NATIONAL ASSOCIATION OF LINks MEMBERS

Patient and Public Involvement in Health and Social Care

ANNUAL REPORT AND FINANCIAL STATEMENT

For the year ended 31 December 2012

Charity Registration Number: 1138181
Company Registration Number: 6598770

NATIONAL ASSOCIATION OF LINks MEMBERS

Patient and Public Involvement in Health and Social Care

WWW.NALM2010.org.uk

Officers for 2012

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THE AIMS OF NALM

The Aims of NALM are to:

1. Provide a national voice for 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 service providers and commissioners to account.

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

6. Promote open and transparent communication and dialogue between communities across the country, the Department of Health, the NHS and providers of health and social care.

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

The following members were elected to the Steering Group for 2012

Elections will be held in 2013

EAST OF ENGLAND
Mary Ledgard
Vacant

EAST MIDLANDS
Barry Fippard
John Martin

WEST MIDLANDS
Dag Saunders
Rob Rijckborst

LONDON
Malcolm Alexander
Sally Brearley

NORTH EAST
Vacant
Vacant

NORTH WEST
Jack Firth
Vacant

SOUTH EAST AND SOUTH CENTRAL
Len Roberts
Anita Higham

SOUTH WEST
Elli Pang
John Langley

YORKSHIRE + HUMBERSIDE
Ruth Marsden
Mike Smith

Co-opted … Elsie Gayle – Specialist in maternity services

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REPORT AND FINANCIAL STATEMENT FOR THE YEAR ENDED 31 DECEMBER 2012

The Trustees have pleasure in presenting their Report and Financial Statement for the year ended 31st December 2012.

Incorporation

This was the second 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

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.

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OBJECTS OF THE 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.

Vision Statement

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

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 service providers and commissioners and the DH to account;
5. To promote open and transparent communication between communities across the country and the health service;

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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

NALM has produced a Manifesto based on its object to provide LINks and the wider public with 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.

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. It facilitates public involvement in the determination of health and social care policy and it is 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.

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NALM MISSION STATEMENT AND ACHIEVEMENTS

A) To provide a national voice for Healthwatch and Healthwatch members

NALM CONFERENCE

The highly successful Annual NALM Conference was held on October 11th 2012 in London and titled: Healthwatch - The People's Launch. It was attended by 170 people - (100 in 2011).

Guest speakers included:

- Norman Lamb MP - Minister of State at the Department of Health
- Anna Bradley - Chair, Healthwatch England
- Tim Kelsey - Director for Patients and Information, NHS Commission Board
- Jill Finney - Deputy Chief Executive of the CQC
- Sue Meeson - Director of Public Affairs and Communications, Monitor

Workshops were led by:

- Peter Walsh - Chief Executive, Action against Medical Accidents (AvMA)
- Elsie Gayle - NALM and Birmingham LINk
- Mike Smith - NALM and Sheffield LINk
- Helen Rowe - Sheffield LINk
- Anita Higham - NALM and Oxfordshire LINk
- David Gilbert - InHealth Associates
- Mark Gamsu - Associate Director of Public Health, Yorkshire & Humber
- Sally Brearley - NALM and Sutton LINk

Conference organisation:

Polly Healy - Richmond LINk
Brian Hennessey - Merton LINk
Leslie Robertson - Merton LINk

Conference facilitation:

AvMA - Ed Maycock and Paula Santos

Photographer: - Aubrey Wade

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NALM is very grateful to all speakers, workshop leaders, AvMA, the Conference organisers and the NALM team who worked tirelessly to make the Conference a great success.
The Conference was followed by the NALM Annual General Meeting.

The objectives for the Conference were as follows:

- To welcome the establishment of Healthwatch England and to examine the empowering relationships that will need to be built between the local and national elements of Healthwatch and the bodies they will influence.

- To explore the opportunities for collaboration and co-operation between Healthwatch England, Monitor, the NHSCB and the CQC in elevating the public voice to build safer and more effective services.

- To raise the profile of Local Healthwatch as bodies led by local people able to have considerable influence on the safety, quality, effectiveness and access to services.

- To discuss the impact of the Mid Staffs Inquiry on the future configuration of health services, especially in relation to the role of Local Healthwatch as the people's representative and agent of change in the NHS.

- To explore the advantages of integrated Local Healthwatch models in which the ICAS, information, monitoring and engaging aspects of Local Healthwatch are seen as the sources of intelligence, to facilitate effective influence in the commissioning of health and social care.

- To examine the role of Health and Wellbeing Board as a vehicle for local people through Local Healthwatch to influence high level strategic planning.

PATHFINDER FUNDING

NALM successfully campaigned for LINk/Local Healthwatch Pathfinders to receive funding to enable them to fully test the Local Healthwatch model. Health Minister, Earl Howe, agreed to provide funding during a meeting held with him on the development of Healthwatch. This amounted to £5,000 for each Pathfinder.

WORKING WITH STRATEGIC HEALTH AUTHORITIES

NALM successfully negotiated with the Department of Health and the Strategic Health Authority for London, to develop proactive support for the development and transformation of LINks into Local Healthwatch organisations. As a result of this agreement, a public involvement adviser was employed to provide support to individual LINks, and several events were held for London LINks.

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HEALTHWATCH ADVISORY AND REGIONAL LINKS GROUP

Several members of the NALM Steering Group (Anita Higham, Dag Saunders, Sally Brearley, Ruth Marsden and Malcolm Alexander) played an active and leading role in the Healthwatch Advisory Group, and Task and Finish Groups, established to continue the work of the main group.

Members of the Healthwatch Advisory Groups, and Task and Finish Group, became disillusioned with the slow progress and the confusing modus operandi, e.g. publications were sometimes sent out by the Department of Health about Healthwatch, without telling the Advisory Group, or the Task and Finish Groups. Members felt that the Department of Health and the Care Quality Commission were not listening to their views.

Diminishing faith in the process was illustrated when only 14 people agreed to attend a high level meeting organised by the Care Quality Commission in Birmingham on the development of Healthwatch England. The meeting was cancelled. The Advisory Group, and all but one Task and Finish Group, were then terminated and replaced by a Regional LINks Representatives Group attended by NALM and regional LINk representatives.

NALM Steering Group members played a very active role in the DH's 'Healthwatch Programme Board'. One of the issues repeatedly raised by NALM, but never dealt with by the Department of Health, was the cost of contracting and subcontracting Local Healthwatch, in light of the legal and contract monitoring costs. Large amounts of money intended for public involvement in Local Healthwatch are likely to be wasted on bureaucracy, instead of being used to improve the safety and effectiveness of care services.

RUTH's MANIFESTO

Shortly after the new NHS Commissioning Board was formed in 2012, a Director of Patient Insight was sought. NALM's Vice Chair publicly applied for the job, and to support her case issued a Manifesto and Press Release. These can be seen in Appendix 1.

THE LOCATION OF HEALTHWATCH ENGLAND IN THE CQC

NALM campaigned to prevent Healthwatch England from being located within the Care Quality Commission (CQC) because we feared its reputation, and freedom to act independently, would be undermined. NALM emphasised the need for Healthwatch England to be accountable to Local Healthwatch through the election of the HWE Board from Local Healthwatch. Despite the strength of our arguments for democratic accountability of HWE to LHW and the public the DH, CQC and HWE rejected these arguments. NALM believes the public confidence in HWE will be strengthened by genuine accountability to the public. NALM has also emphasised the need for the statutory Healthwatch England Committee to be clearly independent and open to the voices of the public.

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NALM has continued to work closely with Healthwatch England during its developmental stages, and has held meetings with the Chair, Chief Executive and other members of the Healthwatch England team.

B) To promote public involvement that leads to real change and the ability to influence key decisions about how care services are planned and run

LOCAL HEALTHWATCH REGULATIONS

NALM was very critical of the Local Healthwatch Regulations and lobbied extensively to get the Regulations amended. It also met with Health Minister, Norman Lamb, together with the NHS Alliance PPI Group.

The Regulations were badly written, confusing and suggested that campaigning to improve patient care and safety would not be permitted for Local Healthwatch. NALM wrote to MPs and members of the House of Lords as follows:

> "The Regulations are written in obscure, inaccessible language, which is extremely confusing to members of Local Healthwatch and to the public – the very people for whom they are written.
>
> The Regulations suggest severe restraint on campaigning, counter to the assurances given to you by Ministers, and the current wording would suggest that any major challenge to Local Authorities and the NHS would be extremely difficult. We are also concerned that a challenge by LHW concerning unsatisfactory local services, could be restrained, because local authorities are in control of LHW budgets, some of which have already suffered severe cuts, e.g. Manchester LHW has already had a 70% budget cut. In such circumstances, LHW would be very vulnerable to termination of its contract by a local authority, if they ran a campaign that challenged the local authority as a commissioner or provider of social care services."

At the debate in the House of Lords, Lords Collins, Harris and Hunt argued vociferously that the Regulations should be amended and refused to withdraw their motion (as is normal practice) resulting in a vote. The House was full but the vote was lost, even though only one Peer spoke against the opposition motion (the Minister).

Earl Howe gave assurances in the House that Local Healthwatch organisations would be free to campaign if they had the public support to do so.

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PUTTING UP A BAR TO TRANSITION FROM LINks TO LOCAL HEALTHWATCH

Effective public involvement, aimed at improving the effectiveness of health and social care, requires experienced and well-trained volunteers. The Department of Health initially accepted the premise that transition from LINk to Local Healthwatch would harness the skills of active service users, and create organisations attractive to larger numbers of people in the local community and be more effective in improving the quality, effectiveness and safety of NHS and social care services.

The Department of Health's Transition Programme was welcomed by NALM. However, the Department of Health abandoned the Programme and created a Local Healthwatch model that made transition from LINks to Local Healthwatch almost impossible - because of the need for the LINk to become a body corporate, and established as a social enterprise. Local Authority competitive tendering processes also made transition unlikely for most LINks.

NALM responded by inviting a solicitor, experienced in Charity Law, to its Annual Conference to provide advice for LINks.

C) 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

PATIENT-LED INSPECTIONS (PLI)

NALM has played an active role in the development of Patient-Led Inspections, through its involvement in the DH's Patient Led Inspection (PLI) Steering Group.

The PLI plan was initiated by David Cameron:

> "A new patient-led inspection regime will be established, covering food, privacy, cleanliness and dignity. The results of these inspections will be reported on publicly, to help drive up standards of care."

Whilst supporting the idea in principle, NALM was surprised that PLIs were being introduced at the same time as Local Healthwatch, the bodies which should be carrying out these inspections. NALM successfully campaigned for LINks and Local Healthwatch to be actively involved in the inspections.

As PLIs developed, NALM was surprised to learn that the 'inspectors' would be closely monitored as they went around hospitals, would not talk to patients and would not need CRB checks. NALM also complained that expecting 'inspectors' to visit for a whole day was unrealistic, and would severely reduce the number of lay inspectors. Then the use of the term

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'inspector' was removed and the process renamed PLACE - 'Patients Led Assessments of Care Environment'.

A great deal of training has taken place, but this whole process appears to be a misuse of resources when LINks and Local Healthwatch are set up and funded to do exactly the same job.

INDEMNITY

NALM repeatedly raised the issue of indemnity for Local Healthwatch members. These issues were raised with the Department of Health Ministers and with Catherine Dixon, Chief Executive of NHS Litigation Authority. NALM argued for the introduction of state funded indemnity for lay people carrying out statutory activities, in relation to the Local Government and Public Involvement in Health Act 2007, and the Health and Social Care Act 2012. This is to enable them to safely visit and inspect the wards, clinics and any places where care is provided.

NALM argued for access to compensation for any losses or harm suffered or caused by the lay people during these visits, or as a result of any action threatened or taken against them by a body they have reasonably criticized, whilst they are carrying out statutory activities.

NALM's arguments in favour of a statutory duty of care towards members of Local Healthwatch carrying out statutory activities were not accepted by the government.

REVALIDATION

NALM sat as a member of the English Revalidation Delivery Board, progressing the implementation of revalidation for every doctor in England.

The statutory licensing of doctors (revalidation) was formally implemented in December 2012. NALM argued successfully for a high level of public involvement in the appraisal and revalidation of doctors. NALM produced a briefing note on revalidation for NALM members, lobbied MPs, the parliamentary Health Committee and worked closely with the GMC, National Voices and Lay Representatives from the Royal Colleges.

NALM has consistently argued that high levels of patient involvement in revalidation will enable doctors to reflect more successfully on their practice and provide safer, more patient-focused care. NALM has also successfully campaigned for the names of the Responsible Officer for every individual doctor to be posted on the GMC website, under the doctor's entry. However, this will be subject to further consultation before implementation.

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INQUEST PROJECT WEBSITE – RULE 43 RECOMMENDATIONS

The Project aims to gather information about Rule 43 Recommendations made by Coroners in relation to deaths that occur during the process of health care, and to build local knowledge about causes of deaths in the NHS that result in inquests. The project aims to publicise the recommendations made by Coroners, and the action taken by the local NHS and related bodies.

The following bodies are targeted for the supply of information about Rule 43 recommendations:

- Local Healthwatch – the public's watchdog in health and social care
- Clinical Commissioning Groups (CCGs) - the bodies that commission local health services
- Overview and Scrutiny Committees - the bodies that can call local health services to account
- Health and Wellbeing Boards – the bodies that have a strategic role in developing health and social care for each local authority area.

After a Coroner makes a Rule 43 recommendation and details are published by the Minister of Justice, NALM asks the body to which it has been made what their response has been. The response is then placed on the website.

NALM will let Coroners know about this process, so that they can be kept informed about whether Rule 43 recommendations are being implemented.

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D) 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

OVERVIEW AND SCRUTINY CONSULTATION

NALM was concerned about plans to fundamentally change the role of Overview and Scrutiny Committees. The DH's consultation on this issue finished on September 7th 2012. Steering Committee members highlighted the following criticisms of the DH proposals:

1. Undermining the independence of OSCs by giving health scrutiny functions to the local authority itself, rather than to overview and scrutiny committees specifically.

2. Creating an unsustainable workload for OSCs, by extending the scope of health scrutiny to include all NHS and health services providers.

3. Making referrals to the Secretary of State and the Independent Reconfiguration Panel difficult by requiring a decision to be made by the whole council, rather than the OSC.

4. Requiring a complex bureaucratic process including the NHS Commissioning Board for some service reconfigurations

5. Burdening local authorities by requiring them to take account of financial issues in addition to the critical issues of safety, effectiveness and the patient need.

The DH response to the consultation is as follows, and new Regulations have been published:

Extending scrutiny to all providers of NHS care, whether they are from a hospital, a charity or an independent provider.

Requiring organisations proposing substantial service changes and the local authorities scrutinising those proposals to publish a clear timescale for decision-making, so patients know when they can expect changes.

Requiring local authorities to take account of the financial and clinical sustainability of services when considering NHS reconfiguration proposals.

Seeking the help of the NHS Commissioning Board in liaising with local authorities and commissioners to secure local agreement on some service reconfigurations and ensuring that proposals for change meet the Secretary of State's "four tests".

http://www.legislation.gov.uk/uksi/2013/218/contents

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PUBLIC INVOLVEMENT IN MONITOR

NALM has concerns about the openness of Monitor to the public, and the refusal of many Foundation Trusts to hold their meetings in public. Monitor's Board meetings appear to be 'for show' rather than making significant decisions in the public arena.

In light of the considerable potential harm to patients through inadequate public monitoring of the health and social care services, and the need to be publicly accountable to ensure good governance and accountability, NALM put the following questions to Monitor:

1) Has Monitor given consideration to the development of local and national Healthwatch?

2) Has any work been undertaken to date with the Care Quality Commission and/or Department of Health to plan for HW?

3) What role do you believe Monitor should have in the development of HW?

4) Does Monitor have views on the independence of HW?

5) What roles and functions do you see Healthwatch England performing in relation to Monitor?

6) Have you considered the role of HW in relation to assessing whether FTs are well governed, efficient and effective in improving patient care?

7) Do you see a role for HW in identifying problems as they start to develop and alert Monitor, the Care Quality Commission and commissioners?

8) What roles and functions do you see HW performing in relation to Foundation Trust Members and Governors?

9) Would you see a role for HW in helping to ensure that FT membership is more representative of the local community?

10) Have you considered the role of HW in supporting the requirement for FTs to cooperate with other NHS organisations?

11) Have you considered giving advice to FTs to review their governance structures in relation to the role of Healthwatch?

12) Is Monitor ready to work with NALM in taking forward the development of HW?

NALM was unable to get detailed responses to any of these questions, but continues to seek a full response.

NALM invited the Chief Executive of Monitor, David Bennett to speak at the NALM Conference, but he declined. It was very fortunate that Sue Meeson - Director of Public Affairs

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and Communications for Monitor - agreed to participate in a joint session with Anna Bradley, Chair of Healthwatch England, Tim Kelsey, Director for Patients and Information of the NHS Commission Board and Jill Finney, Deputy Chief Executive of the Care Quality Commission.

WELSH ASSEMBLY

NALM was invited to speak to the Health Committee of the Welsh Assembly on the development of public and patient involvement in Wales and England. NALM had the opportunity of comparing the English and Welsh systems - LINks and Community Health Councils. The long term stability of Welsh CHCs has enabled them to massively develop their capacity to monitor and influence services, whilst in the English system, repeated abolitions have weakened and handicapped the effectiveness of public influence in health and social care.

E) To promote open and transparent communication between communities across the country and the health service

FREEDOM OF INFORMATION ACT – LOCAL HEALTHWATCH

The DH advised NALM that they had made a decision to add Local Healthwatch to the bodies that are subject to the Freedom of Information Act (FOI).

NALM was pleased to have successfully lobbied for this development. However, it was disappointing to discover that the process of incorporation in the FOI Act mysteriously evaporated, without any statement by the DH or the Healthwatch Programme Board. NALM has raised the issue with the DH who are consulting their lawyers.

The Act has however been amended to include Clinical Commissioning Groups and NHS England.

September 7th 2011. Column 470. Health and Social Care Act

Clause 185 — Establishment and constitution of Healthwatch

Amendment 224, page 172, line 40, at end insert—

‘( ) In Part 2 of Schedule 1 to the Freedom of Information Act 2000 (local government), after paragraph 35C insert—

“35D A Local Healthwatch organisation.”’.—

(Mr Lansley.)

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

HEALTHCARE IN HOME OFFICE DETENTION CENTRES

NALM was concerned about reports of inadequate care for asylum seekers who are detained in Home Office detention centres (IRCs Immigration Removal Centres). It asked the Care Quality Commission about their visiting regime, and suggested that former detainees should be invited to join the Care Quality Commission (CQC) visits to detention centres as 'experts by experience'.

The CQC told NALM that it attends the inspection of all IRCs (regardless of the registration arrangements), with HMIP (Her Majesty's Inspectorate of Prisons) as part of a five year programme that inspects all prisons and IRCs. The CQC focuses upon health provision and it works jointly with the HMIP health lead.

The CQC publishes an individual inspection report for each IRC or, where this does not apply, a service being provided in the establishment from another location. Its findings for all services are also shared with HMIP, as part of the evidence gathering arrangements, and HMIP include Care Quality Commission reports in its published reports.

NALM's proposal to the CQC regarding inviting former detainees to become 'experts by experience', has not been adopted. They responded as follows:

> "To date we have not included 'experts by experience' in our offender healthcare work. There are two specific issues that we would need to address to progress this approach. One is the security consideration. Our Care Quality Commission inspectors go through a lengthy additional security clearance process that is required for this work. ... We do not own this process and have no control over its requirements or criteria for clearance. We are also mindful that we are joining HMIP on this programme – it is their schedule of inspections and we would need to agree any changes with them. That having been said it is an issue we should consider as we develop the use of 'experts by experience' in our other areas of work. The recent excellent (substantial) response to our Chief Inspector of Hospital's invitation to people to get involved may help identify individuals who would be suitable for this work. The use of 'experts by experience' is growing substantially in our inspection activity across (nearly) all sectors. For some years now, Care Quality Commission and the MHAC have included people with experience of detention under the mental health act in visits to mental health units. This approach has grown and is likely to become standard practice for future inspections. "

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Discussion with the CQC continues on this matter with the objective of ensuring that health services provided to vulnerable people in detention are equal to those provided to all other users of the NHS.

EMPOWERMENT OF CHILDREN AND YOUNG PEOPLE

NALM participated in the Project Advisory Group of the National Children's Bureau (NCB) research on evaluating how the emerging health system will enable the involvement of children and young people in strategic decision-making.

This led to the production of the NCB's new publication *'Bringing children and young people to the heart of Healthwatch*', which looks at the lessons learned by Local Involvement Networks, the thoughts of children and young people, and NCB's experiences of LINks over the past three years:

> "Make engagement varied and flexible. Children and young people's commitments and priorities change and this is heightened by external pressures such as exams, caring for family members or siblings, social lives!
>
> Making engagement flexible and not penalising them for being unable to make a regular commitment will help to maintain engagement after all of your hard work to get them involved in the first place.
>
> Accepting a more transient level of participation might help to make their involvement in Local Healthwatch more workable. Ensuring varied opportunities for getting involved will also help to keep people interested and widen the opportunities for people to fit it in with their lives and preferences."
> (Quote from the report).

http://www.ncb.org.uk/media/968116/ncb_healthwatch_print.pdf

STATUTORY DUTY OF CANDOUR

NALM has actively supported the campaign for a statutory Duty of Candour.

When a patient is harmed during medical treatment, there must be an absolute duty for the doctor to tell the patient what has happened and what action will be taken to address the problem and, if possible, reverse the harm. As AvMA (Action against Medical Accidents) put it:

> "Less than complete openness and honesty when things go wrong is totally unacceptable. That is what we mean by a 'Duty of Candour'. In our experience, failure to be dealt with openly and honestly when harm has been caused can often cause

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extreme harm and distress in itself." Patients have a right to know when things go wrong.

NALM jointly signed a letter on this issue with AvMA, National Voices, the Patients' Association and Patients' First. There is clear movement on this issue from government, following support from the Francis Inquiry. Copy of a letter to the Times follows:

The Editor
The Times (Letters)
6.12.12

Dear Editor

The Health Minister's announcement on Tuesday of a 'contractual duty of openness' for NHS trusts seeks to give the impression that the Government is addressing what it admits is a culture which tolerates patients and their families being denied the truth about medical accidents which cause harm. However, this measure on its own will be nowhere near enough.

The Government had promised a 'duty of candour', but is now merely paying it lip service by restricting it to a standard clause in contracts with NHS hospitals or contract holders. This so-called duty would have no statutory force and would not even apply to primary care providers such as GPs and dentists. It would only relate to incidents already reported to official bodies, and would therefore be useless in preventing wholesale cover-ups.

Every other "essential standard of quality and safety" is set out in the statutory requirements for registration with the Care Quality Commission. If honesty with patients really is essential, that is where the 'duty of candour' should be. We urge the Government to reconsider and introduce a statutory duty of candour in addition to anything else it is doing.

Peter Walsh, Chief Executive, Action against Medical Accidents (AvMA)
Malcolm Alexander, Chair, National Association of LINks Members
Jeremy Taylor, Chief Executive, National Voices
Katherine Murphy, Chief Executive, The Patients Association
Dr Kim Holt, Chair, Patients First

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G) To promote accountability in the NHS and social care to patients and the public

PALS AND ICAS LEGACY DOCUMENTS – PATIENTS' COMPLAINTS

NALM asked the DH to ensure that documents from patients' complaints - made through PCT-PALS (which were abolished) and ICAS (the Independent Complaints Advisory Service) - were transferred with the complainant's consent, to the new system.

This matter was raised repeatedly at the Healthwatch Programme Board, and assurances were given regarding the security of complaints documentation. The transfer of PCT complaints was also raised with NHS England, who admitted that they had been ineffective in the way they had handled and transferred patients' complaints.

QUASER

NALM participated in a stakeholder group on a pan-European project on quality and safety in European Union Hospitals. The Project was led by University College London and has developed a 'Research-based Guide for Implementing Best Practice', and a Framework for Assessing Performance (QUASER) in hospitals.

This three-year study explored the relationships between the organisational and cultural characteristics of hospitals, and how these impacted upon clinical effectiveness, patient safety and patient experience in European Union countries.

The key objectives of the Project were to identify organisational and cultural characteristics linked to the effectiveness, safety and patient experience of hospital care, and the quantitative and qualitative indicators of this.

Data was collected from ten hospitals in five countries (two in each of the five countries), with additional studies of two 'clinical micro-systems' in each of five of the study hospitals (one in each of the five partner countries).

http://www.ucl.ac.uk/dahr/quaser/QUASER-Guide_For_Hospitals

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HEALTHWATCH DEVELOPMENT.NET

NALM established this website to collect data about developing Local Healthwatch organisations. Data about budgets, contract length and other key features of Local Healthwatch will be added to the site as it becomes available, as a way of gathering ongoing intelligence about what is happening around the country on the transition from LINKs to Local Healthwatch organisations.

NALM has carried out two major surveys of Local Authorities to gather information about the funding and development of Local Healthwatch.

Labour's Shadow Minister for Care and Older People, Liz Kendall MP, also carried out a detailed survey of Local Healthwatch, but would only share a small amount of the data collected with NALM.

Data collected by the Local Government Association was similarly inaccessible except as headlines.

LINks TRANSFORMATION BOARD

NALM established the Transformation Board to support NALM, and other organisations concerned with the transformation from LINks to Healthwatch. NALM was keen to see improvements in the form of public involvement and its public perception following a period when LINks were deprived of a national body and had inadequate support in many parts of England.

Board Membership 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)

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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:

19. Carol Basham … … … BMA Patients Liaison Group
20. 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

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THE FUTURE OF NALM

The following Motion was passed at the 2012 NALM AGM:

Consequent on the Health and Social Care Act 2012, and the changes coming into effect on 1st April 2013, it was resolved that:

1) The name of the National Association of LINks Members (NALM) be changed to the National Association of Healthwatch Members (NAHM);

2) The elected members of the 2012/13 NALM Committee will remain in post for their elected term being subsumed into NAHM;

3) The elected members of the 2012/13 NAHM Committee should review the governance and present a report to an Inaugural Meeting in September 2013, and recommend any changes necessary 21 days prior;

4) All Bank Accounts and balances, other funds and property, should be transferred to NAHM on 1st April 2013, and NAHM shall be empowered to meet any outstanding Debts;

5) The database, archive, website and any intellectual or other property should be transferred to NAHM on the 1st April 2013;

6) The NALM Committee shall prepare and publish a Legacy Document for NAHM, by the end of May 2013;

7) Between 1st April and the Inaugural Meeting, the Committee shall design and present, 21 days prior to the Inaugural Meeting of the members, a Development Programme for NAHM.

The NALM Steering Group met in December 2012 to consider the Resolution and to draw up a detailed proposal for members to consider. The following Aims and Objectives were agreed, together with a more detailed document in Appendix Two:

AIMS AND OBJECTIVES

1) Supporting the development of Local Healthwatch and Healthwatch England [HWE] as powerful and effective bodies that enable the public to monitor, influence and improve health, social care and public health services.

2) Promoting democratic and accountable public involvement organisations across England, which genuinely empowers patients, care receivers, carers, and all individuals and communities to influence planners, commissioners and providers of health, social care and public health services, in order to achieve safe and effective services.

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3) Investigating, challenging and influencing health, social care and public health bodies which fail to provide or commission safe, effective, compassionate and accessible services.

4) Collaborating with other community and voluntary sector bodies, patients and service users to achieve the Association's objectives.

5) Holding the government to account for its legislative and policy commitments to public influence in health, social care and public health services.

COMMUNICATIONS

NALM WEBSITE

The NALM website is updated daily and provides information about Healthwatch and other major developments in the NHS and social care. The use of the site in 2012 was as follows:

Months	Maximum daily hits	Date of highest number
July – August 2012	294	16 July 2012
August – September 2012	245	17 August 2012
November – December 2012	379	06 December 2012
January – February 2013	834	08 February 2013
March – April 2013	345	05 April 2013
July – August 2013	279	08 August 2013

NALM PUBLICATIONS

REVALIDATION OF DOCTORS August *2012*
Report from NALM and NATIONAL VOICES.

HEALTHWATCH DEVELOPMENT PROGRESS REPORT June *2012*
Transition of LINks to Healthwatch.

NALM HEALTHWATCH BRIEFING NO. 1 April *2012*
A paper explaining what Local Healthwatch and Healthwatch England will look like, and the intentions of the Health and Social Care Act 2012 in relation to public involvement in health and social care.

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LAST RIGHTS … HEALTH AND SOCIAL CARE BILL March *2012*
Consequences of the Government's Healthwatch amendments. NALM's comments on key clauses of the Bill.

NALM's RESPONSE TO THE CONSULTATION ON THE REGULATIONS FOR HEALTHWATCH ENGLAND MEMBERSHIP March *2012*
NALM's response to the Consultation to influence the development of Healthwatch England (HWE) and the membership of the Board.

NALM'S DRAFT RESPONSE March *2012*
Consultation on the Regulations for Healthwatch England membership.

WHAT'S LEFT FOR HEALTHWATCH? *March 2012*
Clarifying the Impact of the Lords' Amendments to the Health and Social Care Bill. The consequences of the government's plans for Healthwatch background.

BRIEFING NOTE ON HEALTHWATCH February *2012*
NALM's Report focussed on the aspiration that Local Healthwatch will be independent, credible, accountable and responsive to the community it serves.

LINk NATIONAL AND REGIONAL DIRECTORIES x 10
Ongoing

MANIFESTO FOR THE POST OF NATIONAL DIRECTOR OF PATIENT INSIGHT WITH THE NHS COMMISSIONING BOARD – RUTH'S MANIFESTO April 10th 2012

PRESS RELEASES

REVALIDATION OF DOCTORS October *2012*

NALM welcomes the GMC announcement of the revalidation of Doctors.

HEALTHWATCH MUST BE THE PEOPLE'S INDEPENDENT, POWERFUL, PUBLIC WATCHDOG IN HEALTH AND SOCIAL CARE July *2012*

MAJOR GOVERNMENT U-TURN ON HEALTH AND SOCIAL CARE BILL March *2012*

DON'T STRIP HEALTHWATCH OF ITS STATUTORY STATUS January *2012*
NALM challenges Minister on downgrading of Healthwatch.

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RUTH'S MANIFESTO – INSIGHT, POWER AND LEADERSHIP April *2012*

PRESENTATIONS

HEALTHWATCH: PRIORITIES, INTEGRATION, ADVOCACY AND TRANSITION
Westminster Health Forum –July 2012

BUILDING EMPOWERING ALLIANCES IN HEALTH AND SOCIAL CARE
IS HEALTHWATCH UP TO THE JOB?
March and April 2012

WEBSITES DRIVEN BY NALM

HEALTHWATCH DEVELOPMENT

Monitoring the transition from LINks to Healthwatch.
This report presents data from a Freedom of Information (Freedom of Information Act 2000) sent to 152 Local Authorities in England in March 2012. We received 100% response to our requests, although in some cases it took up to four months to get a reply, despite the legal obligation to provide a response within 20 working days.

Visit statistics for site = between 100 – 400 visits per day
www.healthwatchdevelopment.com

CORONER'S RULE 43
The aim of this project is to gather information about Rule 43 recommendations made in relation to deaths that occur during the process of health care, and to build local and national knowledge about causes of deaths in the NHS that result in Inquests. The project aims to share recommendations made and the action taken by the local NHS and related bodies.

Visit statistics = between 50 – 150 visits per day
www.rule43inquests.com

ASSOCIATION OF COMMUNITY HEALTH COUNCILS
An archive site celebrating the work of the Community Health Councils between 1974 and 2003.

Visit statistics = between 50 – 230 per day
www.achcew.org

MEMBERS AND AFFILIATES

During the year ended 31 December 2012, 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.

This Report was approved by the Trustees on

_____ 2013

and is signed on their behalf by:

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

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INCOME AND EXPENDITURE ACCOUNT

For the Year Ended 31 December 2012

	Unrestricted Funds	Total
	£	£
Incoming Resources		
Donations	2000	2000
Membership and Conference Fees	8213	8213
Total Incoming Resources	10213	10213

Total Resources Expended		
Event management and photography	2404	2404
Hire of Conference Hall	7065	7065
Steering Group Expenses	192	192
Hire of rooms	1119	1119
Stationery and other administrative expenses	362	362
Total Resources Expended	11142	11142

Net incoming /(outgoing) resources for the year	(929)	(929)

Total funds brought forward	2639	2639

Total funds carried forward	1710	1710

BALANCE SHEET

31 December 2012

Current Assets	£
Funds in hand	-
Funds at bank	2866
Debtors	1720
Creditors	**£**
Amount falling due within one year	2259
Total assets less current liabilities	2327
Reserves	**£**
Unrestricted funds	1710

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 2012 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:

_____ 2013

and is signed on their behalf by:

_____

Malcolm Alexander
Director/Chair

John Larkin
Director/Company Secretary

GLOSSARY:

AvMA	…	…	Action against Medical Accidents
CCG	…	…	Clinical Commissioning Group
CQC	…	…	Care Quality Commission
CRB	…	…	Criminal Records Bureau
DH	…	…	Department of Health
GMC	…	…	General Medical Council
HAPIA	…	…	Healthwatch and Public Involvement Association
HMIP	…	…	Her Majesty's Inspectorate of Prisons
HWE	…	…	Healthwatch England
ICAS	…	…	Independent Complaints Advocacy Service
IRC	…	…	Immigration Removal Centre
LA	…	…	Local Authority
LHW	…	…	Local Healthwatch
NICE	…	…	National Institute of Clinical Excellence
PCT	…	…	Primary Care Trust
PPI	…	…	Patient and Public Involvement

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SUMMARY OF INFORMATION ABOUT NALM

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

NALM contact details:
Tel: 020 8809 6551
Email: nalm2008@aol.com
Website: www.nalm2010.org.uk

Charity Trustees

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

Date of registration as charity
27 September 2010

Governing document
Memorandum and Articles of Association Incorporated 20 May 2008

Charitable Objects

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

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

APPENDIX ONE

Public and Patient Involvement in Health and Social Care
www.nalm2010.org.uk

April 10th 2012 - PRESS RELEASE

National Association of LINks Members

Ruth's Manifesto
Insight, Power and Leadership

Ruth Marsden, the Vice Chair of NALM, the country's leading public involvement charity, today put her hat in the ring for the post of National Director of Patient Insight with the NHS Commissioning Board. Ms Marsden from Cottingham in the East Riding of Yorkshire, will be calling for national support for her application and has issued a Manifesto to make clear what she stands for and what she seeks to achieve for people if appointed to the NHSCB . In her Manifesto, Ruth commits herself to:

- Giving real power to communities in all decisions about the commissioning of NHS services, local, specialist and national.

- Full participation of patients at all levels so that communities can determine what they need and want from their NHS.

- Challenging empty rituals of participation and instead supporting communities to influence the outcomes of all commissioning processes in NHS care.

- Championing citizen control to give people a genuine say in the configuration and accessibility of their local NHS services.

- Opposing all attempts to 'use' patients, e.g. tapping their special skills and insights, but denying them any real clout in decision making.

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Ms Marsden said: “We are fed up of token public involvement and sick of seeing our health budget gobbled up by bureaucracy, while patients are denied healthcare. We are people, not ‘units of data’ to be ‘managed’. It’s time to junk the rhetoric, stop talking about ‘culture change’ and start doing it”.

“I want to ensure that NHS healthcare is solely about us, that’s all of us, see people supported in decision making, so that they can make a visible impact on the NHS services they get. The lack of parity of power, patient-to-system, in commissioning and delivery is as indefensible as the lack of transparency in decision making. Honest sharing is long overdue. What are they afraid of”?

“Patient insight is the most precious tool we have. For too long, patients have been shoehorned into services, not services designed around patients. This must stop”.

“I further intend to fight for the development of truly representative, inclusive, accountable and powerful Local Healthwatch organisations for people. More than ever, a patients’ platform needs securing in the face of this messy model, potentially mired in conflict of interest and vested interest, which the government’s current legislation for LHW has given us.”

Notes for editors:

Ruth Marsden is the Vice Chair of the National Association of LINks Members. She can be contacted on: 01482 849 980 or 07807519933 or ruth@myford.karoo.co.uk

Local Involvement Networks (LINks) were set up by statute in 2008 to give citizens a stronger voice in how health and social care services are delivered.

NALM is the national organisation of Local Involvement Network members and was formed on April 1st 2008. NALM aims to stimulate more powerful approaches to public and user involvement in the NHS and social care and build a major grass roots movement of LINks and LINks’ members which can influence government policy.

The Local Government and Public Involvement in Health Act 2008 established Local Involvement Networks (LINks) to promote and support the involvement of people in the commissioning, provision and scrutiny of local NHS and social care services. They do this by monitoring services and obtaining the views of people about their experiences of care and making reports and recommendations about how services should be improved, to persons responsible for commissioning, providing, managing or scrutinising local care services.

Note of the development of Healthwatch

The local Healthwatch Pathfinders will take on substantial extra duties such as providing information and signposting to the public who need help with understanding how the reformed NHS and social services structures work, and potentially supplying advocacy for those who need help complaining to the NHS about poor treatment.

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LINks are made up of volunteers, supported by a small professional team. They have responsibility for scrutinising all health and social care services in a local authority area. They are tasked, by statute, with providing the voice of those who use our health and social care services.

Despite the mantra of "nothing about me without me" LINks were not included in the NHS Future Forum. LINks are already struggling even before they take on this extra Local Healthwatch work. Funding assigned to Local Authorities to support LINks from central government remains unchanged, but is not ringfenced and local authorities have made massive cuts to the budgets of many LINks up to 70%.

It was intended that Local Healthwatch would be the voice of the user and patient, and a guardian of patient safety. LINks and Local Healthwatch should be the first line of defence against another Mid-Staffs. They have a right to inspect services, and this role becomes even more critical with the cuts to the CQC.

The Health and Social Care Act totally transformed the model; removing leadership by lay people and substituting 'contractors and sub-contractors'. Healthwatch has been privatised.

What the Secretary of State for Health promised before the Health and Social Care Bill became an Act:

- Put patients in the driving seat.

- Develop a culture of active responsibility so that people will be empowered to ask, to challenge and to influence

- Listen to people.

- Empower patients to inform health professionals.

- Support patients collectively in thinking about what quality standards and commissioning guidelines should look like.

- Think local, so decisions about access and design of local services meet local needs.

- Work together to drive improvements in standards and outcomes.

- Give patients the verdict and learn from their experience – design better care, better services and create greater efficiency.

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April 10th 2012

National Association of LINks Members

Ruth's Manifesto
Insight, Power and Leadership

Manifesto for the post of National Director of Patient Insight with the NHS Commissioning Board

The principles that will guide my insight if appointed:

- I will press for power to be given to communities in all decisions about the commissioning of health services – for local, specialist and national services.

- I will not align myself with the disingenuous euphemisms of government which claim to be putting patients at the 'heart of', 'centre of' and in the 'driving seat of' of services. I am in support of real power and influence for patients, carers and the public in the commissioning of services.

- I am against participation without redistribution of power and the similar empty and frustrating processes currently promoted by the government in the name of public participation.

- I will challenge empty rituals of participation and support communities having real power to affect outcomes of all commissioning processes in health care.

- I believe that public participation in commissioning decisions must be about real influence, not a series of exercises dressed-up as 'participation in the process' and 'citizen consultation'.

- I espouse citizen control to empower communities to have genuine influence in the configuration and accessibility of their local services.

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- I will oppose attempts by the CCGs to co-opt and 'use' patients, e.g. utilizing their special skills and insights, but denying them real power in decision making.

- I will work to embed pro-active measures to include those presently excluded from the political and economic processes in relation to the commissioning of health care.

- I will exert active and determined pressure to persuade the 'power holders' – the NHSCB and CCGs, to promote diversity and inclusion of all communities and to oppose paternalism, and resistance to power redistribution.

- I will promote the inclusion of all communities in commissioning through a strategy of information sharing, and the shared determination of commissioning goals and policies.

- I will press for shared decision-making in relation to the allocation of NHS resources and contracts.

- I will fight for the development of representative, accountable and powerful Local Healthwatch organisations, in the face of the alienation, distrust and conflict of interests, which the government's current model for LHW portends.

If appointed to the post of National Director of Patient Insight with the NHS Commissioning Board

I will specifically:

1) Promote citizen participation – but eschew the disempowering approaches in which people are placed on 'rubberstamp' advisory committees or admitted to advisory boards for the express purpose of "educating" them or engineering their support.

2) Support genuine citizen participation, and oppose the distortion of participation into a mere public relations vehicle - information-gathering, and 'letterheads' - trotted out at appropriate times to legitimise service commissioning that benefits the commissioners at the expense of the public they serve.

3) Oppose the establishment of bodies that pretend that the "grassroots" are involved in commissioning, in order to tick boxes for the NHSCB and local Health and Wellbeing Boards.

4) Expose the sham of involvement in commissioning that causes deep-seated exasperation and hostility toward the 'powerholders'.

5) Ensure that resources are made available to local people to enable them fully to participate in complex decision-making in relation to the investment of the health budget in local services, e.g. ensuring they have access to technical expertise, full expenses, advisors and support mechanisms.

6) Promote the targeting of resources to enable citizens to articulate their priorities alongside the increasingly sophisticated commissioning organisations.

7) Ensure mechanisms are in place to inform citizens of their legal rights to participate, engage and influence, and the options available to achieve genuine and legitimate citizen participation.

8) Oppose the tradition of sham/token participation that gives people information about commissioning decisions at a late stage in planning, resulting in them having little opportunity to influence the commissioning processes said to be designed "for their benefit" - e.g. patronage, one-way communication, superficial information, discouraging questions, irrelevant answers, bland or obscure information, lack of feedback, absence of outcomes.

9) Oppose the use of sham local and national public consultations that are clearly decided in advance, and which are not open to real participation and the enduring engagement of the public. I support participation in decisions not 'participation in participation'.

10) Oppose the increasing use of 'Waitrose discs' and eternal simplistic, deterministic surveys of patient attitude and satisfaction, that diminish public participation, patronise service users and limit their influence.

11) Oppose the increasing use of the placement of a few hand-picked "token" people on health Boards and GP practice groups.

12) Support citizen engagement and involvement that includes genuine parity of influence and has a significant impact on the comprehensive planning of services and where local people have direct, shared responsibility with clinicians and planners for commissioning plans and their outcomes.

13) Support the development of commissioning bodies (CCGs) which are elected by and accountable to local people and which have 50% lay membership.

14) Support the redistribution of power in commissioning through genuine negotiation between accountable citizens and accountable powerholders – the CCGs and the NHSCB. This will mean sharing planning and decision-making responsibilities through structures such as joint (50:50 citizens and professionals) policy boards, planning committees and mechanisms for resolving impasses.

15) Support people locally, regionally and nationally to access power and control, which guarantees their share in the leadership, governance and development of all commissioning plans.

Ruth Marsden,
Vice Chair, NALM

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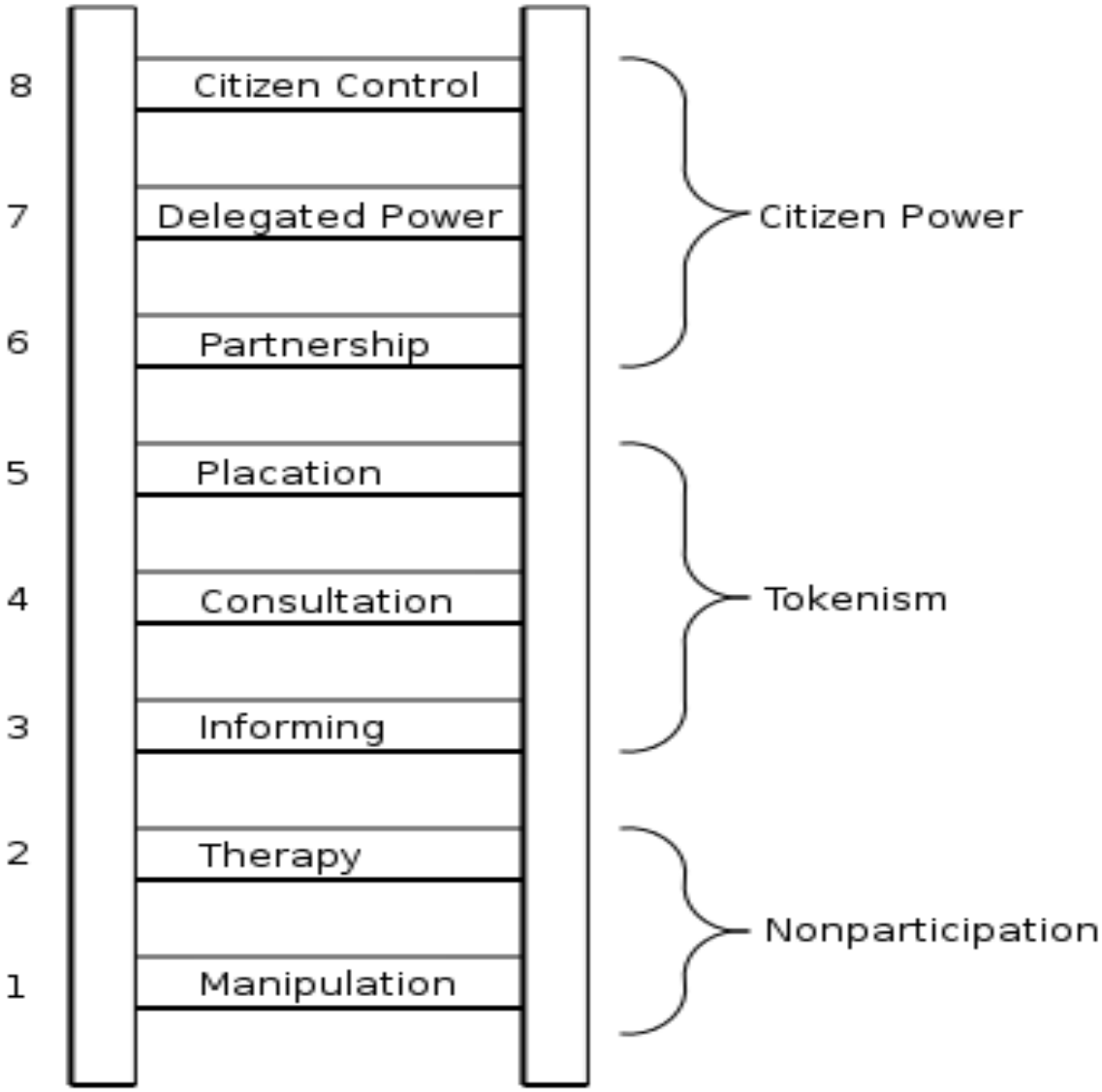

With thanks to Sherry Arnstein, "A Ladder of Citizen Participation," 1969

APPENDIX TWO

HEALTHWATCH AND PUBLIC INVOLVEMENT ASSOCIATION

OBJECTS OF ASSOCIATION

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 and the saving of lives, including the prevention or relief of sickness, disease or human suffering;

and …

(ii) The advancement of the relief and care of those in need by reason of youth, age, ill-health, disability, hardship and other disadvantage, through the provision of health or social care including accommodation

It is proposed that in future the organisation be known as 'Healthwatch and Public Involvement Association' and established as a body for Local Healthwatch [LHW] organisations, Healthwatch members, individuals and organisations who are not part of Healthwatch, but actively work toward creating safer, more effective, more accessible and accountable health, social care and public health services.

The Association will actively work towards and campaign for influential, powerful and effective public involvement.

N.B. The plan is to proceed with HAPIA as a corporate change of name for NALM.

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AIMS AND OBJECTIVES

1) Supporting the development of Local Healthwatch and Healthwatch England [HWE] as powerful and effective bodies that enable the public to monitor, influence and improve health, social care and public health services.

2) Promoting democratic and accountable public involvement organisations across England, which genuinely empowers patients, care receivers, carers, and all individuals and communities to influence planners, commissioners and providers of health, social care and public health services, in order to achieve safe and effective services.

3) Investigating, challenging and influencing health, social care and public health bodies which fail to provide or commission safe, effective, compassionate and accessible services.

4) Collaborating with other community and voluntary sector bodies, patients and service users to achieve the Association's objectives.

5) Holding the government to account for its legislative and policy commitments to public influence in health, social care and public health services.

KEY GOALS

1) To scrutinise the effectiveness of HWE, LHW, IAS (Independent Advocacy Services) and Complaints as vehicles for public influence, redress, criticism and improvement of health, social care and public health services.

2) To reflect continuously on the effectiveness of Healthwatch in relation to recommendations of the Francis Report.

3) To advise on effective ways of influencing commissioners, providers, regulators and policy makers.

4) To advise on effective ways of learning from complaints, incidents, accidents and systemic successes and failures that occur in health and social care services.

5) To communicate key messages and information rapidly and continuously to the Association's membership, communities and the media.

6) To promote the accountability of providers, commissioners and regulators of health, social care and public health services.

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PRIORITIES

1) Equality, inclusion and a focus on all regions and urban/rural diversity.

2) Continuous and timely information flows from and to members and the wider community.

3) Influence through interaction with Ministers, the Department of Health [DH], NHS Commissioning Board (NHS England), Regulators, Local Authorities [LAs], the Local Government Association [LGA] and other national and local bodies.

4) Establish a transitional Leadership Board with each Board Member discharging a specific role and wherever possible representing regions in England.

5) Ensuring that members of the Association shape the strategy and policy that drives the Association's work.

BUILDING RELATIONSHIPS WITH OTHER BODIES AND CHARITIES

Sustaining and developing relationships with LHW, HWE, the DH, LGA, National Voices, Action Against Medical Accidents [AvMA] and other national and local voluntary sector bodies on the basis of shared interests and objectives, e.g. National Association for Voluntary and Community Action [NAVCA], Community and Voluntary Services, [CVS] and the NHS Alliance Patient and Public Involvement [PPI] Group.

FUTURE MEMBERSHIP

Membership will be invited from:

- Current membership
- Local HealthWatch organisations
- Individual Local Healthwatch members/volunteers/participants
- Individuals who support the aims and objectives of the Association and who are active in their community and/or nationally
- Organisations working locally and/or nationally to influence NHS, local authority, social care and public health services.
- Lay people involved in Patient Participation Groups, Clinical Commissioning Groups, Specialised Commissioning Groups, Local Area Teams (NHS England) and Quality Surveillance Groups.

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PORTFOLIOS

- To be agreed with members of the Transitional Leadership Group.

PRIORITIES IN YEAR 1 - INFORMING AND INFLUENCING NATIONAL POLICY

- Being a critical friend and sometimes ally to HWE
- Focusing on independence and accountability of the Healthwatch system nationally and in all local authority areas
- Challenging the health and social care system to respond positively to the recommendations of the Francis Inquiry.
- Proposing major national priorities to influence the health, social care and public health systems, especially in relation to accountability, complaints, major incidents and revalidation of clinicians.
- Advising on short term development issues with Healthwatch nationally and regionally
- Continuing to campaign for a national system for indemnity for LHW members and volunteers.
- Developing a relationship with HWE committee members and briefing them individually on key issues of concern
- Acting as advocate for our members' interests with other bodies
- Building networks to underpin effectiveness
- Building local and national networks to underpin the Association's effectiveness.

PRIORITIES YEARS 2 AND 3 - BUILDING RELATIONSHIP WITH THE PUBLIC

- Holding the health, social care and public health systems to account in relation to their duties to involve and to consult the public and to demonstrate positive outcomes
- Monitoring the effectiveness of HWE and LHW in relation to their statutory duties and accountability to the public

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- Acting as a source of information and advice regarding safety, quality and effectiveness of health, social care and public health services

- Advising lay and community organisations on the levers of influence in health, social care and public health services.

FUNDING

- Subscriptions from individuals, LHWs and other organisations

- Applications for funding to the DH, Department of Communities and Local Government [DCLG], HWE and grant giving bodies.

- Funds to be raised from payments for commissioned research and survey work.

- Income via an independent fund-raiser working on a commission basis.

End