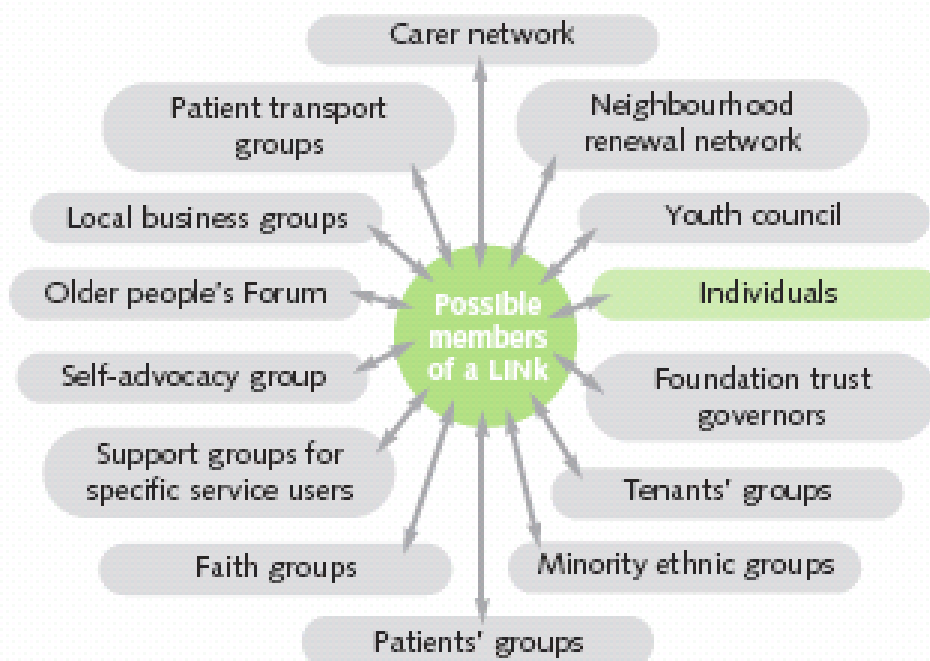


# Local Involvement Networks Consultation 2007



A meeting was held at Leeds Civic Hall for Service Users to discuss the proposals for the Local Involvement Network (LINK) on the 4<sup>th</sup> December 2007. Further Staff Briefings were held during the week commencing 17<sup>th</sup> December 2007. This document brings together the responses to these consultations

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## Service User Event 4<sup>th</sup> December 2007

An event was held at the Civic Hall. Service Users were consulted with for their opinions and comments with regards to the setting up of the LINKs network for Leeds. A number of questions were put forward on the day. The responses for each of these questions are given in this document.

### ***What is important to have a say in.***

**Question:** What do you want a say in?

It was stated that '*Involvement and 'having a say' needs to mean - influence - being able to change things*'

Some felt that they would like to be:

- Able to visit/inspect services
- Work closer with GP surgeries – support them with relevant information

It was felt that having a say was necessary in:

- Long term conditions - carers need to be listened to and told what is happening to their issues and concerns
- Development of the LINK and to influence change Communication
- Homecare services
- Making Involvement meaningful
- Accessibility of information and meetings
- Funding of what works
- Choice of who provides service (Host and Groups)
- I want to have a say in what I want to have a say

Others felt that they would like to investigate 'How GP's communicate with voluntary organisations to help improve the 'patient pathway' – we hope the LINKs will be a tool for this'

### ***What works in involvement***

**Question:** What do you like [...] about involvement currently?

The responders to the event believed that what works in involvement is:

- Information about services, being both good & necessary for grass roots working
- Willingness of organisations to involve service users in design + development of services
- Confidence / trust in service providers

From a **personal standpoint** some responders felt that from their involvement they had '*Learned from each other – sharing information*' and that from this '*Knowledge is Power*' and '*Enabling to make a contribution*'.

Other individual benefits highlighted include:

- Friendship/fellowship communication.
- Seeing enthusiasm.

- Positive – quality of the people working with.
- Meeting people, linking up.

The importance of 'Building skills' was also thought to be important.

The involvement process itself was mentioned with positive aspect expressed:

- We feel people are involved at all levels of the organisation and that our suggestions are listened to and acted on.
- Patients being able to influence NHS services in Leeds

The success of this '**Mainstream inclusion**' was seen to work where those included could see:

- Recognition for projects that work.
- Making things happen, make things change.
- Good results for programme.
- Achievement.

### ***What doesn't work in involvement***

**Question:** What doesn't work well currently?

What would you like the LINK to do about it?

Some responders felt that the involvement procedure is **just a process**, paying '*lip service*' to involvement requirements, with no understanding of the main issues. The comments follow:

- [The involvement process is] 'Show and tell' rather than true involvement.
- Never enough time for meaningful involvement, deadlines are too short.
- More awareness about disability equality is needed.
- "*I hate being given 'lip service' and smiles, then being ignored.*"
- People talking at you.
- Done deals.
- Exclusion from policy making.
- What is planned at a strategic level doesn't work at grass roots – more involvement needed.
- '*What they like (said).*'
- Relationship between commissioners and providers is too close.
- Fighting to raise profile.
- Lack of awareness of the actual issues.
- Misunderstanding - formal, informal

It was thought that where '*lots of new initiatives and different priorities*' the involvement process does not accommodate this. The '*LINK will need to be flexible so it can change & adapt to change*'.

A few responders felt that they are not currently **listened** to or are able to **access** the involvement process:

- If someone has a problem and they are not part of a group, how are they listened to/ heard?
- People do not listen – don't show respect.

One commenter stated that '*Mental health service users are (not) sufficiently listened to, nor [are] their views allowed to influence and improve services*'. The solution to this would be to simply '*listen*'.

There were several comments surrounding the lack of **diversity** in the membership of current involvement mechanisms:

- Too few people are doing all the work in involvement. - Usual faces.
- [There should be] access for all.
- [There is a] focus on defining categories of people and looking at differences between people, not similarities.
- Disadvantaged views [are] not known.
- Lack of diversity.
- Professional Patients' exclude others from involvement.
- [There needs to be] representation of community groups.
- People not connected to each other
- Not cross section of population
- No joined up thinking to deliver solutions
- Too many groups
- Inequalities via not 'pursuing perfection' or not sharing best practice
- Sharing best practice & information
- Access; information relating to access; access to commissioning / commissioners

Some solutions to the lack of **diversity** open to LINKs were discussed:

<b>Problem</b>	<b>Solution</b>
Lack of individual involvement	Individuals to be able to benefit / participate without having to be members of links
Not creative in ways of involvement	Need to ask individuals how they want to be involved or consulted + be creative in accommodating them. - Ensure link HOST undertakes to reach 'hard to reach' groups'
Not enough support for some people to allow them to become involved - carers, travelling costs, childcare etc.	Support volunteers properly through transport/training
Methods of engagement	Need to be more inventive about methods of engaging & make it easier for all people to contribute – go to them, don't expect them to go to meetings every time.

A very few responders felt that the absence of any **cash** benefit was a barrier to effective involvement:

The current mechanisms for involvement were thought to be too **complicated** with unwieldy processes being a '*Barrier to involvement*':

- Bureaucracy - Too much paperwork - Ticking boxes - Repetition of reporting
- Takes time
- Mechanisms don't work - System / approach
- Complicated structures
- Use of acronyms (jargon)
- People don't know what is happening - lack of clarity - don't understand how involvement works
- Governance arrangements don't work

Some solutions to these **complications** were discussed:

<b>Problem</b>	<b>Solution</b>
Complaints can be too intimidating	Develop more options for users who are unhappy with services
Involvement not long term	Need for a long term framework + investment + support for volunteers.

It was felt in many cases that the **lack of adequate feedback** of results from involvement is a failing of the current involvement process:

- Lack of accountability / feedback
- Poor responses build mistrust - people get discouraged from being involved again
- Not sure what happens to suggestions – don't get feedback
- Lack of reaction
- Needs of deaf service users are identified, agreed, but not met

Solutions to **lack of adequate feedback** were:

<b>Problem</b>	<b>Solution</b>
<i>Groups often working on similar projects, but [not] know[ing] what each other is doing – could be working together more effectively.</i>	It was thought that if the LINK should 'Give feedback from consultation'
No results: 'Need action not words'	A transition of power to the service user - 'active citizenry in service provision'
Poor at giving feedback to the public who have been consulted. Public don't know if their input was ever used or listened to.	Listening turned into appropriate action

**Funding** of the involvement process was also thought to be an obstacle:

- Short-term funding.
- Joint funding required for Social & health consultations.
- Searching for funds constantly.
- Lack of financial resources for the forums.

Some responders commented that through involvement change had occurred for '**changes sake**':

- Frequent reconfigurations in health (& then back again) are perceived by the public as a waste of money - change could be better managed + better communicated.
- Reconfiguration of services has had a negative result.

Overall comments were made relating to specific and overall issues with involvement processes:

- GP practices need to take some responsibility for involving minorities (Deaf, disabled etc)
- Cultural ethos wrong for addressing issues raised through involvement

### ***Host Should***

**Question:** What do we want the Host organisation to do?

The following comments are broken down into the respective requirements of the Host organisation that were thought important by the responders of the LINKs event.

Administration requirement of the Host organisation:

- Administration of involvement, practical aspects like photocopying.
- Gather evidence about number of Births etc.
- LINK needs to be setup & work to the COMPACT.
- Needs to be able to enforce timescales.
- .Show care plan being met - monitoring within host - has feedback been acted .upon? - Independent survey data / complaints.
- Track all involvement.
- Very good admin & organisational skills.
- Need plan for LINK and Host to work to - agreed at start and reviewed each year.
- Allocate resources efficiently.
- Co-ordinate involvement.
- Form National forum for LINKs - information sharing.

Experienced and knowledgeable organisation:

- Awareness of all key agencies in the city's health geography.
- Be clear about how people's experiences can make a difference.
- Capture information on knowledge of changing needs.
- Experience in involving people/ working with service users.
- Expertise to make sense of things.
- Have expertise in complaints management - see complaints as a positive experience.
- Host needs to be a 'sign posting' facilitator + communication link + PA to the group.
- Information for people about services - advocacy, complaints, strategic.
- Keep and extend forum support organisation
- Knowledge & expertise of what's available.
- Knows who to contact / network.
- Needs terms of reference.
- Recognise the complexity - 'one size does not fit all'.

- Experience in involvement.
- Experience of volunteers in Leeds.
- Well established.

Locally based organisation with an understanding of the needs of the population:

- Based in Leeds and Citywide.
- Consult with local people not council.
- Experience of working with diverse communities.
- Facilitate people and organisations.
- Good access to local knowledge.
- Link in with how service providers collect info.
- Listen to its members.
- Local knowledge.
- Need to have local contact or employ someone with contacts.
- Recruit group's e.g. Young people, employer networks.
- Respect individual choice.
- Show / prove 'exclusivity' of groups / disabilities.
- Structure to reflect size of the city.
- User friendly – non-threatening.
- Work in Partnership.
- Work to avoid duplication of effort & people leaving LINK.

Financial consideration for the Host:

- Be good value for money.
- Should reinvest profit.
- Offer incentives (end result) to make it worthwhile.

Host should be an outward looking proactive organisation:

- Break down barriers.
- Build trust and confidence - making an impact.
- Get public involved – make aware of what the issues are.
- Feedback to Department of Health at local and national level.
- Have a role in training - community sector representatives - statutory organisations - real people.
- Have a vested interest in developing services.
- Improve working relationships between different organisations.
- Influence statutory authorities.
- Inspire public with trust/ confidence in links.
- Lobbying body.
- Make changes – have control and power.
- Outcome focussed approach.
- Peer support - belief that can change things through peer involvement.
- Role modelling - the positive attitudes.
- Seek to increase membership.
- Vision for future - long term funding - review continuous improvement.

Host should be experienced in communicating with a diverse audience:

- Influencing & authoritative - able to get links views across.

- Plain language Keep things simple to understand.

Overall the Host organisation must be:

- Independent of local authority.
- Transparent in accountability.

### ***Host Shouldn't***

**Question:** What we do NOT want the Host organisation to do?

*'There is a fear that the host will have too much influence and be a barrier between the LINK and the authorities.'*

Also the Host organisation must:

- Not become a 'talking shop'.
- 'Not[be] employ[ed] on price alone', nor must it be allowed to 'Make a fast buck'
- Not be accountants or solicitors

### ***Host Attributes / Visualisation***

**Question:** How do you visualise the Host?

The following is a list of the attributes that were thought important to the Host organisation:

- |                          |                                    |
|--------------------------|------------------------------------|
| • Accessible             | • Non - profit making organisation |
| • Accountable            | • Passionate                       |
| • Always available       | • Positive attitude                |
| • Assertive              | • Proactive                        |
| • Community Organisation | • Reflective                       |
| • Confidential           | • Reliable                         |
| • Decisive               | • Responsive.                      |
| • Deliverer              | • Robust                           |
| • Diverse                | • Self Sufficient                  |
| • Empathic               | • Social enterprise                |
| • Empowering             | • Strategic                        |
| • Enabler                | • Supportive                       |
| • Enthusiastic           | • Trustworthy                      |
| • Equal                  | • Visionary                        |
| • Impartial              |                                    |
| • Listener               |                                    |

The following is a list of the ways that the responders described how they imagined the Host:

- Added value for city & its people
- Candle – providing light (moths around the flame)
- Can step back & let LINKs come forward
- Host has money and power
- Host is like a Personal Assistant
- Less words - more action
- Like a dog on a leash
- Like a library, PALS, CAB
- Tree of Life

## **Staff Briefings Week Commencing 17<sup>th</sup> December 2007**

Staff members were invited to attend one of two LINks briefing sessions held on the 17<sup>th</sup> and 20<sup>th</sup> December 2007.

A presentation was delivered explaining LINks and the timescales and considerations required for the formation of LINks as a replacement for other involvement mechanisms.

A number of questions for discussion were presented and comments were recorded for the purpose of consultation. This document presents those comments in terms of the main themes associated with these.

### ***What works in involvement***

**Question:** What currently works well regarding involvement?

The staff felt that the following areas worked well under current involvement mechanisms:

- Existing forums
- GP Patient surveys
- Expert patient programme - empowers to get involved
- Staff representative of patient - ensure feedback from patients
- Practices involvement - LIFT changes in practices
- Engaging & need
- People appreciate having opportunity to participate & influence service delivery

### ***What doesn't work in involvement***

**Question:** What currently works NOT so well regarding involvement?

The staff comments on this question are listed under there relevant theme:

Lack of **diversity**:

- Diabetes user involvement - not typical diabetic patients
- Not true user involvement

Difficult to **access**:

- Podiatry -have not tapped into involvement resources
- Not enough training to facilitate patient involvement .patient relationships
- Not enough training to ensure staff can manage clinical vs. patient needs

Lack of **resources**:

- Not enough resource - admin of collation of information
- Commissioner/ provider relationship

**Complicated / ineffective**

- Patient survey too long - impact the response rate

- Some better than others - some overlook & not consider or think done & have not
- Think financial, but not think communication or why doing it CI - leads to patient confusion
- People come with personal issues & when not resolved feel dissatisfied
- Strict & commitment expected - not link well with other involvement structures - not joined up
- Structures - what in place & it exists e.g. PPI forums are not that effective

## ***Changes to Involvement***

**Question:** What would we like the LINK to change?

Participants were requested to consider how the LINK would change the mechanisms of involvement. The responses are shown:

Encourage **diversity**:

- Encourage participation from - inarticulate, disadvantaged, and intimidated by the forum scenario
- True representation of the Seldom Heard
- Avoid risk of political lobbying 'hobby horsing' - avoid one voice overbearing
- Inclusion of voluntary organisation will be very beneficial

**Build** on previous work:

- Be smart - reuse what is out there already
- Remove barriers between services
- Tap into what is already there - be more informed

Provide and deliver **training**:

- Training needs to strengthen commissioner / provider relationship
- Training in customer care & managing patient expectations
- Training & development - self care agenda
- Training and enabling of individuals

**Flexibility** for change:

- Develop a formal mechanism for ideas for consideration - to allow feeding in of comments
- Have users party to complete decision - rather than just an adjunct
- Will make public involvement an easy process - informing staff on how to access these services
- Link can give power back to 'Cinderella' services - i.e. those not politically prominent
- Hold organisations to account with additional powers for delivery - access to Overview and Scrutiny Committee

It was thought important that there be '*Feedback of results based on involvement.*'

## ***Host Qualities***

**Question:** What qualities should the Host have?

The qualities required for a good host were given as:

### **Locality:**

- Citywide remit
- Not biased to one area / population
- Leeds based - visible presence - accessible
- Leeds specific issues
- Knows Leeds & best way to involve local people, know health inequalities

### **Experience:**

- Track record
- Not part of a major organisation
- Track record of strategic working - to handle high profile issues
- Established communicator - with good networks
- Good organisational skills, good networks
- Credibility

### **Administrative:**

- Voluntary sector
- Independent
- Encourage setup of LINKs
- Need to be good as involvement but also work strategically

### **People centred:**

- Strong mentoring systems, organising skills - Systematic way of involving & ensure up-to-date
- Social enterprise opportunity
- Inclusive reputation - consider all diversity / populations
- Not-for-profit organisation
- Not politically influenced
- Unbiased

### **Dynamic:**

- Outcome driven
- Deliver
- Responsive

### **Financial:**

- Income generation - feedback to sustain operation

## ***LINK setup difficulties***

**Question:** What difficulties do you think there will be in setting up the LINK and how might we overcome them?

Some difficulties for the setting up of the LINK were highlighted:

- Understanding of the scope of the problem -Needs the present picture of what is happening in social & health care
- Stronger voices may be the only ones heard
- Set up times - establishing the service could take a long time
- Avoiding a watered down version of objectives
- How to sell it - publicity appropriate - so massive might put people off as large organisation, not so personal
- Structures do not need to change but views need to be taken to link carers groups - must have links back to groups
- Political pressure on Host organisation
- Fearful of conglomerate taking this on

Solutions were offered to other difficulties:

<b><i>Problem</i></b>	<b><i>Solution</i></b>
Loss of involvement between old and new mechanisms	Transitional plan required
Fear the loss of previous involvement work and experience	Retain the usefulness of previous measures 'don't reinvent the wheel'
Avoid funding going to estate purchases	An established organisation with existing base avoids unnecessary estate purchase from funding
Getting volunteers to be involved	Encourage new people with recent experience to get involved

## Current Involvement

**Question:** What are you involved in currently?

The groups were representative of the following groups:

- Access Committee
- Adult with Learning Disabilities
- Advocacy Network - Leeds
- Advocacy Support - Contact with various BME communities trying to access health & social services
- Alliance of Service Users & Carers
- Black Health – front line work emotional health, sexual health of BME communities
- BME communities access to maternity services
- Carer Awareness - Training in GP Practices
- Dental Health – difficulties in accessing NHS dental care. Questionnaire carried out
- Disability Reference Group
- Equal Access - Leeds Blind & Partially Sighted
- Equipment supply - all aspect of community equipment
- Health & Well being Scrutiny Board
- Hospitals - particularly services for the deaf - staff training - raising awareness
- Independent
- Independent Living Project
- Leeds Jewish Blind Society (LJWB)
- Leeds Learning Disability Reference Group
- Leeds Muslim Consortium
- Leeds Partnership Foundation Trust
- Leeds PCT PPI Forum
- Leeds Voice – Helps increase representation of vol. community + faith sector groups at a strategic level (i.e. MLB)
- LGI Kidney Patient Association - linked to National Kidney Federation
- Linkage & many involvement mechanisms for older people
- Locality Networks
- Mental Health – service modernisation, service user newsletter - Interpreter services for the deaf - involvement issues - Improving the say of service users
- Moor Allerton Elderly
- MS Federation
- National Federation of the Blind (Leeds Branch, other national organisations)
- NW Locality Development Scheme
- Older People's Forum / Reference Group
- Plus Group - provides medical information, legal, support, action plans for recovery - training for carers
- Positive Care Programme
- Scrutiny Board – co-opted member
- Service-user involvement work + arranging consultation
- Single issue – Local & National
- Skippko – Community Arts Programme
- Society for Deaf & Blind (formerly)
- South Leeds Development Scheme
- Supporting community Health Projects - Support health skills - involvement - wide variety of communities
- Tenants Association
- V.A.L – Physical sensory impairment network + others
- Volition