

National Association of LINKs Members

Patient and Public Involvement in Health and Social Care

Members' Newsletter ☀ June 2008

Building the National Association!

Members across the country have done a massive amount of work to get the new LINKs system running. In many areas new structures have been established and a start made to begin the task of monitoring and influencing what happens in our local NHS and social care sectors. The task of rebuilding the capacity to monitor services after the Government's second abolition of health care monitoring organisations in five years is an immense one. NALM has been in the vanguard of demanding that a major government priority across the country must be high level support for the development of effective monitoring, inspecting and reporting on health services for patients and users of social care services.

NALM is busy recruiting across the country and aims to recruit 1000 individual members by the end of 2008. We are well known for effectively lobbying for significant improvements to the legislation that established LINKs and we are becoming a driver in the development of the LINKs locally and as a national and regional force. We have developed a high profile with Ministers, the Department of Health, amongst parliamentarians, local government, with the Healthcare Commission and many other national and local bodies. In addition to promoting the development of new effective community organisations, we are producing information and developing proposals on a range of health and social care issues, the first of which will be about cancer services and pandemic flu. We now have a formal legal structure, which should serve us well. All this has been achieved on a very small budget and with the active and dynamic support of members across the country. Steering Committee members are working tirelessly to build the National Association.

Urgent Action: Many private providers are exempted from monitoring by LINKs. These include services contracted before April 1st 2008 by NHS Trust or PCTs. Please ask your MP to write to the Secretary of State for Health to request the production of additional Directions from the Department of Health, to bring all contracts for health and social care within the scope of LINKs.

**National Steering Group: North West: John Amos, Audrey Meacock.
North East: Patricia Bottrill, Trevor Gauntlett. East Midlands: Hali Qureshi, Iris Parker Smith. Yorkshire & Humberside: Ray Crocken, Ruth Marsden.
South West: Bob Maggs, Elli Pang. South East: William Hatton, Len Roberts.
East of England: Anthony Darwood. London: Michael English, Malcolm Alexander**

The Annual Health Check

The Healthcare Commission (HCC) are committed to obtaining as much data as possible from LINKs members, former Forum members and anyone who has direct experience of health services (hospitals and PCTs) over the past year. NALM has agreed to encourage our members to participate in the process. The HCC are also developing a way to capture experiences (both positive and negative) from health services users and community/user groups using personal commentaries. The forms (containing personal commentaries) will be sent to HCC analysts who will then extract information and give it a data quality and weighting score. The information will then be fed into the HCC assessment process and applied to one or more of the core standards.

Urgent Action: Have you information about the effectiveness of services provided by a local NHS Trust, Foundation Trust or PCT that you have not yet provided to the Healthcare Commission? Do you know of any patient, user, carer or voluntary sector group that has something to say about access to or the quality of health services? If so please send this information to the Healthcare Commission Head Office or to the Regional Office (shown at the end of the Newsletter).

**HCC, (Head Office), Finsbury Tower, 103 Bunhill Row, London, EC1Y 8TG
020 7448 9200**

Monitoring the national picture

To the annoyance of a few local authorities NALM has been gathering information about their commissioning of Hosts, how they have spent their money and their progress with fulfilling their statutory obligations. We have asked every local authority to supply basic information about their progress and although most have been very happy to supply information, some have claimed that our expectation that they meet their statutory obligations under the Freedom of Information Act is too onerous. All of the data that we collect is being compiled into a report that will be presented to our members, local authorities, Ministers and the Health Select Committee. We have also offered to meet with any local authority across the country that wishes to discuss the development of Hosts and LINKs.

Criticisms of NALM. A former Forum member expressed concern that the NALM has no mandate to act on behalf of LINKs and expressed surprise that we are seeking information about development of LINKs in his area. In the absence of any national liaison body from April 1st, we believed it was innovative and wise to set up a co-ordinating body. Had we not done so it might have taken years for LINKs to do what we have done in a few weeks. We are not attempting to act on behalf of LINKs and have no mandate to do so. We are a body of those LINKs members who choose to join us. Early in 2009 when LINKs

have been established across the country we will hold a national members meeting and elections will be held amongst all our members. Our ambition is to support the continuity of PPI, to encourage people to join LINKs, support and advise potential LINKs members and provide a vehicle to influence and advise government in relation to how the new system could be best supported and services developed. The pace of development is very slow in some parts of the country and without pressure, some LAs might take a very long time to get the local LINK going. There is also some very poor practice across the country, e.g. transitional LINKs dominated by PCTs and a failure to ensure transitional monitoring of health and social care services. Our pressure and support for local members is making a real difference.

The Audit Commission's Role in the Creation of LINKs

Steve Bundred the Chief Executive of the Audit Commission has the duty to investigate the effectiveness of the process for creation of Local Involvement Networks (LINKs) in England and has been asked to publish a table of local authority compliance during the quarter April -June 2008 in the following areas:

- 1) Date of appointment of "host" organisations, i.e. when the contract passed the seal of the local authority.
- 2) Date "host" certifies to the local authority that the LINK has been created.
- 3) When appropriate, date that the transitional LINK (means of carrying out LINK duties) was brought into existence by local authority (acting as transitional host).
- 4) Details of activities carried out by local authorities through the transitional LINK, where this has been established to comply with the legislation.

What can LINKs members Enter and View? Major Loophole in LINKs visiting rights in Foundation Trusts.

In addition to adult social care and health services provided directly by the NHS and Local Authorities, LINKs members can "enter and view" publicly funded services provided by the private sector, but only those for whom contracts were signed **post 1st April 2008**. Services contracted between Foundation Trusts and the private sector are beyond the scrutiny of LINKs members. The position has been clarified by Health Minister Ann Keen:

Ann Keen (Parliamentary Under-Secretary (Health Services), Department of Health; Brentford & Isleworth, Labour)

On 1 April 2008 we issued Directions to organisations commissioning health and social care services. Under these Directions those organisations must ensure that new contracts with independent providers allow for authorised representatives of local involvement networks (LINKs) to enter and view, and observe the carrying on of activities in, premises which are owned or controlled by the independent provider. **The Directions do not apply to NHS Foundation Trusts.**

Urgent Action: Please ask your MP to write to Stephen Hay the Chief Operating Officer of Monitor requesting that all Foundation Trusts are obliged to agree to provide LINK members full access to their services for the purpose of entering, viewing, monitoring and reporting of the quality of those services.

**Stephen Hay, Monitor
4 Matthew Parker Street
London
SW1H 9NP**

Stephen.Hay@monitor-nhsft.gov.uk & michael.moruzzi@monitor-nhsft.gov.uk

Some other parliamentary answers

- **Monitoring funding for Hosts and LINKs:** “The level of local authority contribution to the LINKs is a matter for individual councils. Area based Grant is a non-ring fenced general grant and as such there are no requirements for local authorities to report separately on how the grant is utilized”. (John Healey MP Department of Communities and Local Government)
- **Funding of LINKs:** “We have no plans to review the funding allocations of LINKs”. (Ann Keen MP, Department of Health)
- **Indemnity:** There are no central arrangements to provide indemnity for those involved in local involvement networks. This is a matter to be determined locally”. (Ann Keen MP, Department of Health)
- **Expenses for LINK Members:** “It is for each LINK to determine its own policy regarding payment and reimbursement, including the payment of allowances and expenses. We have reminded LINKs and the host organisations, that the Department’s Reward and Recognition: The principles and practice of service user payment and reimbursement in health and social care document provide a useful guide on these matters”. (Ann Keen MP, Department of Health)

- **Independence:** “LINKs will be independent and will have the power to develop their own priorities and agendas. They will need to develop relationships with a number of stakeholders to fulfil their statutory role”. (Ann Keen MP, Department of Health)
- **Regional and National Networks:** “In certain circumstances LINKs may want to work in partnership to monitor services provided, for example, cancer networks, mental health services or ambulance trusts, across more than one local authority boundary. LINKs may also wish to work together in regional groups, or even nationally to share experiences and findings. There is nothing to prevent LINKs using some of their funding to establish local, regional and national networks if they wish”. (Ann Keen MP, Department of Health)

Who are the independent providers?

How is a LINK to know (a) which private providers there are on its patch (b) when their contracts date from and therefore whether they are accessible to LINK scrutiny?

NALM Vice Chair, Ruth Marsden sent an FOI to the Department of Health asking for a list of contractors for each NHS and social care body and discovered the Government doesn't know. She received the following reply:

Thank you for your email June 4, 2008, requesting, under the Freedom of Information Act, a list of independent sector providers in England. The Department does not hold centrally a list of all independent sector (IS) providers operating in England. Nor does it hold centrally a list of IS providers providing services to the NHS through local arrangements.
David Winks
Customer Service Centre
Department of Health
freedomofinformation@dh.gsi.gov.uk

We are now writing to all Strategic Health Authorities with a similar request.

No Residential Requirement for Membership of LINKs

Misunderstanding about a 'residential qualification' for membership of LINKs have been clarified by the Department of Health and the Centre for Public Scrutiny, which is one of the partners of the National Centre for Involvement and responsible for production of the guides produced for LINKs members:
<http://tinyurl.com/5uxtft>

Any person can join any LINK in England. This includes people from Scotland, Ireland and Wales, who can join LINKs in England and may wish to do so if they are receiving care from an English health or social care service. A LINK may

decide in its governance arrangements to bar someone from outside its area from joining, but our advice is that this would probably be unlawful.

However, the big problem is that a hospital group or other Trusts, which covers a number of local authorities, e.g. the South London and Maudsley Trust in London, is likely to be monitored by the LINK in which the headquarters of the organisation falls. This will effectively exclude patients from all the other boroughs where services are provided by the Trust and prevent proper discussion by users and the public about service quality. Advice, support, resources and guidance are badly needed to remedy this huge weakness in LINKs.

A Culture of Secrecy? LINK refused information about contract with Host

A LINK member who made a Freedom of Information Request(B222 190) to his local authority requesting information on payments in relation to the contract for provision of services to the LINK by the Host got the following shocking reply:

“Unfortunately, the information you have requested is exempt from disclosure under Section 43 (Commercial Interests) of the Freedom of Information Act 2000 because:

- Disclosure of this information would commercially disadvantage the Host should they decide to tender for the position of host for any of the other available contracts in the region.
- Disclosure would unfairly benefit other companies tendering for similar projects.
- Disclosure would detrimentally affect other authorities who have yet to complete their tender exercise for a LINK host as the market would be distorted.

This is a *qualified* exemption. This means that we have had to apply a public interest test and balance the public interest in withholding the information against the public interest in making it available. After careful deliberation, the balance has been in favour of withholding the information.”

A complaint is being made to the Local Authority and the Information Commissioner.

"Towards a strategy to support volunteering in health and social Care"

This draft volunteering strategy for health and social care was launched by the Department of Health in June 2008 and attempts to articulate the key actions needed to address obstacles to developing a new vision for volunteering in health and social care. The consultation runs until 30 September 2008 and the final strategy is expected in early 2009. There are a number of workshops as shown below: <http://tinyurl.com/6fhvng> Gateway number: 9841

Workshop Dates:

East Midlands - To be confirmed
South West - 2nd September 2008
London - 3rd September 2008
North West - 8th September 2008
Yorkshire and Humberside - 11th September 2008
North East - 12th September 2008
South East - 16th September 2008
West Midlands - 23rd September 2008
Eastern Region - 29th September 2008

Bookings forms and contacts for workshops will be available on D of H website

What NALM seeks to do

On April 1st we began building a national, user-led, organisation of LINKs members as well as supporting and advising members during the transition to LINKs. We are committed to highly effective, inclusive local community involvement and accountability in health and social care services. **We must make LINKs work.**

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. 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

Our approach is to:

Harness the expertise and knowledge of all those people who have the skills and knowledge to monitor their local NHS and social care services by creating effective local LINKs:

- Actively encourage the involvement of all local people who are not currently involved yet have an interest in improving health & social care
- Lobby for adequate funding of LINKs to support outreach and community development activities
- Build a regional and national infrastructure, fully-funded, to monitor and develop specialist, mental health, ambulance and paediatric services
- Work with voluntary sectors organisations which specialise in particular health conditions to improve the effectiveness of local monitoring and service development
- Be diligent in ensuring that the voices of all local patients and users are heard loud and clear in the NHS and in social care.
- Put LINK members in touch with each other
-

Action NOW! Get involved, join the LINK, join NALM, collaborate in the selection of the Host in your area and make sure that a competent host is selected, that the Host is accountable to members of the LINKs and that the new LINKs have the resources and support they need to be effective

Health Select Committee:

Please write to the Chair of the HSC or your own MP asking the Committee to collect evidence and produce a report on the effectiveness of transitional arrangements for the monitoring of health and social care since abolition of Patients' Forums, and the adequacy of the resources, support and monitoring for the LINK system. The Committee can call Health Ministers and any other organisations to give oral and written evidence.

- Rt Hon Kevin Barron (Chairman), Rother Valley, barronk@parliament.uk
- Charlotte Atkins, Staffordshire Moorlands, ATKINSC@parliament.uk,
- Peter Bone, Wellingborough, bonep@parliament.uk
- Jim Dowd, Lewisham West, Jimdowd.newlabour@care4free.net,
- Sandra Gidley, Romsey, Gidleys@parliament.uk
- Stephen Hesford, Wirral West, hesfords@parliament.uk
- Dr Doug Naysmith, Bristol North West, naysmithd@parliament.uk
- Lee Scott, Ilford North, scottle@parliament.uk
- Dr Howard Stoate , Dartford, stoateh@parliament.uk
- Robert Syms, Poole, edwardson@parliament.uk
- Dr Richard Taylor, Wyre Forest, pricemah@parliament.uk

Regional Offices of the Healthcare Commission

Bristol, Dominions House, Lime Kiln Close, Stoke Gifford, Bristol, BS34 8SR
0207 448 8158

Leeds, Kernel House, Killingbeck Drive, Killingbeck, Leeds, LS14 6UF
0207 448 8179

Manchester, 5th Floor, Peter House, Oxford Street, Manchester, M1 5AX
0207 448 9100

Nottingham, Maid Marian House, 56 Hounds Gate, Nottingham, NG1 6BE
0207 448 8188

Solihull, 1st Floor, 1 Friarsgate, 1011 Stratford Road, Solihull, B90 4AG
0207 448 9200

Contacting NALM

Malcolm Alexander - Chair - 0208 809 6552/07817505193

Ruth Marsden - Vice Chair - 01482 849 980/ 07807519933

Steering Group Members of NALM:

Region	Name	Address	Email
EAST MIDLANDS	Iris Parker- Smith	55 Hillsway Crescent, Mansfield NG18 5DR	
	Mrs Hali Qureshi	27 Lucknow Drive, Mapperley Park, NOTTINGHAM NG3 5EU	hali.qureshi@btopenworld.com
EAST OF ENGLAND	Anthony Darwood	14 Bramerton Lodge, Bramerton, NOWICH NR14 7EQ	anthony.darwood@btopenworld.com
HUMBERSIDE & YORKSHIRE	Ray Corken	2 Elder Close, BATLEY WF17 0DD	ray.corken@aol.com
	Ruth Marsden	The Hollies, George St, COTTINGHAM HU16 5QP	ruth@myford.karoo.co.uk
LONDON	Malcolm Alexander	30 Portland Rise, N4 2PP	maixa49@aol.com
	Michael English	12 Denny Crescent, Kennington, SE11 4UY	
NORTH EAST	Patricia Bottrill	25 Carolyn Crescent, WHITLEY BAY, Tyne & Wear NE26 3ED	davepatbottie@btinternet.com
	Trevor Gauntlett	133 Donvale Road, Donwell, WASHINGTON NE37 1DW	
NORTH WEST	John Amos	15 Carr Hall Gardens, BARROWFORD	johnamos15@yahoo.co.uk

	Audrey Meacock	NELSON. BB9 6PU 20 Kelsall Close, Oxton, Prenton, WIRRAL CH43 2LD.	rob_audreymeacock@btinternet.com
SOUTH EAST	William Hatton	40 Wilmington Close, HASSOCKS. BN6 8QB	billhatton@btinternet.com
	Len Roberts	Ridlands Farmhouse, Ridlands Lane, OXTED. RH8 0SS	roberts@ridlands.demon.co.uk
SOUTH WEST	Eleonore Pang	10 Yonder Street, OTTERY ST MARY, Exeter. EX11 1HD	elli@ellipang.wanadoo.co.uk
	Bob Maggs	6 Dublin Crescent Henleaze Bristol BS9 4NA	bob.maggs@virgin.net

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MEMBERSHIP ENROLMENT FORM

FOR USE BY INDIVIDUAL MEMBERS

Kindly complete and return as indicated below

1 Member's Full Name: _____

2 Member's Full Address: _____

3 Member's Email/Telephone/Fax: _____

I, the above-named hereby apply for enrolment as a registered Member of National Association of LINKs Members.

4 Signature of the Member _____

Notes:

- Members shall be entitled to attend meetings of the Assembly and vote thereat
- The membership fee is: £5-00 for individuals. Cheques should be made payable to National Association of LINKs Members. Rates for organisations on request.
- The completed enrolment form and payment must be lodged with the National Association of LINKs Members, either at 30 Portland Rise, N4 2PP (South) or at The Hollies George Street, Cottingham, East Yorkshire HU16 5QP (North)

5 Date of Application _____

6 Your previous experience:-----
