LINk
COUNTY DURHAM

Shaping the Local Involvement Network In County Durham

Friday 2nd March 2007 Glebe Centre, Murton
A report of the event

Shaping the Local Involvement Network
In County Durham

"**build** on what's already there"

"**must** be independent"

"**properly** resourced"

"**diverse** and representative"

"**less** talking, more action"

LINk

Contents

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Introduction

On 2nd March 2007, 126 people came together in the Glebe Centre Murton to discuss the development of a Local Involvement Network (LINk) in County Durham.

The LINk will promote and support the involvement of patients, service users, carers, the general public and voluntary and community groups in the commissioning, provision and scrutiny of all local health and social care services. The LINk will be funded, it will have legal powers and its recommendations will be listened to and acted on (see Appendix A).

County Durham has been chosen as one of nine early adopter areas in the country to pilot the LINk's approach (see Appendix B). This event was the start of the process to help shape the local LINk. It brought together people from voluntary and community groups, user and carer groups, members of Patients Forums and staff, councillors and directors from health and local authority services.

The next steps

March	we will write up the event and, based on what you told us, develop questions (see below) which will give us a clearer idea of what the County Durham LINk could like.
April	we will send out this report to everyone who came to the event and to those who were invited but couldn't attend.
April/May/June	we will visit groups and organisations covering the major themes you identified and covering each district to discuss the questions and what a LINk would look like.
June/July	we will bring all this information together and develop guidance on how the County Durham LINk might operate and be structured.
July	we will share this information and draw up a draft specification for the organisation (Host) which will set up and support the LINk.

We expect that the Act to set up LINKs will get final approval in November 2007 and that a County Durham LINK is launched in Spring 2008.

We would hope to have first discussions with potential HOST organisations in Autumn 2007 and, subject to the national situation, funding etc, to have a contract in place by the start of 2008.

Questions about LINks

Based on what you told us at the event, these are the questions we are looking to you to answer in April, May and June.

Q You told us the LINk should build on what is already there - what networks, partnerships and forums should the LINk be working with?

Q The LINk should be properly resourced – what resources (money, people, events, personal assistance and so on) would a LINk need to work effectively and make sure you could take part?

Q You told us the LINk should be diverse and representative - how can the LINk best involve people and groups whose voice is often ignored or not heard?

Q You were concerned about groups who couldn't make it to the event because of distance and travel. How could a LINk best involve both rural and urban communities in County Durham?

Q You want more action, less talking – what would a successful LINk be doing and achieving?

Q The LINk must be independent – how can we best achieve that? Who should the LINk be accountable to?

Q You wanted to be kept informed – how should a LINk share information, how can we best keep in touch with you?

Q What would be the most important activity for the LINk to carry out?

The event was sponsored by the Commission for Patient and Public Involvement in Health (CPPIH) with support from the One Voice Network, Durham County Council and Durham Primary Care Trust.

If you live or work in County Durham and would like:

- More copies of this report
- A copy of the report in a different format or language
- Further information about the LINk's project in County Durham
- Someone to come and talk to your organisation about the LINk
- To provide an answer to some or all of the questions

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Welcome and presentations

Tony Jameson from the North East Change Centre welcomed everyone and briefly ran through the purpose of the event and the format for the day.

Sally Young, Northern Area Director of the Commission for Patient and Public Involvement in Health, gave an introduction and background to Local Involvement Networks and the County Durham Early Adopter Project.

Michele Armstrong is Chair of the One Voice Network, which aims to give the voluntary and community sector in County Durham a strong voice. She looked at the opportunities and challenges posed by LINks for voluntary and community organisations in County Durham.

John Hudson, a member of the County Durham Primary Care Patient and Public Involvement Forum and a Forum member since 2003, gave a personal view of the role and future of Forums as we move towards LINks.

Sally Young ran through the background to Local Involvement Networks and explained that this was a proposal which was still going through Parliament and was subject to change.

She identified the key points of a LINk and their central role in influencing the future commissioning of health and social care services (see Appendix A for more information on the key points of a LINk)

Sally went on to explain why County Durham had been chosen as an Early Adopter project, to test out how LINks might work in a large county with an urban and social mix and significant pockets of deprivation.

She then explained the role of the County Durham Project Group (see Appendix B) and what the Group wanted to achieve today:

- Get people's views on what works ... and what doesn't
- Start to map out the gaps in the system
- Get names of others who should be involved
- Get ideas for the future
- Draw together views, issues and concerns to test out over the next few months
  In the future the Project Group will:
- Continue to focus on engagement and involvement
- Test out the information from today with others in County Durham
- Let more people know about the LINk

- Attend events in different areas – so let the Project Group know if there is something they should be attending

- Based on what you tell the Group, agree the principles of how the LINk should work and what it should look like

- Keep the process moving forwards

Michele Armstrong posed a number of issues facing the LINk:

- Durham is a diverse area with a mix of rural and urban and different structures for community involvement. For example, Wear Valley is covered by Community Partnerships, Teesdale has Parish Councils.

- Specialised groups such as Deaf Groups, Blind Groups and Stroke Groups will be worried that their concerns and views do not become diluted in a LINk.

- How can volunteers, already stretched by providing a service be supported to take part in a LINk?

- We already have a wide range of community engagement structures – community networks; Voluntary Sector Forums; Carers Forums; Local Strategic Partnerships, thematic groups and Boards.

The challenge for the LINk is not to duplicate, not to reinvent the wheel and to not burden existing volunteers, many of whom already do many more hours than paid workers.

Michele pointed out that we have heard that the local authority will be required to contract with a voluntary or not-for-profit organisation which will support the work and activities of the LINk. This HOST organisation will be very important and it must:

- Be independent of all public bodies.

- Be sympathetic to volunteers and support new faces to become volunteers.

- Ensure equality across the county – be rural proof and equality proof.

- Help the LINk to identify an Agenda and ensure an overview of health and social care.

- Help the LINk to influence and change services.

Today must be the beginning of the process. If the LINk is to be supported by and involve the voluntary and community sector then it must be developed and owned by the voluntary and community sector.

Public bodies have an important role in acknowledging this ownership and in supporting, resourcing, respecting and co-operating with the LINk's process.

John Hudson made it clear that he was giving a personal view. He had been a member of Chester le Street Primary Care Forum for nearly 3 years, was a non-medic and had a number of community links, including work with the CAB, DASH, Housing Company and the Local Strategic Partnership.

John felt that the Forum had been enthusiastic, worked effectively as a team, got things done as a Forum and met the commitments they gave. However, the Forum wasn't representative, being mainly older and middle class, with only one member in paid employment. The Forum, whilst known to specialist groups, wasn't well known in the community, was weak on publicity and the public didn't attend meetings or know of them.

There had been some successes and increased awareness, for example their work around diabetes, dental services, osteoporosis and services for older people. The Forum had carried out visits to GPs and dental practices, had been able to suggest improvements, praise staff, build up Links and become aware of problems. However, there were a number of frustrations:

- Forums were often heard (by the Primary Care Trust) but not always listened to.
- Negative impact of central government decisions and policies such as the introduction of the GP and dental contracts
- Change for change sake, with CHCs to PPI Forums to LINks in less than five years, leading to a loss of members
- There had been too many surveys and not enough action.

Looking at LINks, John felt that they could:

- Have a more representative membership
- Balance local, county, strategic and national issues
- Work more easily with the Overview and Scrutiny Committee
- Ensure there adequate resources to support local activities
- Widen the input into residential, health and social care
- Work more easily with local government re-organisation
- Have a clearer role in the Local Area Agreement and LSP

John concluded that overall he would give PPI Forums 65 / 100

Workshop 1

In order for a LINk to work we must / must not...

We allocated people to one of ten workshop groups and tried to 'mix and match' people by interest, where they lived or worked and whether they came from the voluntary or statutory sector.

Each workshop had a facilitator and a scribe. People stayed in the same workshop for the morning and afternoon. The idea was that this first workshop would feed into the thinking in the second.

We were looking here for a key list of things we must do and things we must not do if a LINk is to work.

People were asked to write their three top 'must dos' and three top 'must not do's' on post-its.

There was one idea per post-it, yellow for must do, pink for must not do.

Each group discussed and grouped their ideas to come up with some key issues.

We combined all the workshop ideas over lunch and fed back at the end of the day.

This is what they said...

In order for a LINk to work we must...

- ✔ Be properly and well resourced – good engagement costs money and volunteers can't be bought cheaply. Value us!
- ✔ Be independent of the local council and Primary Care Trust.
- ✔ Be diverse and representative – remember young people, faith groups, people with long-term conditions, people under 40...
- ✔ Be clear about the role of the LINk, its powers and structure, and what we can influence and change – too much freedom can lead to nothing happening.
- ✔ Develop trust and good working relationships between the LINk members and with all health and social care providers (not just the PCT and local authority).
- ✔ Focus on the commissioning end of services, not just the delivery, and be well informed about what's out there.
- ✔ Communicate what we are doing clearly, using language and methods that people understand. Not the same old same old.
- ✔ Listen to the public and always, always, feed back.

- ✔ Make sure that concerns about services – mental health, patient transport/ambulance, hospitals – can be heard but don't just focus on the medical all the time.
- ✔ Acknowledge the good work and trust that went before but don't get stuck in the past.
- ✔ Involve, involve, involve - be creative and pro-active about encouraging everyone to get involved and always remember the non-engaged.
- ✔ Work with existing networks and partnerships, don't re-invent the wheel and don't try and replace what works.
- ✔ Reflect local structures, neighbourhoods and boundaries but remember things are changing in Durham.

In order for a LINk to work we must not...

- ✗ Just be a talking shop – we want action.
- ✗ Change things just for the sake of it, don't re-invent the wheel, but don't be closed to ideas and ways of working.
- ✗ Try to change the world or look for short-term/quick-fit answers to everything.
- ✗ Take on too many issues at once, get bogged down in details.
- ✗ Assume one-size fits all or try to take over our existing groups and structures.
- ✗ Just change the name but carry on in the same old way.
- ✗ Do another mapping or listening exercise – we know who we are and what we want.
- ✗ Let the statutory sector take us over or absorb and patronise us.
- ✗ Make it difficult for people to take part, always meet at work times, provide no support, exclude young people and ethnic minorities.
- ✗ Just have meetings and more meetings.
- ✗ Use jargon, abbreviations, talk over people's heads.
- ✗ Just talk at, need to work with.
- ✗ Be taken over by self-interest groups.
- ✗ Exclude people, including individuals who may have something to say.
- ✗ Have a fixed or closed membership – we need to be different to the Forums.
- ✗ Be run by anyone except the community.

Workshop 2

Who needs to be involved and how can we best involve people...

A Local Involvement Network is about trying to work differently, involving the whole community in deciding the health and social care services that they want, in the way and place that they want them provided.

We looked at the work plans of the main four Patient Forums which have members living in County Durham. We came up with the seven top issues that the Forums are working on this year and asked each workshop to pick one issue to look at.

- Supporting older people
- Caring for carers
- Supporting mental health and wellbeing
- Young people staying well
- Disabled people leading independent lives
- Having a healthy pregnancy
- Access to local services

We asked each workshop to tell us who the LINk would need to involve in looking at their chosen issue and what methods would they use to involve them.

This is what they said ...

Supporting mental health and wellbeing

Six out of the ten workshop groups chose to look at this, which reflects the importance people put on mental wellbeing.

We should involve ...

People who use mental health services.

Carers of people who use the services.

Voluntary organisations and support groups looking at mental health issues. Use existing groups and networks and their contacts.

Expert Patients Groups.

Minority groups who may feel excluded and/or have very different views on the way services are provided.

Travellers groups and ethnic minority communities.

Advocacy groups, supporting people to have a say.

Schools and colleges.

Employers.

Organisations that help people back to work.

GPs and community mental health workers.

Family support services.

Leisure and sports services, which can prevent ill-health and encourage a sense of well-being.

Probation officers and social workers.

Prisoners and prison staff.

People who run and provide accommodation.

Transport providers/services.

Staff in the NHS Trusts.

People who live in rural areas and may feel isolated.

People not already involved, including the general public.

Patient advice and complaint services, what issues are they picking up?

We would involve people in thinking about mental wellbeing by

Attending staff meetings to engage with, and listen to, the people who provide the services.

Working with Primary Care Trust Involvement Team and their contacts.

Providing training and maybe a buddy so people feel confident about taking part.

Getting and then distributing information from the main service providers.

Providing a safe and comfortable environment for people to talk in.

Carrying out a survey of needs and concerns.

Giving presentations to other groups about what the LINk can do.

Maximising the use of new technology, text, website, email, community TV, to contact people. We don't always need a meeting.

Inviting people to a workshop or event, but give them the choice of where it will be.

Providing people with clear information, remove the fear/stigma of mental health.

Taking the issues out to the people rather than expecting them to come to us.

Making it fun, running social events.

Making sure the people who commission/buy the services tell us what they are doing and that they know what we are thinking.

Being clear what the task is and what we hope to achieve – offering people results if they take part.

Telling people what we have done and what we have achieved.

LINks will need the personal touch to form trusting relationships.

LINks needs to involve people in a variety of ways, formal and informal.

Access to local services

Three out of the ten workshop groups chose to look at this. These are the main additional points that were made.

We should involve...

What's already there.

Patients, users and carers groups.

Voluntary and community groups and community associations.

Decision makers, not just middle managers.

All transport providers, including the bus companies and the ambulance service.

Young people, older people, travellers, new and established minority ethnic communities.

All the service providers.

Very local networks.

Communities of interest.

Extended schools network.

Sure Starts.

Local elected councillors, parish, district and county.

We would involve people in thinking about access by...

Road shows, mobile van, video box, plays taking the issues out to people.

Planning for real exercises.

Good communications – newspapers; TV; posters; local and parish newsletters; text; web.

Contacting local places of worship.

Remembering it may be easier to contact some communities at venues outside of County Durham.

Access surveys, involving disability groups.

Connecting with the Local Area Agreement – influencing the commissioning decisions at this level.

Disabled people living independent lives

One workshop group chose to look at this issue.

We should involve ...

Disabled people.

Carers, including people who provide informal support.

People who fund/commission the services.

Doctors, nurses and therapists.

Health, voluntary, council and independent providers.

Education, training and employment services.

Architects and planners.

Housing providers.

Decision makers and local councillors.

Leisure and sports providers.

Role models who inspire.

We would involve people in thinking about this by ...

Involving Disabled people in the design of services and buildings.

Encouraging and supporting people to have a voice on small and individual issues as well as the larger scale.

Identifying good practice, here and elsewhere, and sharing this locally.

Establishing a network of Disabled people and carers who can offer advice and support to service commissioners and providers.

Offering solutions not problems, working with partners in a very positive way.

Making events inclusive not exclusive, engaging with people through social events.

Reinforcing and supporting existing action, groups, lobbyists.

Publicising positive outcomes and achievements.

What next

Following feedback from the workshops, Sally Young thanked everyone for coming, for their contributions and feed back. She noted that a number of people had emphasised the importance of geography, location and a sense of place in County Durham. This must be taken into account when a LINk was established.

Sally explained what would happen next:

- we will write up a report of the main points raised at the event and sent it to everyone who came and who was invited to the event.
- we will share what you have said with the national LINk's team and with other projects across the country.
- we will ask you for any further thoughts you may have had on LINks.
- we will meet with groups, especially those not represented here today, to talk through what we have learned.
- we will pull this all together and come back to you with ideas about what the County Durham LINk should look like.
- we will keep you up to date with what is happening nationally on LINks, what is agreed and when things will start to happen.
- we will make sure that all this information is given to the people drawing up the contract in County Durham.

We would like you to:

- tell us what you think about the LINk, especially once you have read the report of the event.
- share this report with other people and groups you are involved with.
- invite us to talk to local networks, forums and events about the County Durham LINk.

Shaping the LINk – 2nd March 2007

People who came and signed the register

Lelsey El Alami	JB Skillcare
Liz Allan	Co Durham Primary Care Trust
Alison Appleby	NOTPV FSO
Ann Armstrong	Durham County Council
Cllr Geoff Armstrong	Chester le Street District Council
Michele Armstrong	One Voice and 2D
Keven Ashburn	Primary Care PPI Forum
Caroline Atkinson	H and D Alzheimers Trust
Jane Atkinson	Durham Deafened Support
Katrina Bage	Co Durham Primary Care Trust
F Barrett	VRS
Cllr James Barrett	Chester le Street District Council
Michael Bladen	NMP
Dave Bolton	Sedgefield Access Group
Lyn Boyd	Mental Health North East
Peter Brookes	Durham County Council
Rachel Burton	SURF
Mrs Elizabeth Carr	Primary Care PPI Forum
Audrey Chapman	Derwentside Carers Support
Margaret Chappell	Primary Care PPI Forum
Alan Charlton	CD&D Diabetes Network
Carol Cooper	CPPIH
Mark Cotton	North East Ambulance Trust
Sandra Cottrell	Co.Deaf
Ross Cowan	CPPIH
Mr Michael Dalton	Ambulance PPI Forum
Tracy Davidson	H and D Alzheimers Trust
Amanda Dexter	Co Durham Primary Care Trust
Carol Dodd	Canvas, Derwentside
Mrs Joan Durkin	TEW Valleys PPI Forum

Dr Marta Evans	Primary Care PPI Forum
Malcolm Fallow	East Durham Trust
Joe Farrey	CD&D SU Forum
Verna Fee	Co Durham Primary Care Trust
Michelle Fenwick	Investing in Children
Mr Brian Ferguson	Ambulance PPI Forum
Paul Frank	Co Durham Primary Care Trust
Sid French	Primary Care PPI Forum
David Gallagher	Co Durham Primary Care Trust
Karen Gates	Brandon & D Valley Sure Start
Tim Gilling	Centre for Public Scrutiny
Jackie Graham	Durham Deafened Support
Ms Sheila Grant	Primary Care PPI Forum
Pam Gwynn	Co Durham Primary Care Trust
Mr Malcolm Harrison	D&D Acute Hospital PPI Forum
Cllr Ralph Harrison	Chester le Street District Council
Arthur Harkness	Primary Care PPI Forum
Jane Hartley	Pioneering Care Partnership
Tina Hatton	H and D Alzheimers Trust
David Haw	Age Concern Durham County
Mr Mike Hemingway	Ambulance PPI Forum
Mark Henderson	SURF
Allison Hicks	Orchard Young Carers
Geoff Holmes	Canvas, Derwentside
Hayley Hood	Pathfinder
Mr Alan Horsfield	TEW Valleys PPI Forum
Mr John Hudson	Primary Care PPI Forum
Katharine Humby	Co Durham Primary Care Trust
Cllr Edna Hunter	Durham County Council
Mr Ken Ibbotson	Primary Care PPI Forum
Heather Inglis	Co Durham Primary Care Trust
Tony Jameson	North East Change Centre
Feisal Jassat	Durham County Council

Sarah Jay	Tees Esk & Wear Valleys NHS Trust
Peter Kaszefco	Racial Equality Council
Geoff Kelly	Durham Dales Action for Carers
Jo Laverick	DRCC
Bronwen Lewis	British Red Cross
Lee Ling	Durham County Council
Karen Leech	CPPIH
Alan Mackay	Co Durham Volunteer Centres
Norman Mackie	East Durham CD Trust
Jayne Maitland	CPPIH
Sarah Marsay	Inhouse South Tyneside FSO
Lesley Mawson	Tees Esk & Wear Valleys NHS Trust
Jamie McBain	Teesdale User Group
Mary McHale	Easington District Crossroads
Victoria McManus	Co Durham Drug Action Team
Keith McMillian	Derwentside Community Network
Dorothy Mills	CPPIH
Jayne Mills	Durham County Council
L Molloy	Lipspeaker
Craig Morgan	Durham County Council
Richard Moriarty	Co.Deaf
Andrew Nash	CPPIH
Carol Newsom	Sure Start County Durham
Alex O'Donnell	Durham County Council
Sue Orton	Sedgefield Carers Centre
Richard Oughton	Centrepoint
Caroline Peacock	St Cuthbert's Hospice
K Phillips	Wear Voices for All
Bill Pike	Durham County Council
Cllr George Porter	Durham County Council
Linzi Quinn	Co Durham Primary Care Trust
Vicki Richardson	Norcare
Margaret Rowe	Durham Local Advisory Group

Helen Rutter	D and D NHS Foundation Trust
Rose Seabury	Derwentside Community Network
Mandy Sharp	Lipspeaker
Deborah Siddle	Inhouse South Tyneside FSO
Cathy Smith	Sedgefield Borough Council
Mike Smith	NHS Direct
Derek Snaith	Durham County Council
Clive Snowdon	CMP
Dianne Spark	UTASS (Teesdale)
Angela Stobbart	Investing in Children
Jayne Taylor	NCI Research
Ms Joan Taylor	Primary Care PPI Forum
Peter Taylor	Norcare
David Taylor-Gooby	Inhouse South Tyneside FSO
Gerald Tompkins	Durham County Council
Charles Tremeer	Inhouse South Tyneside FSO
Paul Turner	North East Ambulance Service
Stephanie Varah	National EAP Project Manager
Dr June Wainwright	Teesdale User Group
Janis Walsh	CMP
Geraldine Waugh	Durham County Council
Jim Welch	Blind Life in Durham
Margaret Welch	Blind Life in Durham
Tom Whellans	Durham County Council
Miss Margaret Williams	TEW Valleys PPI Forum
Dawn Williamson	User Forum
Marian Williamson	User Forum
Colin Wilson	Healthcare Commission
Sally Young	Area Director, CPPIH
Anne Yuill	Co Durham Primary Care Trust

Who else needs to know about LINks?

Using large maps of County Durham and post-its, we asked people to tell us who else they thought needs to know about LINk.

BME community reps
Bridge Education Centre, Chester le Street
Colleges
Employment Agency
Faith groups
Lions
MIND
MPs
Parish Councils
People with a learning disability
Police service
Polish community
Prison service and prisoners
Pupils on school councils
Rehabilitation services
Rotary club
School parent governors
Streetwise
Teesdale Village Hall Consortium (30 village halls)
University
Young people (more)
Womens Institutes
Working people, in good health

Appendix A: Some key points about Local Involvement Networks (LINks)

- The Government looked at patient and public involvement as part of the 'Our Health, our care, our say' review of community based health and social care services in early 2006.
- Their initial ideas and a series of questions were published in a report called 'Stronger Local Voice' which was consulted on during the summer and autumn of 2006.
- The Government's proposals, to establish new organisations called Local Involvement Networks (LINks), are now in the Local Government and Public Involvement in Health Bill (published in December 2006). The details are still being worked on and are subject to parliamentary scrutiny and review, so they could change.
- LINks will replace Patients Forums, probably in early 2008. Patients Forums will continue, with their existing powers, until the same time.
- There will be one LINk in every local authority area with social services responsibility.
- LINks will be primarily a network involving, and representing the views and concerns of, voluntary and community groups, patients, carers and individual members of the public in their area.
- LINks will promote and support the involvement of local people in the 'commissioning, provision and scrutiny of care services'.
- LINks will obtain the views of people about their needs and about their experiences of local services.
- LINks will look at both health and social care and at what local people feel keeps them healthy.
- LINks will look at the services of all care providers – NHS, local authority, private companies, social enterprises and voluntary and community organisations.
- Members of the LINk will have the right to enter premises to observe and assess the nature and quality of services – not all members will want to do this but those that do will probably have to be CRB checked and formally appointed in some way and get appropriate training.
- LINks will be able to request information from service commissioners and providers and receive a response within a specified time.

- LINks will produce reports and recommendations which the commissioners of services must respond to.
- LINks will be able to refer matters to local authority Overview and Scrutiny Committees (OSC), who must respond. The local LINk and OSC will be expected to work closely together but will be totally independent of each other.
- The Primary Care Trust should involve the LINk in producing a local health prospectus.
- There will be funding from the Department of Health in the form of a specific targeted grant to each local authority to be used to set up and pay the running costs of the LINk. The grant will be for three years.
- Each local authority will be required to contract with a voluntary or not-for-profit organisation (known as a Host organisation) which will support the work and activities of the LINk.
- The members of the LINk (not the local authority or the Host) will decide on their work plan and will be responsible for how money is spent.
- The local authority will award the first contract for the Host organisation but they are strongly encouraged to involve local people and organisations in the process.
- The contract will be based on core requirements provided by the Department of Health with a local element.
- The Health Overview and Scrutiny Committee will be encouraged to hold the council to account for how the contracting is carried out.

The development of the Local Involvement Network in County Durham is currently being supported by the Commission for Patient and Public Involvement in Health. You can get more information about LINks and read the background information on their website at: www.cppih.org >> go to the KMS >> the changing NHS >> LINks

or directly at: http://147.29.80.160/portal/topics/1168954353272_LINks-LocalInvolvementNetworks?topic_id=44700004

Appendix B: The County Durham Early Adopter Project

Trials to test how the new LINk's system might work are being carried out through nine 'early adopter projects' across the country. Each project will test the LINk's approach by identifying different models and ways of working. The projects will be evaluated to enable learning to be captured, and to help future LINks to be developed effectively.

County Durham is one of the nine project areas. The other areas are listed below. The Project in County Durham allows us to think particularly about how a LINk might work in an area which has three levels of local government (county, district and parish / town councils), a large number of local voluntary and community groups and a strong mix of rural and urban areas.

You can read more information about LINks in the Government's response to a document called A Stronger Local Voice, available from the following website >> go to the KMS >> the changing NHS >> LINks

Each of the Early Adopters:

- will have a project group made of local stakeholders who own and direct the project. Members of the Durham project group and the group's Terms of Reference are listed below.
- is essentially a community development project looking at the structures required to empower and support community engagement in health and social care.
- will have significant freedom to work with local partners in the most appropriate way to look at the issues for LINks. For example, they might set up a formal shadow LINk and test it for 4 to 6 months; they might develop a series of local working groups looking at local LINk issues; or they might hold a local conference looking at individual issues or communities of interest.
- will run alongside existing Patient Forum activity in their area.

Some of the issues the Project might look at over the next year include:

- What practical and other support does a County Durham LINk need to make it work?
- What are the local issues in health and social care and how would an issue become something the LINk would look at?
- What opportunities are there are for the LINk and what are the challenges and threats?
- Who needs to be involved in the LINk and what interest is there?

- How would a LINk engage with the wider community and how can it improve on equality and diversity?
- How can the LINk add value to what is already happening and how would it relate to, for example, the Local Strategic Partnerships and to the Local Area Agreement?
- How would the LINk be organized? This could include looking at membership, constitution and structures; the balance between individual and organization membership; how will the LINk be held to account; how might non-members or contributors get involved.
- How would the LINk relate to the regulators such as Healthcare Commission and other partners such as the Overview and Scrutiny Committee.

The nine Early Adopter Projects

- County Durham
- Doncaster
- Dorset
- Hertfordshire
- Leeds and Bradford
- London Borough of Kensington & Chelsea
- Manchester
- Medway
- South West Peninsula

Members of the County Durham Project Group

Durham County Council: Peter Brookes (to end March 2007); Geraldine Waugh; Carole Payne; Lee Ling; Gerald Tompkins (from April 2007)

One Voice Network: Jane Hartley; David Haw

Patient and Public Involvement Forums: – two from Jim Rochester; Carol Briggs; Audrey Chapman

Overview and Scrutiny: Feisal Jassat; Stephen Gwillym

Local Strategic Partnerships: Two members, to be confirmed

Local National Health Service: Paul Frank; Pat Keane

Healthcare Commission: Colin Wilson

Forum Support Organisation: Charles Tremeer

CPPIH: Sally Young; Ross Cowan

Terms of Reference

The Project Group will oversee the initial establishment of the early adoptor LINk for County Durham.

Aims

The arrangements for the County Durham LINk should aim to ensure that

- health and social care services are responsive to what the people using them want and need
- health and social care services are accountable to service users and local communities
- people are empowered to be active partners in their health and social care rather than passive recipients
- the LINk builds on and develops existing local mechanisms for engagement
- the LINk should be flexible, adaptive and transparent
- Promote and support the involvement and influence of local groups and individuals from across the community

Objectives: The project group will

- Shape local outcomes for the LINk
- Draw up an implementation plan for the early adopter site
- Set up arrangements for a local Seminar to help develop the LINk
- Lead the design and development of the local model
- Develop the specification for the service in the light of national guidance and the local commissioning and engagement processes
- Support communication with stakeholders
- Engage with local communities
- Support the CPPIH Transition Coordinator, and enable their access to local networks
- Performance manage the project and the effective use of resources
- Contribute to national and regional learning
- Scope existing networks across client groups and the different areas of County Durham
- Contribute to the national evaluation of the early adopter projects and the implementation of LINks

Appendix C

We asked you if you to send us examples of events, networks or forums that you have been involved in.

We wanted to know what was good involvement, and what was bad.

This is what you told us...

Good involvement...

Principles

- Is honest and clear about what people can and can't influence – if you are just informing us what you plan to do, tell us that!
- Involves people, isn't just a series of presentations, usually just telling you what will happen
- Uses existing structures
- Responds to our Agenda, based on the issues that concern us
- Values the people who take part
- Values local knowledge, needs and wants

Preparation

- Has a clear Agenda, which people get in advance
- Mixes people from different sectors and organisations. Badges with names and organisations helps people to mix.
- Targets people and groups for specific issues or meetings and supports them to attend and take part
- Provides training and support so that people can make a real contribution

During the Process

- Clearly states at the beginning of the event or process what the objectives and time-scales are and why we are doing this.
- Is clear about the time people will need to spend on something and sticks to it
- Focuses on a small number of issues of questions
- Mixes people from different sectors and organisations and supports people on their own

- Has strong leadership / chairing to ensure self-interest groups don't take over and who defuses things when they get heated
- Takes place in an ordered but informal atmosphere where people feel comfortable contributing
- Keeps it short
- Is interesting and exciting – uses a mix of methods
- People listen to what is being said, reflect and consider and then share their ideas
- Short sessions with breaks

Accessible and inclusive

- Held pre-consultation meeting so we could influence the process and what was in it
- Provides support services ensuring inclusion of partially sighted and hard of hearing and deaf participants
- Organisers, facilitators and speakers are all Deaf aware
- Smaller working groups, supporting people who may be hesitant about taking part
- Is inclusive, making sure people with a learning disability can take part
- Involves families, perhaps by providing freebies for taking part
- Information and presentations use more visual material, pictures and illustrations, and are not too complicated
- Holds events in local communities including those living in rural areas
- Holds events in a central venue

Accountable and leads to something

- At an event, give people a summary of what has been said and what will be taken forward
- Acknowledges and records disagreements and alternative proposals
- Has the support of senior staff who can make a difference and who listen to what is being said
- Must lead to action / results, based on what people have said
- Produces a report including what has happened / what will happen
- Feeds back with follow-up meetings

- Only involves people when 'they' want to change something
- Is always looking for the 'real voice' of the people – what's wrong with the people who give up their time to get involved
- We do the work, they make the decisions

Poor Preparation

- Just based on articles, leaflets and posters – you need to get out and meet people
- Thinks involvement is about translating leaflets – you need to get out and meet the different communities

Poor Process

- Is not representative and people just come to grind their own axe
- Allows a small number of people to co-op an event for their own purposes
- People sat in rows being talked at
- Seriously over-runs on time, without everyone's agreement
- People interrupting each other and speaking over the top of each other

Excludes people

- Power point presentations with too much information, text too small and no handouts or summaries
- Putting the lights out for presentations which means people can't see their communication support workers - signers, interpreters, notetakers etc.
- No opportunity for people to contribute
- Uses jargon no one else understands
- Ignores the views of children and young people
- People talk too fast
- Lacks outcomes
- No choice or chance to influence an outcome
- Writes our own views on a flip-chart and reads them back to us – and?
- Asks us what we think of 'their' ideas
- Tells you what is going to happen and
- asks you to inform your organisation

- Being told it's due to cutbacks or overspend
- PCT re-configurations – everyone knew the decision had already been made so why bother. Look at what's happened!
- Goes through the motions – no one said they wanted a replacement for the County Hospital at Earls House but that's where it's going!
- Suggestion boxes, no response and no action
- No idea what has happened as a result of my involvement
- People who never feedback anything, even when they promise they will

Notes

Shaping Health

Better decisions
Better health

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www.cppih.org>>go to the KMS>>The changing
NHS>>LINks>>LINks Early Adopters>>County Durham EAP

LINk