

# **NATIONAL ASSOCIATION OF LINKs MEMBERS**

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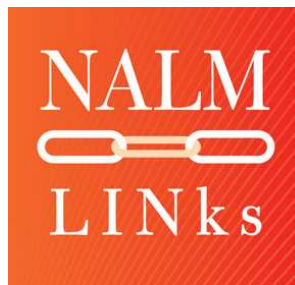
## **Patient and Public Involvement in Health and Social Care**

### **ANNUAL REPORT AND FINANCIAL STATEMENT**

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**For the year ended 31 December 2011**

**Charity Registration Number: 1138181  
Company Registration Number: 6598770**



## NATIONAL ASSOCIATION OF LINKs MEMBERS

Patient and Public Involvement in Health and Social Care

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[www.nalm2010.org.uk](http://www.nalm2010.org.uk)

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# Contents

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The Aims of NALM	...	...	...	...	...	...	...	...	...	4
Steering Group Members	...	...	...	...	...	...	...	...	...	5
Report and Financial Statement for the Year Ended 31 December 2011	...	...	...	...	...	...	...	...	...	7
<hr/>										
Incorporation	...	...	...	...	...	...	...	...	...	7
Directors and Trustees	...	...	...	...	...	...	...	...	...	7
Objects of the National Association of LINKs Members	...	...	...	...	...	...	...	...	...	8
Vision Statement	...	...	...	...	...	...	...	...	...	8
Mission Statement	...	...	...	...	...	...	...	...	...	8
NALM Manifesto	...	...	...	...	...	...	...	...	...	9
The Role of NALM	...	...	...	...	...	...	...	...	...	9
Achievements and Activities	...	...	...	...	...	...	...	...	...	10
The Future of NALM	...	...	...	...	...	...	...	...	...	23
Election of the NALM Steering Group	...	...	...	...	...	...	...	...	...	24
NALM Publications 2011	...	...	...	...	...	...	...	...	...	25
Members and Affiliates	...	...	...	...	...	...	...	...	...	26
Income and Expenditure	...	...	...	...	...	...	...	...	...	27
Balance sheet	...	...	...	...	...	...	...	...	...	28
<hr/>										
Notes	...	...	...	...	...	...	...	...	...	28
Glossary	...	...	...	...	...	...	...	...	...	29
Summary of information about the National Association of LINK Members	...	...	...	...	...	...	...	...	...	30

# THE AIMS OF NALM

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## The Aims of NALM are to:

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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.

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## NATIONAL ASSOCIATION OF LINKS MEMBERS – STEERING GROUP

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NATIONAL ASSOCIATION OF LINKs MEMBERS – STEERING GROUP

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# Report and Financial Statement for the Year Ended 31 December 2011

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The Trustees have pleasure in presenting their report and financial statement for the year ended 31st December 2011.

## **Incorporation**

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This was the first full year since the organisation achieved registration on the Charity Commission's Register of Charities with effect from 27th September 2010. Since the incorporation of the company in 2008, NALM's Memorandum and Articles of Association have been in the model format for a charitable company as issued by the Charity Commission. Its objectives and activities are those of a small registered charity, as described more fully in this report.

NALM was originally incorporated on 20th May 2008 under the Companies Act 1985 and it remains a not-for-profit private company limited by guarantee, with no share capital, registered with the name of National Association of LINKs Members. The nature of the company's business is covered by the classification code categories: 86900 - other human health activities, 88990 - social work without accommodation, and 94990 - other membership organisations.

## **Directors and Trustees**

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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:

- o Malcolm Alexander
- o Michael English
- o John Larkin
- o 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 the National Association of LINKs Members

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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;

## Vision Statement

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The National Association of LINKs Members (NALM) is a registered 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

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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 promote open and transparent communication between communities across the country and the health service;
6. To promote accountability in the NHS and social care to patients and the public;
7. To support the involvement of people whose voices are not currently being heard, and to promote inclusivity, diversity and equal opportunities.



## NALM Manifesto

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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.

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## THE ROLE OF NALM

NALM is the national voice of Local Involvement Networks (LINKs), supporting members to achieve better services, greater access and improvement to all health and social care services at local, regional and national levels. We facilitate public involvement in the determination of health and social care policy and we are especially committed to hearing and acting on the voices of those who are usually not heard. NALM actively promotes diversity, inclusivity and equal opportunities in relation to the improvement of health and social care services.

# ACHIEVEMENTS AND ACTIVITIES

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## ANNUAL CONFERENCE – SEPTEMBER 30, 2011

We held a very successful conference in 2011 at the NUT conference centre in London attended by 150 delegates. Speakers included: Cynthia Bower, Chief Executive of the CQC and David Behan, Director General of Social Care, Local Government and Care Partnerships. A message from Health Minister, Earl Howe was presented to the conference (<http://tinyurl.com/cudrl7r>) as well as messages from David Bennett, the Chair of Monitor (<http://tinyurl.com/8f3qbaw>) and Yves Buckland, Chair of the NHS Institute of Innovation and Improvement (<http://tinyurl.com/9vnp2on>).

### Workshops were run on the following issues:

- Complaints and Advocacy - led by Valerie Harrison and Peter Walsh
- Future Forum - led by Jeremy Taylor and Jason Stamp
- Local HealthWatch as Corporate Bodies - led by James Sinclair Taylor, solicitor
- Signposting/info and Advice - led by John Larkham
- The Future of NALM - led by Sally Brearley

NALM is indebted to the following people for supporting the conference:

### Conference organisation:

Polly Healy, Richmond LINK  
Rianne Eimers, Kingston LINK

### Conference facilitation:

AvMA - Ed Maycock and Paula Santos

### Photographer:

Crispin Hughes- <http://www.crispinhughes.co.uk/>

### Leading and supporting conference workshops:

Amjad Rahi, Anita Higham, Dave Shields, Geoff Mitchell, James Sinclair Taylor, Janice McCulloch, Jason Stamp, Jeremy Taylor, Jilla Bond, John Larkham, Mike Smith, Nick Kennedy, Nigel Thompson, Patrick Vernon, Peter Walsh, Sally Brearley, Valerie Harrison

### Receivers, Scribes, Meeters and Greeters:

Barry Silverman, Dag Saunders, John Hellings, Mark Platt, Mary Ledgard, Mike Roberts, Richard Smith, Tony Lloyd, Trevor Begg.

**The NALM conference for 2012 will be held on October 11<sup>th</sup>.**

## **DEVELOPMENT OF THE NALM WEBSITE**

During 2011 the website underwent continuous revision and upgrading and we now have an excellent site which is updated on a daily basis and contains the most recent information on matters related to NALM's objects. The site has high rates of usage (hits) and provides access to all of NALM reports. We are indebted to Neil Woodnick and Polly Healy for their continuing support for this important development and Polly Healy for production of publicity materials.

## **MISSION STATEMENT**

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### **1) To provide a national voice for LINKs and LINKs' members**

#### **MEETINGS WITH EARL HOWE, PARLIAMENTARY UNDER-SECRETARY OF STATE**

NALM had a number of meetings with the Health Minister, Earl Howe, who leads on HealthWatch for the Department of Health. Amongst the issues discussed with Earl Howe was funding for Pathfinder LHWs. These bodies are intended to explore and lead the transition from LINKs to LHW but were unfunded by the DH. Following representations from NALM, Earl Howe agreed to provide £5000 for each HealthWatch Pathfinder (there are 75 in England). NALM also emphasized the importance of Pathfinders sharing their learning with all LINKs – especially those which have not operated well. NALM also made successful representations to NHS London to obtain funds for the development of LINKs in London.

The main concerns raised with Earl Howe at our meeting with him on December 14<sup>th</sup> 2012 were (<http://tinyurl.com/cd93wbp>).

- Independence of HWE and LHWs
- The influence of HWE with the NHS Commissioning Board, Monitor and the CQC
- Elections to HWE
- Effective transitions from LINK to LHW
- Loss of lay leadership for LHW
- Unlawful replacement of LINK hosts by local authorities
- Current and proposed funding arrangements through LAS, including ring-fencing.
- Proposed duty of CCGs to consult/involve LHWs
- Election of LHW members to the HWE board
- Funding of HealthWatch Pathfinders
- Failure of the Future Forum to adequately include LINKs representation in its work

#### **MEETINGS WITH PARLIAMENTARIANS**

During 2011 NALM had many meetings with parliamentarians especially in relation to serious problems with the Health and Social Care Bill. We briefed peers – including Lord

Toby Harris, Baroness Meral Ece, Lord Naren Patel, Baroness Margaret Wheeler and Baroness Lindsay Northover - on the public involvement sections of the Bill and a number of detailed briefings and proposed Bill amendments were prepared for MPs and Peers. NALM was pleased that matters evidenced in our briefings were frequently debated on the floor of the House. NALM is very critical of the government for creating Local HealthWatch bodies that lack independence and which have no formal relationship with Clinical Commissioning Groups (CCGs) in relation to commissioning. NALM believes that the proposed accountability relationship between LHW and HealthWatch England is weak and does not include a process of elections from LHW to HWE to ensure appropriate and credible accountability.

We believe that the proposed new arrangement will fail to promote services that meet the health and social care needs of people who use services, will increase mortality and will not be sufficiently independent or robust enough to prevent and relieve sickness, disease or human suffering in health and social care services.

## **PARLIAMENTARY HEALTH COMMITTEE**

NALM provided oral evidence to the Health Committee on commissioning of healthcare (see: <http://tinyurl.com/c98mwmx>) and highlighted the importance of public involvement in the planning of services. We also submitted a statement on the committee's investigation into the handling of NHS complaints.

## **HEALTHWATCH PROGRAMME BOARD**

The Department of Health 'Programme Board' was established to deliver national support for implementation of the HealthWatch programme. NALM was concerned that the DH would provide no guidance to local areas and that consequently LHW would not develop into influential representative organisations. In response to NALM's concerns, the DH agreed to produce an options paper for LHW but failed to do so. NALM has also expressed concern about the leadership role being given to HWE in relation to LHW. We argued that to be consistent with the localism agenda, LHW should lead HWE, and that HWE should actively support the development and empowerment of LHW. The matter which has most concerned our members and which NALM has raised continuously is the critical need for LHW to be independent.

NALM successfully raised with the Board the minimal relationship with Monitor, as a significant risk to the successful development of HealthWatch England. Monitor is expected to be a key resource in the empowerment of HealthWatch.

Membership of the Programme Board includes key health and social care agencies, civil servants from the HealthWatch Team and NALM members: Dag Saunders, Anita Higham, Nick Kennedy and Malcolm Alexander.

## **ADVISORY COMMITTEE - HEALTHWATCH PROGRAMME BOARD**

The Advisory Group comprised a committee of 50 representatives with active participation from LINKs and many other organisations. NALM members Ruth Marsden, Sally Brearley and

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Nick Kennedy chaired three of the Task and Finish Groups established by the Advisory Committee. NALM was of the strong opinion that the Advisory Committee had insufficient influence on the Programme Board and it was difficult to demonstrate a significant level of impact on Programme Board decisions.

We have actively promoted the transition of LINKs to LHW to ensure that the expertise, local knowledge and skills of LINK members carry forward into LHW. The DH produced a 'transition plan' but since that time has shown decreasing interest in effecting a successful transition. NALM believes that the approach of the DH will lead to the development of ineffective and dysfunctional LHWs. We have argued that LHWs, if established without an effective transition from LINKs, will need to build new capacity to develop and run effective LHW bodies – this in the view of NALM would take about two years.

The NALM Steering Group agreed to establish an intelligence hub on the NALM website, to gather data about the transition from LINKs to LHW in every local authority area of England. LINKs and local authorities are encouraged to submit information about local developments.

## **MEETINGS HEALTH AND SOCIAL CARE BODIES AND REPRESENTATIVES**

During 2011 NALM met with many colleagues to develop collaborative opportunities to improve the effectiveness of public involvement in health and social care and to increase the influence and profile of NALM. These meetings included:

- Alice Williams – NHS Institute for Innovation and Improvement to discuss joint work in relation to the Productive Ward
- CQC's Executive Group meetings – attended by Dag Saunders
- David Bennett, Monitor, to discuss their role in relation to HealthWatch
- David Wood, Chief Executive of Attend, to discuss indemnity
- Design council – Membership of the Reducing violence and aggression in A&E Board
- Diane Abbot MP, Shadow Minister for Public Health
- Ian Winter, Deputy Regional Director, Social Care and Partnerships
- Jo Williams, Chair, CQC, to discuss the development of HealthWatch England
- Joan Saddler, DH National Director for Patient and Public Affairs, to discuss the development of HealthWatch
- Mary Simpson, Head of Healthwatch Programme
- Mid Staffordshire Inquiry Seminar
- National Cancer Network – to give a presentation to member of local networks
- NHS Consultants Association AGM, York
- Nial Dixon, GMC, to discuss revalidation of doctors
- Nick Warren of Competition and Collaboration Panel, Treasury, to discuss public involvement in merger proposals and methodology for public involvement during the consideration of mergers
- Nigel Thompson, CQC, to discuss the development of HealthWatch
- Patrick Vernon, Chief Executive, Afiya
- Paul Hodgkin, Patient Opinion

- Paul Streets, Director of Patient and Public Experience, DH, to discuss the development of HealthWatch
- RCN Congress, Harrogate. “Changes to patient and public involvement in the health service and the new HealthWatch, opportunities for staff’s closer engagement”
- NHS London Board, to request funds for the development of LHW in London
- Welsh Assembly, regarding the development of Community Health Councils
- Tim Gilling, Centre for Public Scrutiny, to discuss the development of HealthWatch
- Tony Butterworth, NHS Institute for Innovation & Improvement
- Una O’Brien, Permanent Secretary at the DH
- Valerie Harrison, POWhER, ICAS provider
- Written and oral evidence to the Lords’ European Union Committee, Sub Committee on Social Policies and Consumer Protection, “Mobility of Healthcare Professionals in the EU”.

NALM attempted to meet with Malcolm Grant as Chair of the interim NHS Commissioning Board, but despite advising him of the importance of LINKs as the voice of the public in promoting and developing safer and more effective services in the NHS, we were unable to arrange a meeting with him.

## **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**

### **NALM’S HEALTHWATCH TRANSFORMATION BOARD**

NALM established the LINKs/HealthWatch Transformation Board to explore the views of key players on the proposed development of LINKs into HealthWatch. NALM used information gained from evidence sessions of the Board to inform policy and practice in the development of HealthWatch. We invited the following people to participate as Transformation Board members:

#### **From the NALM Steering Group:**

- 1) Mike Smith – Sheffield LINK
- 2) Ellie Pang – Devon LINK
- 3) Len Roberts – Surrey LINK
- 4) Ruth Marsden – East Riding of Yorkshire LINK
- 5) Malcolm Alexander – Hackney LINK
- 6) Mary Ledgard – Norfolk LINK
- 7) Michael English – Lambeth LINK

### **As independent public involvement specialists:**

- 8) Ros Levenson
- 9) Christine Hogg
- 10) Angeline Burke

### **For the LINK Hosts:**

- 11) Jilla Bond - Shaw Trust
- 12) Saima Khan, Communities in Partnership (Leicestershire LINK)

### **From National Voluntary Sector Organisations:**

- 13) Sally Brearley - Healthlink
- 14) Patrick Vernon - Afiya Trust
- 15) Jeremy Taylor - National Voices
- 16) Janet Grant - Diabetes UK – Users’ Panel
- 17) Rosie Newbigging - Asthma UK
- 18) Katherine Murphy, Patients Association

### **From National Partner Organisations:**

- 18) Carol Basham, BMA Patients Liaison Group
- 19) Avril Davies, Centre for Public Scrutiny

### **Witnesses invited to submit evidence to the Transformation Board:**

Care Quality Commission - Frances Hasler, HealthWatch Development Lead  
Consumer Focus – Philip Cullum, Acting Chief Executive  
Department of Health - Mary Simpson, Head of Healthwatch Programme  
National PALS Network - John Larkham, Chair  
POWhER (ICAS provider) – Valerie Harrison, Chief Executive  
Royal College of Nursing – Mark Platt, Policy Adviser

## **PUBLIC KNOWLEDGE OF HEALTHWATCH**

NALM attended workshops with Spencer du Bois, the consultant hired by the CQC to create an identity for HealthWatch. We felt that Spencer du Bois operated professionally and sensitively, but were concerned at the cost of the approach adopted by the CQC and value for money. We requested sight of costs and the CQC provided the following information:

“Spencer du Bois was commissioned, following a competitive tender process, to develop a visual identity and logo that will be the trademark for HealthWatch England and local HealthWatch. The commission included the development of a communications toolkit for use by local authority, pathfinder and other colleagues. These development activities are required of CQC under the Health and Social Care Act 2012.

As part of the development process the agency delivered a comprehensive research project to test images and messages with the public, provide valuable insight into the brand development and to ensure the brand supports local HealthWatch organisations as representatives of diverse local communities. This research included workshops with hard to reach groups, general public research sessions, interviews with social care professionals and local authority commissioners and an online survey.

The overall project, which runs from November 2011 to 2013, when local HealthWatch is launched, will cost approximately £75,000. This figure includes the broad research detailed above and work to develop the tools and messages for use locally to support local communications and awareness building. It also includes in the region of £5000 for the cost of the final HealthWatch logo that we will trademark”.

## **THE CARE QUALITY COMMISSION AND HEALTHWATCH**

NALM had considerable concerns about the performance of the CQC in relation to the establishment of HealthWatch, and raised these directly with CQC officers and the Chief Executive, Cynthia Bowyer. There was evident disconnect between public statements and practice in relation to valuing public involvement. We were also concerned about the difficulty of contacting CQC inspectors. Information regarding access to inspectors was initially denied to NALM, but after submitting an FOI, this information was provided and has now been placed in the public arena (<http://tinyurl.com/czhqk57>). We followed up concerns over the development of HealthWatch within the CQC in a letter to Cynthia Bower, Chief Executive of the CQC, and highlighted the following points:

- The CQC failed to consult the HWE England Task and Finish Group (HWE T&F) chaired by NALM Steering Group member Sally Brearley, before publishing ‘Preparing for HealthWatch’. Neither the document nor the press release were shown to the Chair or members of the HWE T&F Group prior to publication.
- ‘Preparing for HealthWatch’ failed to mention the word ‘independent’ at all, despite the clear intention of Ministers that HealthWatch England should be independent.
- Working with the CQC feels like working with colleagues who pretend to consult but fail to practice inclusion and involvement or to promote empowerment.
- Accountability of HWE to LHW has been ignored by the CQC and replaced with claims that HWE will provide ‘leadership for LHW’. NALM believes leadership must be earned by reputation, not imposed.
- CQC ignores the importance of HWE’s accountability being achieved through LHW having elected places on the board of HWE.
- CQC has a poor understanding of the needs of newly formed LHW. The CQC focuses on collecting and processing information, instead of developing LHW organisations and their capacity to carry out their five statutory functions effectively. LHW will need support, training, advice, resources and expertise on policy and legal processes if it is to take off quickly.
- HWE needs to develop an expert team with appropriate knowledge, experience and expertise, to build HWE, support the transition of LINKs into LHW and rapidly take on the roles and activities required of LHW.



### **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**

#### **MID-STAFFS INQUIRY**

NALM met with the Inquiry solicitors and gave detailed evidence about the role of public involvement in reducing incidents and accidents in healthcare and improving patient safety. Some of our proposals were included in the final statement to the Inquiry. NALM also attended a seminar organised by the Inquiry team.

#### **MEETING WITH ATTEND – INDEMNITY FOR LINK-HEALTHWATCH MEMBERS**

NALM is very concerned that LINK and HealthWatch members carrying out statutory activities consequent upon an 'act of parliament', might suffer harm, cause harm or be threatened with legal action; and therefore need indemnity to protect them from the risk of being sued. NALM met with ATTEND, a voluntary sector organisation of hospital friends groups, to learn about the work they have carried out on indemnity for hospital volunteers, which we felt would be of benefit to LINKs. They have negotiated with their insurers an indemnity scheme with 3 levels of cover, which LINKs and LHWs could find useful in the face of the government's unreasonable refusal to provide indemnity cover. NALM has consistently raised this issue with the DH and HealthWatch Programme Board, and has now referred this issue to the NHS Litigation Authority for advice (<http://tinyurl.com/bu2s29n>). NALM has amassed a considerable amount of information on indemnity, which has been sent to the DH and a paper has been presented to the HealthWatch Programme Board by the DH (<http://tinyurl.com/czyx9an>).

#### **HEALTHWATCH TASK AND FINISH GROUPS**

NALM was actively involved in several DH Task and Finish Groups. Our Steering Group members chaired two of these - the HWE Group (Sally Brearley) and the Transition to LHW Group (Ruth Marsden), which initiated a Bulletin to cascade information across the country. Unfortunately, its production was soon attenuated by the DH/CQC and it proved impossible to get freedom of action with the DH and CQC to distribute information from Task and Finish Groups to the public.

#### **LHW as CORPORATE BODIES**

NALM is concerned that very few LINKs will transform their organisations into corporate bodies to become LHW. The stated intention of transition and evolution originally proposed by government has in practice been abandoned. NALM provided access to a solicitor at the 2011 NALM Conference, who was willing to produce documentation that all LINKs could use if they wanted to become LHW. Many local authorities have widened the LHW brief to include other services, making it more difficult for existing LINKs to transform themselves and bid for local government contracts. This approach is likely to submerge LHWs and make

them inaccessible to the public. NALM pressed for the option of 'grant in aid' for local authorities committed to a genuine transition. NALM is also concerned that in rural areas options are very limited for bodies to replace LINKs. NALM has established a page on its website for LINKs to share brief summaries on the commissioning/tendering process in their areas.

## **UNLAWFUL ACTIVITIES BY SOME LOCAL AUTHORITIES**

NALM discovered that several local authorities had dismissed the host they had contracted to support the local LINK, and were acting as hosts themselves - despite this action being expressly excluded by the Local Government and Public Involvement in Health Act 2007. The DH and DCLG are not willing to take any action to halt this unlawful practice. This augurs ill for LHW, in that it suggests there is neither appetite nor mechanism to ensure legislation is adhered to, in relation to statutory public involvement organisations.

### **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**

## **OPPOSING THE GOVERNMENT'S PUBLIC INVOLVEMENT SILOS**

We have been dismayed about the confusion the Department of Health has created through their sponsorship of different forms of public involvement without thinking through any connectivity. Whilst promoting active engagement with the public by CCGs, the DH has refused to join up the duty of Local HealthWatch to influence commissioners and the duty of CCGs to involve the public in commissioning decisions. Neither has the DH given thought to collaborative work between Patients Participation Groups and Local HealthWatch. This approach confuses the public, is poor value for money, weakens the potential influence of LHW – and tends to confirm the view that the DH wants weak and diffuse public involvement organisations with little influence. We believe it is an appalling waste of public money to encourage CCGs to involve the public, but not to promote the role of LHW as a leading vehicle for engaging the public in commissioning decisions made by CCGs. Consequently, many GPs have chosen patients they 'get on well with' to be their public involvement leads. Few GPs are knowledgeable about or committed to PPI and most would benefit from the expertise of LINKs/LHW. Confusion has been added by the proposed creation, at the behest of David Cameron of Patient Led Inspections, to start in April 2013 - the same time that LHW begins.

## **NHS FUTURE FORUM – FAILURE TO SHOW REGARD TO THE MEANS OF ACHIEVING EFFECTIVE PUBLIC INVOLVEMENT IN HEALTH AND SOCIAL CARE**

The NHS Future Forum was set up to have 'conversations with patients, service users and professionals to provide independent input on four themes including how to ensure the public's health remains at the heart of the NHS'. We were fortunate to have a Steering Group member Sally Brearley serving on the panel in a personal capacity, but remain very

concerned that no attempt was made through NALM or any means to elect a LINK representative to sit on the Forum. Pressure on Ministers and the DH led to Jason Stamp being appointed from a LINK in a personal capacity; he worked with Jeremy Taylor from National Voices to hold a series of meetings on the second stage of the Future Forum. The Future Forum ignored the views of LINKs – set up by the government to represent the patients' voice, and thereby undermined the influence of patients, users and carers in the development of the NHS. Of the 252 meetings of the Future Forum, only 17 were attended by the Future Forum Lead on PPI, and none of these were outside London.

NALM asked the Future Forum to support the following changes to government policy:

- LINKs should by transition develop into HealthWatch – not be abolished as intended by government
- The excellent work carried out by many LINKs should evolve as a continuum into Local HealthWatch
- LHW funding should *not* be via LAs but from HWE to ensure independence
- As LHW will monitor local authority services, it is not appropriate for LHW to be accountable to the local authority; they should be accountable to the local community and HealthWatch England.
- Funding for LHW should be ringfenced.

None of these proposals was adopted by the Future Forum and in the view of NALM, as a result of the Future Forum's lack of insight into the means of achieving effective public involvement and influence, it has substantially weakened and disabled public involvement in health and social care in England.

Other matters raised by NALM with the Future Forum were conceded by government:

- Boards of GP Consortia (CCGs) must meet in public
- Consortia papers should be available in public domain
- Patients should have representation on all Consortia boards
- Monitor should be accountable to the public

NALM has been particularly worried by the reluctance of Monitor to meet with NALM's HealthWatch Transformation Board. The Chief Executive, David Bennett, was invited to speak at the NALM conference but was unable to do so and instead submitted a statement. He was represented at the conference by Tom Youlden. NALM continues to coax Monitor to develop appropriate mechanisms of accountability to the public.

## **ACTION LEARNING SETS FOR LINKs**

During 2011 NALM consistently raised with the DH the importance of establishing action learning approaches to the development of LINKs to enable their transition to LHW. There were considerable and unacceptable delays in organising this support for LINKs. NALM continuously raised this issue with the HealthWatch Programme Board.

## **5) To promote open and transparent communication between communities across the country and the health service**

### **FREEDOM OF INFORMATION ACT – HEALTHWATCH**

NALM campaigned for LHW to be subject to the Freedom of Information Act 1997 (FOI) (Clause 185, European Union Act 2011). We believe there must be a duty laid on LHWs as public bodies to provide information requested by the public. The DH conceded on this matter and the duty has been put into law. We are continuing to raise the importance of the FOI Act being amended to place a duty on private and independent providers of state funded healthcare, to provide information about these services to the public. Our experience is that most private and independent providers of services refuse to answer reasonable questions put to them by the public. Refusal is usually on the spurious grounds of 'commercial confidentiality'. We believe that CCGs should include a clause in contracts to make such providers subject to FOI. We have raised these issues with the Campaign for Freedom of Information (<http://www.cfoi.org.uk/>).

### **PALS – ADVICE, INFORMATION AND SIGNPOSTING**

NALM has been active in raising concerns about the loss of PCT PALS (Patient Advice and Liaison Service), which have provided advice, information, signposting and support (including casework) for people with complaints. NALM has expressed concerns that casework will be terminated and people supported by PALS left with no replacement service. Instead of transferring the whole service to LHW the government intends to salami slice PALS, transferring a small element with minimal funding to LHW and abolishing the rest of the service. Although the NHS Commissioning Board is expected to deal with complaints against GPs, dentists, opticians and pharmacists, it is anticipated that there will be no arrangements to provide support or advocacy to people who make complaints through this process. In many areas the PALS service worked closely with public involvement leads who will now be phased out in many areas, although it is possible that some Clinical Commissioning Groups will develop a cadre of staff for outreach and engagement work.

### **ICAS – INDEPENDENT ADVICE AND LIAISON SERVICE**

NALM has expressed concerns to the DH about the impact of transferring the ICAS, which is currently centrally commissioned, to 152 local authorities. We emphasized the need to ensure that ICAS is integrated into LHW, to create organisations that provide advocacy for patients and social care users in their local community. We have emphasized the importance of ensuring that information from complaints, monitoring of services and the investigation of incidents and accidents is made available to LHW; this data is crucial to the success of LHW in supporting the local community and gathering 'hard' data to influence commissioning. We have also expressed concerns to the HealthWatch Programme Board that all people receiving an ICAS service now must have seamless continuity into the new service if their complaint is unresolved at the transition stage.

## **6) To promote accountability in the NHS and social care to patients and the public**

### **STATUTORY DUTY OF CANDOUR**

We have actively supported proposals for a statutory Duty of Candour following harm or potential harm to a patient. The campaign led by AvMA seeks to introduce the duty of candour as a requirement in the Regulations covering registration with the Care Quality Commission (CQC) in England and with Healthcare Standards for Wales (and the equivalent bodies in the rest of the UK). This would mean that any organisation registered to provide healthcare would have a statutory Duty of Candour. Failure to demonstrate compliance could result in refusal or removal of registration, fines, and/or requirements to take remedial action.

NALM issued the following statement in support of the campaign:

"NALM is committed to the protection of patients in health care and believes that there should be a legal 'duty of candour', which places a duty on all health care professionals to be open and frank with patients. We are disturbed that the opportunity to introduce a legal 'duty of candour' has been side-stepped by Government, which has decided to introduce a requirement to report adverse events in health or social care in England to the regulator, but not to patients and carers who should be at the centre of health care. We will be demanding that the Government amends the draft regulations for Care Quality Commission (CQC) laid before Parliament this week to include a duty of candour to patients as well as regulators".

The government agreed there should be a contractual duty of candour, but refused to make this duty statutory. NALM continues to work with AvMA and National Voices on this issue.

### **REVALIDATION OF DOCTORS**

NALM has worked closely with National Voices to participate in the development of the process for revalidation of doctors in the UK. Through National Voices, we were offered a seat on the English Revalidation Delivery Board. National Voices also has a seat on the UK Revalidation Programme Board and there has been excellent collaboration between National Voices and NALM on this process, which will require all doctors in practice to have an annual appraisal and re-license every 5 years. NALM and National Voices have pressed the GMC to incorporate a higher level of continuous patient and public involvement in the annual appraisal of doctors. NALM will continue to encourage LINKs to get actively involved in working with doctors in their areas to ensure active inclusion of patients' views and commentary in doctors' appraisals. NALM produced a briefing note for LINKs on the revalidation of doctors (<http://tinyurl.com/dxalq5u>).

### **LOCAL HEALTHWATCH AND HEALTH AND WELLBEING BOARDS (HWBB)**

NALM has welcomed the proposed new role for LHW on HWBBs. This new statutory role should provide opportunities for additional influence on the strategic direction of local

services. We have expressed concern about potential conflicts of interests, as LHW may be sitting on HWBBs as voting members with a single vote on major decisions, that may be opposed by local communities; this would potentially put LHW in opposition to those it should be representing. NALM also expressed concern that LHW will have to bid for its own funding from the local authorities on the basis of their perceived 'value for money', whilst on some occasions vigorously contesting local authority decisions. NALM believes this contradiction will significantly weaken and disempower LHW

## **WORKING WITH THE HEALTH SERVICE COMMISSIONER**

NALM worked with the Health Service Commissioner and colleague from the DH, CQC, National Voices, Monitor and NHS Information Centre, to forge a joint agreement called: 'Driving improvement and learning from NHS complaints information'. The signatory organisations agreed there is a clear need for meaningful, comparable complaints information, which can be used to help drive improvement in healthcare and strengthen the quality of services for patients and the public (<http://tinyurl.com/chdhh7m>).

### **7) To support the involvement of people whose voices are not currently being heard, and to promote inclusivity, diversity and equal opportunities**

NALM has been concerned about the HealthWatch Programme Board's commitment to diversity and inclusion in relation to the development of HealthWatch. We raised this issue at the very first meeting of the Programme Board and asked for the Board to prioritise a commitment to diversity and inclusion in all its work. This commitment was supported by the Chair and members of the Programme Board and the issue has gained status in the Board's priorities, especially in relation to the inclusion of children and young people through work with the National Children's Bureau. As a result of pressure on the DH they have similarly agreed to extend the remit of Healthwatch to include social care for young people and children.

Many LINKs and Patients Forums before them have been insufficiently reflective of the diversity of their local populations in relation to protected characteristics: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex and sexual orientation. NALM has persistently raised this issue with the DH and as a result the legislation for Local HealthWatch specifically refers to the requirement for Local HealthWatch to be representative of the community it serves:

"Local HealthWatch will have to be inclusive and reflect the diversity of the community it serves. There is an explicit requirement in the Health & Social Care Act that the way in which a local Healthwatch exercises its functions must be representative of local people and different users of services, including carers".  
<http://healthandcare.dh.gov.uk/what-is-healthwatch/>

## THE FUTURE OF NALM – VIEWS OF THE STEERING GROUP

NALM is funded by its members – LINKs and individuals who support our work. We have never received direct funding or support from the DH or any other body. NALM's success has always depended on the hard work and dedication of the Steering Group and the volunteers who carry out NALM research, prepare publications, maintain the website and undertake a wide range of activities at our annual conferences. The Steering Group discussed whether NALM should develop into an Association of HealthWatch, and agreed that the potential value of an Association of HealthWatch Members had been well demonstrated by NALM's successful work with LINKs and central government, and that funding for a HealthWatch association needed to be secured. The potential undermining of NALM's independence is the major reason for NALM to consider very carefully the risks associated with accepting money from government sources. The Steering Group felt that ACHCEW (Association of CHCs for England and Wales) had operated independently for 25 years and that evidence could be taken from the 6 former chief executives of ACHCEW to establish the strengths and weaknesses of that model. It was also agreed that in view of the inherent weaknesses of the HealthWatch system in terms of independence and accountability, a national organisation of HealthWatch that was not subject to pressures from government was crucial. It was agreed that the Charity must continue to meet its objects to act for the public benefit through initiatives that promote:

- The advancement of health
- The saving of lives
- Prevention or relief of sickness, disease or human suffering, and
- The relief of those in need by reason of youth, age, ill-health, disability, hardship or other disadvantage.

The Steering Group agreed to seek proposals from the current NALM members about potential models for a national organisation to include the following themes:

- Build on the positive reputation of NALM;
- Press for funding for an independent association of LHW and LHW members;
- Build proposed models on what is needed, not necessarily through the evolution of NALM;
- Consider the case for an independent association for LHW and LHW members in collaboration with FT Governors and other voluntary patient and public representative organisations with a watchdog role;
- Discuss this issue with the Chair of HWE when appointed;
- Seek a meeting on this proposal with Paul Streets, Director of Patient and Public Experience, and Joan Saddler, the National Director for Patient and Public Affairs at the Department of Health;
- Raise this issue with Earl Howe

## **ELECTIONS TO THE NALM STEERING GROUP**

The following people were elected to the Steering Group in 2011 to serve until December 2012 (or until LINKs are abolished). NALM has retained regional boundaries formerly used by the NHS. Where there are vacancies members have been invited to apply to be co-opted members. NALM Steering Group also agreed to co-opt two Host representatives to gain a host perspective, and invitations were issued to the Shaw Trust and to Communities in Partnership, the Host for Leicestershire LINK. The Steering Group re-elected Malcolm Alexander as Chair and Ruth Marsden as Vice Chair for a further year. NALM is indebted to Lynn Clark for organising the elections.

### **SOUTH EAST + SOUTH CENTRAL**

Len Roberts  
Anita Higham

### **SOUTH WEST**

Elli Pang  
John Langley

### **YORKSHIRE + HUMBERSIDE**

Ruth Marsden  
Mike Smith

### **WEST MIDLANDS**

Dag Saunders  
Rob Rijckborst

### **EAST OF ENGLAND**

Mary Ledgard  
Vacancy

### **LONDON**

Malcolm Alexander  
Sally Brearley

### **NORTH EAST**

Vacant  
Vacant

The following members were co-opted to the Steering Group in 2011:

### **NORTH WEST - Co-Opted Member**

Jack Firth  
Vacant

### **EAST MIDLANDS - Co-Opted Members**

Barry Fippard  
John Martin



# NALM PUBLICATIONS 2011

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<b>Response to Consultation ...</b>	October 2011
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NALM's response to the consultation on the allocation of additional funding to Local Authorities for Local HealthWatch, NHS Complaints Advocacy and PCT deprivation of liberty safeguards.

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<b>Revalidation of Doctors – Briefing Note 1 Public Involvement in the Appraisal of Doctors</b>	September 2011
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Patients are in a powerful position to contribute towards the annual assessment of doctors' practice, because they observe doctors throughout their career. This report highlights the systems needed to enable patients to talk about their experiences and to support more effective licensing of doctors.

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<b>Evolution or Abolition – LINK Funding 2011/2012</b>	September 2011
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A report documenting data from two surveys of LINKs and Local Authorities, which contains recommendations that were presented to Ministers and the HealthWatch Programme Board.

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<b>The NHS Future Forum – What is HealthWatch?</b>	May 2011
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LINKs evolving into HealthWatch – Funding – Development – Independence – Accountability – HealthWatch England – Independent Advocacy.

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<b>First Steps – Preparing for HealthWatch</b>	May 2011
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A document providing a check-list to enable Local Authorities and LINKs to measure progress towards HealthWatch.

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<b>Last Rights – Health and Social Care Bill</b>	March 2011
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NALM's comments on key Clauses of the Bill.

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<b>Health and Social Care Bill – Public Involvement - HealthWatch and Commissioning Consortia</b>	February 2011
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NALM's proposed amendments to the Bill.

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<b>HealthWatch – Making it Happen</b>	January 2011
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This document explores some of the strengths and weaknesses of the proposed system of public involvement.

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<b>Health and Social Care Bill</b>	January 2011
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Key points from and criticisms of the Bill.

## Members and Affiliates

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During the year ended 31 December 2011, membership continued to grow steadily and LINKs as statutory bodies continued to join in significant numbers.

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 both to Local Involvement Networks, and to individuals who live anywhere in the UK, who are members of a Local Involvement Network. Members are entitled to attend meetings of the Charity and to vote thereat.

The annual membership fee for individuals is £10 and for Local Involvement Networks the fee is £50. 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 Charity, but not to vote thereat.

The annual Affiliation fee for local and regional groups/organisations is £50 and £200 for national organisations.

New Affiliates are welcome to join.

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This Report was approved by the Trustees on

\_\_\_\_\_ 2012

and is signed on their behalf by:

\_\_\_\_\_  
Malcolm Alexander  
Director/Chair

\_\_\_\_\_  
John Larkin  
Director/Company Secretary

# Income and Expenditure Account

For the Year Ended 31 December 2011

	<b>Unrestricted Funds</b>	<b>Total</b>
	£	£
<b>Incoming Resources</b>		
Donations	2000	2000
Membership Fees	8010	8010
<b>Total Incoming Resources</b>	<b>10010</b>	<b>10010</b>
<b>Resources Expended</b>		
Event management and photography	4066	4066
Hire of Conference Hall	1920	1920
Steering Group Expenses	1133	1133
Hire of rooms	953	953
Stationery and other administrative expenses	2185	2185
<b>Total Resources Expended</b>	<b>10257</b>	<b>10257</b>
<b>Net incoming /(outgoing) resources for the year</b>	<b>(247)</b>	<b>(247)</b>
<b>Total funds brought forward</b>	<b>2886</b>	<b>2886</b>
<b>Total funds carried forward</b>	<b>2639</b>	<b>2639</b>

## Balance Sheet

31 December 2011

<b>Current Assets</b>	<b>£</b>
Funds in hand	585
Funds at bank	2054
	2639
<b>Creditors</b>	<b>£</b>
Amount falling due within one year	-
Net current assets	2639
Total assets less current liabilities	2639
<b>Reserves</b>	<b>£</b>
Unrestricted funds	2639

### Notes

1. These accounts have been prepared in accordance with the provisions applicable to companies subject to small companies' regime.
2. For the year ended 31 December 2011 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 charity and a registered company limited by guarantee and not having a share capital; it is governed by its Memorandum and Articles of Association.

This Financial Statement was approved by the Trustees on

\_\_\_\_\_ 2012

and is signed on their behalf by:

Malcolm Alexander  
Director/Chair

John Larkin  
Director/Company Secretary

## GLOSSARY:

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AvMA	...	...	Action against Medical Accidents
CCG	...	...	Clinical Commissioning Group
CQC	...	...	Care Quality Commission
DH	...	...	Department of Health
GMC	...	...	General Medical Council
HWE	...	...	HealthWatch England
ICAS	...	...	Independent Complaints Advocacy Service
LA	...	...	Local Authority
LHW	...	...	Local HealthWatch
NICE	...	...	National Institute of Clinical Excellence
PCT	...	...	Primary Care Trust
PPI	...	...	Patient and Public Involvement

## SUMMARY OF INFORMATION ABOUT NALM

### Company Secretary:

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John Larkin – Flat 6, Garden Court, 63 Holden Road, LONDON, N12 7DG

### NALM contact details:

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Tel: 020 8809 6551  
Email: [nalm2008@aol.com](mailto:nalm2008@aol.com)  
Website: [www.nalm2010.org.uk](http://www.nalm2010.org.uk)

### Charity Trustees

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- |                   |                     |
|-------------------|---------------------|
| * John Larkin     | * Malcolm Alexander |
| * Michael English | * Ruth Marsden      |

### Date of registration as charity

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27 September 2010

### Governing document

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Memorandum and Articles of Association Incorporated 20 May 2008

### Charitable Objects

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1. The advancement of health or the saving of lives, including the prevention or relief of sickness, disease or human suffering.
2. 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.

### Classification

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#### What

- \* The advancement of health or saving of lives.

#### Who

- \* Elderly/old people
- \* People with disabilities
- \* People of a particular ethnic or racial origin
- \* The general public/mankind

#### How

- \* Provides advocacy/advice/information
  - \* Sponsors or undertakes research
  - \* Acts as an umbrella or resource body
-