

National Association of LINKs Members

Patient and Public Involvement in Health and Social Care

A Brilliant Launch!

The first NALM Conference held on 2nd April, 2009 was an inspiring and uplifting event. Excellent speakers, stimulating workshops and a fantastic networking for LINKs members from across the country. Patient and Public Involvement in Health and Social Care is now firmly on the agenda at a local and national level and the Conference laid the foundation for the building of a national movement of LINKs' members that we believe will have an important and powerful role in the development of health and social care policy.

We attach a list of motions that were presented to the Conference but not taken due to the time constraints. We will have events later in the year to discuss these motions but in the meantime let me know which ones you support and if you would like to work with other LINK members on these issues. We would also like to know which of the issues your LINK has prioritised would benefit from national action.

Individual membership of NALM is growing rapidly and there is a steady growth in the number of LINKs joining. Our priority is to recruit a majority of LINKs across the country. We have held our elections and the following people were elected to the Steering Group. Vacancies will be filled throughout the year and as the movement grows.

Humberide and Yorkshire: Ruth Marsden; North East: Pat Bottrill, Trevor Gauntlet; North West: John Lyon-Taylor, Martin Rathfelder; South East: Len Roberts, John Kapp; East: Anthony Darwood; South West: Bob Maggs, Elli Pang; London: Michael English and Malcolm Alexander
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Malcolm Alexander
Chair

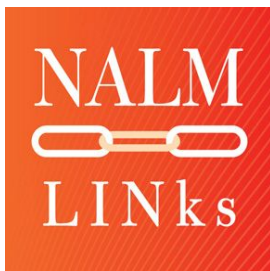
Ruth Marsden
Vice Chair

April 20th 2009

Directors: Malcolm Alexander (Chair) Ruth Marsden (Vice Chair)
John Larkin (Secretary) Michael English

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Malcolm Alexander, Chair, 30 Portland Rise, N4 2PP
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A short summary of presentations follows. A more detailed report with photos of the launch will follow shortly

NALM was launched by Sir Cyril Chantler, Chair of the King's Fund, a champion of effective public involvement and a member of his local LINK. He said that the poorest are in the worst health and they get the worst healthcare and that reversing this situation must be a priority for action. He spoke about the importance of NHS and social care services being held to account and the need to be constantly alert to the voices of those whom we serve. Cyril Chantler said that LINKs must make themselves known if they are to be accountable and ensure the wider population and the hard to reach are informed and included. He said the government must give LINKs time to develop and not keep re-arranging the system.

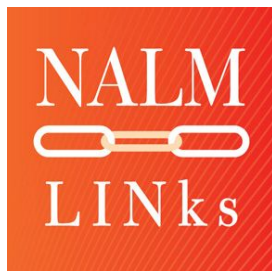
Baroness Young, Chair of the Care Quality Commission said that the public is not sufficiently involved in health and social care and that her first principle is to bring users to the heart of what the CQC does. She said that the CQC will be focussed on outcomes and if care does not get better, CQC will have failed. Barbara Young said that the big trick in the CQC relationship with LINKs will be to draw on LINKs' experience and views. The CQC and LINKs share a common purpose and have much to gain from a two-way relationship, LINKs bringing their experience and information and the CQC being an improver of services and also of systems. Barbara said that the CQC will shortly publish a "Statement of Involvement" containing its commitment to work with LINKs. She said there is a rich range of ways to involve patients nationally and locally and LINKs will play an important part.

Norman Lamb, Shadow Secretary of State for Health, Liberal Democrats said that the lesson of the last ten years is that stability is necessary for effective monitoring of services and that the constant revolution in the system of PPI has diminished effective public challenge. He said the events at Stafford Hospital demonstrated that the local voice of patients is vital. Norman Lamb said that the trend in FTs is for less transparency, less openness. FTs often meet in private, yet they operate with public money and we have a right to know how they spend it. He said that resources for LINKs are wholly inadequate and that LINKs need recognition and reputation to get people on board: the message is clear - 'Leave us alone to get on and develop and give us more funding'. He said he has complete commitment to NALM and admiration for you all as volunteers.

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David Pink, Chief Executive of National Voices shared his reflections on LINKs and involvement. He said that National Voices is a central liaison body for 169 organisations; all voice-organisations, including some third-sector providers. National Voices is a legitimate user-voice at national level and is a vehicle for members, especially the seldom heard. David Pink said that LINKs should be networks, keep their independence and build on previous good experience. He said there had been too frequent reorganisations of PPI and that the DH should bring more commitment and leadership to public involvement. David said there are very few mentions of LINKs in national policy, yet LINKs are key mechanisms. If LINKs are spending most of their time complaining about lack of resources and power now, then the likelihood is that they can look forward to things getting worse - more resources and power will flow from using today's opportunities to good effect. David said there is an imminent election and this should be a spur to action for LINKs - LINKs will succeed or fail in relation to their success in engaging with the health and social care agenda. So in 2009, get going and know what you are trying to be; the voice of service users or the voice of people.

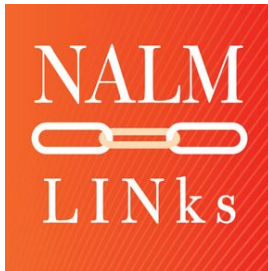
Stuart Jeffery, health spokesperson for the Green Party said that privatisation of the NHS has been introduced without a democratic mandate and is opposed by the majority of the population. He said there are many concerns about private companies in health care, particularly because they are accountable to shareholders not the public. Referring to the situation in Derbyshire where the most inexperienced bidder, United Health, was awarded a contract for a GP practice, he said the PCT did not listen to the public until the PCT decision to award this contract was overturned by Judicial Review. Stuart said that despite this, many PCTs were opening the door to the independent sector in primary care without adequate consultation and do not take their 'duty to consult' seriously. He said bringing in the independent sector was the worst way of running the NHS, because this sector had none of the statutory duties to consult and involve the public that are enshrined in the legislation for the NHS.

Sandra Berry and Helen Hutson (LINK members) and Jilla Bond from a Host (the Shaw Trust) spoke about LINKs and Hosts 'storming and performing'. Sandra and Helen described the excellent progress they had been making in setting up their LINK - not only the necessary creation of governance documents but also work

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plans and a major publicity and recruitment drive. Without warning, they were 'sacked' by their Host, apparently for making insufficient progress - in 4 months - with recruiting a diverse membership. Efforts were made to marginalise the Steering Group but, after several attempts to meet the Local Authority to resolve the situation, with the support of NALM and Olivia Nuamah (the DH representative) the Steering Group asked for - and were promised - independent mediation. To date this has not happened, although two local councillors have investigated the situation and come up with a way forward. The process is ongoing and the SG members remain determined to look after the interests of their local community.

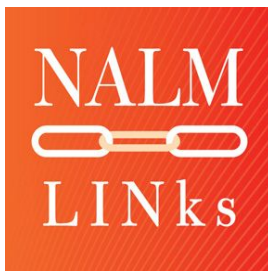
Jilla Bond made it clear that she was not a party to the dispute nor could comment on it. She said the key issues were about managing expectations, working with LINKs members to achieve effective communications and a clear understanding what the LINK wants and what we the host can deliver. Jilla underlined that Hosts are accountable to Local Authorities financially but operatively to the LINK and tensions are caused by every LINK having a different focus. She said the host is not just 'the secretary', but has a role to create contacts and promote the LINK in the community and to facilitate the work of the LINK as the 'Sir Humphrey' to the LINK. She suggested that ways through these difficulties included using detailed 'activity reports', openness, lots of talking and building trust. Jilla suggested that the LINKs and Hosts might agree a Service level Agreement outlining how the roles dovetail to create a productive partnership.

Graham Box, the Chief Executive of the National Association for Patient Participation said that Patient Participation Groups have existed for more than 30 years. Around 40% of English general practices now have one, each of which evolves to address local needs. Graham positioned PPGs as part of the non-statutory element of PPI, whereas LINKs are in the statutory sector. It makes sense for them to nestle up to the LINK in their locality and, with their strong focus in primary care, PPGs can help LINKs to drive real changes aimed at improving

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health. PPGs can provide valuable grass roots involvement, helping to identify gaps in the service and working with practices to bring about change. Over time, Graham expects Patient Participation Groups to become more involved in commissioning and research, whether through informal methods such as chatting to patients in the waiting room or by helping to design and deliver bespoke surveys to address key local questions. The National Association for Patient Participation is currently working closely with the Department of Health and other key national stakeholders to deliver more, and better, PPGs across the country. Central to this objective will be ensuring that PPGs are valued as an essential element of modern general practice.

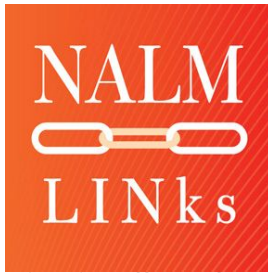
Sue Slipman, Director of the Foundation Trust Network said that FTs are still part of the NHS but have commercial freedoms and new ways of being accountable. Are they privatisation by the back door? Not necessarily. They yield economic efficiencies. There are 116 FTs out of 264 Trusts. 82 FTs are acute trusts. They are not answerable to the Sec of State but to MONITOR. They bring a new era of stakeholder involvement, more strategic. They can make surpluses, the proviso being they must re-invest these in local health. Having FTs is moving from looking up to the Sec of State to looking out to your populations. There are already 1.3 million FT members and there are 3000 Patient Governors. The Governors appoint the Chair and the Board. If the Governors are not satisfied with these people, they can get rid of them. Governors have an ambassadorial role. FT members have a huge role to play. FTs have a clear statutory relationship with LINKs - to supply information requested, to allow 'enter and view', to receive comment and recommendations from the LINKs. FTs will benefit from collaborative working with Links. We have a real opportunity for a positive relationship between FTs and LINKs, based on trust and respect. There is a need for understanding. I suggest the following: 1) Rules of engagement 2) Points of contact and communication 3) Processes and procedures, e.g. notice given re 'enter & view' 4) Ways to resolve conflict.

Peter Walsh the Director of AvMA said his organisation would assist anyone who has been the victim of medical accident, including helping them to obtain legal redress and compensation. He said that AvMA works with the NPSA (National Patient Safety Agency) on the 'patients for patients' safety' project and that Patients' Champions are an important mechanism in joint work with the NPSA - Patients' Champions are located in every SHA area. Peter said that these 22 Champions work together with other local people to create an evidence base - AvMA wants each LINK to nominate a member as a 'safety activist', to work with their local Patients' Champions, passing on relevant information and keeping

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'safety' well up the agenda of their LINK. About 3000 people die each year in England due to errors during their care. Even though the numbers are down, many think this figure is still an underestimate. Older people are the largest cohort of victims. The more services become fragmented, with different recording systems, the more things slip through the net. LINKs must forge good relationships with government, Non-Executive Directors, Foundation Trusts, and many other bodies if they are to be accepted as legitimate statutory bodies.

MOTIONS

Motions presented to the conference by NALM members. We will have events later in the year to discuss these motions. Please let me know which ones you support and if you would like to work with other LINK members on these issues. We would also like to know which issues your LINK has prioritised which would benefit from national action.

1) Publicising LINKs

This NALM AGM notes with great concern the tragedies that occurred at Stafford General Hospital and the inadequate action taken by the NHS in response to public concern. The AGM calls upon the Secretary of State for Health to make known the existence of LINKs through a national advertising campaign so that members of the public can obtain support and advice when NHS and local authority services are failing.

PROPOSER

Bene Afolabi

SECONDER

Ruth Marsden - East Riding of York LINK

2) Funding of LINKs

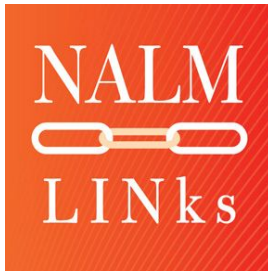
This NALM AGM notes with concern that many LINKs are not receiving adequate funds to carry out their activities. The AGM instructs the Steering Group to lead a national campaign to ensure that LINKs budgets match their responsibilities to effectively monitor health and social care services.

PROPOSER

Bene Afolabi

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SECONDER

Ruth Marsden - East Riding of York LINK

3) Indemnity

This NALM AGM calls upon the Government to indemnify all members of LINKs carrying out agreed activities on behalf of their LINK, including enter and view, monitoring and inspection of NHS and social care services.

PROPOSER

Malcolm Alexander - Hackney LINK

SECONDER

Ruth Marsden - East Riding of York LINK

4) Prioritising Healthcare Standards

This NALM AGM agrees to prioritise four of the 'healthcare standards' for national focus and action by LINKs in 2009-10 and to coordinate national responses to the Care Quality commission on these prioritised standards.

PROPOSER

Andrew McCabe - Hackney LINK

SECONDER

Shirley Murgraff - Hackney LINK

5) Polyclinics

This first NALM AGM of LINKs and LINKs members, welcomes the purpose intended by the proposal to create polyclinics. It cannot be justified to concentrate even the simplest services used by general practitioners in hospitals serving larger and larger areas, if polyclinics can provide more effective and more local service provision.

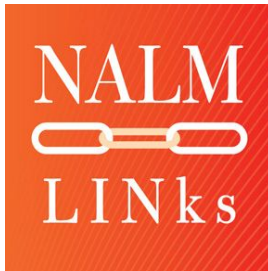
PROPOSER

Michael English - Lambeth LINK

SECONDER

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6) Regulation of Ambulance Services

This NALM AGM calls upon the Care Quality Commission to regulate emergency ambulance services and patients transport services provided by independent providers.

PROPOSER

Joseph Healy - Southwark LINK

SECONDER

Ruth Marsden - East Riding of York LINK

7) Access to dentists

The NALM AGM calls upon the Government to implement the promise made in 1999 that everyone would have easy access to an NHS dentist.

PROPOSER

Emmerson Walgrove - Bradford LINK

SECONDER

Ruth Marsden - East Riding of York LINK

8) Disclosure of information from complaints

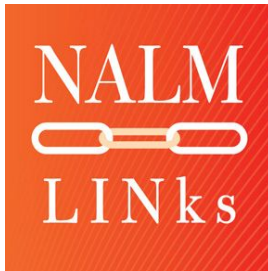
This NALM AGM calls upon the Departments of Health and Local Government/Communities, Strategic Health Authorities, Monitor and the National Patients Safety Agency, to support the public disclosure of anonymised details of complaints and patients safety issues and any recommendations made in respect of these events, for each PCT, NHS Trust, Foundation Trust and local authority.

PROPOSER

Andrew McCabe - Hackney LINK

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SECONDER
Bene Afolobi

9) Commissioning of social care

This NALM AGM notes with dismay the lack of real involvement of patients, users and the public in social-care commissioning and instructs the Steering Group to work with ADASS (The Association of Directors of Adult Social Services) to negotiate for the involvement of LINK at all levels and stages of the commissioning cycle.

PROPOSER
Ruth Marsden - East Riding of Yorks LINK
SECONDER

10) Access to care homes

This NALM AGM is concerned that only 'public areas' of social care establishments are open to monitoring by LINKs' members and instructs the Steering Group to work with the Care Quality Commission to overcome this limitation on LINKs by developing and undertaking joint visiting programmes.

PROPOSER
Ruth Marsden - East Riding of York LINK
SECONDER
Emmerson Walgrove - Bradford LINK

11) Personal budgets

This NALM AGM notes with concern the implementation of 'personal budgets' and the impact this may have on equality of access to social care services.

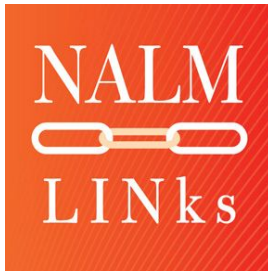
PROPOSER
Pat Bottrill - North Tyneside LINK

SECONDER
Hilda Bell - North Tyneside LINK

12) Human Rights

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This NALM AGM instructs the Steering Group to work with the Commission for Equalities and Human Rights and with national voluntary sectors organisations, to promote awareness and training in implementation of the Human Rights Act and the Disability Discrimination Act amongst LINKs members.

PROPOSER

Kenneth Jones - Wakefield LINK

SECONDER

13) Communications between LINKs

This NALM AGM notes with concern that inter-LINK communication is hampered by lack of transparency as to the identity of LINK Chairs (lead), and instructs the Steering Group to request all Local Authorities and Hosts to place the name of the Chair (lead) of the LINK/s in their area in the public domain

PROPOSER

Andrea Darrington - North Yours LINK

SECONDER

Ruth Marsden - East Riding of Yorks LINK

14) Independence of LINKs

This NALM AGM believes that key objective of NALM should be:

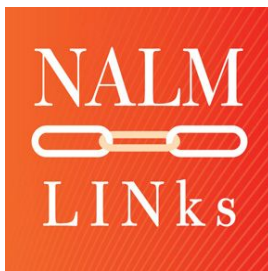
-the maintenance of the independence of each LINK, from the Department of Health, Local Authorities and those NHS Organisations that their remit requires them to scrutinise, as this is fundamental to their objective of securing the delivery of improved Health and Social Care

-to encourage LINKs to work together, at both Regional and National levels to achieve this objective so that the powers given to LINKs by Parliament be concentrated to make the exercise of those powers greater than the sum of the parts, and in particular when Commissioning and/or Service Delivery is pan Regional(s) or influenced by National policies

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-to promote coordinated working arrangements that include delegated Representative Powers and which are conducted by Organisations created by, and democratically controlled by, LINKs members.

Conference notes the emerging forces that could threaten the objectives and, in particular:

-the efforts of The London Development Centre, an organisation funded by London NHS and the Dept of Health, which declares itself on its website to be 'accountable to London NHS, to establish, in the London Region, separate Networks of Chairs, Hosts and Local authority LINKs Leads

-that the LDC seeks to encourage LINKs to sign up to Protocols which are said to have the benefit of guiding relationships with NHS Trusts and Social Care Authorities but which can be seen to be restrictive of LINK Freedom to Act and so limiting of the independent exercise of the LINK remit

-that the LDC has declared that participants in its proposed Networks do not have any representative role in respect of LINKs and/or Health and Social Care policies

Accordingly Conference declares that such proposed Networks in London or elsewhere, cannot possibly provide the independent, pan Region coordination, of the exercise of the LINK remit; and, particularly that in respect of LINKs scrutiny of Healthcare and Social Care Commissioning, and Provision, when that is wider than a single LINK area, which coordination it believes to be necessary to make the outcome of LINK activity a potent force in influencing National and Regional policies.

Therefore, Conference instructs the Steering Group:

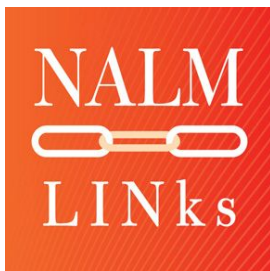
-to warn LINK Members of the risks of engaging with Organisations, funded by those whom they have a duty to scrutinise, in respect of preserving the Autonomy and Independence of their local LINK

-to warn LINKs Members to be wary of influences bearing down on their Host from Host Networks of which they may be unaware

-to advise LINKs Members to be wary of centrally initiated Protocols and to examine such proposals closely, since they are likely to be designed to limit a LINKs Freedom to Act rather than to enhance it

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-to advise against involvement in a Protocol unless the LINK itself wishes to enter into one because it has itself identified benefits

-to build a national picture of centrally initiated and funded endeavours in respect of both Regional Networks and proposed Protocols advising Members of their findings and conclusions in respect of similarity, if any

-not to enter into this kind of engagement itself as an alternative to establishing bottom up, local LINKs funded, Organisations, which it should help to facilitate in every Region

-to seek recognition of itself as the Network Voice of local LINKs, as against that of any other Charity or Organisation that might be more preferable to the Department of Health and to be wary of becoming a Member of any such Organisation and becoming subsumed by it.

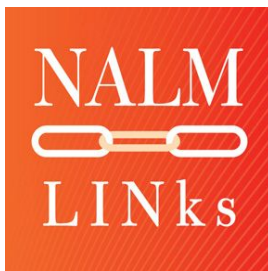
PROPOSER
Barry Silverman - Southwark LINK

SECONDER
Martin Saunders - Southwark LINK

Elected members of the National Association Steering Group

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Ms Ruth Marsden The Hollies George Street Cottingham, HU16 5QP	Tel:01482 849 980 Email: ruth@myford.karoo.co.uk LINK: East Riding of Yorks LINK, known as ERYLINK Region: HUMBERSIDE AND YORKSHIRE
Mr Malcolm Alexander 30 Portland Rise London, N4 2PP	Tel:0208 809 6551 Email: maiexa49@aol.com LINK: Hackey

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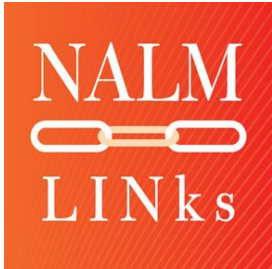


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Mr Trevor Gauntlett 133 Donvale Road Donwell, Washington, NE37 1DW	Tel:0191 416 1347 LINK: Sunderland Region: NORTH EAST REGION
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EX11 1HD	LINK: Devon Region: SOUTH WEST REGION	

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