

LINKs'

BEST PRACTICE

Local Involvement Networks



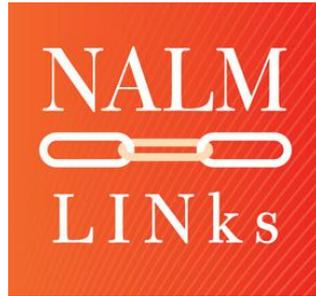
NATIONAL ASSOCIATION OF LINKs MEMBERS

Company Limited by Guarantee • Company registered in England

Company No. 06598770

Established for charitable purposes.

Registered Office: 6 GARDEN COURT, HOLDEN ROAD, WOODSIDE PARK, LONDON, N12 7DG



NATIONAL ASSOCIATION OF LINKs MEMBERS

Patient and Public Involvement in Health and Social Care

www.nalm.org.uk

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THE AIMS OF NALM

The aims of NALM are to:

1. Provide a national voice for LINKs' members

2. Promote public involvement that leads to real change and the ability to influence key decisions about how care services are planned and run

3. Promote the capacity and effectiveness of LINKs' members to monitor and influence services at a local, regional and national level and to give people a genuine voice in their health and social care services

4. Support the capacity of communities to be involved and engage in consultations about changes to services, influence key decisions about health and social services and hold those services to account

5. Promote diversity and inclusion and support the involvement of people whose voices are not currently being heard

6. Promote open and transparent communication between communities across the country and the health service

7. Promote accountability in the NHS and social care to patients and the public

LINKs' Best Practice

BEXLEY LINK

Chair: Barbara Loughton

Host: The Shaw Trust

www.bexleylink.org.uk

Bexley is particularly proud of the joint working that is happening between the three LINKs – Bexley, Bromley and Greenwich – working together to present a joint approach to South London Healthcare NHS Trust and Oxleas Foundation NHS Trust, both of which cover the three Boroughs.

The Trusts were pleased to have to work with only one group, instead of three different ones. The Mental Health Trust has offered the three LINKs seats on its User Carer Council, and also the opportunity for there to be a LINK Governor from each LINK.

Prior to each meeting of the Acute Trust Board, the three LINK representatives and host organisations take turns to host a meeting at which the Board papers are discussed at length, along with any issues that might need to be raised. This meeting has proven to be very worthwhile, and provides opportunities to share best practice and ideas.

BLACKBURN AND DARWEN LINK

Chair:

Host: Carers Federation

As a result of patient feedback, press reports and the decision of Lancashire County Council to conduct a Scrutiny Review of the Blackburn Royal's Emergency and Urgent Care Department, by providing an independent patient and user perspective, the LINK was asked to look at cleanliness and use of hand gels.

Trust managers were invited to a Public Meeting to speak about hospital infections and this highlighted increases in levels of MRSA and C.difficile. The LINK then agreed a programme to Enter and View over a Friday, Saturday and Monday – critical time periods.

The LINK team reported that areas visited were clean and tidy, with full hand gel dispensers. However, not all visitors were using the gels, and signage had insufficient prominence and visibility. Following the LINK's report, the Trust has accepted the findings and agreed to address the issues.

BROMLEY LINK

Chair: Richard Lane

Host: The Shaw Trust

www.bromleylink.org

Bromley LINK, in partnership with Bromley Council, runs a stakeholder group on Supporting Independence in Bromley (the local name for Transforming Social Care). The initiative had little engagement with stakeholders previously, so Bromley LINK has convened the group to include voluntary sector organisations, private providers, experts by experience, members of the public and local authority officials.

The group will raise awareness of the culture change in social care, working alongside Bromley Council to communicate the key messages of the programme, and shape the direction of the programme by feeding in the views of those most directly involved with it.

The group will be co-ordinating information days for:

- Providers - to understand funding streams, good practice, and how their business will react to the change in market
- People with learning disabilities - run by a company who specialises in events for those with learning disabilities
- Carers, service users and the public - explaining the pros and cons of the initiative and the potential for increased independence

These events will also allow direct feedback from those who will be affected by the changes proposed by the Transformation Agenda.

CAMDEN LINK

Chair: Neil Woodnick

Host: The Shaw Trust

www.camdenlink.info

The Camden LINK has made an impact and is working well. As a result of LINK concerns and intervention, podiatry is being reinstated at James Wigg, a 21,000 patient practice. The LINK is querying why there is no facility to have blood tests done at the polyclinic hub. The LINK is also pushing for more diagnostic equipment in the polyclinic hubs.

The LINK has ensured that the leads of the main voluntary groups, and GP Managers in Camden and Camden Reach, are made aware that patients who cannot get to St. Pancras to get the Tamiflu vaccine, may have it delivered to them.

A member of the Camden LINK Steering Group is negotiating with NHS Camden with regard to the monitoring of newly commissioned services, so that these services can be monitored closely and regularly.

Camden LINK has developed stronger associations with two voluntary organisations from the BME community (now represented on the Steering Group) – the African Health Forum (which represents various African groups within the Borough, and the Gambian Senegalese Welfare Association. A Camden LINK African Committee Sub Group (CLAR) has been established to focus on pockets of smaller hard-to-reach African groups. Issues such as female circumcision have already been identified as areas for concern.

The Chair of the Camden LINK has proposed a 'Question Time' event in 2010 to take place in the south of the Borough. This will involve five representatives from the PCT, the Royal Free and UCLH to answer questions from the BME community. The PCT has agreed to this, in theory.

The Host has also been door knocking in some of the most deprived parts of Camden, in order to be as fully representative of the needs of the community ... and to feed back concerns. Engagement has also been carried out with the younger Camden audience (including Camden Young Health Ambassadors, for example), in order for LINK membership to be as inclusive and diverse as possible.

LINK in CORNWALL

| | | |
|--------|-------------------------------------|--|
| Chair: | A Co-operative Group | |
| Host: | Cornwall Rural Community Council | |
| | Penwith Community Development Trust | |
| | Age Concern Cornwall | www.linkincornwallrcc.co.uk |

The LINK became aware of a lack of mental health out-of-hours service provision. At its Cornwall Theme Group Event, the issue became an immediate priority for action. Following research and an invitation to feed into the Primary Care Trust's (PCT) Draft Mental Health Commissioning Strategy for Mental Health, the LINK set up a Task Group to look at what could be done to improve services.

LINK participants, voluntary organisation representatives and the people who plan and run services, created a simple questionnaire to ascertain the public's knowledge of these services and what it would like from a service in the future. A report, outlining the main recommendations suggested, was submitted to the PCT for consideration/feedback; to the PCT's Mental Health Commissioning Strategy and to the Care Quality Commission Mental Health Strategy Consultation, and the Department of Health's New Horizons Consultation. Initial feedback has been very positive.

EAST RIDING OF YORKSHIRE LINK

Chair: Ruth Marsden (Interim Chair)

Host: Humber and Wolds Rural Community Council

www.erylink.org.uk

The East Riding is a very large authority. Recognising this, ERYLINK's launch was not an event on a day, but a bus for a fortnight. The ERYLINK 'battle bus' – manned by host staff and by LINK members – spent two weeks crossing and re-crossing the country, calling at market towns and villages. The bus had walk-on facilities, a confidential area, and was lettered and liveried with the LINK logo and mandate. We talked and listed to hundred of people, taking in two or three places in a day. This initiative grabbed attention and got the message out.

Further, the LINK used its own members' expertise to provide training for 'enter and view' and safeguarding. Training sessions were held at no cost, and we now have in place teams trained and CRB checked. A sample indemnity policy was obtained by the Host. LINK members amended it to their requirements, and cover was obtained against their specification.

DUDLEY

Chair: David Orme

Host: The Shaw Trust

www.dudleylink.org.uk

Drop-in Sessions

These events have been very successful in being able to gather issues and experiences direct from the community. Events have mainly been held in community centres when there is something already taking place (such as a lunch club, mother and toddler group, bingo and even in a surgery waiting room), which means that local groups are already present and all have been willing to take part too.

The LINK has had good collaboration with Dudley Council Community Renewal staff, who regularly email details of events coming up. Comments gathered have contributed to the LINK Work Plan. There is also regular contact with Dudley Mind, a local charity working with residents with mental health issues. The LINK is invited to take part in this group's discussions and now knows many of those involved and, again, some really good issues have contributed to the Work Plan.

LINK Thumbs Up!

This was such a simple idea. Simple write a few questions on a board and let the locals comment by putting a thumb-up card – or a thumb-down card below the question. This proved really useful when working at the young volunteer’s event. Lots of thumbs on the boards gave the LINK an indication of the opinions of younger people. This was more effective with this group than a questionnaire.

The LINK will be using this idea again in the future, especially for gaining the opinions of those with learning disabilities.

HARINGEY LINK

Chair: Helena Kania – Acting Chair

Host: The Shaw Trust

www.haringeylink.org.uk

The Haringey LINK has worked hard to secure true representation at the strategic level of health and social care planning in the Borough, and has a co-opted place on the Health Overview and Scrutiny Committee which has led to involvement in each of the key area sub-committees. This offers a direct conduit to the top table for public opinion. The LINK Chair has an observer status seat at the Board of the Primary Care Trust, with the right to ask questions during the meeting.

HAVING LINK

Chair: Med Buck

Host: The Shaw Trust

www.havinglink.org

The Having LINK has built strong and effective associations with other groups, reaching into the community through ICAN and other community based groups, thereby developing the network of networks mode.

A programme of LINK promotional events is currently under way, to reach all parts of the Borough and to seek out local opinions on services. Having has recognised the benefits of doing this, in collaboration with other organisations and events giving the opportunity to tap into different aspects of the community.

HERTFORDSHIRE LINK

Chair: Henry Goldberg

Host: The Shaw Trust

www.hertfordshirelink.org.uk

Influencing the Decision Makers:

To influence decision making, the LINK has established an extensive network of representation with which it provides a public voice on health and social care services. LINK observers sit on all five Hertfordshire Trust Boards, the Herts Community Health Service Board, the Joint Commissioning Partnership Board for mental health and learning disabilities, and project teams for new services. The LINK also has representatives on a number of Practice Based Commissioning (PBS) groups and the PCT's PBC Governance Committee. LINK observers are on the County's cabinet panel on adult care and health and the Children's Trust Strategic Stakeholders group.

Additionally, the LINK Chair has informal quarterly meetings with the CEOs of the Hertfordshire health trusts, Director of Adult Care Services, and Scrutiny Committees' Chairs.

The LINK has already been able to use these channels to make contributions to a number of policy initiatives and to raise issues of concern and have them addressed by decision-makers.

Clinics for Children with Downs Syndrome

Hertfordshire LINK was approached by a parents' group call Up on Downs. There is a very successful clinic for children with Downs Syndrome in East Hertfordshire, and they were seeking support to get the NHS to provide similar clinics across the county. The clinic is a twice a year event, run at Hertford Hospital. All parents of under-fives are invited at the same time for talks, access to professionals and to meet one another. It is the unity of that time, place, social group and availability of practitioners, which are important.

The LINK approached the Hertfordshire PCT (as commissioners of services), and the East and North Herts Hospital Trust (who run the Hertford clinic), supporting the proposal from Up on Downs. As a result of our approach, we now learn that the commissioner for children's services at the Hertfordshire PCT is reviewing these services for the whole of the county.

Access to dentists in East Herts

In 2008, the East Herts Citizens' Advice Services carried out a survey of the concerns of their users. One of the main concerns was access to NHS dentists. The LINK discussed these results with the PCT, which is responsible for NHS dental services. The PCT undertook to talk to the East Herts Citizens' Advice Services to clarify the rights of patients in respect of

dental services. The PCT also produced a card and poster giving a help-line telephone number for those people wanting to find an NHS dentist. A further survey, carried out by East Herts Citizens' Advice Services in the middle of 2009, showed that there had been a significant improvement in access to NHS dentists in the area.

Improving social care for adults with Autism or Asperger's Syndrome

The Herts LINK was approached by the Herts representative of the National Autistic Society (NAS), who had concerns about the lack of care and support services for adults with Autism and Asperger's Syndrome. The LINK arranged for these NAS representatives to meet with the Director of Herts Adult Care Services. At the meeting, proposals were presented to the Director on joint working between Adult Care Services and the NAS for improvements in adult care in a number of areas. As Assistant Director of Adult Care Services has now been instructed to negotiate with the NAS representatives on the implementation of their proposals. These talks have led to a conference being organised for December 2009, by Adult Care Services, NAS, and Carers in Hertfordshire on 'A brighter future for people with autism'.

Mobile breast screen service

At Potters Bar, a mobile breast screening service was withdrawn because the site it used became unavailable. As a consequence, women had to go to Barnet Hospital for screening, and this involved longer journeys and difficulties with parking. A Herts LINK board member campaigned for the resumption of the local service and, as a result, a new site in Potters Bar was found for the mobile screening unit, and the local service is now to continue.

ISLINGTON LINK

Chair: Olav Ernstzen

Host: Islington Voluntary Action Council

www.ivac.org.uk/link

Islington LINK has developed a community research programme to tackle an issue raised by the local community at the LINK's Annual Fair.

Interested LINK members, who demonstrated a willingness to develop research skills, were invited to take part in a 6 month project to carry out a piece of research in the local community. Members were trained in developing research aims based on what was already known on the subject area, selecting appropriate research methods and writing good research questions. Their proposal was then validated by an Ethics Committee.

Members of the LINK have undertaken interviews with people in the local area to find out more about their experiences of leaving hospital. The findings will be written up in a report, due in November 2009.

LEEDS LINK

Chair: Arthur Giles and Joy Fisher – Joint Chair

Host: The Shaw Trust www.communityvoicesonline.org.uk

In June 2009, the Leeds LINK held an exciting event on Briggate in the city centre, to encourage people to become involved in the local network. Over 1,600 people dropped by during the course of the day, including the Deputy Lord Mayor who came along to officially launch the Leeds LINK.

The event provided an opportunity to start getting ideas from the public about what it considers to be areas for improvement in health and social care, and these ideas are now forming part of the Work Plan.

Different kinds of entertainment were scheduled throughout the day for the public to enjoy – from African drummers to face painting to Bollywood dancers. It was a fun day and reflected the strong focus of the LINK volunteers to engage widely within the public. There were also different stalls from voluntary and statutory organisations within Leeds providing information.

The launch was publicised widely during the run-up to the event and articles appeared in the Yorkshire Evening Post, the BME Voice newspaper, as well as various voluntary organisation newsletters.

The LINK also organised a four week campaign for the launch to be advertised on 200 buses across Leeds. The event has helped to strengthen the reputation of the LINK and to create a strong foundation for the subsequent work in the community.

LEWISHAM LINK

Chair: Alan Bailey

Host: Parkwood Healthcare www.lewishamlink.org.uk

The Lewisham LINK has established a regular cycle of meetings with the statutory health and social care providers in our area. The meetings act as a conduit for us to receive information, improve communication, as well as help us shape our work and influence their engagement approach.

LINCOLNSHIRE LINK

Chair: Preston Keeling

Host: The Shaw Trust

www.lincolnshirelink.org.uk

The Lincolnshire LINK has always been conscious of the need to communicate with the local community as widely and as effectively as possible. The LINK has produced its information in many formats, including easy-read and translated languages. However, more recently, the local LINK Communications Committee felt it would be valuable to pursue the need to product LINK information in a format that would be useful to a number of different audiences.

The LINK has worked in partnership with South Lincolnshire Blind Society to produce audio transcriptions of LINK literature. This has been valuable, not only to those with sight loss, but also for those who may have other difficulties in accessing the written word.

The audio transcriptions were funded through the discretionary budget are available for dispatch. Lincolnshire is now trying to further develop their understanding of effective communication by working with sensory impairment groups to look at training and ways forward to support the local community in accessing LINK information and facilitating involvement.

LUTON LINK

Chair: Neville White, MBE

Host: The Shaw Trust

www.lutonlink.org.uk

The Luton LINK is a dynamic group of very active people from all parts of the community. The Host is regularly invited to discuss health issues with many different community groups, and LINK members are well embedded with the health and social care providers to be able to carry the messages to the decision makers.

There is so much activity happening, that the decision was made by the Core Group to meet every other month, and to use the intervening months for Focus Group work and information sessions on services, planning and community needs, so that LINK members can be well informed.

The understanding of the importance of commissioning, led to the Luton LINK organising a comprehensive study day on commissioning, to which all LINK members were invited. This was a very successful and informative day and a follow-up event is now being considered.

PETERBOROUGH LINK

Chair:

Host: The Shaw Trust

www.peterboroughlink.co.uk

Members of the management committee of the Peterborough LINK represent a wide diversity of interests and experiences, and members have worked hard to forge strong relationships with commissioners and service providers.

As a result, the LINK has been involved from the outside, in decision making and the commissioning, development and monitoring process of health and social care services in Peterborough. For example, in its first year, the LINK has been involved in decisions concerning community services for people with diabetes, the recently opened mental health unit, the Walk In Centre and the new general hospital which is due for completion next year.

REDCAR AND CLEVELAND LINK

Chair: Ron Wood

Host: The Shaw Trust

www.communityvoicesonline.org

Pharmacy Appeal – Ings Estate, Redcar

The LINK was asked to support the appeal for provision of pharmaceutical services on the Ings Estate in Redcar.

The LINK gathered evidence about the local community and made a decision based on the evidence to support the appeal. The LINK sent representation to the appeal to present the evidence gathered.

The LINK was informed that the appeal had been a success and the pharmacy would open in the next six months. It was also informed that there would be provision made for a GP surgery on the estate.

RUTLAND LINK

Chair:

Host: The Shaw Trust

www.rutlandlink.org.uk

Leicester, Leicestershire and Rutland NHS have currently undertaking a review of maternity services. To capture views, they posted a questionnaire to 1,500 ladies who had babies in April/May 2009. The questionnaire was posted on its website. Three stakeholder events in Leicester and Leicestershire were also held. No wider efforts had been made to target a specific demographic (women of child bearing age), and no events have taken place in Rutland.

Two weeks after the elections, the Rutland LINK decided that it was important to ensure that the views of parents in Rutland were captured in this survey. To this end, the LINK visited a number of mother and toddler groups and scoured the newspapers for 'diary dates' for community groups for children, to put together a focus group to receive views and responses to the survey. The survey is also on Community Voices Online.

It is strongly felt that, without this effort, no-one from Rutland would have had the opportunity to take part in this survey unless they were one of the fortunate 1,500 who have received a questionnaire through the post.

STOCKTON ON TEES LINK

Chair: James Newton

Host: The Shaw Trust

www.communityvoicesonline.org

Dial-a-Ride Service – Change in Service Commission

Concerns were raised to the Stockton LINK regarding the Dial-a-Ride service by registered users of the service, one of whom was a LINK member representing Blink UK.

The LINK made enquiries about the service, to ensure that they would not duplicate any work undertaken by Stockton Borough Council. The LINK was informed that the Health Select Committee was proposing a review of all transport services in the area. The LINK notified the Select Committee of their intention to investigate further and was invited to table a report at the beginning of September 2009.

The LINK investigated by holding discussions with local organisations whose members were registered users of the service. They held an open meeting at which the Dial-a-Ride Service Manager made a presentation and answered questions. The premises of the service was

visited to see how the day-to-day operations worked, and to talk to the staff. The booking system, capacity and utilization of vehicles were flagged up as main issues.

A detailed report was sent to the Select Committee for consideration. The Committee was very grateful to the LINK and valued the input. A decision was made by the Cabinet, in early November, that the present service was inadequate and another provider needed to be commissioned to provide the service, which would be a taxi-based service. The LINK viewed this as a successful Work Plan topic and will continue to monitor progress.

SUFFOLK LINK

Chair:

Host: The Shaw Trust

www.suffolklink.org

The Suffolk LINK is collaborating with the Bangladeshi Support Centre to create five events across the county specifically reaching Bangladeshi, Asian, Kurdish, Turkish and North African communities in order to get viewpoints on the health and social care services they can access or need. Working with the Support Centre ensures that the LINK can reach minorities who often remain unheard, and the LINK is very enthusiastic about this project.

Following democratic elections to the Core Group, the LINK host has also adopted a positive approach to new participants, by making individual contact with the new Core Group members, to discuss their vision of the LINK, why they became involved and what issues they feel need to be brought to the group for attention. Comments have been listed and are displayed at the Core Group meetings. Support has also been offered for reaching out into their localities or specific area of interest to gain wider public opinion.

In making this contact, and offering a specific staff member to work with them, has helped integrate the members at a faster rate than was thought possible, and has also given a greater sense of the wider objectives. The Core Group members are very happy with this approach.

WAKEFIELD DISTRICT LINK

Chair: Bill Storey

Host: The Shaw Trust

www.communityvoicesonline.org

Hospital NHS Trust 'Joint' Discharge Policy

Concerns had been received, via the LINK participants, about the Hospital Trust's Discharge Policy. A LINK Task Group was formed in February 2009 from twelve LINK members and participants, who volunteered to take part. A survey audit was carried out of all GPs in the Wakefield District. GPs were asked their views and experiences on the subject of quality discharge information. The response to the questionnaire was very good, with 124 GPs responding.

The primary recommendation of that report was that commissioners of secondary care should monitor the quality of the discharge procedure, including continued aftercare, as communications between hospital doctors and community care was unsatisfactory.

The LINK suggested to the commissioners that they should examine procedures adopted. A copy of the LINK report was also submitted to the OSC, who backed the findings of the report and asked that the PCT adhere to the recommendations of the LINK.

The Hospital Trust has now asked clinical leads to put into practice mechanisms to lead improvement within their service. The PCT agreed to a collaborative approach to monitor safe transition of care to any setting to enhance the patient journey.

Crisis Resolution (Mental Health)

The aim of this Task Group was to look at the provision of services for people with mental health problems undergoing a crisis, and to investigate changes that could be made to give service users a better experience. Local groups of service users have expressed dissatisfaction with the current service, particularly around accessing the service and its eligibility criteria.

The LINK invited the Head of Commissioning to talk about the Crisis Resolution service which the PCT commissioned. It was explained that the service offered met the criteria of the National Service Framework.

Council members are at present on the group, and LINK participants will be invited to join, together with service users interested, now that more information has been obtained.

Outcomes and Achievements

The LINK has sought and obtained a copy of a report, commissioned by the Mental Health Trust, and carried out by a local Mental Health Advocacy Organisation about Crisis Resolution services across the whole of the Mental Health Trust’s area. Due to the difficulties faced in obtaining the report, the Chief Executive of the Trust was invited to meet the task group members to discuss the issues and take the matter further. This meeting was extremely positive, and the Chief Executive pledged his support to the work of the LINK and valued the input.

LINK members have now been invited to an Action Day to discuss the outcome of the Crisis Resolution Report. The Task Group leader plans to attend meetings of all the Wakefield District Mental Health dialogue groups to offer them the opportunity to get involved. The Task Group will then talk to providers and commissioners to look for ways of implementing solutions to issues identified.

WESTMINSTER LINK

Chair: Paul Wilson
 Host: Voluntary Action Westminster (VAW) www.westminsterlink.org.uk

Westminster LINK has asked the Council for a complete list of Key Performance Indicators (National, Local Area Agreement and Local) used by Adult and Community Services.

The LINK is also asking for all targets set by the Care Quality Commission. It wants to see if any responsibilities are not covered. The LINK thinks that Adult and Community Services may be tempted to sideline areas where there is no indicator or target, and it hopes to negotiate with the Council for new targets to cover the gaps.

WORCESTERSHIRE LINK

Chair: Ann Montague-Smith
 Host: The Shaw Trust www.communityvoicesonline.org

Autumn Show, Malvern - Issues and Experience Tree

A pretend tree was made and different coloured leaves were cut out for people to write down their issues and experiences. These were then attached to the tree. This interactive event drew attention to the presence of the LINK, as well as being a valuable tool for collecting a wide selection of specific issues concerning the public.

Stourport High School – Health and Social Care Class

Using GPs as an example, the students wrote down their experiences onto speech bubbles which were then placed on a diagram. This gave tangible evidence of young people's viewpoints and then seven out of the eight young people joined the LINK.

Street Stalls

The LINK has had stalls in some high streets throughout the county. This proved to be an excellent way to raise awareness amongst different people who may not attend health or social care related events.

Head and Neck Cancer Services

The LINK continues to work hard by investigating and requesting information regarding the proposal that the surgical element of head and neck cancer in the three counties, be located on one site. The LINK is highlighting the lack of transparency in the decision making process and the logic for reviewing the decision.

Carers

The LINK is working with the University of Worcester to carry out a survey on carers. Focus groups have been held, consisting of organisations that work with carers, to help determine the types of questions to ask. The LINK aims to access, not only registered/recognised carers, but also hidden carers. The feedback will be analysed with the help of the University, and investigations and recommendations to the relevant providers will follow.