

# Shaping Camden's Local Involvement Network (LINK)

the new body for  
service user, patient and public involvement  
in health and social care



## Report Camden LINK Event Thursday 6 December 2007

This report can be made available in braille, on tape or in large print on request. Please contact Camden Community Empowerment Network (Camden CEN) for further information in any of the following ways:

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# **1. introduction**

## **1.1 about LINKs**

In April 2008 Local Involvement in Health and Social Care Networks (LINKs) will replace Patient and Public Involvement Forums (PPIFs). LINKs will be networks of organisations, groups and individuals (patients, service users, carers and people with an interest in health or social care) who can represent the views of the range of different people that use local health and social care services. Their powers will include elements of scrutiny and reporting on local services and making recommendations for service improvement.

There will be a LINK in each Local Authority area, for which the Local Authority will get a grant from the Department of Health (DH). In each area a host organisation will be responsible for setting up the LINK and providing ongoing support. The host will be accountable to the LINK.

Camden Council is responsible for procuring a host organisation for the Camden LINK, but the LINK will be independent of the local authority. To begin the LINK development process Camden Council approached the

Camden Community Empowerment Network (Camden CEN)<sup>1</sup> to host a LINK event for local stakeholders.

## 1.2 about the Camden LINK event

The aim of the event was to give local groups and individuals in Camden an opportunity to shape their future LINK. There were three main objectives:

- To increase understanding of the LINK and some of the opportunities and challenges that may lie ahead in establishing a LINK in Camden;
- To explore ways in which local people and organisations could get involved in the LINK, and to generate ideas for an appropriate structure for Camden's LINK;
- To discuss the role of the LINK host organisation in Camden, and to generate ideas about what might be included in the specification for the host.

Sixty-five people attended the event, which took place at the London Irish Centre on Thursday 6 December 2007. The participants reflected a range of LINK stakeholders including statutory health and social care service providers, individual practitioners, and the voluntary and community sector.

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<sup>1</sup> *Camden CEN is an independent membership structure that brings together Camden's voluntary and community sector organisations around areas of mutual interest and promotes the sector's engagement at a strategic and policy level in the borough.*

Most importantly there was significant involvement from service users, service user groups, Public Patient Involvement Forums and the public – who between them made up over 50% of the participants.<sup>2</sup>

The programme for the day involved four key elements:

- **Context setting** – providing information about LINKs and about the local experience of public involvement in health and social care;
- Focusing on **involvement** in the LINK – who should be involved, and how might they be;
- Sharing **hopes and fears** for the LINK;
- Focusing on **the host** – what type of organisation is needed and what should be its priorities.

The day started with a series of presentations and plenary question and answer sessions, which were then followed by round-table discussions and exercises in nine mixed stakeholder groups. The groups were facilitated by staff from the Local Authority and the Camden CEN.

Feedback on the event was very positive, and generally participants welcomed the event as a promising start to the process of developing Camden's LINK.<sup>3</sup> More than a third of

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<sup>2</sup> See Appendix 1 – participant profile

<sup>3</sup> See Appendix 2 – event evaluation summary

participants expressed an interest in being kept informed, and in being involved further in the development of the LINK at this crucial formative stage. In response to the interest generated in the LINK, this report contains an action plan for the Local Authority which has the creation of an information loop as its first priority to ensure that this communication and involvement happens.

### **1.3 about this report**

This report captures the main elements of the discussion and the ideas generated at the event, and is intended both as a record of the day but also as a practical tool to be used to inform the next steps in the LINK's development; particularly the procurement of the host and the host's own planning to take forward the LINK.

## 2. an introduction to LINKs

### 2.1 setting the context

The first part of the event was intended to set the context and inform participants about LINK developments to date at the national and local level.

Dean Stokes (Head of the London Borough of Camden's Strategy and Projects Team at the Camden Strategy Unit) gave the opening presentation. He introduced LINKs; explained what is new and different about the LINK idea; talked about Camden's current thinking on how the LINK could be developed locally; and highlighted some of the local good practice that Camden might build on.

#### **Key messages:**

- There is a lot of good practice in user involvement in the borough to learn from and Camden is committed to building on this in the development of the LINK.
- The LINK is likely to have a core group but beyond that will need to have a lot of flexibility in its approach and the structures it uses to engage people.
- A group of Council officers has met to discuss developing a Camden LINK. Following the event the Council is keen to expand this group to have wider user involvement for the next stage of planning Camden's LINK.

The second presentation was given by Peter Flavell (LINKs Transition Co-ordinator, Commission for Public and Patient Involvement in Health) who shared information on the development process and learning from the Medway LINK (an Early Adopter Project). Peter talked about the process undertaken by Medway to first recruit a project group, then undertake a consultation using a variety of methods, and then establish a LINK steering group. He highlighted the learning from their experience about what worked well and what didn't work so well.

**Key messages:**

- Setting up a small steering group with both health and social care representation proved extremely useful as a way of taking forward the work, and is to be recommended.
- Consultation with local people requires a lot of creativity and a wide range of methods if it is to really generate interest and enthusiasm for the LINK amongst more than the usual suspects.
- The idea that the LINK should have a core group and then a range of subgroups or other activities outside of the core has been positively received as a way forward in Medway.

## 2.2 building on existing foundations

Two local users of health and social care services gave a perspective based on their personal experience of public and patient / social care involvement their experience of having a say in decision-making about their care or the care of others.

The first account came from the perspective of a Public & Patient Involvement Forum (PPIF) member, Mr Neil Woodnick. Mr Woodnick's presentation identified some of the gains for all parties when patient and public involvement is done well, and moved on to identify a number of challenges that might face the LINK. These included getting people involved, retaining people's interest once they are involved, engaging effectively with Foundation Trusts, and, for voluntary organisations, maintaining independence.

### **Key messages:**

- The recruitment of new members has always been one of the greatest challenges faced by PPIFs, and it is likely to be the major challenge of the new LINK.
- To retain members, the LINK could learn from the PPIFs' experience that it helps to give people meaningful work and a specific role within their areas of interest.
- It will be important that the LINK invests in developing people's capacity to participate – eg. through support and training.

The second personal account came from an individual who who talked about the social care he receives. He has taken control of his care via the Direct Payments system. This system gives users of social care services the power to manage their own budget for elements of their care. Mr Babu Bhai Patel shared his story of using the system after a stroke rendered him in need of significant care in the home. Mr Patel outlined the support given him by a local voluntary sector organisation to enable him to take charge of his care and make the key decisions about how his allocated budget should be spent. He also touched on the benefits and learning he had experienced as a result.

**Key messages:**

- Having the power to make important decisions about how money is spent on one's own care can have extremely positive results.
- Making the shift to taking control of one's own care requires support and advice in the beginning as it does bring responsibilities that need full understanding.
- That support and advice needs to come from an agency that has the service user's interests at heart, and that understands the service user's needs.

## 2.3 participant questions and concerns

Following the morning's presentations, participants had the chance to address questions to the speakers during a lively question and answer session. The concerns raised during the session fell under three main headings – questions about involvement in the LINK; questions about the development process for the LINK; and questions about the remit and powers of the LINK once established.

### *Involvement*

**Communications and Inclusion:** Several participants raised issues of inclusion, for instance in regard to non-English speakers and those who might have communication or other support needs. The conclusion of the discussion that ensued was that this issue must be considered if the LINK is to be truly inclusive, and the budget implications carefully thought through by the host organisation, as no national or central budget exists for communication or access support costs.

**Demography and Diversity:** The point was raised that Camden is a very diverse borough and it will be a considerable challenge to the LINK to represent this and address such a wide range of needs and interests as are present in the borough. This issue was explored further during round table discussions about involvement.

## *Process*

**Building on what's there:** Several questions reflected a concern about the connection between the new LINK and existing bodies – what would be the relationships between them, how could good work and effective relationships that have taken time to build, be sustained. The hope was expressed that the LINK might pull together and streamline what's already there that's working well rather than reinvent wheels.

**Choosing the host:** There was some interest in the process for choosing the host, in understanding who would be involved. Clarification was given that a group of Council officers has begun to meet to discuss developing Camden's LINK and that this group will be expanded to have wider user involvement for the next stage of planning the LINK.

## *Remit and Powers*

**What can or can't be a LINK issue:** Specific questions were raised about particular issues and whether these would be the kinds of issues the LINK would deal with, eg. about inspection, or issues relating to charges for services. The conclusion was that careful consideration must be given to what would make something a LINK issue, who would decide and what would be the criteria for their decision. It was felt that the process for identifying appropriate LINK issues must

be considered at an early stage because spanning both health and social care means there is potential for the LINK to be overloaded with issues to take forward. There will need to be a robust and transparent mechanism for identifying and prioritising issues.

***Independence of the LINK:*** Questions were raised about who could run the LINK, with one participant curious about whether or not the Council could do this. Dean Stokes clarified that the legislation precludes this and explained that the Council can only procure the host and the host must be independent of the local authority.

***Balance:*** A concern was raised that as PPIFs are health-based and the LINK will take over from them, it might be difficult to ensure that the LINK is focused equally on both health AND social care. The panel response suggested that the key to getting the balance right will be ensuring the widest possible involvement so that the LINK is not health-dominated.

***Powers of the LINK:*** One participant asked what “teeth” the LINK would have, for instance in regard to powers of inspection. The panel members explained that the legislation allows that the LINK will have clear powers, including the power to enter certain premises and view services provided;

the power to request information about services and get a response within a specified timescale; the power to make reports and recommendations and receive a response within a specified timescale; and the power to refer matters to a health or social care overview and scrutiny committee and receive a response.

## 3. involvement in the LINK

### 3.1 who and how?

Facilitated 'round table' discussion groups enabled participants to explore and map out who should be involved in the Camden LINK, and why and how. The results were recorded as involvement 'maps' on paper table cloths. At the end of the exercise maps were passed around so that groups could review each other's and identify areas where there was common agreement about priorities.

Each group approached the exercise slightly differently, focusing on the aspects of involvement participants felt most strongly about. For example some groups focussed on the challenges for the LINK, whilst others mapped more detailed involvement structures. The information and ideas captured within the 'maps' combined to build up a detailed picture of local concerns and expectations of the LINK both regarding how it is developed and what it might look like (its structure).<sup>4</sup>

Taken together the 'maps' captured how very wide the involvement in the LINK should be, generating a long list of potential stakeholders, along with ideas about how they could be engaged.

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<sup>4</sup> See Appendix 3 for some examples of 'maps' created on the day.

There was strong support across the groups for the idea of some sort of a core at the heart of the LINK and then a range of different other elements, subgroups, activities, etc. outside of the core. It was felt this model would allow different types of involvement at different times for groups/individuals for whom involvement in a core group may not be the preferred way of engaging. There was a consensus that for the LINK to be accessible to everyone, it will only achieve this if it relies on different mechanisms for different groups or tasks, and if it is well enough resourced and managed. The right host organisation was felt to be crucial in this regard.

There was a clear view that the core representative group must be balanced between both health and social care interests.

Around the core some of the other 'groups' identified included: issue-specific working groups; expert patients and other knowledgeable individuals; client groups; special interest groups, etc.

The table below captures the "who" and the "how" of involvement that emerged on the day. It lists all the organisations and individuals mentioned within all nine maps (encompassing under general headings the range of specific

organisations that were mentioned). It also lists groups' ideas for how these people and organisations might be involved.

The involvement of statutory sector service providers and practitioners was the main area where opinion differed across groups. There was a lack of consensus about the appropriate level and type of participation for them within the LINK. A few participants felt strongly that the Council and National Health Services (NHS) should not be represented in the core group. Most, however, identified good working relationships with those service providers as essential to an effective LINK. Clinical practitioners in particular were singled out as important to involve if the LINK was to have proper access to some NHS services.

| STAKEHOLDER   | DETAILS OF POSSIBLE INVOLVEMENT   |
|---|---|
| Client groups (eg. patient and social care service user groups)                     | Inform and advise the core group and the host. Represented on core group.   |
| Current PPIF members  | Involved in various ways including core group, advice, information and working groups.  |
| Voluntary and community sector  | Represented on core group and networked with the LINK. Specialist advice, access to hard to reach communities and working groups. |
| National health and social care charities   | Networked with the LINK and able to collaborate on specific issues as needed.   |
| Individual health and social care service users and other knowledgeable individuals | Advice, expert patient or witness, working groups and connected to core group.  |
| Working groups  | Short life groups of stakeholders carrying out specific tasks.  |
| Individuals   | Anybody who wants to get involved generally or through specific work or interest areas.   |
| Faith groups  | Networked with the LINK. Access to communities. Involvement in working groups.  |

| STAKEHOLDER  | DETAILS OF POSSIBLE INVOLVEMENT  |
|--|--|
| Carers and carers groups                               | Core group, specific interest groups and working groups.   |
| School governors, schools, colleges                    | Networked with LINK. Young people's representation or sub group, working groups, advice and information.   |
| Tenant groups  | Consultation and working groups.   |
| Existing Camden networks and forums                    | Networked with LINK. Information-sharing, knowledge and expertise.   |
| Health and social care commissioners and practitioners | Liaise with LINK and with host. Working groups, talks and presentations  |
| Camden Council   | Liaise with LINK and with host. Core group   |
| NHS  | Liaise with LINK and with host. Core group.  |
| Islington and London                                   | Shared part of the LINK with neighbouring borough – could be through existing agencies that are cross-borough.<br>Networked with all London LINKs through pan-London LINK. |

## 4. a vision for the LINK

Throughout the day groups were asked to list their hopes and fears for the LINK as they arose during discussion. The lists that were created have been summarised here and we hope they will serve as a useful checklist of potential pitfalls to avoid, and potential goals to aspire to, in the planning process for Camden's LINK.

In summary, many of the hopes for the LINK were in relation to achieving real inclusion, diversity and independence. There were also hopes that the LINK would have real powers – an ability to undertake meaningful work and make a real difference.

Many of the fears expressed were in relation to resourcing, a fear that there would be insufficient resources; the need to balance power and manage political issues within the LINK in order that these issues don't distract from the work of the LINK; and again a fear that the LINK would be unable to realise its full potential and exercise its powers to make a real difference.

## 4.1 hopes

- Organisations and services can **work together**, and existing structures and networks support the LINK
- The LINK will **work effectively with others**, particularly groups that already exist
- The LINK will be truly **inclusive**
- The LINK will be able to **reflect the needs of all** the various local populations
- As a larger and more representative group the LINK will provide **a stronger voice** for people
- The LINK will be **independent** of the council
- The LINK will have **good communication** with clinicians and practitioners
- The LINK will really **achieve** something and not just be a kind of talking shop
- The LINK will be able to **influence** GP surgeries about concerns from patients
- A real **tension** between the LINK and service providers will exist to show that the LINK is working
- The LINK will work from **a social, not a medical model** of health and social care
- The LINK will manage to be meaningful and accessible so that **people will want to get involved.**
- The LINK will tackle **communications challenges** and take them seriously in trying to be truly inclusive.

## 4.2 fears

- The LINK will be **under-resourced** (in terms of a budget for research, admin, outreach and accessibility support)
- The LINK will struggle to be part of the solution process and could end up **just an identifier of problems** and giver of opinion
- The LINK will **lack transparency** in key areas – budget, governance, membership
- The LINK will be hampered by **lack of real power** to effect change and will become a tokenistic body
- The LINK will be **dominated** by either larger organisations drowning out the voices of smaller organisations, or by dominant individuals with their own particular issues
- The LINK will be **dominated** by the usual suspects
- The LINK will be unable to attract a broad spectrum of the population and will attract **just current service users**
- **Politics between organisations** will interfere in the effectiveness of the LINK
- The LINK will be **unable to gain access to services**, eg. foundation hospitals, GP practices
- The LINK will be unable to link health **and** social care
- The LINK may be unable to secure **true independence**

## 5. the host organisation

During the afternoon session each group looked at the role, responsibilities and key characteristics of a future “Host Organisation” for the LINK and then presented their two top priorities back to the conference. The lists below capture the items most commonly suggested by those present as important considerations for a strong and effective host.

### 5.1 immediate role and responsibilities

Develop an effective and creative communication strategy

Promote the LINK and publicise LINK issues

Set up a LINK steering group

Produce programme and action plan for setting up the LINK

Recruit, induct and train members and staff

Establish an equitable and transparent governance system

Develop policies, terms of reference, code of conduct

Carry out mapping exercises and clarify LINK priorities

Carry out effective research and reporting

Facilitate collaboration, visits, expert advice, consultation

## 5.2 ideal characteristics of the host

A local organisation

Local knowledge and well networked – including a broad knowledge of all potential individuals, groups and organisations

Good working relationships with LB Camden, PCT and groups in Camden

Approachable – user-friendly, able to build links and work with everyone, accessible

In-depth knowledge of health and social care

Experience and track record in community engagement and participation

Transparent financial management

Ability to manage resources to best effect for the LINK

Responsible and responsive

Able to manage people's expectations

Policy and change knowledge

Able to enable the LINK to work truly independently of the local authority

Able to bridge and pull together both health and social care

## **6. what next**

### **6.1 moving forward - action plan**

The Shaping Camden's LINK event was intended as the beginning of the process to commission a host and develop a LINK.

Camden Council have made a strong commitment to building on the work started at the event and ensuring that views shared at the event are fed into the development process for the LINK. The Council is currently working up a detailed commissioning and procurement process, which will help determine the timescales for procuring a host organisation for the LINK. The action plan below provides an indication of the steps that will be taken over the next few months to procure the host and develop Camden's LINK.

In the coming months the Camden Community Empowerment Network will continue to work alongside the Council to ensure a good flow of information about the development of the LINK not just to those who expressed an interest in being involved at the event, but also to their wider networks of individuals and organisations with an interest in health and social care in Camden.

| WHEN                                    | WHO                                | ACTION   | OUTCOME   |
|---|------------------------------------|--|---|
| Dec 2007                                | CCEN                               | Create mailing lists building on information shared by event participants on feedback forms – eg. for briefings, invitations to meetings, etc. | Useful contact lists (and expressions of interest in involvement) ready to be passed on to future host organisation |
| Dec 2007                                | LB Camden                          | Contact people who have expressed an interest in the commissioning process for a host organisation   | Service user perspective included in commissioning process  |
| Jan – Mar 2008 (or until Host in place) | CCEN & LB Camden                   | Continue to build mailing lists and keep people informed about how the LINK is progressing via websites/newsletters /email briefings           | Interest and involvement in LINK development maintained and built upon  |
| Jan 2008                                | LB Camden & LINK Development Group | Use event data and findings to develop service specification for host, and draft a timetable for procuring the host                            | Host that is eventually contracted meets stakeholder expectations   |
| Apr 2008                                | LB Camden & LINK Development Group | Event report and detailed data used to brief host about local concerns and expectations for the LINK   | Host able to take up role with some understanding and direction for ongoing LINK development                        |

## 7. for more information

To find out more about the development process for the LINK, or to add your details to the new LINKs mailing lists that are being created, you can contact the Camden Community Empowerment Network (Camden CEN) or Camden Council in any of the following ways:

### ***Camden CEN***

Email: [camdencen@vac.org.uk](mailto:camdencen@vac.org.uk)  
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WWW: You can also look up the new LINK page on the Camden CEN website at [www.camdencen.org.uk](http://www.camdencen.org.uk)

### ***Camden Council***

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## **8. appendices**

### **8.1 participant profile**

### **8.2 summary of event feedback**

### **8.3 examples of involvement 'maps'**

## appendix 1 - participant profile

|                                    |                           |
|------------------------------------|---------------------------|
| Voluntary & Community Sector       | 15 (incl. 5 facilitators) |
| Social Care Service User           | 12                        |
| Public                             | 10                        |
| London Borough of Camden           | 10 (incl. 8 facilitators) |
| Patient & Public Involvement Forum | 9                         |
| National Health Service            | 5                         |
| Social Care User Group             | 2                         |
| Health Practitioner                | 1                         |
| London Borough of Islington        | 1                         |
| Total                              | 65                        |

## appendix 2 - feedback summary

We received 25 event evaluation forms. The forms asked for general feedback without asking specific questions. This is a summary of what people chose to comment on:

### Positives

#### ☺ **Organisation (10/25)**

10 participants recorded that they felt the event was well organised.

#### ☺ **Useful/informative (19/25)**

9 participants described the event as 'useful' with 4 more just saying it was good without specifying precisely why. A further 6 participants stated that they had found the event interesting and/or informative.

#### ☺ **Structure/activities and participation (8/25)**

5 participants were positive about time-management, chairing and facilitation whilst 3 chose to comment positively on the balance between listening and active involvement and remarked that they were pleased with the level of opportunity to participate.

#### ☺ **Venue/facilities (5/25)**

5 participants chose to comment positively on the venue and facilities, including catering.

### Areas for Improvement

#### ☹ **Audio/microphone services (2/25)**

2 participants commented on problems with microphones which affected their ability to hear parts of the event.

#### ☹ **Support for the hearing impaired (2/25)**

2 participants commented on the late arrival of the text-to-talk service and non-arrival of signers who were booked but did not turn up.

#### ☹ **Structure (2/25)**

2 participants felt they would have preferred not to have reviewed others' 'maps' but instead just continued working on their own map a little longer.

#### ☹ **Timing (2/25)**

2 participants suggested the event should be repeated on an evening or weekend so as not to exclude those who work from the process.

## **appendix 4 – involvement ‘maps’**

We attach here three examples of the maps that were created on the day to give a flavour of people’s work on ‘involvement’ in the LINK.

## Map 1



### Groups with specific needs

- #### How to Involve?
- Open meetings – quarterly – everyone can attend
  - Website – discussion /chat forum
  - Regular briefings/report-backs
  - Accessible communications budget
  - Information in libraries, community centres, health centres, etc.

## Map 2

Opinions In ...

### **Groups whose views need to be captured**

Health trusts; Businesses; Individuals; Hard to Reach Groups; BME groups; Faith groups; GPs; LGBT; PCT; Local communities; Council; Voluntary Sector. Consider support groups for specific users

### **Opinions Pathway**

- Bottom up approach – how could this be done?
- How could a wide range of views be captured and fed into the LINK?

### **Core**

Even split between Health & Social Care.  
How do we ensure representation? How do we ensure no one voice dominates?  
Need good skills mix

### **Project Output Pathway**

Health/Social Care - How do the two areas link? When is it desirable to conduct separately? Important to identify areas of overlap and also important to make sure all can take part.

### **Projects Out ...**

Physical Disabilities. Sensory Needs, HIV. Learning Disabilities. Older People. Mental Health. Substance Misuse

### Map 3

