

Gathering the Learning

What we have found out so far about Early Adopter Projects across England

Introduction

This document draws on the experience of the nine Early Adopter Projects and provides a brief checklist of issues and factors that other communities might want to consider when establishing their own LINK.

The purpose of this briefing paper (read in conjunction with the other 'Getting ready for LINKs' resources) aims to provide a flavour of the key achievements and findings from the Early Adopter Projects. The idea is that these can help you to think through how a LINK might look and feel in your area.

These are not intended to give a prescriptive view of how LINKs should work in the future, but more of a snapshot of some of the innovative and creative ideas that the Early Adopter Projects (EAPs) have come up with in order to make LINKs successful.

Some aspects of the LINK programme of development have become clear in the early days of the projects whilst others require further thought and exploration – this is precisely why we are supporting the EAP work. There is a great deal of activity still underway and this report is a work in progress which aims to share learning to date.

Examples of key achievements and successes to date

- A total of 570 people have been involved in the 9 regional Events across the Country. These have included people from Local Authorities, Patient and Public Involvement Forums, the Voluntary Sector and the NHS. Outcomes from the events are available at ¹www.nhscentreforinvolvement.nhs.uk
- A range of innovative ways of working have been developed including the projects in **Hertfordshire and Kensington and Chelsea** setting up specific sub-groups to look at issues around commissioning, the **Medway** project developing text messaging and web-based communication channels and the **Durham** project exploring how LINKs will work with children and young people.
- Evidence exists that engagement has been a positive experience for those taking part in stakeholder events. For example, in the **South West** test site, 87% of people who completed evaluation forms regarding the June 2006 stakeholder event rated the event either 4 or 5 out of a possible 5.
- In **Leeds/Bradford**, a Health Participation Network has been established made up of interested groups and individuals including a young person's advice centre, Irish Health and Homes, Women's Health Matters, ten of the community groups already involved in Leeds Involvement Project (LIP) and two Speakout seldom heard groups.

¹ www.nhscentreforinvolvement.nhs.uk/what'snew

- Through raising awareness events supported by the Centre for Public Scrutiny, the Health Overview and Scrutiny Committees (HOSCs) in **Bradford and Leeds** have now included in their workplan a number of issues raised by the Health Participation Network. These include: enhancing communication skills of frontline staff in particular relating to patient dignity and respect, equality and diversity issues also improving how personal care and assistance in hospital is provided to patients.
- A training module, (describing why the Healthcare Commission wishes to engage with patients and the public and the ways in which they do this, including 'experience tracking') has been devised and is currently being accredited. It is anticipated that this will be launched later in the year.
- Worked up models of what a LINK may look like have been developed by the **Kensington and Chelsea** Early Adopter Project.
- In the **South West** Site a network, made up of ten community groups and / or individuals will be established in each of the local authority areas, i.e. Plymouth, Devon and Cornwall. The network members will be trained and supported to engage with the wider communities on specific core standards e.g. focusing on patient privacy and dignity.
- In other Early Adopter sites ways are being explored to ensure that LINKs structures are fit for purpose in meeting the needs of local communities by giving consideration to geographic factors, the structure of the NHS and social services and the diversity of their local populations.
- It is anticipated that the support organisations will work with the Healthcare Commission to develop a tailor made online community. This will support communication between network members, support organisations and the Healthcare Commission across a predominantly rural area.
- The County **Durham** EAP has used a community development approach and supported over 70 meetings and events and engaged with over 700 people including a large countywide event for 120 people.
- In **Leeds and Bradford**, two public stakeholder events were held in March and June 2006 attended by approximately 160 people. Due to huge interest, the second event was oversubscribed. Key messages from the people who attended these events included the importance of: actively reaching out to excluded groups, providing feedback and sustaining involvement over the long-term, communicating clearly and appropriately, and working in partnership with existing organisations in order not to 'reinvent the wheel' where good work is already being undertaken.
- The **Manchester** EAP hosted a city wide event which attracted 150 people. A sub group of the local forum has been formed to work on an issue in a 'LINK-like' way focussing on Stroke services.
- In **Hertfordshire** an event was held specifically to focus on how LINKs will work with, and for, people who use mental health services and people with learning disabilities.
- In **Dorset**, in recognition of the rural nature of the area three separate events were held taking a drop in approach aimed at reaching the maximum number of people possible whereas **Medway** held two events at different times including an event in the evening to attract people who work.
- Concrete resources and tools have also been produced which will be shared widely. These range from DVDs and booklets highlighting the key features of different approaches to engagement through to Stakeholder Engagement and Communication Strategies.
- An outcome of working with the Healthcare Commission test sites has seen the development of a patient experience questionnaire (based on five Healthcare Commission core standards as described in ² *Standards for Better Health*) and an issue/experience tracking form.

² Standards for Better Health, DH, 2004. This document establishes the core and developmental standards covering NHS health care provided for NHS patients in England

Learning from Experience

A number of recommendations and learning points have been gathered so far in this project phase that will influence the final guidance and suggested ways that a LINK may operate. These include:

Engagement and gathering information

- Engagement via existing community groups can help to increase access to stakeholder groups, particularly seldom heard groups.
- Information gathering through face-to-face methods rather than questionnaires appears to have gathered higher quality data, as well as being appreciated by participants.
- Participants have reported finding some of the language and jargon used across health, social care and in involvement off-putting, and this should be avoided. From experience this feedback often particularly focuses on avoiding the use of acronyms and such like.
- Consider how to structure an initial stakeholder event – for example ‘market place’ format with participants travelling from one ‘stall’ to another. Other approaches might include group problem solving exercises to stimulate debate, and using music and film making to engage seldom heard groups and present their views.
- In urban areas, consider how to structure the LINK depending on the geographic makeup of the area. Similarly, in small towns and villages where there is a more ‘disparate’ community, different structures may work better for example working with parish councils and talking with distinct local groups.

Sharing the Learning

- Across the projects and sites, there are several examples of locally initiated collaboration between organisations in order to prepare for LINKs, and the majority of sites have actively contributed to feeding in information for dissemination through the ³Commission for Patient and Public Involvement in Health and the ⁴NHS Centre for Involvement websites.
- Learning is also shared on an ongoing basis between staff working in the Early Adopter Projects and tests sites and their colleagues locally. ⁵A national LINKs bulletin has helped to give a sense of national identity and a platform for sharing experiences. Early Adopter sites such as **Durham** and **Hertfordshire** have also produced local newsletters and information. Thought should be given to creating a ‘localised’ local LINK bulletin.

Developing a sustainable approach to patient, service user and public involvement

- Early learning from the projects has shown that LINKs will be most effective when the staff responsible for leading work on the ground have local knowledge and experience. A key feature of sustainability is ensuring that adequate resources are in place. Successful engagement is incremental and should be built up over time.
- Positive experiences of initial engagement events will be vital in order to build the foundations for sustainability. Initial feedback from events across the Country attended by patients and members of the public is largely positive, and it seems that progress has been made in terms of raising awareness of LINKs.

³ www.cppih.org.uk/

⁴ www.nhscentreforinvolvement.nhs.uk/

⁵ <http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/PatientAndPublicinvolvement/index.htm>

Working in partnership

- Staff in the Early Adopter Projects and test sites found that there is no 'one size fits all' approach to engaging with NHS organisations. Due to the wide range of different types of organisation in a typical local health economy a customised approach is necessary.
- A clear message has come through that in order to avoid duplication of effort and save time and resources, ongoing involvement and dialogue with local statutory organisations is essential.
- The capacity of local voluntary organisations is a further important consideration, especially in areas where the voluntary and community infrastructure is under-developed.

Enabling wider ranging, representative engagement

- Stakeholder mapping and profiling of the local community are essential first steps in establishing a LINK. Local authorities may wish to commission these activities in advance of their work to procure hosts for LINKs.
- Included in such an exercise should be the identification of the most seldom heard groups – and in this regard, no assumptions should be made about who these groups are. For instance, in some areas students and those who work normal office hours have proved to be the least likely to engage.
- Members of Patient and Public Involvement Forums will undoubtedly have an important role to play in the setting up and being involved in LINKs, due to their extensive experience and local knowledge, but the LINKs model is distinctively different, and this will have to be clearly communicated and recognised.

Governance, accountability and procurement

- Issues exist around deciding how the membership of LINKs should be constituted – and in particular what weight is accorded to organisational versus individual membership. There is unlikely to be a universal approach to this, but it should be recognised as a key question to be discussed and agreed accordingly.
- Procurement processes can often be complex, resource intensive and therefore challenging. In addition, a number of rumours associated with procurement have been aired throughout the evaluation to date, including the view that processes will not be fair. Local authorities need to work to address this view.

Designing for Impact

- LINKs ultimately need to be set up and designed with a view to achieving their goals: influencing service design, enhancing accountability, and feeding in to scrutiny and regulatory processes.
- There are some concerns about LINKs becoming, or being perceived as simply a further complaints function. There is a level of uncertainty about what will constitute a 'genuine' issue for a LINK to take on, and where staff or volunteers should be signposting to other organisations.
- Simulations can usefully be undertaken, as demonstrated in the **South West** test site, to bring together potential 'host' organisations. This makes it possible to examine how they would work together as a consortium and to identify strengths, weaknesses and potential synergies and sources of conflict at an early stage.
- Experience suggests that organisations that are good at engagement may not necessarily have the skills required for the kind of analysis and synthesis of data that LINKs will collect and likely to be useful to providers, commissioners and regulators of health and social care organisations.



The National Centre
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Further information

If you want to find out more, go to

Commission for Patient and Public Involvement in Health

www.cppih.org

go to the Knowledge Management System (KMS)

go to Changing NHS:LINKs, Early Adopter pages

Department of Health

www.dh.gov.uk/patientpublicinvolvement

Search for 'Local Involvement Networks'

NHS Centre for Involvement

www.nhscentreforinvolvement.nhs.uk

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