NALM Conference Speeches – July 8th 2010

Message from Earl Howe
The Parliamentary Under Secretary of State for Quality

"To realise our ambition for the NHS patients must be at the heart of everything we do. We want to create an NHS that is led by the front-line, not the top, so that services are more responsive to individuals and their communities. We cannot under-estimate the importance of involving local people in helping to implement this vision so LINks will play an increasingly important part in designing and providing feedback on local services. The NALM conference gives you a very timely opportunity to discuss the future role of LINks within patient centred care."

Joan Saddler - National Director for Public and Patient Affairs
Extracts from Joan's speech

NALM certainly manages to bring you in from far afield. Thank you to NALM for being involved and staying involved.

We are here to connect with real experiences because what we deliver must. We really want this dialogue with you for the creation of the ongoing agenda –'freedom, fairness and responsibility'. These objectives were signalled in the Coalition's Document. Democratic legitimacy of the NHS can complement the greater public trust that GP commissioning will create. We want to lever up localism. There are tensions. But we aim for building, not destroying. The Secretary of State has confirmed this. We all await the White Paper. You want me to tell you what is in it. I can't because I am also waiting to see what's in it.

LINks do a great deal of excellent work, but does the wider community know about them? They need a higher profile. How? They must have a role in assurance, in health commissioning and in local authority commissioning to create a coherent whole, because patients are not interested in 'separate organisations' for their care. Do LINks have adequate powers? We need to build on them and yes, we can, but there will be trade-offs.

The Secretary of State says that LINks need more powers to be consulted more fully and on a statutory footing. t Bow, he said,"Patients first". We will establish Healthwatch, but we want to co-produce what it and LINks will be and the structures that build them. We need your advice. We look to you, the stakeholders, to make it real.

Local Authorities have had their Strategic Needs Assessments, GPs their commissioning clusters, but these have not worked very well, we need to build the process and make it more effective. For 20 years there have been tensions between health and social care and always patients lose out. There is rising demand. The NHS Constitution should be a lever for user-power.

That LINks become effective intermediaries is vital. Local Authorities must make greater use of public health information. Social care must work respectfully with diversity. LINks struggle with diversity. Will all this integration help? But above all we must recognise user and carer led expectations.

There are challenges; engagement cannot be maintained without a systematic coalition of patients, the public, local authorities, and GPs. There are budgetary pressures which will mean some rebalancing across health and social care.

Andrew Lansley says "outcomes are more important than processes". Focus on outcomes, reduces silo thinking. Do professionals understand communication with GPs? [GPs will have £60-80bn to spend]. Do GPs understand social care and the campaigns such as Disability Rights? The patients' voice must be a thread though the entire system together with service users and empowered staff. Our motto should be 'nothing about us without us', not the old hamster wheel but transparency and accountability.

Calls from Secretary of State are for localism and for culture change. Can LINks lever up power? The Total Place pilots showed local leadership with commitment were successful, but nationally determined targets and funding were an impediment. We cannot be too directive.

We are hearing from LINks that their issues are:

- The public voice is an important one
- Continuity is vital
- Board level work and commissioning work is essential
- This cannot be just local, it needs a national construct
- Health and social care must be considered together
- Problem of variability of host organisations
- Progress is also necessary with the patient and public voice in strategic planning

There is critical ministerial support now with Health Minister Earl Howe. He is listening. LINks and Healthwatch are a possible model. What are others? Andrew Lansley has patients at the heart of everything.

Paul Streets Director of Patient and Public Experience
Extracts from Paul's speech

I have brought a colleague with me today, a new member of my team, to 'join the real world'. There is a new government and new rhetoric, but it's a real pleasure to be here.

Just about ten years ago, the Transitional Board oversaw the move from CHCs to PPIFs. Timing can be fortuitous or disastrous. But, I am here to listen, to take messages back to the DH and to detail the early signals from the Secretary of State on PPE and service-user engagement. At the Bromley by Bow (health centre), the Secretary of State was desperate to talk to patients first. That was his first major policy speech. It was symbolic. 'Patients at the heart' means participants' sharing-decision making. It means individual patient-choice plus voice, which crucially is what LINks were set up to do. Information must be shared at every point.

There must be the driving of standards. There must be accessible information for all. People must be empowered to ask, challenge and intervene. LINks and eventually Healthwatch must push outcomes not targets.

We have PROMs, QIPP etc etc but what do patients say? We have to change the nature of the relationship. Patients must be information-rich, and LINks too. Engagement must not be passive.

The American system has patient-centeredness, visits, participation, service design, shared decisions, open records, choice of date of operations etc. There is a vital balance. What is the future? See Stephen Eames article in the HSJ, " ffordability–Public Opinion" for an interesting view.

It was turbulent before the election. All Parties said they would cut. The Conservatives pledged a real term increase in health and stuck to it. QIPP has to produce a saving of £15–20bn and this money will be reinvested to meet the growing demand for care for the ageing. We have got to take the public with us. It's a massive ask.

There will be savage cuts, yet health is doing quite well though there's 20% of the budget to redistribute. You can reject it, and campaign, or you can work to decide where it should be re-invested. Patients want services that are different, want more primary care. If a hospital closes, the money can be reinvested in primary care. Vested interests will fight this, but this is reality.

Do respond ... respond to what you read in the White Paper ... respond early. Engage through NALM, get patients converted, focus on the DH and its consultations, use its formal consultations. When the White Paper is out, be clear about what you don't like. You can't all speak to us. You must be *very* focussed and work with key groups like NALM, tell us what LINks think. Use NALM and your Government Officers. Joan and I are the patient advocates in the system. We need real information, real responsiveness. Learn from the past, take forward what was good from CHCs, from PPIFs and LINks. Work with NALM. Tell us what you like or don't like, but *work with the government*. The past was not perfect.

The LINks' nnual Reports are vital for us to find ammunition and arguments to take to ministers. There are risks, but you must build on what you have done, help us with the detail behind the headlines. It's the service users who must hold services to account, not the centre. Your voice is more important now than at any time since 1948. It's the biggest opportunity ever to get centre stage.

Questions and Answers

Q Don't forget the carers.
A 'Patients and the public' includes carers. For every patient there is a carer. But keep reminding us. Paul Burstow, Minister for Social Services leads on carers.

Q Health is not just for the old. How can LINks attract the young?
A Young persons? This is for you, you've got organised now, the centre won't tell you how to do it. Work with what you've got. Youngsters won't go to LINks' meetings. Don't be into 'representativeness' but act as representatives, linking to the diversity of the community.

Q LINks' funding goes through the Local uthorities. Will our funding be hit?
A There's no answer to this one. There's not going to be anything ring-fenced. There won't be. How to make it happen? N LM will work with Joan and with me."

Malcolm Alexander
Chair of NALM

Can I welcome all delegates – especially those who have come far and got up at the crack of dawn to contribute to our important discussions today.

A special welcome also to Joan Saddler National Director of Patient and Public Affairs, and Paul Streets Director of Patient and Public Experience, who are at the centre of policy development as we enter this new phase of public influence in health and social care ... and Elizabeth Manero from HealthLINk who has campaigned for many years for a powerful public voice in health and social care.

There is sometimes a real danger that we get lost in battles about process, how we set up organisations, and who leads them, what sort of governance and sometimes we get stuck in debates and arguments that are not focussed on safety, healing, respect and dignity.

The terrible events at Stafford Hospital are a constant reminder of what can go wrong if we lose sight of the objectives of public involvement ... if we fail to listen to what people in the community are saying ... if we find bureaucratic reasons for not doing the systematic, careful monitoring of services. Looking at incidents and accidents, infection rates and complaints we are failing the communities we seek to seek represent.

LINks are public guardians in health and social care.

Putting the patient in the centre of health and social care may sound like empty rhetoric, but I take the aspiration very seriously. I think the question for us is: are we always the highly effective and articulate advocates and representative of the people receiving health and social care that we aspire to be?

Are services far better as a result of what we have done? Have we negotiated with PCTs, to improve access and quality of services? Have we identified failing services and how often can successes be attributed to our work?

HealthWatch may offer us an opportunity to build and develop LINks; to evaluate strengths and weaknesses, to ask the right questions about what people in our communities are trying to achieve in their services, and particularly to know how we can measure our success.

How can a national HealthWatch help us to do this? What sort of body should it be? Should it be run by democratically elected people from LINKs, what influence might it have on government, the CQC, the NPSA?

Today's meeting brings together 100 experts. You have worked to develop the LINks model for over two years. You know more than any think-tank, government department or academic department about how to create effective public involvement organisations. You have experienced the frustrations and sometimes the anger, which always goes with building new organisations.

Across the country many LINks are now achieving important successes and have become organisations of influence. But some of you are in LINks that are still struggling; I hope our discussions today will give you optimism for the future development of your LINk. The workshops today are your opportunity to create a blueprint for the development of LINks and the creation of Healthwatch.

By next week, we shall have a draft document that will bring together all the proposals that you prioritise today. We will send this document out for discussion and then submit it to the Joan Saddler and Paul Street who are to speak shortly. But time is short and we need to have working proposal to give to the DH very soon.

So let us think about what we have achieved and learned and how we can use our experience to create local and national bodies that are powerful advocates of all communities.

Let us stop asking what the Secretary of State for Health is going to do, instead start the process of creating effective, workable proposals, that will guide Ministers in the pursuit of a model of community involvement that will be valued by the public and will be a powerful agent for change in our health and social care services.

Now, let me read to you a short message to the conference from Health Minister Earl Howe, the Parliamentary Under Secretary of State for Quality:

> "To realise our ambition for the NHS patients must be at the heart of everything we do. We want to create an NHS that is led by the front-line, not the top, so that services are more responsive to individuals and their communities. We cannot underestimate the importance of involving local people in helping to implement this vision so LINks will play an increasingly important part in designing and providing feedback on local services. The NALM conference gives you a very timely opportunity to discuss the future role of LINks within patient centred care."

The important thing I have to tell you is that he has agreed to meet NALM to discuss the outcome of this conference.

Finally a word of thanks to Ruth Marsden, for the tireless work that she has put into the building of NALM.

Ruth Marsden
Vice Chair of NALM

It's good to look upon the faces of the flock. No apologies for the agricultural allusion, because I come from up north and that's more my world.

This is a significant day for LINks, an event for members, by members. It is a signal achievement. LINks have attracted people of passion, commitment, expertise, courage and sacrifice. colleague of mine, who cannot be here today, reminds that 'we are not in this for therapy!'

Today, we can only bring ourselves, not the hours, days, weeks, months of dedicated work. For many there is never a free day, yet it is done for free. It's an amazing testimony to the generosity of spirit, which is what volunteering is all about.

This Conference is a crossroads because it's a chance for us to meet each other, for me to put faces to the names on the e-mails. But also because something new has been brought into the equation – HealthWatch. Let's remind ourselves that LINks are about participative democracy and whatever's coming needs to be of the same stock, conceived on the same side of the blanket. LINks must have a hand in shaping it. LINks were meant to engage with the 'seldom heard', not to *be* the seldom heard.

London is a very, very different place from where I come from. Some few days before Conference, I received a desperate message from a colleague whose computer connection had failed because of thunderstorms and the sheep! Yet she's here today. Our patches are places where you have to drive 80 miles to get to a meeting before you can do the business.

But I know all LINks, however different, have concerns in common. My in-box tells me so, very regularly. So whatever the name of what comes – HealthWatch, CareWatch – it must recognise and address these concerns. All of us who have worked so tirelessly, for free, deserve no less.

When the previous model of statutory PPI, Patient and Public Involvement Forums, was coming to an end, the DH, through the Commission for Patient and Public Involvement in Health, set up the National Association of Patient Forums to carry committed volunteers forward, into the new system, LINks. Now, because LINks' members have set up N LM, we're here to be part of that same process, working to carry you forward, without complexity, without rehash, without any administrative Armageddon, but strongly and simply.

'N LM' is not an acronym of elegance. If it had been B SH, or J B or even BED, it might have had more cache, and looked more slick ... but N LM didn't start with the intention of looking or being slick. It started because there were unmet needs, real needs, and then as now, no-one else was adequately addressing them. Meeting those needs is what NALM

does. It explains, it informs, it connects, it updates, it supports and above all, it's responsive, it's there when called on, it does what its members ask of it. N LM is an honest organisation doing an honest job.

Today, two years on, we're still here, still doing that honest job, bringing colleagues together, supporting them to make their voices heard, enabling each and every LINk member from Dorset to Northumberland and from Cumbria to Kent to tell it like it is for them, sharing with Joan and Paul your collective vision for the future of your organisations.

NALM has no big budget, no glossy offices. In this current economic climate, we're a model of exactly what's needed. I make no apology for blowing this trumpet because we have *earned* the right to a place at the negotiating table.

Usually, it's my inbox that's full, but today, it is my heart that's full. God bless you.