

*The national voice for LINKs members*



# NALM members say ...

## **The National Association of LINKs Members**

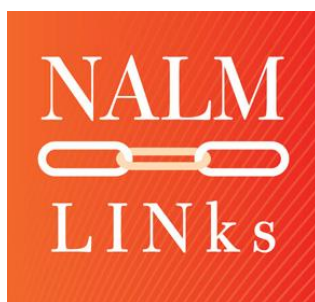
*Public and Patient Involvement in Health and Social Care*

**2009 - 2010**

COMPANY LIMITED BY GUARANTEE \* COMPANY REGISTERED IN ENGLAND  
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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

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[www.nalm.org.uk](http://www.nalm.org.uk)

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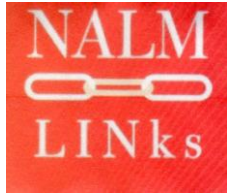
**Presented by: Polly Healy – Richmond Local Involvement Network**

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## Contents

---

The Aims of NALM ... .. 3

The Steering Group ... .. 4

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NALM members say ... .. 6

---

NALM Publications – Front Covers ... .. 17



## The Aims of NALM

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The aims of NALM are to:

1. Provide a national voice for LINKs' members

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

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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

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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

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

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

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

## NATIONAL ASSOCIATION OF LINKS MEMBERS - STEERING GROUP

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## NATIONAL ASSOCIATION OF LINKs MEMBERS - STEERING GROUP

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REGION	MIDLANDS
<p style="text-align: center;">Nominations pending for this region.</p>	

## NALM members say ...

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NALM keeps us slap bang up-to-date with information, and recently told us exactly what a Quality Account is, in order that we might make LINK comments on service improvements by our service providers. NALM let us know what is happening in health and social care, and what is new. In addition, NALM gives us advice on how to influence the decision-making processes.

Most recently, we have been kept right in the picture about the future of LINKs and how we can influence the outcomes from Parliament, in order for us to be favoured with future funding to help our local communities have a '*stronger local voice*' in their health and social care services.

**Jane Stubbings**  
**Chair, Nottinghamshire County LINK**

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The true value of NALM is the way in which it is able to keep local LINK members in the national information loop, as well as keeping central government informed of what is happening 'on the ground'.

The present structure of LINKs does not provide any incentive to Hosts to look beyond their local authority area.

Without NALM, therefore, it is difficult to see how any LINK members can be fully informed.

**Martin**

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You help answer my questions, and I don't know how we would have managed without that.

**Ann**

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NALM finds out so many things that I would never have known about otherwise.

**David**

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After CPPIH, I can quite understand the reluctance to put another national body in charge of PPI. But the need for a network is painfully obvious, and the regional support is variable.

NALM has filled the gap and made us feel a little less isolated. The information sharing – especially in recent weeks – has been excellent. No other body, whether nationally or regionally, has felt it was their job to pass on important information. It is important that volunteers in this field – who have suffered in recent years – have the information they need to stay motivated.

**Melvyn**

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Without NALM, those of us who cannot afford to subscribe to the HSJ, for instance, and who have neither the time nor perhaps the inclination to surf numerous health websites, and to monitor Parliament and the political parties, would either have to do it all ourselves or, more probably, fail to do it and be horribly under-informed. I find that because of NALM, I am often ahead of the professionals (and certainly ahead of my LINK Host), in knowing what is actually going on.

I also regret to say, but there is ample evidence that it is true, that some LINK Hosts prefer an uninformed and disempowered membership – and powerfully dislike NALM accordingly. This, for me, is one of the prime reasons why NALM should continue to exist and inform.

There is finally, no other means by which we are able to keep in touch with other LINK members – even the dreaded KMS of the CPPIH days, was miles ahead of what we have now as an alternative.

There is no other means of keeping in touch – the old Centre of Excellence website (a) wasn't a centre for anything, and (b) was infested by Host staff and is no moribund.

There would be absolutely nothing without NALM, and many of us have only carried on with LINK involvement because of it – isolated and fragmented as we would otherwise be, life in LINKs would be pretty well intolerable without an organisation at our disposal which was not dominated by those who seek to manage, corral and control us.

**Robert Jones**  
**Stewardship Group – Isle of Wight LINK**

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LINKs are not doing what was intended. They are not representative of the NHS users and they are in the hands of an unrepresentative 'proletariat' using it to its own ends.

The only defence against the misuse is NALM. We must keep up the good work.

**John**

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I keep on membership of NALM as a link with the old PPI. I find most of the information provided by NALM extremely useful ... and some, I must confess is way over my head. I can often take it further as an internet user, and get knowledge of how different parts of the country are using – or not using – the LINKs strange organisational ways.

I should like to thank NALM for all this input.

**Pat Wilson**

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As a Host organisation, I really appreciate the support of a national organisation that circulates the kind of information that you do – policy, etc. relating to health, social care, involvement and LINKs.

Thank you for all the hard work.

**Emma**

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NALM's most valuable asset is that of being a central fount for communicating information across the country. I value, especially, the Hansard and DoH information which I am then able to pass on to my fellow LINK colleagues.

NALM has enabled me to 'sort out the chaff from the wheat' of the whole 'involvement' world and agenda – all of which would otherwise have been impossible.

The NALM Conference on 08 July will also be an important opportunity to clarify the likely confusion between LINKs and the new HealthWatch concept.

**Anita Higham**  
**Stewardship Group, Oxfordshire LINK**

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In my LINK, I am the only member of NALM and my LINK is not a member due to the resistance of some of our original members.

Our LINK has had trouble with our Host and I went to NALM for help. I have had absolutely fantastic support and help from the NALM Executive when I had nowhere else to go.

Many other members of the LINK have now decided to join NALM as individual members and, if we are further elected to serve on the Governance Group, we shall become NALM members.

Our Chair has been using the advice I have received from the NALM Executive.

The information sent out to us by NALM is valuable. It is also important for one LINK to know what the others are doing, and how they are serving the people of their area.

I do believe it is important for us to work together, and the only way of doing this is to have a national body such as NALM.

**Dr. Shobha Srivastava**  
**Governance Group, South Tyneside LINK**

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The main value of NALM for me, personally, is the 'in-time' electronic message information received.

As with many organisations, supporting members through providing a gateway for relevant information is very helpful.

**Margaret**

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A view and a compliment ...

- The sense that there is someone independent and understand the 'system'
- Being in touch with the government and the DoH
- The continuous information flow is greatly appreciated

We appreciate all the NALM information – the newsletters, surveys and reports – that are so invaluable.

NALM must be the only organisation that has an overview and understand – as is proven by these various publications.

NALM offers support and receives queries – simply leaving things between the Host, LINKs and the local authority is unacceptable.

**Ellie**

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I find all the information you pass on keeps me up-to-date. No-one else is passing out the information that NALM does. I often pass these things on to my local LINK and I also share them with our Enter and View group.

NALM is invaluable and keeps us on our toes. I hope that you can keep up the good work.

**Marlene Moura**

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Thank you NALM for what you have done and for what you are doing, which is invaluable.

**John**

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I should just like to say that I think NALM does a marvellous job keeping members informed of everything that is happening in the NHS. I always enjoy reading your emails. They make me feel involved and informed of how our health service is changing.

**Rose Mary Hassoon**

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I particularly value all your reports and updates, whether they are about the NHS or current government strategy.

I don't always read the whole article upon receipt, but they make me aware of current developments.

**Sandra Boyle**

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NALM provides a valuable service in keeping us up-to-date by reporting the policies of our politicians in the House of Commons and the House of Lords – as well as informing us of reports and developments.

**Marina Taylor**

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Being new to LINKs, I find the email updates you send out to be very valuable. There appears to be nowhere else that up-to-date information is circulated. The content is great and informative.

**Pat Harris**

**Links Development Officer – Torbay LINK**

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I have been constantly impressed at the amount of information that NALM has shared with LINKs' members.

Informed communication is the basis of networking and has given a greater understanding of the *bigger picture*. Without this, we would have been confined to our local Host's information pathways which can be – unintentionally – restricted to information from the larger statutory services in place.

**Tess Jelen**  
**Steering Group, Westminster LINK**

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NALM has provided me with a really valuable service in keeping us (West Berkshire LINK) up-to-date with the wider environment in which LINKs operate. Without NALM, we would be unaware of many really important initiatives going on elsewhere.

For those without a subscription to Health Service Journal, NALM also goes some way towards filling the gap when that body went 'subscriptions only'.

On a personal basis, advice to get in contact with Sandra Berry (Kingston's LINK and Cliff Bush (Surrey LINK) has been really helpful when we were in dispute with our Host organisation.

At times one can feel pretty lonely and frustrated chairing a LINK when one has the Host and local authority on one's back all the time saying that the problems that they have caused, or contributed to, are all really the fault of the unco-operative, unpaid LINK volunteers!

NALM's last Annual Conference was also helpful for the contacts that I made. We all need a bit of encouragement from time to time.

NALM also plays a really important role in representing the LINKs up and down the country to politicians and other national bodies, though the recent report about the government's plans for HealthWatch, did make me wonder whether there was any real future for LINKs.

What NALM doesn't seem to do is promote better communications between LINKs and, in particular, circulate examples of good practice and innovative thinking.

I have, for example, been most impressed by some of the work that the Liverpool LINK has done. For volunteers to produce reports of this quality is truly impressive. We need to know about these things.

As a suggestion, why doesn't NALM collect all the Annual Reports and put them up on the website.

**Tony**

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NALM has been very supportive of our efforts. In particular, without a national organisation, we would not be able to tackle – in an effective way – the many issues that are common to all LINKs.

The members of our local LINK have had extremely good responses from NALM when requesting information and advice.

We also channel suggestions for improved procedures via NALM and its good relationship with the Department of Health and other bodies.

**Bob M**  
**Bristol LINK**

NALM has been wonderful in keeping me up-to-date with what is going on nationally in the NHS and in Parliament.

The local authorities have the Local Government Association; as far as I can make out, the Hosts talk to each other; the DoH and NHS have their internal communications systems; NALM is the only nationwide organisation for LINKs members – and your Regional Directories which you sent out a day or two ago, are a tremendous asset.

I do not know how you manage so much on the modest membership fees you ask.

**Catherine Willmetts**  
**North Yorkshire LINK**

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Comment:

- 'Hot off the press information' ahead of LINKs' Host staff, by far.
- HSJ highlights – which would be missed.
- Latest news and views from Parliament

Above all, NALM is always willing to listen and advise.

NALM gives LINKs' members the missing link, and inspires us to carry on beavering away volunteering when, at times, it seems futile.

**Andrea**

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I am happy to support NALM in its efforts to promote patient awareness nationally – and the support that it gives to individual LINKs.

The information given out on the political views on patient involvement has been invaluable over the build-up and election period, has been very helpful.

NALM is absolutely great at being the first organisation – usually way ahead of the DoH itself – to send out information relevant to LINKs' work and invariably passes the most pertinent selections directly to our Host who is most grateful, as are other LINK members.

**Neil Hughes**  
**Cumbria LINK**

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The information flow which NALM supplies, is invaluable.

**Ken Hoole**  
**LINK Southwark**

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I find the information you are sending most valuable, as we do have a rather difficult situation re. LINK in Devon.

**Alfred Boom**  
**Devon LINK**

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The material that NALM produces is extensive, relevant and excellent – authoritative and, in many cases, illuminatory of major and minor issues in the odyssey of development that is LINKs.

The forwarding of material from Parliamentary debates, official reports, other organisations etc. is not only very useful, but essential to the campaign to legitimate LINKs ... and to improve it and make it more cost effective and efficient. I do not know how you do it!

Please keep up the good work and convey my thanks to the Executive.

**Dr. James Lynch**  
**Chair, Devon Health and Social Care Forum**

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As an individual member of Hertfordshire LINK, I receive mostly local information about NHS services, but as a NALM member, I receive a wide range of interesting and topical information which I value as background reading.

I also value your campaigning work at national/DoH level, to gain better recognition for the work of LINKs and of other patient involvement.

**John Wright**

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From the HOST's opinion, I believe that NALM serves its members well by doing the following:

- Producing and distributing LINKs Directories
- Sending regular emails about national developments in Health and Social Care
- Organising events which LINK members can attend
- Having NALM Board Members from a variety of LINKs
- Meeting with key people, such as Joan Saddler

**Alvin Kinch**  
**Team Leader, LINK Southwark**

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Keeping us up-to-date on government statements about health, major issues arising and challenges in improving PPI, is most valuable.

Any more on public health could be useful too.

**Nigel Crawford**

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I absolutely agree with all the comments I have read about NALM so far. I just hope NALM can keep up the good work and finally LINKs will be able to do the work we all set out to do.

**Tony**

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NALM was very helpful prior to the formation of LINKs in influencing the DoH and the government to make improvements to their plans for LINKs. Since then, we have been kept up-to-date with all government and DoH matters, which has been very useful.

I have personally found the ability to ask for information and advice on aspects of the LINK's work extremely helpful.

**Gillian Seward**  
**Bristol LINK**

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NALM helps me by sharing relevant information and keeping me up-to-date. Many thanks.

**Anne**

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I have very much valued my membership of NALM for the following reasons:

When Patient Forums were disbanded, we felt very much adrift. Some of us were not appointed to the successor to Forums (LINKs) and you helped us feel we still had something to offer. In our case, our local LINK chose to completely ignore Acute Hospitals and you kept us in touch with what was happening in the rest of the country where this was not the case. So we did not feel that we were 'odd'!

The information you have sent us on a regular basis, both before the General Election, during it and now, has been invaluable. We are very grateful to you for this. NALM has encouraged us not to 'jump ship' but to stay around and hopefully HealthWatch will have something for everyone. Volunteers cannot just be cast aside – we have lots to contribute.

Thank you all for your tireless hard work, your valuable links with people at the highest level. We hope you will still be in evidence when HealthWatch comes in.

**Jackqui**

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I feel that getting all the very informative emails, assists in undertaking our work. I use information provided in that way to give me useful information that I then use when meeting with the Overview and Scrutiny Committee, which our LINK does every month. This gives us the opportunity to take to task where needed, our local health and social care services, bringing the LINK (public) perspective to the discussions.

There have been several occasions when information from NALM has been of use in these discussions.

**Helen  
Sheffield LINK**

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I have always enjoyed and benefitted from NALM emails covering wide and varied areas of interest for LINK membership, particularly changing health policies and the role of LINKs in pushing forward the agenda for continuous improvement in health and social care.

NALM has also done well in keeping LINKs in the limelight.

**Amjad**

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I should like to comment on the help and advices from NALM.

- Governance and Legislation advice.
- National recognition through support by NALM Chair (eg: Camden LINK AGM).
- Regular updates regarding local and national government, stakeholder and other national bodies regarding health and social care issues.

- Knowledge and confidence of support and information from NALM upon request.
- Membership of NALM and its support network for LINKs.

**Carl**

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My views on what NALM does for me:

NALM performs the function of representing LINK members and LINK bodes, as a whole, at the top levels, putting their views, concerns and suggestions – apparently effectively – to government, DoH, major bodies, etc.

A body to do this (as a ACHCEW had done for the CHCs) was not included in the legislation setting up LINKs – probably intentionally, because an effective, combined voice at high level can embarrass those that it is talking to! The individual LINKs themselves shows no sign, as far as I could see, of immediately getting together to create one, and NALM seems to have stepped in and fulfilled this essential function very well.

NALM provides a ‘press cutting’ and information service which keeps me well informed about events, statements, intentions and proposals occurring within the ‘health economy’ which have implications for LINKs, for me and my own functions within that – and, of course, for the whole ‘constituency’ which we serve.

On several occasions, I have been able to inform colleague LINK members about matters relevant to us, of which they were not aware due to the lack of any similar comprehensive source of information for them/us. Very helpful!

The AGM last year, and the accompanying Conference, were very interesting and informative events, enabling me to see and listen to a range of key people and organisations active in the field in which LINKs operates, and learn from that. I am now looking forward to this year's event. Again this provides an experience which does not seem, as far as I am aware, to have been made available in any other way in LINKs, or at least in my area to date.

All in all, NALM is filling a range of key needs within LINKs which do not seem to have been, or are likely to be, provided otherwise. Well done, and keep it up!

**Dave Review**  
**Surrey LINK**

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NALM has continuously supported, given information on LINKs' development, encouraged individuals to stay engaged in the process, and made every effort to ensure that LINKs – despite obstacles – have indeed started to show green shoots, if not roots.

The publications have been well received and utilised by Hosts and LINKs and demonstrate that a national overview is required to keep a track of both progress and lack of progress.

**Pat**

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Thank you for the efforts you at NALM are putting in.

With the changes which the coalition seem about to make, the position of LINKs may well change. Nevertheless, since our LINKs system in Hampshire is so tardy in getting going, it would be nice to know how others compare.

I see some clues in things you send, and I guess there are as many solutions as there are LINKs, but I detect that some are doing very well. They are all too busy, probably, to give time to explain their progress, but how many produce newsletters, for example, which could be published and broadcast for others to learn from.

We have at last got a management board produced by an AGM, but activities are not very directed to helping patients.

I am still not sure we have the right office support team.

**Gordon**

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I am informed, by many Hull PCT staff, GPs, Practice Managers, VolCom and HC Council staff, etc. that I am one of the few volunteers who says, asks and suggests very challenging things. A few worry about my safety at times. However, to be able to act in this way:

- (a) I do not have a job to lose. I am completely independent, self-employed physiotherapist with a duty of care to my patients.
- (b) I have information, often well before the NHS staff etc. who attend the same locality board, sub-committees, sub-groups as myself.

This is very much due to NALM as a tremendous fount of specific knowledge and advice, which I find very reassuring.

You may not be surprised to learn that some NHS staff quietly thank me for raising specific issues and then acting like a Rottweiler.

You save me so much time.

**Denise**

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Communications from NALM are very helpful regarding PCT general information, government information on thoughts of how to save money.

I regularly attend two PCT meetings – Main Board (as a member of the public) and Commissioning Board (as a patient rep – LINK member). A number of times a communication from NALM has alerted me to listen for some particular item on the Agenda.

I say to my fellow LINK members, that we all hold pieces of the jigsaw (knowledge gained at meetings) and sometimes these fit together to show an overall picture or direction of travel and if we do not share them with each other, the picture will never be.

**Roy Prytherch**  
**Sutton LINK**

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Some of the things that NALM does very well, from my own experiences, are as follows:

- Keeps me up-to-date with national matters that are cascaded down the line.
- Provides an excellent source of information.
- Helps in advising of where to access information.
- Organises meetings with high level bureaucrats in the NHS.

**David**

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From the standpoint of a LINK Chair, the support from NALM has been invaluable.

Firstly, the information that NALM circulates to LINKs on Parliamentary and other government statements, is essential for us to know and, of course, LINKs do not receive this – or indeed any information directly from the DoH, DCLG, SHA or Government

Regional Offices – so we would not know about these otherwise.

Secondly, the meetings that the NALM Chair and Vice Chair have with key people at national level, gives us up-to-date news and is the only mechanism that LINKs have for getting its voice heard at national level.

To cite just one example: NALM informed LINKs of the overdue reporting to the NPSA of Patient Safety Alerts. We were able to take these up with our local NHS Trusts who have now assured the LINK that all of the Alerts have been responded to. We report this in our latest Annual Report.

Thirdly, and perhaps most importantly, NALM brings LINKs together so that we feel we are not alone and do not have to re-invent everything afresh by ourselves. NALM enables us to feel part of a national community of LINKs which again, of course, has not been provided to LINKs through the formal establishing arrangements.

**Mike Smith**  
**Chair, Sheffield LINK**

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NALM has helped us to keep up-to-date with all the changes that are being brought in. We believe NALM does fantastic work and is much more useful than our local LINK.

We receive Hansard from NALM and, therefore, know exactly what the politicians are thinking. We have passed much of your information onto our local LINK and other campaigners.

Well done NALM! Keep up the very good work!

**Margaret**

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NALM provided essential information to LINKs during the complex transition period from PPI Forums to LINKs in 2008.

NALM regional members have run workshops which have helped to bring LINKs members together and have distributed practical information.

The NALM Chair and Vice Chair were personally very supportive, and offered mediation between the elected LINK's Chair and Host organisation when a situation arose which threatened the independence of a LINK. The situation arose after the local authority set impossible performance targets in the contract made with the Host in 2008, which were in conflict with Legislation and the Department of Health directives.

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NALM provides a search resource of publications, DoH and government announcements that has allowed LINKs to stay informed of the ever-changing health and social care environment – not affordable by one LINK on its own, and not easily understandable as a need by Hosts.

NALM provided a unifying force for LINKs in respect of actions taken, and relationship with Commissioners by other LINKs, which have aided local negotiations.

Tirelessly presented a LINK view in higher circles and into National Voice

**Barry**

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NALM offers a very valuable and responsive service, which greatly benefits the work of Leicestershire LINK. Without NALM, scant Host resources would be used searching for specific national policy and LINK related information from other sources.

Not only does NALM send volumes of extremely relevant and current information,

they also offer an excellent advice service, which we have used on several occasions.

Leicestershire LINK was also extremely fortunate in having Malcolm Alexander speak at our first Annual Conference, and this was a huge success.

If it were not for NALM, many of the key factors, information and health and social care policies, would be oblivious to members.

Leicestershire LINK would, therefore, wish to take this opportunity to thank NALM for its support and hope that this continues into the next phase of LINKs on a much firmer footing.

**John Baker  
Chair, Leicestershire LINK**

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NALM is absolutely fantastic in keeping me and our LINK in touch with what's happening in other LINKs and in health and social care policy and the NHS generally. No other organisation does this.

NALM compiled a Directory of LINKs and keeps it up-to-date. I know that it is doing its utmost to ensure that LINKs and LINK members will be influential in whatever arrangements for PPI the new government are in the process of cooking up.

The best value there is for £5.00!

**Sally Brearley  
Sutton LINK**

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I had intended to write to you and thank you for the work you do and I am really sorry that cannot be with you at the Conference, as I would like to express my support and thanks in person.



Since becoming a member of NALM, I really value the information from a wide range of quality sources that you share with the membership. This keeps me totally up-to-date with current health issues – from the perspective of a concerned member of the public- as well as giving me the political, social and environmental background. Most importantly, without the spin!

With best wishes for a successful Conference.

***Helen Caton Hughes***  
***Warwickshire LINK***

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National Association of LINKs' Members was born. Malcolm has been an excellent Chair, with exhaustive relationships building and promoting NALM. Ruth (Vice Chair) has been a pivotal and invaluable central influence – from those earliest days with issues such as the imbalance in the use of CPPIH finances, starving PPI Forums of funds, to today's regular mailings to the whole of the NALM membership.

I'm looking at my NALM mailbox and I cannot begin to list the breadth and variety of essential information Ruth has provided us with. She is truly astonishing.

***Mike Cox***

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