

National Association of LINks Members

Annual Report and Financial Statement 2009



NATIONAL ASSOCIATION OF LINKS MEMBERS

Patient and Public Involvement in Health and Social Care

www.nalm.org.uk

CHAIR: **MALCOLM ALEXANDER**

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VICE CHAIR: RUTH MARSDEN

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THE AIMS OF NALM

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1.	Provide a national voice for LINks and 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, and to promote inclusivity, diversity and equal opportunities
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

REGION	EAST OF ENGLAND				
	Anthony Darwood				
	14 Bramerton Lodge, Bramerton, NORWICH, NR14 7EQ				
	Tel: 01508 537 021 Email: anthony.darwood@btopenworld.com				
	Mary Ledgard (Co-opted)				
	38 Mount Pleasant, NORWICH, NR2 2DG				
	Tel: 01603 503098 Email: <u>ledgard@clara.co.uk</u>				

REGION	LONDON
	Malcolm Alexander
	30 Portland Rise, LONDON, N4 2PP
	Tel: 020 8809 6551 Email: <u>maiexa49@aol.com</u>
	Michael English
	12 Denny Crescent, LONDON, SE11 4UY
	Tel: 020 7582 9970

REGION	NORTH EAST			
	Patricia Bottrill, MBE, FRCN			
	25 Carolyn Crescent, WHITLEY BAY, Tyne and Wear, NE26 3ED			
	Tel: 0191 252 2832 Email: davepatbottie@btinternet.com			
	Trevor Gauntlett			
	133 Donvale Road, Donwell, WASHINGTON, NE37 1DW			
	Tel: 0191 416 1347			

REGION	NORTH WEST				
	Martin Rathfelder				
	22 Blair Road, MANCHESTER, M16 8NS				
	Tel: 0870 013 0065 Email: admin@sochealth.co.uk				
	John Lyon Taylor				
JRT Cons	JRT Consultants, Victoria Leisure Bus Centre, The Promenade, SOUTHPORT, PR9 0DS				
Tel	: 07817 420664 / 01704 547905 Email: <u>irtconsultantsltd@tiscali.co.uk</u>				

NATIONAL ASSOCIATION OF LINks MEMBERS - STEERING GROUP

REGION	SOUTH EAST				
	John Kapp				
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	Len Roberts				
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REGION	SOUTH WEST				
	Eleonore Pang				
	10 Yonder Street, Ottery St. Mary, EXETER, EX11 1HD				
	Tel: 01404 812 268 Email: elli@ellipang.wanadoo.co.uk				
	Bob Maggs				
	6 Dublin Crescent, Henleaze, BRISTOL, BS9 4NA				
	Tel: 0117 962 8649 Email: bob.maggs@virgin.net				

REGION	YORKSHIRE AND HUMBERSIDE
	Ruth Marsden
	The Hollies, George Street, COTTINGHAM, HU16 5QP
	Tel: 01482 849 980 Email: ruth@myford.karoo.co.uk
	Mike Smith (Co-opted)
	The Circle, 33 Rockingham Lane, SHEFFIELD, S1 4FW
	Tel: 0114 253 6690 Email: info@sheffieldlink.org.uk

REGION	MIDLANDS	
		Nominations pending for this region.
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NATIONAL ASSOCIATION OF LINKS MEMBERS

ANNUAL REPORT AND FINANCIAL STATEMENT FOR 2009

December 31st 2009

Company Registration Number: 6598770

Report and financial statement for the year ended 31st December 2009

The Trustees have pleasure in presenting their report and financial statement for the year ended 31st December 2009.

Incorporation

The company which was incorporated on May 20th 2008 under the Companies Act 1985 is a not-for-profit private company limited by guarantee, with no share capital, registered with the name of National Association of LINks Members. Its Memorandum and Articles of Association are in the model format for a charitable company as issued by the Charity Commission. Its objectives and activities are those of a small unregistered charity, as described more fully in this report. The nature of the company's business is covered by the classification code categories: 8514 - other human health activities, 8531 - social work with accommodation, and 9133 - other membership organisations.

Directors and Trustees

The directors of the company are its Trustees for the purpose of Charity law. As provided in the Articles of Association, the directors have the power to appoint additional directors.

The Trustees who have served during the year and subsequently are:

Malcolm Alexander Michael English John Larkin Ruth Marsden

The National Association of LINks Members comprises members of the public including patients and carers who are members of Local Involvement Networks. The office of National Association of LINks Members is located in London.

Objects of National Association of LINks Members

The Company was formed as a not-for-profit company with exclusively charitable objects. The Company is committed to act for the public benefit through its pursuit of wholly charitable initiatives comprising:

(i) The advancement of health or the saving of lives, including the prevention or relief of sickness, disease or human suffering; and

- (ii) The relief of those in need by reason of youth, age, ill-health, disability, hardship or other disadvantage, including by the provision of accommodation or care, and ...
- (iii) the company is dedicated to the pursuit of its objects as a small unregistered charity with a view to registration with the Charity Commission as and when appropriate.

Vision Statement

The National Association of LINks Members (NALM) is an unregistered charity which aims to provide a national voice for Local Involvement Networks (LINks) and help build the capacity of LINks members to achieve change and improvement in health and social care services at local, regional and national levels. NALM aspires to facilitate the involvement of all people in the determination of health and social care policy, especially those whose voices are not currently being heard. NALM actively promotes diversity, inclusivity and equal opportunities in relation to the improvement of health and social care services.

Mission Statement

- 1. To provide a national voice for LINks and LINKs' members;
- 2. To promote public involvement which leads to real change and the ability to influence key decisions about how care services are planned and run;
- 3. To promote the capacity and effectiveness of LINks' members to monitor and influence services at local, regional and national levels and to give people a genuine voice in their health and social care services;
- 4. To support the capacity of communities to be involved with and engage in consultations about changes to services, to influence key decisions about health and social services and hold those services to account;
- 5. To support the involvement of people whose voices are not currently being heard, and to promote inclusivity, diversity and equal opportunities;
- 6. To promote open and transparent communication between communities across the country and the health service;
- 7. To promote accountability in the NHS and social care to patients and the public.

Activities and Achievements

NALM Manifesto

NALM has produced a Manifesto based on the objects of NALM to give LINks and the wider public a better understanding of NALM's work. The Manifesto is based on the following key points:

- Build NALM as the independent national voice for LINks and users of health and social care services.
- Promote, for the benefit of the public, the long term development and strengthening of LINKs, as powerful, independent and influential bodies for patient and public involvement in policy, strategy and delivery of care services.
- Support the growth and development of the NHS as the provider of health services free to all at the point of use.
- Campaign for the right of all vulnerable people to get the care and support they need to lead fulfilled lives.

NALM Good Practice Guide

To support the development of LINks, NALM has collected examples of 'best practice' from LINks across England. A short description of each contribution has been placed in a Best Practice Directory which has been distributed to LINKs to inspire them in their work to improve the quality of local services.

The NALM Directory

NALM has produced a national directory of LINks showing contact details and listing the major health and local agencies in each area. The purpose of the directory is to create opportunities for patient, citizens and health and social care agencies to easily contact each other.

Good communications across the sector improve opportunities to share information about problems with services and recommendations for improvement. Regional directories have also been produced and updates distributed each month.

Working with LINks

NALM runs a highly effective communications system with LINks across the country. Members are provided with newsletters, information updates several times a week and are notified of major events, consultations and new developments. Regular visits are also made to LINks across the country.

Support for LINks facing start-up problems

A major role for NALM has been the support given to LINks that were not functioning well. NALM advised members about the duties of Local Authorities and relationships between LINks and Hosts. In some cases NALM has facilitated the provision of legal advice to LINks when serious problems have arisen. NALM has offered its services wherever a dispute has threatened the effectiveness of the LINk and hampered its ability to provide support for communities through the monitoring of services and identification of problems that affect care provided to local people.

Parliamentary Work

Parliamentary activities in which NALM has been involved include presentations to meetings of the All-Party Parliamentary Group on Patient and Public Involvement. The Group has been supportive of NALM's work and has provided opportunities for NALM publications to be forwarded to Ministers. Work with the All-Party Group has enabled NALM to promote issues raised by LINk members concerning the effectiveness of public involvement in health and social care.

NALM has also met the Chair of the Health Select Committee to ask for a further review of the effectiveness of patient and public involvement and to press the committee to support greater involvement of LINks in the commissioning of appropriate local health and social care services.

NALM regularly meets with key civil servants and policy makers in the Department of Health.

Development of LINks

NALM carried out research into LINk development in the period April 1st 2008 - August 8th 2008 and published the report in 2009 entitled LOCAL INVOLVEMENT NETWORKS (LINks) An interim report on the start-up and development of LINks.

The report was based on Freedom of Information (FOI) requests put to all 152 local authorities (LAs) in England with social services' responsibilities and examined the following issues:

- the way the 'pump-priming' £10k has been used by LAs
- the way funding has been used so far by LAs
- the current status of the LINks
- the effectiveness of transitional arrangements from Forums to LINks

The research revealed a wide range of appropriate uses for the £10,000 pump-priming money. These included a variety of events, publicity, procurement and transitional activities. Other LAs spent the LINk money on their own costs. Only 6 specifically spoke of using the £10k to support transition.

LINk funding retained by Local Authorities – We were surprised by the range of practices by LAs to pay for governance of contracts with the Hosts. Some LAs had taken nothing for themselves, preferring to give as much as possible to the Host and LINk; others intended to take significant amounts to cover their costs, e.g. 15% (Kensington and Chelsea) and 12.6% (Haringey, taking £64,900 from the 3-year budget total for the LINk of £514k); Sefton will retain for itself £52,934 out of a 3-year allocation of £513K; North Yorkshire, retaining £68k over the three years out of a total allocation of £660k; and Cornwall, retaining £60k out of a total LINk allocation of £756k.

NALM is concerned that with such low budgets to cover activities for a three year period, money is being used by some LAs to cover their own costs, rather than passing the money to the Host so that it can be used by LINks' members on the front line.

NALM is concerned that there is neither any intention nor mechanism for the DH to monitor the financial relationship between LINks, Hosts and LAs and that the Audit Commission has declined to take on this role. Neither are there plans for the DH to monitor the development of the new LINks system.

Top-slicing of LINks budgets

NALM is concerned that the DH has top-sliced the LINk budget to fund their own staff in the regions. In total £3 million has been top sliced from the national LINks' budget to fund these DH staff and other DH activities. We have called on the Government to return this money to LINks and use part of it to fund NALM activities.

Indemnity for LINk Members

NALM made a powerful case to Ministers for state funded indemnity for LINk members to enable them to carry out their duties on behalf of the public effectively. Support was also sought from Baroness Neuberger, the then government's 'independent volunteering champion', asking her to support NALM's case for state-backed indemnity for LINks' members. The Centre for Public Scrutiny which formerly provided information and guidance on behalf of the DH was also asked to produce a guide on indemnity for LINks but declined to do so.

Our case for indemnity is based on the view that lay people representing the public must have legal cover when they make statements in public meetings or to the media that are critical of the services they have monitored. Indemnity should also cover any harm caused by or endured during a monitoring visit by a LINk member. We believe any liability when a LINk member is representing the LINk should be collective. The DH has not conceded our arguments and NALM is continuing to make the case for indemnity cover for all LINk members. NALM intends to produce a guide for LINks on indemnity issues.

Working with National organisations

NALM has developed effective working relationships with national bodies including the Care Quality Commission, NICE, AvMA, National Voices, Patients Association, Unison, the Royal College of Nursing, the Nursing and Midwifery Council, the NHS Alliance, GMC, General Pharmaceutical Council (GPhC), NHS Support Federation, and many other bodies. Regular contact has also been established with DH civil servants who lead on public involvement policy. Work with many of these organisations continues also at a regional level.

Work to establish more influence on DH policy continues under the umbrella of the duty of DH to promote the role of voluntary organisations in the NHS and social care. NALM is committed to actively engaging with the DH, meeting regularly and building relationships that will support the development of more effective public influence and involvement.

Appointment Commission

Improving democracy and accountability in the NHS is key to enabling the public to influence the quality and effectiveness of health and social care and to creating safer services. NALM has therefore collaborated with the Appointment Commission to develop a framework for public involvement in the selection of PCT chairs. This would include the active participation of LINks.

Wales, Scotland and Northern Ireland

We have maintained a strong relationship with the Welsh Association of Community Health Councils, and worked with them closely during a period of their reorganisation. We are in regular contact with sister organisations in Scotland and Northern Ireland and hope to improve relations with these bodies in 2010. Our primary objectives in this work are to learn from their approaches to PPI and collaborate on cross border issues where this will improve the quality of care for patients and users of social care.

Meetings with the Care Quality Commission

NALM met the former Chair of the CQC, Baroness Barbara Young, after she had spoken at the 2009 NALM AGM, to press the CQC to establish effective contact with LINks. We are particularly concerned about the ability of the CQC to respond to issues raised by LINks. We attempt to maintain regular contact with CQC staff, including CQC regional managers, to ensure that if a further disaster for patients occurs, like the breakdown of care at the Mid-Staffordshire Hospital, local relationships are in place to ensure a rapid response.

Stafford meeting

The Chair of NALM, Malcolm Alexander, was invited to chair a meeting of 200 people in Stafford Town Hall. They were protesting about the major breakdown of care at the Mid-Staffordshire Hospital. Speakers included 'Cure the NHS', local MPs, AvMA, the Patients Association and a medical negligence lawyer. NALM supported the call for a Public Enquiry, to ensure that the tragic events that occurred at Mid-Staffordshire Hospital could never happen again. A meeting has also taken place with David Colin Thome, the National Director for Primary Care, to discuss early warning systems where care is not adequate or hospital systems have broken down.

Social Care

NALM has actively encouraged members to get involved in the commissioning and monitoring of social care services.

In our response to the Social Care Green Paper NALM called for all social care to be fully funded by the state, in a way comparable to the state funding of health, and free at the point of use. We strongly objected to any suggestion of enabling insurance companies to make a profit out of social care users and carers.

We drew attention to weaknesses in the Green Paper in relation to people who do not communicate well by virtue of language or disability, and called for a much stronger emphasis on advocacy as a source of empowerment. NALM called for more resources for carers, respite care for both carers and users, enforcement of anti-discrimination legislation and a full rights-based system to support independence.

Duty of Candour

NALM has joined the campaign to introduce a legal Duty of Candour for health care bodies. The duty would require these bodies to inform patients or relatives when a medical accident occurs. The government's position is that culture change and adequate training and support for staff are required, rather than a legal Duty of Candour. We have argued that after many years of avoidance of candour, a change in the law is now required to bring about the appropriate cultural change. Failing to take action may only fuel distrust between injured patients, their families and health providers, and sends out the wrong message - that the government gives low priority to this problem and that dishonesty with harmed patients, whilst frowned upon, will not be taken seriously.

Casualty Watch

In order to support Enter and View activities used to monitor the effectiveness of the health care provision, NALM has promoted the use of Casualty Watch amongst LINks. Casualty Watch enables LINk members to enter into A&E Departments to collect data about the length of time patients are waiting on a trolley before being discharged or admitted. Once in the public domain this data can have an important impact on local practice and policy leading to improvements in the quality of emergency care and much shorter waits for patients.

Public Access to Foundation Trust Board Meetings

NALM members have expressed major concerns about the decision of some Foundation Trusts to hold their Board meetings in private. The breakdown of services at the Mid-Staffordshire Hospital, accompanied by a secretive style of management and closed Board meetings, raised more general concerns about the culture of hospitals which feel the need to hold private Board meetings. It is NALM's view that secretive organisations are more likely to discourage open reporting of incidents and accidents that could harm patients.

NALM raised this matter with Monitor who had replied that Foundation Trusts have no obligation to hold Public Board meetings. NALM also raised the matter with Ministers. Ben Bradshaw, the former Minister of State for Health Services, agreed in a Parliamentary Health Committee inquiry that it was desirable for FTs to hold their meetings in public and that new legislation may be required to enforce this.

Members and Affiliates

All the Trustees are members of the Company. During the year ended 31 December 2009 the Company also enrolled several hundred other members of the Company. Each member guarantees, in accordance with the Company's Memorandum of Association, to contribute up to £10 to the assets of the Company in the event of a winding up.

Membership is open to Local Involvement Networks, and individuals who live anywhere in the UK, who are members of a Local Involvement Network. Members are entitled to attend meetings of the Company, and to vote thereat. The annual membership fee for individuals is £5 and for Local Involvement Networks the fee is £20-00. New members are welcome to join.

Affiliation is open to other organisations and individuals with an interest in supporting the objects of the organisation. Affiliates are fully entitled to attend meetings of the Company but not to vote thereat. The annual Affiliation fee for local and regional groups/organisations is £50 and £200-00 for national organisations. New affiliates are welcome to join.

This report was approved by the Trustees and is signed on their behalf by:

Malcolm Alexander Director/Chair		John Larkin Director/Company Secretary
	Date	

Income and Expenditure Account

For the year ended 31 December 2009

Company Number 6598770

	Unrestricted Funds	Total
	£	£
Incoming Resources		
Donations	9,597.50	9,597.50
Membership fees	2,885.00	2,885.00
Total Incoming resources	12,482.50	12,482.50
Resources expended		
Hire of Conference Hall	10,633.19	10,633.19
Steering Group expenses	919.05	919.05
Hire of room	787.86	787.86
Stationery	1,468.14	1,468.14
Total resources expended	13,808.24	13,808.24
Net incoming / (outgoing) resources for the year	-1,325.74	-1,325.74
Total funds brought forward	1,928.65	1,928.65
Total funds carried forward	602.91	602.91

Balance Sheet

December 31, 2009

December 51, 2009	
	£
Current assets	
Cash at bank	602.91
Creditors	
Amount falling due within one year	-
Net current assets	602.91
Total assets less current liabilities	602.91
Reserves	
Unrestricted funds	602.91
	602.91

Notes

- 1. These accounts have been prepared in accordance with the special provisions for small companies under Part 15 of the Companies Act 2006.
- 2. For the year ended 31 December 2009 the Company was entitled to exemption under Section 477 of the Companies Act 2006.
- 3. No notice from members requiring an audit of the accounts has been deposited under Section 476 of the Companies Act 2006.
- 4. The Directors acknowledge their responsibility under the Companies Act 2006 for:
 - (i) Ensuring the Company keeps accounting records which comply with the Act

and

- (ii) Preparing accounts which give a true and fair view of the state of affairs of the Company as at the end of its financial year, and of its income and expenditure for the financial year in accordance with the Companies Act 2006, and which otherwise comply with the requirements of the Companies Act relating to accounts, so far as applicable to the Company.
- 5. The National Association of LINks Members is a registered Company limited by guarantee and not having a share capital; it is governed by its Memorandum and Articles of Association. It is an unregistered charity whose income is hitherto insufficient to fulfil the criteria for compulsory registration with the Charity Commission.

This financial statement was approved by the Trustees on----- 2010 and is signed on their behalf by:

Malcolm Alexander Director/Chair

John Larkin

Director/Company Secretary

Glossary:

AvMA Action against Medical Accidents

CQC **Care Quality Commission** DH Department of Health GMC General Medical Council

NICE National Institute of Clinical Excellence

PCT **Primary Care Trust**

PPI Patient and Public Involvement