L-R) Jonathan Appleton, Helen Blanchard, George Campbell, Barbara Langdale

LINK Office

In 2009-10 the LINK office was at Centre 88, an independent charitable trust which provides office accommodation to a wide range of voluntary and community organisations in Hull. In June 2010 the LINK office will be moving to The Strand on Beverley Road in Hull, our host's newly purchased and refurbished offices.

Governance Framework

This is the document that sets out how Hull LINK is run, together with policies covering: complaints and grievances; equal opportunities; code of conduct; conflicts of interest; elections and expenses. Hull LINK is committed to good governance and has adopted the Nolan Principles of selflessness, integrity, objectivity, accountability, openness, honesty and leadership. During 2009-10 the Governance Framework was kept under review by the Steering Group. The Framework can be viewed on the LINK website and copies are available from the LINK office.



Personalisation Event
December 2009

Membership is a way we keep in regular contact with people, giving updates on our work, results of investigations and how to take part. Members can put forward issues they would like the LINK to investigate, and can vote in elections to the LINK Steering Group.

Definitions

Individuals: people who live within the Hull City Council area, or live outside but use primary care services in the city.

Groups: voluntary and community groups that are based in or operate in the Hull City Council area.

Individual associates: people who live outside of Hull but who are interested in the work of the LINK.

Group associates: workers or volunteers from groups that already have a nominated person as lead contact for the LINK.

Stakeholders: people from the statutory, private or commercial sector who have an interest in the work of the LINK but do not play an active part in our work.

Of the above categories, individuals and group members have full voting rights. All categories of members receive newsletters, information and invitations to LINK events.

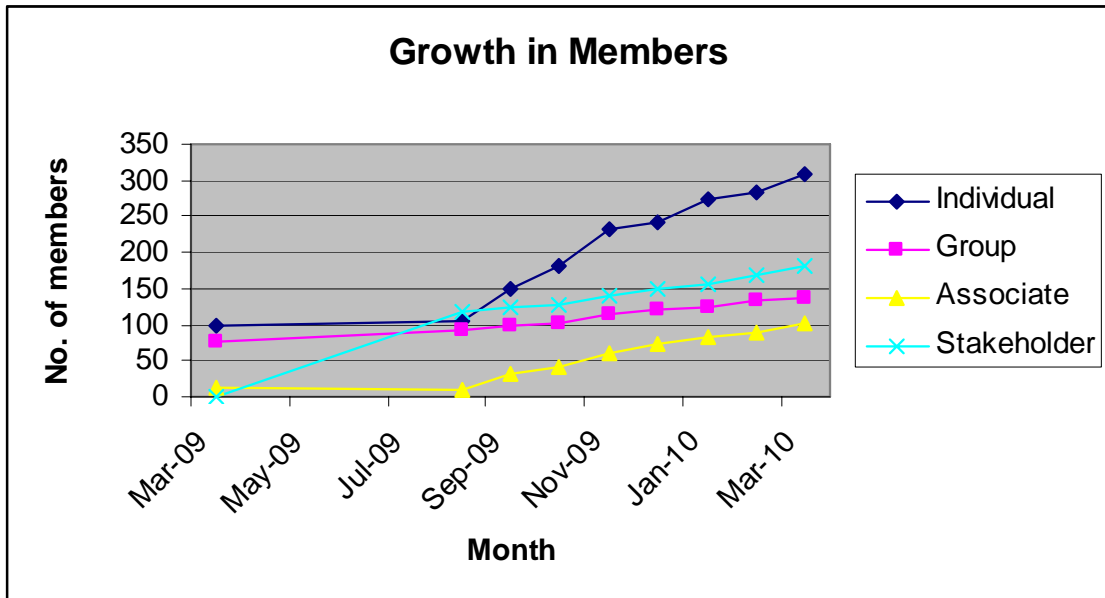
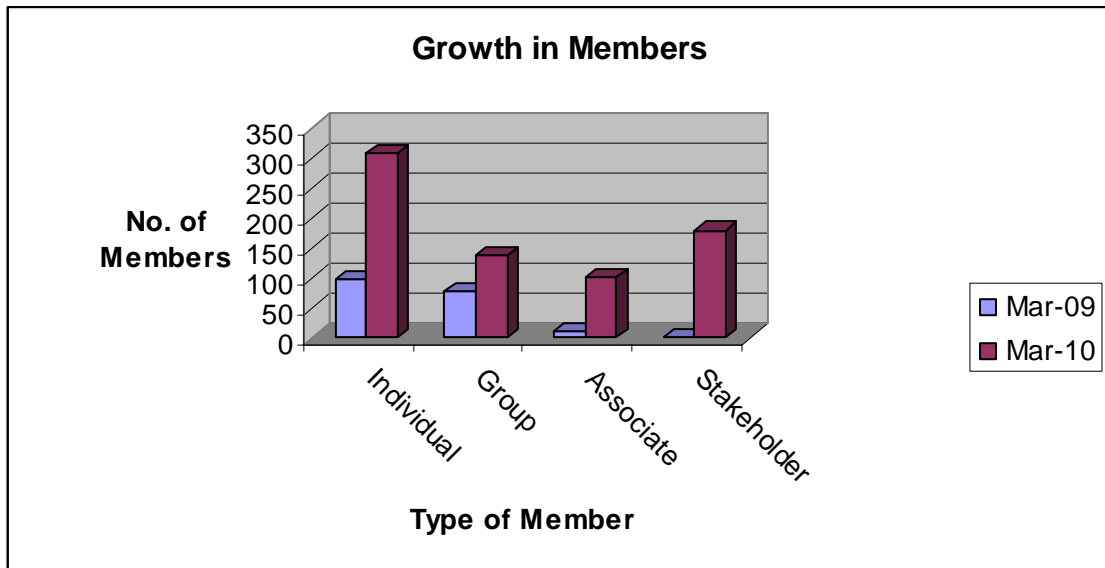
Membership in 2009-10

We're pleased to report a big increase in LINK membership over the course of the year, active membership having almost trebled in this time.

Membership Figures

This table gives the number of LINK members in each category of membership.

Active members – category	1 April 2009	31 March 2010
Individual	99	308
Group	77	138
Associates	12	101
Total Active Members	188	547
Stakeholders	Not recorded at this time	180



Ethnic Origin

Information on ethnic origin is requested from individual and individual associate members. This table shows the ethnic origin of those who gave us this information.

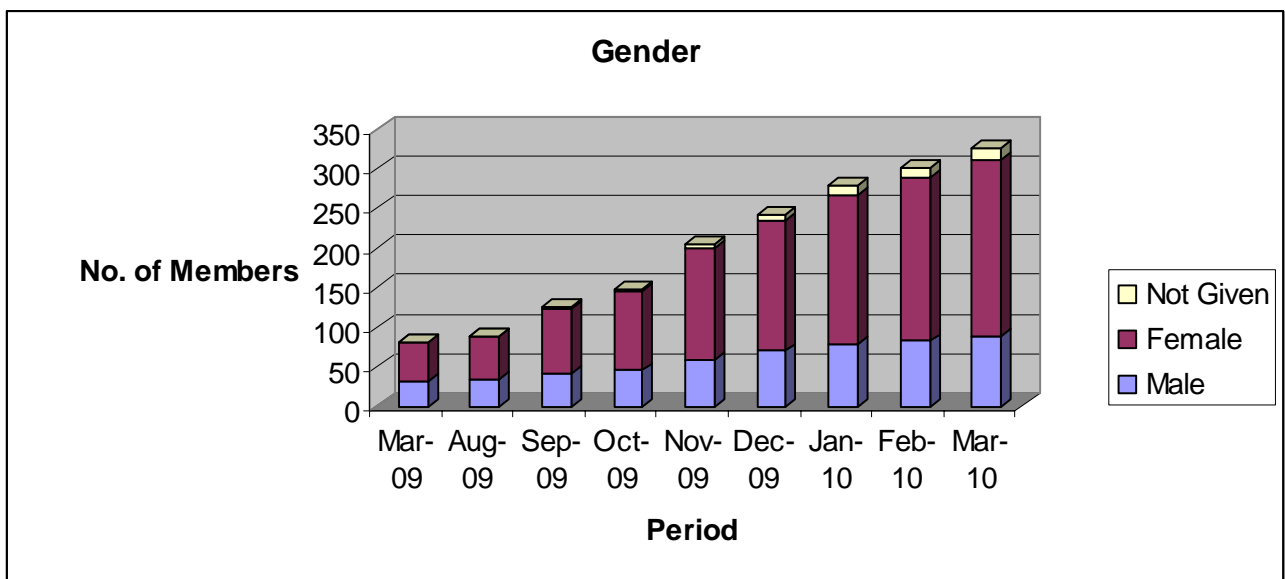
According to the last Census conducted in 2001, 2.3% residents in Hull were of a BME origin. This figure has almost certainly increased since then. Based on the information provided in the equal opportunities monitoring forms up to 31.03.10, the LINK membership is made up of 12% of members of a BME origin and 88% of a white origin.

	1 April 2009	31 March 2010
White – British	77	283
White – Irish	1	2
White – Other	0	3
Chinese	1	1
Indian	0	4
Pakistani	0	12
Bangladeshi	0	1
Caribbean	0	1
African	0	14
Black – Other	0	1
Other Asian	1	2
Mixed Background (unspecified)	0	1
Other Ethnic Background	1	1

Gender

This information is requested from individual and individual associate members. This table shows the gender of those who gave us this information.

	1 April 2009	31 March 2010
Male	32	88
Female	49	223



Disability

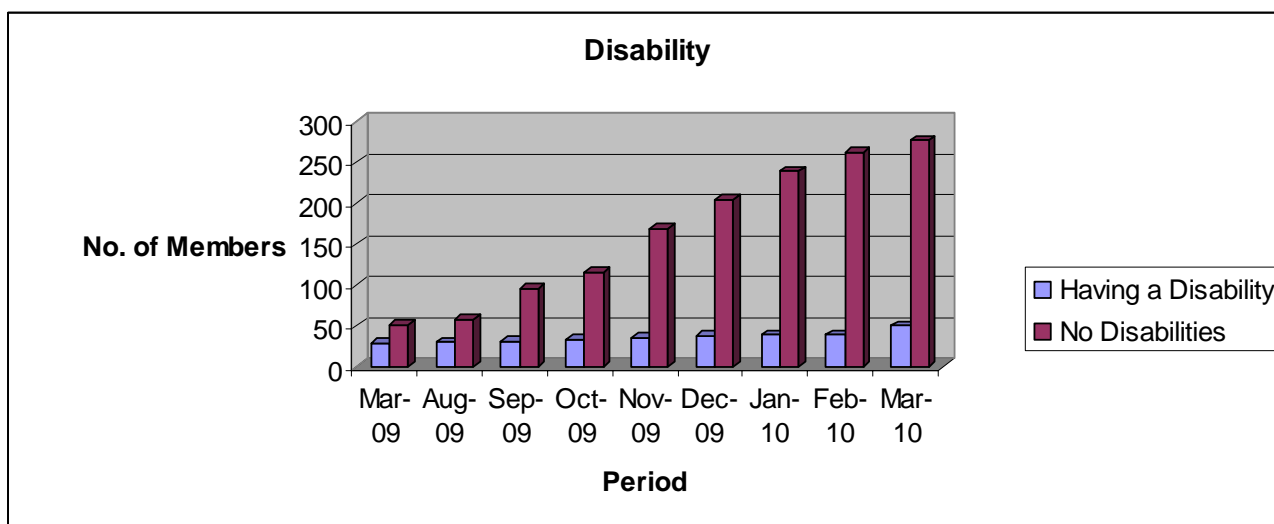
We ask individual and individual associate members if they have a disability. This table shows information on disability from those who gave us this information.

According to the 2001 Census, 20.7% of the population in Hull have a long term limiting illness.

A further survey conducted in 2004/5 reported that 17.45% of the working age population in

Hull have a disability. Based on the information provided in the equal opportunities monitoring forms, 15% of the LINK membership reported as having a disability compared to 85% stating that they do not have a disability.

	1 April 2009	31 March 2010
Having a Disability	29	50
No Disabilities	52	276



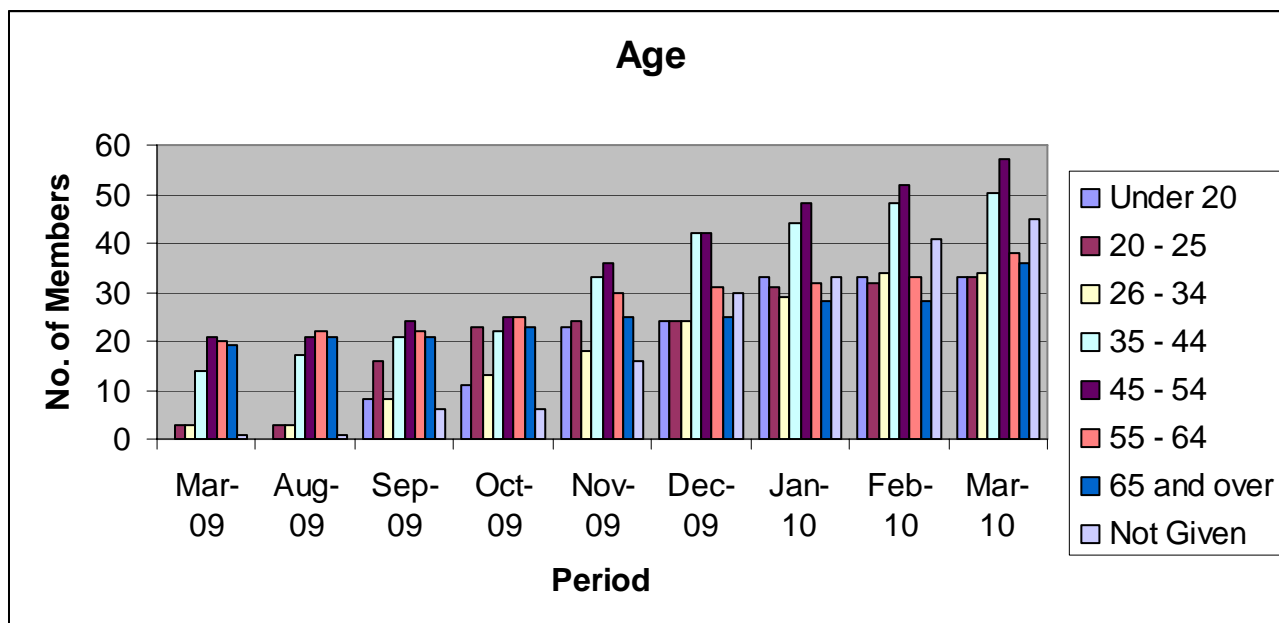
Age

This information is requested from individual and individual associate members. This table shows the age bands of our members who gave us this information.

	1 April 2009	31 March 2010
Under 20	0	33
20 - 25	3	33
26 - 34	3	34
35 - 44	14	50
45 - 54	21	57
55 - 64	20	38
65 and over	19	36

The table opposite compares the age of the LINK membership (as at 31.03.10) to the overall population of Hull (as per the 2001 Census) by age group.

	LINK (%)	Hull (%)
Under 25	20%	34%
26 - 44	26%	29%
45 - 65	29%	22%
65 and over	11%	15%
Not given	14%	N/A



Area of Interest

We ask all our members which areas of health and social care they are interested in. This table shows how many of our members who gave us this information are interested in each issue.

	1 April 2009	31 March 2010
Adult social care services	100	258
Primary & community health services for adults/children	115	270
Hospital services for adults or children	97	247
Learning difficulties services	63	200
Health or social care service user issues	94	190
Services for older people	107	224
Mental health services	95	285
Carers' issues	86	192
Disability services and issues	104	265
General interest in local health & social care matters	134	318
Patient Transport	0	18
Other	29	53

Analysis – Our Membership

It is important that LINKs represent all parts of the communities they serve, so one of our key aims in 2009-10 was to build a membership that reflects our city. We have included demographic information to allow for comparisons between our overall membership and the wider city of Hull.

As can be seen above we have made considerable progress in boosting our membership among all groups. We are however aware that in the area of gender our membership has an uneven balance, with less men than women signed up. And while we are pleased with our progress in recruiting more young people, the proportion of young people among our whole membership is still lower than the city as a whole.

In some ways these points are unsurprising, as men and young people are among those who are traditionally harder to engage with on health and social care issues. We have acted to address these issues by:

- Engaging with the community in a number of different ways. This ensures that people can give their views even if they don't wish to become a member.
- Conducting targeted recruitment among groups in the community we know are under-represented.
- Taking care to ensure that the priority issues we investigate reflect a range of health and social care issues, and that our workplan is not too narrowly focussed.



Spring Forum
March 2010

Engagement

For Hull LINK there are many elements to engagement, our main aim being to gather people's views, experiences and suggestions and use this information to secure improvements in health and social care services. It's also about breaking down barriers and working to make the LINK accessible to all.

Over the past year we have held successful public meetings and forums. But perhaps the biggest shift within our organisation has been the number of times we have gone out into the local community and encouraged people to give us their views. Rather than expecting people to come to us, we've gone to them.

This year we have attended approximately 100 meetings and events to encourage active involvement in the LINK. In the process we reached at least 1500 people, many of whom joined as members, 'had their say' in ongoing investigations, or both.

We have endeavoured to talk to as many local individuals and groups as possible. For us, effective engagement is about hearing what people have got to say. It's giving individuals and groups the chance to express a full range of opinion and emotion. Some people had a good experience and couldn't be more satisfied with services. But others told us about problems they had experienced with services, and suggested how things could be improved in future.

This willingness to engage has strengthened our relationship with individuals and organisations. Together we have produced work which has benefited the people of Hull, as evidenced by the success of recent LINK reports.

Everybody's Views Matter

The LINK exists to reflect the views of the whole community, not just its members. Some groups in our community are not used to having their voices heard, and we have to ensure that we include them.

This year we've worked hard to involve people who may be traditionally excluded. Through our voluntary and community group members we can reach people who come into contact with them and use their services. Examples this year have included carers groups, housing providers and groups supporting people with addictions.

LINK membership ensures we can keep in touch with people we come into contact with and fully involve them in our work, but we recognise that not everyone wants to become a LINK member. Some people choose to have their say on a particular issue of interest to them and are happy to leave it there. If someone doesn't wish to join they can still give us their views, and our surveys can be completed anonymously.

Engagement is about creating a dialogue through building relationships. We want to continue encouraging the involvement of members as well as being proactive by involving new groups and individuals. We will continue to strengthen links with the local community.

How People Have Got Involved

Here are the main ways local people can have their say and have a direct influence on service improvements:

Surveys: people can participate in any LINK investigation by completing a survey. This enables people to provide evidence by sharing both their opinions and experiences in a convenient way. Surveys are easily accessible on the Hull LINK website or available on request. It's an easy way to 'have your say' and make a difference.

Interviews: people can request a one to one interview as part of a LINK investigation. Many of our interviews have taken place with workers and managers of local groups and organisations that support people in the community. This has led to a great deal of valuable evidence.

LINK @ Events: this is a flexible way in which groups and organisations can request a consultation with Hull LINK. Quite simply a LINK representative visits a group and gathers views in the most convenient way possible. This could be having a stall at an event, facilitating a focus group or talking to people informally at a coffee morning. Many groups request a LINK visit to 'have their say' in a current LINK investigation, others to receive a general update on LINK activities.

Public Events / Forums: these give people the opportunity to 'have their say' on the day. They also offer help to individuals and groups strengthen relationships in the sector by providing a networking opportunity. Our forums have become a useful mechanism for information sharing and finding out about projects and services. Our events and forums in 2009-10 included:

- Low Flying Heroes, September 2009 – exploring new LINK priorities
- LINK Christmas Forum, December 2009 – reporting back on progress.
- Personalisation events, June and December 2009 – see 'What We Did in 2009-10 for details.

Getting In Touch: people can write to or phone the LINK in confidence with their concerns. Whether it's an enquiry about an ongoing investigation or a separate issue people are welcome to get in touch. We also have comment cards for people to fill in if there is a new issue they would like to suggest for us to examine.

Sometimes it is difficult to involve people. Health and care issues can be sensitive and sometimes people are understandably reluctant to share their experiences. However Hull LINK will endeavour to find the most effective method of engagement in order to involve as many people as possible. We will continue to make every effort in responding to the different needs of groups, individuals and communities.

This is the legal power LINKs have to go into health and care premises to observe services being delivered and see whether things are working well. Enter and View visits are a valuable tool to help us investigate issues of concern and gather service users' feedback. Enter and View is a key part of our legal powers, but it's important that it is used in the right way and that we operate within safeguards.

Preparing for Enter and View

The first step in creating Hull LINK's system for Enter and View visits was for us to develop the right procedures to ensure we would operate within legal regulations, that people doing the role would be suitable for it, and that our visitors would be properly prepared and trained for the role. This involved:

- Our Steering Group agreeing policies and procedures covering how Enter and View would be used, and also recruitment, training and support for visitors. We consulted with local NHS Trusts and the local authority in developing these.
- Recruiting Enter and View visitors from our membership through our agreed procedure, which includes applications, informal interviews, references and taking up Criminal Records Bureau checks through our host Hull CVS.
- A training programme of five sessions covering communication, dealing with difficult situations, legal issues and recording feedback.

Our Enter and View Visitors

The following people were approved as Hull LINK Enter and View visitors (authorised representatives) in 2009-10:

- Julie Corbett (stood down April 2010)
- Barbara Dalby
- Karen Hillison
- Helen Laws
- Ivy Penny
- Pam Quick
- Heather Satchell
- Pat Stange
- Penny Stephenson
- Karen Stretton

Our Use of Enter and View in 2009-10

At an early stage our Steering Group decided that Enter and View visits should not run in isolation but should be used as part of our priority investigations. Of the issues we examined in our 2009-10 workplan the one that seemed most appropriate for use of Enter and View was our work on hospital discharge.

We felt the power to Enter and View would be a good opportunity to speak to patients directly about their experiences of discharge and to see how services were being delivered. We arranged for a total of four visits to be made to Hull and East Yorkshire Hospitals NHS Trust premises in January 2010. Visits were made to:

- Castle Hill Hospital Ward 5
- Castle Hill Hospital Ward 21
- Hull Royal Infirmary Ward 10
- Hull Royal Infirmary Patient Lounge

A total of eight visitors were involved, with two people visiting each location.

What did we learn from our Enter and View visits?

Our visitors spoke to over 30 people and we gathered some extremely useful feedback for use in our report, covering issues such as communication with patients and their families, support for people after leaving hospital and waiting times for medication for patients being discharged. For more information see the item on our hospital discharge investigation in the 'What We Did' section. Feedback from our Enter and View visitors will be used to develop our training programme and use of the Enter and View power.



Low Flying Heroes Event
September 2009

Summary of our key activity

Formal Information Requests

Request	Made to	Date	Response received within 20 days?
Information on cancer treatment waiting times (Cancer investigation)	Hull and East Yorkshire Hospitals Trust	October 2009	Yes

It should be noted that this was not the only occasion we requested information from health and care service providers. We obtained information on many other occasions through our regular contact and liaison with service representatives.

Reports with Recommendations

Report	Sent to	Date	Responses received within 20 days?
Safeguarding and Personalisation	Hull City Council; and Hull and East Riding Safeguarding Adults Board	November 2009	Yes
Living Well With Dementia – Shaping the Service	Hull City Council; and NHS Hull	January 2010	Yes
Mental Health Services for Young People	Humber Foundation Trust; NHS Hull; and Hull City Council	January 2010	Yes
Cancer Diagnosis – Report on Patients’ Experiences of Local Services	Hull and East Yorkshire Hospitals Trust; and NHS Hull	March 2010	Yes

All reports can be found on the reports page of our website www.hull-link.org.uk

Safeguarding and Personalisation

The Issue

Safeguarding means making sure vulnerable people are safe from abuse and neglect. Personalisation means giving users of social care services more control over how the money for their care is spent. Local people welcomed plans to give people more control but were concerned about how this would work.

What We Did

Working with other partners North Bank Forum, East Riding of Yorkshire LINK, Carers Centre Hull, ONE HULL VCS Forum and Skills for Care, we held an event for local people and groups to find out more and have their say in June 2009. We used the feedback from over 100 people and groups to produce our report and recommendations.

Our Recommendations

We called for:

- More communication – local people and groups need to be kept informed of progress with personalisation. This includes regular reports and feedback from the local authority.
- Protection – service users need to be protected from potential abuse.
- Support – people need help and advocacy to understand their rights and to benefit from personalisation.
- Annual Reviews – we called for yearly checks to ensure that personalisation is working well.



Personalisation Event
September 2009

Response

Local services agreed to:

- Provide regular update reports on personalisation and attend information events.
- Use the Safeguarding Adults Board to ensure vulnerable people are protected, and to publicise information on how to tackle abuse.
- Use the new coalition of advocacy practitioners to ensure people get the right help and support.
- Conduct annual reviews of the progress of personalisation.

Next Steps

- A follow up information event was held in December 2009, when people and groups were able to ask council representatives about progress with personalisation.
- Further work to find out about people's experiences of personalisation, and use this feedback to influence services, is due for summer 2010.
- We have made links with the newly created Hull Safeguarding Adults Board and will use this to influence services.

'Thank you for involving us, our tenants often pass comments on various issues and it was good for them to have the chance to have their say, especially on these topics which greatly affect them. Thanks again.'

Sue Carrick, Community Support Manager, Hull Churches Housing Association

Living Well With Dementia – Shaping the Service

The Issue

People told us they were concerned about how people with dementia were cared for. As the population ages more people will develop dementia, creating increased need for support and care services. In Hull about 2500 people have dementia, a number set to rise to almost 3000 by 2020. In February 2009 the Department of Health launched the new National Dementia Strategy to improve care and raise awareness of the condition.

What We Did

Hull LINK worked with local partners including the Alzheimer's Society, North Bank Forum and Age Concern Hull to review local dementia services and explore how the voluntary sector can develop services. Feedback from a partnership event for local voluntary organisations in November 2009 was presented in our report with recommendations.



Living Well with Dementia Event
November 2009

Our Recommendations

We called for:

- Training to increase health workers' knowledge and understanding of dementia.
- Information on dementia and local support to be made available to the public.
- Increased service user choice and control through seeking the views of users and carers, and adapting services accordingly.
- More partnership working between the NHS, city council and voluntary sector.

Response

Local services have:

- Formed a new partnership to implement the National Dementia Strategy priorities in Hull, including tackling stigma, improving services and ensuring earlier diagnosis. Our recommendations will be included in the local implementation plan.
- Ran an awareness raising campaign in local media in spring 2010.
- Begun preparing a commissioning strategy to fund improved services for people living with dementia.

Next Steps

- The LINK has taken up a place on the local implementation group developing plans for improved services.
- Summer 2010 will see the LINK doing more work with the local voluntary sector to explore how groups can help deliver the stepped care model for dementia care.

'Carers Centre Hull has been involved in several of the consultations carried out by Hull LINK. Both users of the Centre and staff have had the opportunity to participate in the consultations and have been happy to give their views and talk about their experiences. By taking part people have felt that their experiences and views matter and that positive change will come about through consultation.'

Margaret McHugh, Carers' Support Worker, Carers' Centre Hull

Mental Health Services for Young People

The Issue

When we first asked people and groups involved in the LINK which issues they would like us to investigate they told us they were concerned about mental health services for young people. Background research showed that young people sometimes feel that services aren't appropriate for them, and that they can get lost in the system at age 18.

What We Did

We researched local services and asked local young people, and voluntary and community groups working with them, for their views. We found that:

- Many young people report a stigma associated with mental health problems, with over half saying they would feel embarrassed to admit they had a problem, and many not knowing where to seek help.
- Many young people and groups reported problems when they are transferred from children's to adults' services, leaving them without the right support.
- People said they would like to see a wider range of services that improve mental health by boosting self-esteem.
- Whilst there was praise for much existing work such as the PSYPHER service, some were concerned about a lack of services available out of hours and at weekends.

Our Recommendations

We called for:

- Increased publicity for mental health services, and more opportunities for young people to have a say in services.
- Better communication between services for children and adults.
- More services and activities such as sport, education and life skills coaching to boost confidence and self-esteem.
- More local services available out of hours and at weekends.

Response

Local services have agreed to:

- Create new joint protocols between children's and adults' services to ensure young people don't get lost in the system.
- Build on existing work to develop young people's well being and give them a say in how services are run.
- Present the report recommendations at two key commissioning bodies within the local NHS.

Next Steps

- LINK will be presenting the report findings to the Humber Foundation Trust board in summer 2010.
- Key NHS personnel have been invited to report on progress with implementing the recommendations at a forthcoming LINK forum.

'We believe it is important to work with Hull LINK because it gives a voice to parents and families and aims to improve the accessibility of health services for children, young people and families.'

Sharon Igoe, Senior Practitioner, Bude Park Children's Centre

Cancer Diagnosis

The Issue

Tackling cancer is a key priority for the NHS in Hull, with a goal set to reduce the mortality rate from cancer by 20%, meaning that around 70 fewer people under 75 would die from cancer each year. March 2009 saw the opening of the Queen's Centre for Oncology and Haematology at Castle Hill Hospital, a new regional centre of excellence. It therefore seemed a good time for us to investigate people's experiences of how cancer services were meeting their needs.

What We Did

We decided to focus our first piece of work on this issue on diagnosis services, our aim being to find out people's experiences and give them a chance to suggest improvements. A survey was distributed among patients at the Queen's Centre and also at local support groups and services.

What We Found

The survey showed that most people were happy with the services they had received at the time of their diagnosis, whilst also providing some useful feedback based on direct experiences of patients and their families.

- The importance of appropriate investigations and early diagnosis was highlighted.
- Explanations to patients about diagnosis and treatment need to be clear and accessible.
- Ongoing support for patients is crucial, including information resources, support groups or other medical services.
- Car parking at Castle Hill was highlighted as an ongoing problem.

Response

- Hull and East Yorkshire Hospitals NHS Trust agreed to share the report with relevant units and develop an action plan for further work to improve services, including a more targeted survey to further explore issues we highlighted.
- NHS Hull have commissioned work to gain more understanding of people's awareness of cancer signs and symptoms, and will be delivering in depth work to address the issues raised, including those in our report.

Next Steps

- Hull LINK will be in regular contact with NHS services to monitor developments with service improvements.
- In 2010 our Steering Group will discuss the focus of our next piece of work on cancer services.
- The feedback on car parking at Castle Hill is being used to inform plans for a new priority issue on our 2010-11 workplan exploring transport issues for patients.

Hospital Discharge

The Issue

Hospital discharge was the top priority issue when we asked people involved in the LINK for their views, with many people reporting problems and concerns about how discharge from local hospitals was operating, and how people were supported through the process.

What We Did

This investigation has been Hull LINK's biggest to date, with over 100 people and groups having their say on the issue. Our work included:

- A survey of patients and carers.
- A survey and more detailed one to one interviews with staff and volunteers from groups supporting patients.
- Enter and View visits to Castle Hill Hospital and Hull Royal Infirmary to speak to patients about how discharge worked for them.

What We Found

Whilst some people were happy with services, our investigation has highlighted a number of problems:

- Poor communication with patients and carers, and also between different services.
- Long waits for medication from the hospital pharmacy when patients are discharged.
- Inadequate assessment of people's care needs, and of how they will be able to manage at home.
- Not enough support for patients after they have been discharged.

Next Steps

Feedback collected in this investigation is to be presented in a report to local services for submission in May 2010. Our recommendations will include:

- Training for hospital staff to improve communication with patients and carers.
- An action plan at local hospitals to reduce waiting times for medication.
- Services to work together better to ensure people's need are assessed before they return home.
- Improved information for patients on sources of help in the community after they are discharged.

We will monitor responses from local services and watch closely for developments to improve services.

'We recognise that to continually improve services the clients' input is absolutely essential. We see the beneficial outcome of working with Hull LINK as an important opportunity for our clients to continue to voice their concerns regarding specific experiences, and in turn to assist in changing services to be more responsive and user friendly.'

Jean Templeton, Hull Churches Home from Hospital Service

Other Issues in 2009-10

As well as our main priorities, the past year has seen Hull LINK working on a number of other health and care issues. Our work on these has included collecting views of service users and voluntary and community groups, influencing strategies and services reviews, and supporting other group leading on the issue concerned.

Extra Care Housing

Hull LINK has worked with Hull City Council to collect residents' views on the council's plans for Extra Care Housing in the city. Extra Care Housing is a type of housing designed to meet the needs of older people and also working age people who have disabilities or mental health problems. Housing is designed to be adapted to current and future support needs of residents, with access to care and support available either on site or by call. Following a request for members' thoughts on the overall strategy we launched a more detailed survey seeking views on facilities and services people would like to see included in the scheme. The results are being collated into a report for presentation to the council in May 2010, and we will keep members informed of progress.

Learning Disability

For the past year the LINK has been represented on the health sub group of the Hull Learning Disabilities Partnership. The group examines current practices, makes recommendations based on members' experiences and expertise, and promotes good practice. Recent work has included an action plan to improve health services in the light of the 'Healthcare for All' and 'Six Lives' reports. This year we have also attended advocacy groups for people with learning disabilities to explain our work.

Carers Issues

The LINK has worked with Carers Centre Hull to ensure that carers' views and experiences are represented in our work. Our work has included events during carers week and at other times to promote services for carers, engagement on the new carers' strategy and also liaison with the NHS regarding funding for carers.

Sexual Health

The LINK has been involved in Hull's Sexual Health Modernisation Forum, a group which brings statutory and voluntary services together to co-ordinate improvements in the city's sexual health services. Recent work has included developing user friendly pathway documents to assist workers responsible for giving advice and assistance to clients needing services such as contraception and testing.

Opening Times at NHS Premises

A number of people told us they were concerned that opening hours at NHS premises such as GP surgeries and clinics did not meet their needs. Through liaising with NHS Hull we learned that this theme had featured in responses to their major 'We're All Ears' consultation in 2009. An action plan is now being put into place to secure improvements, and the LINK will be monitoring progress with this and seeking a progress report later in 2009.

Ambulance Services

March 2010 saw Hull LINK join with twelve other LINKs in the region to hold a joint conference with Yorkshire Ambulance Service. The aim of the event was to explore how we can most effectively together and, particularly on common areas of concern. The event was attended by the Trust's Chairman, Chief Executive and lead Service Directors, giving us a good opportunity to raise concerns with key personnel. Hull LINK obtained useful information to feed into our new transport priority for 2010-11, and as a result of the conference measures are being put in place for a more unified approach to tackling regional issues.



Low Flying Heroes Event
September 2009

Hull LINK is committed to working partnership with colleagues from all sectors to ensure we can deliver our key aim of securing a stronger voice in health and social care.

Overview and Scrutiny Commission

The relationship with Hull City Council's Health and Well-being Overview and Scrutiny Commission is a key one for Hull LINK. LINKs have the legal power to make referrals to scrutiny committees, and the protocol we developed with the local Overview and Scrutiny Commission in 2008 built on this and set out how we work together. We have implemented this by:

- Providing quarterly progress reports to the commission.
- Presenting major pieces of work, such as our report Mental Health Services for Young People at commission meetings.
- Sharing workplans and agendas with the commission, enabling information exchange and joint work where appropriate.

Although Hull LINK made no formal scrutiny referrals in 2009-10, we feel the positive relationship we have developed with the commission has helped secure greater interest in our work and furthered our aim of increased influence for the community over services.

'Since the inception of the LINK to it has always been the aim of both the LINK host and the Health and Social Well-being Overview and Scrutiny Commission to work in partnership to scrutinise services and deliver real health outcomes and improvements to local people through our work.'

The Health and Social Well-being Overview and Scrutiny Commission recognised at an early stage that the LINK could support the Overview and Scrutiny Commission in terms of gauging the views and experiences of patients and the public of local adult health and social care services.

During this last year the Overview and Scrutiny Commission had referred a number of issues to the LINK for them to investigate such as hospital discharge and the delivery of local CAMHS (children's and adolescents' mental health services).

The LINK investigated these issues and reported back to the Overview and Scrutiny Commission its findings which are now being taken up by relevant Health Trusts and Local Authority Managers.

On behalf of the Commission, I would like to thank the LINK Steering Group and its membership for the collaborative work undertaken with Scrutiny in Hull this year and hope that this will continue into next year and beyond.'

Councillor Simone Butterworth
Chair of the Health and Social Well-being Overview and Scrutiny Commission, 2009-10

NHS and Local Authority

The LINK has worked hard to develop positive working relationships with local NHS Trusts and the City Council. As key planners and providers of services, it is essential that we are able to share issues and present feedback in a constructive manner, always mindful of our independence and duty to represent the local community. Key features of this work in 2009-10:

- Helping to set up and participating in Hull Cross Sector Engagement Group – a partnership of NHS Trusts, Hull City Council Community Care Service and Council Scrutiny Officers which plans and co-ordinates engagement activity and examines shared issues.
- Involvement in the local NHS Shared Membership group – a partnership of local NHS Trust membership schemes and the LINK which plans shared work and activities.
- Regular liaison between LINK host staff and our lead contacts at each of the local NHS Trusts (NHS Hull; Hull and East Yorkshire Hospitals NHS Trust; Humber Foundation Trust) and Hull City Council to ensure regular communication and provide clear lines of accountability.

'During 2009/10 Hull and East Yorkshire Hospitals NHS Trust has continued to develop a good working relationship with Hull LINK. Regular meetings are held between the Hull LINK Team Leader and the Trust's Head of Quality and are used to share information in relation to projects the Hull LINK Task and Finish groups undertake. It also gives the Trust an opportunity to update the LINK with initiatives being undertaken and allows it to tap into some of the 'hard to reach' groups with which the LINK has contact.

The Trust welcomes the open and transparent way in which the LINK performs their duties and, in particular, sharing their work plan for the year ahead. Information requests are clear and concise and provide the Trust with the opportunity to discuss the request to ensure the LINK receives the information it requires to inform its investigations.

The LINK has carried out two investigations during 2009/10 in relation to secondary care services - Cancer Diagnosis: Patient Experience of Local Services; and Hospital Discharge. Both reports have been received and the Trust welcomes and is considering the recommendations as a result of the Hospital Discharge investigation. The outcome of the Cancer Diagnosis investigation demonstrated that, on the whole, users were happy with the services provided and therefore no formal recommendations were received from the LINK. However, the survey undertaken did highlight some areas that the Trust is keen to improve upon.

Hull and East Yorkshire Hospitals NHS Trust will continue to build upon the good working relationship already developed to ensure that the services provided for the local population continuously improves.'

Margaret Parrott, Head of Quality, Hull and East Yorkshire Hospitals NHS Trust

'NHS Hull is proud of its relationship with the Local Involvement Network and values the information produced by the LINK. This year the LINK has been very active and worked on agendas that are very important to us, for example, dementia, mental health services for young people and cancer diagnosis. We always take the reports produced by the LINK very seriously and value their independence and their critical friend approach. The findings sometimes support issues we are aware of and at other times provide us with new information. We are very keen to take action on the findings as appropriate but also to include those findings to the ever increasing patient experience data bank.

During this year the partnership working between NHS Hull and the LINK gained momentum as we have searched for ways of working more closely. An example of this would be the LINK undertaking further investigation of NHS Hull's Listening Exercise findings, or us modifying the Patient Transport Services consultation to accommodate the LINK approach.

I look forward to another year of very productive partnership working.'

Heather Kelly, Head of Engagement, NHS Hull

'At the end of the LINK's second year this is a good opportunity to reflect on the work the LINK has undertaken with regard to Hull City Council's work improving the health and well-being of the community.

Most notably staff and members of the LINK have worked with the City Council consulting its membership on the extra care housing project. This brought a much welcomed addition to the on-going consultation and engagement process and has provided a positive example of the added value the LINK can bring.

The LINK has also contributed to consultation events on Dementia, Learning Disability Better Health sub group, Personalisation and Safeguarding. LINK has also contributed to the local 6 Lives action plan.

We welcome all the feedback we receive on our services. In some cases the LINK has highlighted issues we are already working on and support the proposed changes already underway. In the coming year we would hope the reports reflect that. We consider carefully the recommendations put to us by the LINK and always endeavour to reply with a full account of proposed actions, work done so far and plans we already have in place to develop and improve services. Along with other partners we are keen to involve the LINK in plans to generate solutions, as has been the case with the Dementia Strategy Implementation Group. Working with the LINK provides an opportunity for us to give feedback on the work undertaken to the wider LINK membership

We look forward to our continuing relationship with the LINK in the coming year.'

Mariette Glover, Assistant Head of Social Care and Housing, Hull City Council

Care Quality Commission

This is the independent regulator of all health and adult social care services in England. Their role is to ensure that quality standards are being met everywhere care is provided, and to help providers improve their services.

Hull LINK submits copies of all reports on our investigations to the commission. This helps them build up a picture of how local services are working and the kind of improvements people want to see. In 2009-10 we also met with the commission's lead for our area to discuss our work and arrangements for providing information to the CQC on local priorities.

Other LINKs

Although there is no formally constituted national or regional umbrella body for LINKs, we recognise the importance of working with other LINKs. This ensures that common issues are addressed and enables us to share ideas and strategies. Work on this has included:

- Regular attendance at regional networking events for LINKs in the Yorkshire and Humber region, organised in 2009-10 through the Minding the Gap programme. This included giving a presentation on Hull LINK's work to date in 2009.
- Quarterly meetings with host staff of other LINKs in the Humber area (East Riding of Yorkshire; North Lincolnshire; and North East Lincolnshire) to share workplans and discuss common issues.
- Regular liaison with East Riding of Yorkshire LINK to share reports and avoid duplication when examining shared services such as hospitals.

Voluntary and Community Sector

As well as involving the local voluntary and community sector through group membership and engagement in our workplan priority investigations, Hull LINK has taken steps to develop formal relationships with key sector bodies.

ONE HULL VCS Forum is the body that supports voluntary and community sector participation in the ONE HULL Local Strategic Partnership and other local decision making bodies. In December 2009 our Steering Group developed a protocol with the forum covering information sharing, collaborative and joint working and attendance at meetings.

As well as employing the LINK staff team and providing key services such as office premises and financial management, LINK host Hull CVS provides support with event management and recruitment to the LINK through its knowledge and membership of local voluntary and community groups. CVS involvement in areas such as volunteering, grants and funding advice enables the host to spread awareness of the LINK through these channels.

Communication is a key element of our work. If people and groups are to give us their views, experiences and suggestions for service improvements they need to know what we do to take these forward.

LINK Newsletter

This bi-monthly publication, issued to all members either by post or electronically and also available on our website, is one of the primary ways of keeping in touch with the community. It includes details on current investigations, information on how to have your say, feedback from reports, and local and national health and care news items.

LINK Website www.hull-link.org.uk

Early 2010 saw the launch of our new website. The new design makes it easier to find out about the issues we are working on and how to get involved. The LINK in Action page includes reports, events and progress on each issue in our workplan. The Have Your Say feature enables people to give their views via easy to complete surveys. New members can join up online quickly and easily via the Join Us page.

The following table shows a steady growth in traffic on our website over the year.

Month	Unique Visitors	Number of Visits	Total Hits
April 2009	314	687	28218
May 2009	311	636	17865
June 2009	282	668	17919
July 2009	552	1890	29841
August 2009	488	1734	21835
September 2009	565	1914	30141
October 2009	569	2017	43897
November 2009	517	1845	27769
December 2009	443	1972	32345
January 2010	561	2311	40347
February 2010	520	2143	48052
March 2010	628	2405	36894

Press and Media Coverage

2009-10 saw a growth in awareness and interest in the LINK among the local media in our area. This has helped to generate interest in the LINK among people and groups who were previously unaware of us, and has also encouraged more people to come forward to give their views. Highlights have included:

- Radio interviews on BBC Radio Humberside, KC FM and West Hull Community Radio.
- News item in Yorkshire Post on Mental Health Services for Young People report 18 February 2009.
- Article in Yorkshire Post on LINK work on dementia services 29 March 2010.

Regular contact with health reporter at Hull Daily Mail, with a number of opportunities to comment on health and care stories.



Living Well with Dementia Forum
November 2009

Hull LINK Income and Expenditure 2009-10

Income	£
Money Received from Hull City Council	156,454
Carried forward from 2008/9 Budget	15,576
Total	172,030

Expenditure	Budget £	Spend to 31/3/09 £	Balance £
1) Staffing, Administration, Overheads			
Total	124,405	118,538	5,867
2) Management, Training, Supervision			
Total	19,150	19,150	0
3) LINK Participation Expenses			
Volunteer Expenses	2,100	588	1,512
Volunteer Travel/Training	4,050	1,106	2,944
Total	6,150	1,694	4,456
4) LINK Communication Costs			
Events/Meeting Costs	5,775	3,596	2,179
Newsletters/Mailouts	4,600	8,785	(4,185)
Marketing/Promotion	4,500	2,723	1,777
Total	14,875	15,105	(229)
5) Reserves held for development, outreach work			
Reserves	7,450	0	7,450
Total 1 - 5	172,030	154,486	17,544

Notes to Budget

a) The carry forward of £15,576 from the 2008/9 LINK budget was allocated to budget items 1 and 2 to cover costs of the new LINK Membership Engagement Officer post as agreed by Hull CVS and the LINK Steering Group. Underspend of £5,867 carried forward due to staffing changes over the year.

b) Staffing, administration, overheads costs cover salaries, national insurance, pension and travel costs for the four members of the LINK staff team. Overheads cover rent, telephones, internet and ICT equipment for the LINK office.

c) Management, training, supervision cover Hull CVS costs and staff support/training.

d) LINK participation expenses cover travel costs for LINK Steering Group members and Enter and View visitors to attend meetings/conferences/training courses. Underspend of £4,456 carried forward.

e) LINK Communication costs:

- i) Events/meetings cover costs LINK quarterly forums and events in support of LINK workplan priorities. Underspend of £2,179.
- ii) Marketing/promotion covered updates of the LINK website, and printing of LINK leaflets and promotional material (pens, posters, carrier bags). Underspend of £1,777.
- iii) Newsletter/mailouts covered postage and printing costs of newsletter to LINK members, general promotional mailouts and printing and postage of LINK reports. Overspend of £4,185 over year due to increase in membership meaning more welcome packs and newsletters printed.
- iv) In total the LINK communication costs budget was overspent by £229.

f) The 2009/10 budget total underspend of £17,544 will be carried forward to cover salary costs of employing the LINK Membership Engagement Officer until March 2011.

g) During 2010/11 Hull CVS and the LINK Steering Group will monitor spend against the budget to ensure full spend by the end of the contract in March 2011.

As we have seen, 2009-10 was a year that saw Hull LINK start to deliver real progress in its key aims of gathering views and experiences, investigating issues of concern and making reports and recommendations to services.

With the early work of setting up the LINK and creating the right governance arrangements completed in the previous year, we were able to focus more on our main function to provide the community with a real opportunity to improve services.

LINKs are still relatively new, and we've learned some important lessons this year as we've worked together to deliver our aims. These have included:

- Ensuring that as many people as possible can engage with us and give their views, even if they are not LINK members.
- Being specific about issues the LINK will examine – if an issue is too broad or not clearly defined any investigation will lack focus.
- Creating clear project plans and timescales for each investigation.
- Putting in place arrangements to review progress with our investigations.

Although work is completed on a number of reports on priority issues, it is important that these are not now treated as closed items. Part of our role is to monitor progress with delivery of recommendations, so we will ensure that in 2010-11 we monitor progress and seek updates from services.

Looking ahead, the LINK Steering Group and staff team will continue to promote membership and engagement in the work of the LINK, particularly from under-represented groups and individuals. Communicating the impact of the LINK will also continue to be a priority.

A number of main priority issues for 2010-11 have already been identified through our regular engagement with the public and at events such as our Spring 2010 forum. Our workplan for the 2010-11 will include:

Transport

- Getting to and from Castle Hill Hospital and Hull Royal Infirmary by bus, car and other forms of transport.
- Using car parking facilities at both hospitals.
- Accessing NHS Non-emergency Transport services.

Alcohol Services

- Information on alcohol services.
- Rehabilitation and detox services.
- Aftercare and support.

Eating Disorders

- Gathering views on local services.
- Exploring experiences and barriers to services.
- Making recommendations for improvements in services.

Maternity

- Researching people's experiences of services.
- Services during pregnancy, labour and birth.
- Care received at home.

Project plans and timescales for each issue have been agreed. To find out more visit our website www.hull-link.org.uk or contact us by telephone or email.

Other issues will be taken on as new priorities as time and resources allow, and we'll be consulting with our members to identify what they should be.



Personalisation Event
December 2009

Hull LINK would like to thank everyone who has been involved in our work over the past year.

Get Involved

- Fill in a survey – on our Have Your Say page, or call us for a paper copy.
- Sign up as a member – it's free and quick to join. Visit the Join Us page or call us for the form.
- Come to an event – look out for our regular forums where you can give your views.
- Ask for a visit – if you run a group where people would like to find out more, contact us and we'll arrange to come to you.
- Check our regular newsletter – for the latest news and opportunities to have your say.

LINK Office in 2009/10:

Hull LINK
Centre 88
Saner Street
Anlaby Road
Hull
HU3 2TR

Telephone 01482 221372
Email: link@hull-cvs.co.uk
Website: www.hull-link.org.uk

From 28th June 2010, the LINK Office will be at:

Hull LINK
c/o Hull CVS
The Strand
75 Beverley Road
Hull
HU3 1XL

Telephone 01482 324474
Email and website remain unchanged

Site Web

Search

Thursday, 17th June 2010

Watchdog looks for views on car parking at busy hospital

Published Date: 29 April 2010

By Alexandra Wood

PEOPLE are being asked for their views on parking problems at one of the region's busiest hospitals.

The lack of car parking spaces at Castle Hill Hospital has long been a cause for frustration.

Hull and East Yorkshire Hospitals NHS Trust is adding 200 more spaces to the 1,600 it already has at the hospital in Cottingham, near Hull, which is a specialist heart and cancer centre for the region.

But local health watchdog LINK, which has the legal power to call for improvements in NHS services, is exploring other possible solutions, including introducing a pass system and staggering visiting times to try and reduce pressure on spaces.

The survey – being held aboard the City of Hull Environment Forum's bus on Friday next week – will also examine views about patient transport ahead of the service being retendered next year. Hull LINK team leader Jonathan Appleton said: "We are investigating hospital transport and car parking as this is a massive area of concern for local people. Nearly 200 people have given us their views so far and many people have expressed their frustration about car parking at Castle Hill Hospital.

"We're also keen to hear people's experiences of NHS patient transport services as these are currently up for review.

"It is particularly inconvenient and upsetting for people who are in there for long-term treatment day in and out and faced with the costs and driving around looking for somewhere to park. Should they be looking at a system of passes?"

The bus will be parked in Queen Victoria Square on Friday next week from 10am to 2pm.

People can also complete a short survey by calling Hull LINK on 01482 221372 option 2, emailing link@hull-cvs.co.uk or completing a survey online at www.hull-link.org.uk

Newspaper Articles:

Above:

Article by Alexandra Wood
Yorkshire Post
29th April 2010
www.yorkshirepost.co.uk

Right:

Hull Daily Mail
29th March 2010
www.thisishull.co.uk

Lifeguards interested in working for the NHS should visit www.mli.org.uk/jobs

Dementia care concern

HULL: Health watchdog Hull Local Involvement Network (Link) has recommended improvements for dementia services in the city.

It is estimated there are more than 2,500 people in Hull with dementia and the condition leads to 60,000 deaths in the UK each year.

The report Living Well

With Dementia – Shaping The Service has recommended training for health

professionals, more public information, more input from sufferers/carers and increased partnership working between the NHS, councils and the voluntary sector.

NHS Hull has agreed to the use of recommendations.



TEAMWORK: A report has stipulated the need for more information.

Care shake-up as city prepares for massive growth in dementia

Mark Branagan

A MILLION-pound shake-up is on the cards for dementia services in Hull, benefiting nearly 3,000 present and future sufferers and their families.

Nationally, dementia is estimated to cost the UK economy £1.7bn a year. In the next 30 years, the number afflicted is forecast to double to 1.4m, trebling the costs to £50bn a year.

As part of a new National Dementia Strategy, the Government is providing £150m, to be shared among 152 primary care trusts.

In Hull, it will pay for the biggest improvements to deal with the illness since those set out in an Audit Commission report in 2000.

Ageing population expected to bring huge future costs

A report by Hull's independent health watchdog Hull LINK (Local Involvement Network) will be the guiding light of the improvements.

The NHS has now agreed to the use of recommendations from the LINK report, called *Living Well with Dementia - Shaping the Service*, in its local dementia strategy, ensuring sufferers and carers have a higher quality of life.

Historically, because Hull has had an average lower life expectancy than many other cities, it has fewer sufferers. But the national trend is for people to live longer, making them more prone to the condition.

Of the 36,400 people in Hull who will be over 65 this year, it is forecast 2,554 will have dementia, rising to 2,679 by 2015 and 2,949 by 2020.

LINK Team Leader Jonathan Appleton said: "It is essential that people with dementia, their carers and families receive the best standard of care available."

"We're delighted that the report has had such a positive response and hope that local people will enjoy the benefits of better services."

Hull LINK worked with local voluntary and community organisations, such as Age Concern and the North Bank

Forum, to review dementia services.

The report calls for more training for health professionals and recommends information be made available in public places about dementia. It also calls for local support and for closer working and consultation between the NHS, local councils and the voluntary sector.

Mr Appleton said: "People told us training among staff and volunteers working with old people needed to be improved to deliver more personalised care for people with the condition, and there needed to be more public awareness."

"There was also a feeling that

the older people and their carers who use the services often do not have much of a say what happens to them when they become ill.

"They were being told what services they were entitled to and left to live with it."

"Generally, it is felt dementia has been off the radar. People living with it are often isolated. It is one of those hidden illnesses where people retreat into their own lives," Mr Appleton continued.

"Society tends to forget them. But there is a feeling now things have to change and people have had a raw deal for too long."

"One thing which is quite

exciting is a new system of dementia advisers."

These named personal advisers would be appointed when relatives were just getting concerned about loved ones losing their memory or who have just been diagnosed with the illness.

Their role will be to help families with practical difficulties, such as access to benefits and support schemes, as well as advising on matters such as medical treatment.

"People tend to think there is nothing they can do because it is not a curable disease."

"But people are encouraged to make diaries about the stuff they enjoy - food or activities - so carers can take account of likes and dislikes," he added.

mark.branagan@ypn.co.uk

Health pledge for younger people

Simon Bristow

HULL'S newest health organisation has pledged to be more accessible to young people following criticism from patients.

A report into mental health services in the city has found that many young people experience problems when being transferred from children's to adults' services.

City health watchdog Hull Link has found that many patients felt

distressed, frustrated and isolated when making the transition.

The report, to Humber NHS Foundation Trust, which replaced Humber Mental Health NHS Teaching Trust this month, also found that more than half of young people would feel too embarrassed to admit they had a mental health problem.

Dave Knapp, head of patient experience at the trust, said: "We value the feedback we get regard-

ing our services from initiatives such as this.

"We look forward to working closely with the staff at the Link and the other agencies involved in commissioning and providing mental health services to young people to make them more accessible."

Anyone who would like to help to improve services in the city can join the trust by calling 01482 389132.

Newspaper Articles:

Above Top:

Article by Mark Branagan
Yorkshire Post
29th March 2010
www.yorkshirepost.co.uk

Above:

Article by Simon Bristow
Yorkshire Post
26th February 2010
www.yorkshirepost.co.uk



Hull CVS Ltd is the host organisation for the Hull LINK



Hull CVS
'community and voluntary services'

Hull Community and Voluntary Services Ltd.

Registered in England No. 1570120 Registered Charity No. 514311

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