



*The national voice for LINKs' members*



**LINK members discuss  
HealthWatch/CareWatch  
Local Involvement Networks**

# **100 Experts Speak about the Development of HealthWatch**

---

## **The NALM Conference**

**July 8<sup>th</sup> 2010**

---

**The National Association of LINKs' Members**  
*Public and Patient Involvement in Health and Social Care*



# **NATIONAL ASSOCIATION OF LINKs' MEMBERS**

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

---

## **100 Experts Speak on the Future of LINKs and the Development of HealthWatch**

---

### **A NALM Report July 2010**

---

<b>CHAIR:</b>	<b>MALCOLM ALEXANDER</b> 30 Portland Rise LONDON, N4 2PP	<a href="mailto:Nalm2008@aol.com">Nalm2008@aol.com</a> 0208 809 6551
---------------	--	---

---

<b>VICE CHAIR:</b>	<b>RUTH MARSDEN</b> The Hollies George Street COTTINGHAM, HU16 5QP	<a href="mailto:ruth@myford.karoo.co.uk">ruth@myford.karoo.co.uk</a> 01482 849 980
--------------------	---	---

---

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

---

# THE AIMS OF NALM

---

**The aims of NALM are to:**

---

1. Provide a national voice for LINKs' members.

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

---
2. 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.

---
3. Support the capacity of communities to be involved and engage in consultations about changes to services, influence key decisions about health and social services, and hold those services to account.

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

---
4. Promote open and transparent communication between communities across the country, and the health service.

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

---

## Special thanks to:

---

### Speakers:

---

Joan Saddler	National Director for Patient and Public Affairs
Paul Streets	Director for Patient and Public Experience
Elizabeth Manero	Director of HealthLiNk

### Support with planning, preparations and support on the day of the Conference

---

Sandra Berry	Kingston's LiNk
Polly Healy	Richmond LiNk

### Facilitators and scribes for workshops:

---

John Barnes	Sandra Berry	Harry Bhamah
Jilla Bond	Pat Bottrill	Sally Brierley
Alan Carter	Peter Cragg	Amanda Hames
Anita Higham	David Hogarth	Mark Hope
Tessa Jelen	Mary Ledgard	Ruth Marsden
Kath Murray	Helen Rowe	Dave Shields
Natalie Teich	Catherine Willmet	Andrea Darrington

### Conference organisers

---

Helen Mansfield	AvMA
Kay Marbiah	
Ed Maycock	

# CONTENTS

<b>Executive Summary</b>	...	...	...	...	...	...	...	6
--------------------------	-----	-----	-----	-----	-----	-----	-----	---

<b>Conference Objectives</b>	...	...	...	...	...	...	...	7
------------------------------	-----	-----	-----	-----	-----	-----	-----	---

<b>Key Recommendations</b>	...	...	...	...	...	...	...	8
----------------------------	-----	-----	-----	-----	-----	-----	-----	---

<b>Summary and Themes</b>	...	...	...	...	...	...	...	10
---------------------------	-----	-----	-----	-----	-----	-----	-----	----

<b>Recommendations from Workshops</b>	...	...	...	...	...	...	...	12
---------------------------------------	-----	-----	-----	-----	-----	-----	-----	----

- (1) Developing the LINKs-HealthWatch local perspective  
*... powers, duties, funding and naming*
- (2) Developing LINKs-HealthWatch – national perspective  
*... powers, duties, funding, hosting and naming*
- (3) A LINKs-HealthWatch Transformation Board?  
*... objectives, membership and accountability*
- (4) Developing the capacity to monitor social care
- (5) What have LINKs achieved? What have we learned?

## **The Future of Local LINKs in the Context of HealthWatch :**

A DRAFT POLICY PAPER	...	...	...	...	...	...	...	23
----------------------	-----	-----	-----	-----	-----	-----	-----	----

<b>Conference Speeches:</b>	...	...	...	...	...	...	...	27
-----------------------------	-----	-----	-----	-----	-----	-----	-----	----

- JOAN SADDLER, NATIONAL DIRECTOR FOR PUBLIC AND PATIENT AFFAIRS
- PAUL STREETS, DIRECTOR FOR PUBLIC AND PATIENTS EXPERIENCE
- MALCOLM ALEXANDER, CHAIR, NALM
- RUTH MARSDEN, VICE CHAIR, NALM

## **Appendices:**

1. THE WHITE PAPER.	...	...	...	...	...	...	...	33
2. THE STATUTORY ROLE OF LINKs	...	...	...	...	...	...	...	35
3. WORKSHOP REPORTS	...	...	...	...	...	...	...	38
4. THE LESSONS OF THE TRANSITION ADVISORY BOARD (TAB)	...	...	...	...	...	...	...	54
5. CHCs, PPIFs and LINKs LESSONS FROM HISTORY	...	...	...	...	...	...	...	57

## Executive Summary

---

We have had the opportunity, since 2003, to compare three unique models of PPI, each having been developed with the intention of empowering the public. There has simultaneously been concern about opportunities in the community to influence access, quality and outcomes of services. The effectiveness of PPI systems has been highly variable.

NALM welcomes HealthWatch at a local and national level. We believe this development will substantially increase the power and influence of local people, and enable communities across the country to monitor services, have a voice in the local, regional and national development of health and social care policy, and influence commissioning at every level.

But to do this effectively, HealthWatch locally and nationally must be fully independent and democratic, with appropriate statutory powers to monitor the NHS and social care. The HealthWatch system must also have duties to involve the public at a local and national level.

Whilst fully supporting the HealthWatch model, we fundamentally disagree with the dependent relationship that HealthWatch will have on the CQC and Local Authorities. We believe this approach will be expensive to establish and will undermine the independence of HealthWatch – it must not be dependent upon the bodies it monitors and holds to account.

We understood the Big Society model was meant to dismantle the ‘command and control’ approach to public services, but the model proposed intensifies centralised command and control. Instead of empowering communities, it offers an expensive and rigid model, that we believe will undermine the freedom of communities to build powerful local and national bodies, that reach out to local people and empower them to radically improve services.

In relation to the funding of HealthWatch, delegates to the conference made the powerful point that without security of funding, at least for an initial period, HealthWatch would be vulnerable and would not thrive in its new metamorphosis. HealthWatch must monitor, scrutinise and work with local people. Volunteers are versatile, imaginative and hard working, but they need stability, continuity and their own staff to get PPI in health and social care back on the road. LINKs can build a highly efficient and effective HealthWatch system at low cost, if freed from the constraints of bureaucracy and central control.

NALM believes that an independent HealthWatch will thrive and be able to hold the regulators and the whole of the health and social care system to account, providing current legislation is modified so that relevant government departments, statutory bodies, local authorities and providers and commissioners of health and social care, are required to involve HealthWatch in decision making, commissioning and service development.

To be successful the new system must be widely advertised and a duty place on commissioners and providers to publicise HealthWatch to all users and carers.

HealthWatch provides a significant opportunity for growth, development and real outcomes for public involvement, if the community is freed to use its talents and imagination to build this new system.

## Conference Objectives

---

The conference was held to consider the future of LINKs and the development of Local and National HealthWatch. The key objectives of the conference were as follows:

- 1) To review and reflect on what we have learnt from the LINKs model of public and patient involvement, and what we would recommend to ensure sustainability and effectiveness in the future.
- 2) To consider the method of funding and support for Local HealthWatch
- 3) To review the powers and accountability of Local and National HealthWatch
- 4) To consider the development of more effective methods to monitoring and influencing the commissioning of social and health care.
- 5) To consider the development of effective partnership at a local and national level with statutory and voluntary sector bodies.
- 6) To propose a model for National HealthWatch, and its roles, responsibilities and relationships with Local HealthWatch
- 7) To plan for the development of a Transitional Board for the creation HealthWatch.
- 8) To advise Ministers on the most effective means of developing a successful HealthWatch system.

Those attending the conference were amongst the most experienced health and social care volunteers and activists in the country.

## Key Recommendations from the NALM Conference

---

- **National HealthWatch should not be located within the CQC. It must be an independent, 'bottom-up' democratic body led by elected representatives from Local HealthWatch.**
- **Local HealthWatch should be fully independent of local authorities and must not be accountable to any body that it monitors.**
- **National and Local HealthWatch must be wholly independent, able to hold the regulators, and the whole of the health and social care system, to account.**
- **Local HealthWatch must have centrally provided ring-fenced funding. They are unlikely to survive without secure funding.**
- **National HealthWatch should be the guarantor of the rights, duties and independence of local HealthWatch.**
- **The statutory duties of National HealthWatch should be vested in the national bodies that it holds to account, by amendments to current legislation, e.g. the duty of CQC to consult HealthWatch should be established through an amendment to the Health and Social Care Act 2008**
- **Local HealthWatch must have the power to enter and view the premises of all health and social care providers regulated by the CQC at any time they believe is appropriate.**
- **There should be a statutory duty for all health and social care commissioners and providers to advertise Local HealthWatch**
- **HealthWatch will require statutory powers to refer commissioning decisions, if these decisions are believed to be detrimental to the quality and outcomes of health or social care. HealthWatch must have a statutory role in health and social care commissioning.**
- **HealthWatch should be able to require NHS and social care staff, and representatives, to attend their meetings for questioning about the design, quality and outcomes of health and social care.**



- **National HealthWatch must be able to give legal and policy advice to local HealthWatch and have resources to communicate local and national issues to the public.**
- **National HealthWatch must provide draft governance documents and guidelines to Local HealthWatch for local modification.**
- **Clear accountability is essential for both the Local and National HealthWatch. These bodies must be able to demonstrate how they are serving the community, and what action they are taking with respect to concerns raised about services in any part of the country.**
- **Public awareness of HealthWatch is essential. Local and National HealthWatch must be comprehensively advertised to the public. Inexpensive advertising is available through many community agencies and local authorities.**
- **National HealthWatch must promote and share good practice.**
- **National HealthWatch must be a source of responsive and expert advice; hold the PPI specialist library, have access to DH and other department libraries,**
- **An information system of successful HealthWatch work should be maintained by the National HealthWatch, to show what can be achieved.**
- **Local and National HealthWatch should ensure that their work is outcome focussed and their achievements well publicised to the public, local and national government.**
- **LINK Members must be actively involved in all aspects of the transition to HealthWatch.**

## Summary and Themes from Workshops

### Session led by Elizabeth Manero, HealthLINK

---

1. **Clarity** – on governance is essential. Training for LINKs must be of a higher quality across the whole country, and the role and powers of LINKs must be clarified and enhanced.
2. **Publicity** – to others, nationally and locally about HealthWatch, is an essential means of strengthening public understanding of how they can influence health and social care.
3. **More power to HealthWatch** – clearer powers are needed, e.g. to use for Enter and View monitoring. HealthWatch must have speaking rights on OSCs and PCTs and the power to steer the future of HealthWatch through the proposed Transitional Board.
4. **Collaboration and networking is essential -**
  - At national level
  - At local level
  - Between the two
  - To provide a collective voice locally and nationally
  - With MPs
5. **Accountability and transparency –**
  - Of national HealthWatch (e.g. through a Constitution)
  - Of Local HealthWatch (e.g. through elections of members)
  - On performance (e.g. through national data gathering from HealthWatch on how well GP commissioning is working locally)
  - Of Hosts – avoid the *'dog being wagged by the tail'* (LINK by the Host). Local HealthWatch must have power to choose their Hosts - or indeed whether to have one at all, or to employ their own staff
6. **National and local coherence –**
  - National HealthWatch must be 'bottom up'
  - Support should be provided from national HealthWatch to LINKs on *how* to fulfil their role successfully, (e.g. in social care or the Dignity in Care campaign)
  - Local HW should pull together issues that need support from HealthWatch at a national level
  - HW might act as a 'national Host?'
  - HW could act as a messenger/channel between LINKs and other national bodies (messages down and messages up)
  - HW must be totally independent
  - Transparency for HealthWatch and NALM is essential– what is it doing and saying on behalf of LINKs
  - A consistent quality framework for LINKs must be created – e.g. on research or the host role

## **7. More Effective Relationships –**

For example:

- Between LINKs and local authorities and PCTs.
- Between one LINK and another.
- Between NALM and any Transitional Board – how would representation of LINKs be guaranteed.
- Between NALM and HealthWatch.

## **8. Integration**

- Of the complaints system into the Health roles – both in relation to themes arising from complaints, and HealthWatch monitoring how well the complaint support process is working.
- Of Local HealthWatch with GP commissioning – perhaps channelling Local HealthWatch money through this mechanism instead of local authorities.
- Of Local HealthWatch in the social care monitoring conducted by OSCs.

## **Recommendations from Workshops**

### **Full text in Appendix 2**

---

#### **1. Developing HealthWatch – local perspective**

---

**Are LINKs' powers about right, or do they need greater powers and duties? What support should they get from a national body?**

---

**How should LINKs build and promote diversity and inclusion?**

---

- Recruitment of an active, influential and diverse membership is paramount.
- Local HealthWatch should work consistently and strategically with all communities, and ensure that they have the opportunity through the Local HealthWatch to influence health and social care in their area.
- Where specific groups or communities currently have a low level of participation in service development, proactive outreach work is essential.
- Local HealthWatch should support the development of culturally sensitive services.
- Local HealthWatch members may need training in the duties and requirement of the Equalities Act 2010 - and the most effective methods of promoting diversity and inclusion
- The use of social media is essential to include individuals and community.

#### **Local HealthWatch members and staff - training**

---

- National HealthWatch should lead on the training of LINK members and staff.
- There should be a core national curriculum in relation to training and induction, but the training should be delivered locally. A basic skills-set should be established in relation to the competencies that both Local HealthWatch members and staff require to operate effectively and this training should be certificated. A strong emphasis on social care monitoring is essential
- A major focus on training should be to gain a deeper and clearer understanding of the duties and rights of HealthWatch, the bodies they work with and remedies where HealthWatch is prevented from carrying out its duties.

## How can LINKs get the balance right between health and social care?

---

- Local HealthWatch should take a lead in preventative health campaigns in relation to both health and social care.
- A focus on mental health should be a high priority for Local HealthWatch.
- Local HealthWatch should monitor all local health policies to ensure that they consider the social care implication for patients.
- Local HealthWatch must have a major role in the development of new commissioning arrangements, both in relation to GP/practice based commissioning and specialist regional and national commissioning.
- LINKs must have access to private and voluntary sector commissioners and providers of health and social care, and rights of access to information equivalent to rights of access in the public sector.

## Funding and status of HealthWatch

---

- Local HealthWatch should be funded centrally, and resources must be ring-fenced.
- Funding through local authorities has **not** been successful in many parts of the country and should not be repeated. There are major conflicts of interest as local authorities provide and commission services monitored by LINKs.
- Local HealthWatch must have clear statutory rights and duties.
- Steering groups must be democratically elected by local people and the voluntary sector.
- Accountability must be to the community.
- Local HealthWatch should become legal entities in their own right, able to employ staff and fund projects.
- The statutory sector should commission LINKs to carry out research and outreach work.
- Local HealthWatch must be completely independent of government, government quangos and other bodies that provide and commission services
- Where Local HealthWatch and Hosts agree that the relationship has been successful, support from the Host should continue. Where the relationship has not worked, Local HealthWatch should have the option of choosing its own staff or hosts. An 'arms length body' can provide the 'pay and rations' arrangements, contracts of employment etc. This body could be a local authority, the CQC or a specialised voluntary sector body.

- Mentoring arrangements should be developed to support Local HealthWatch if they are not functioning well. The mentors should come from other Local HealthWatch.
- Paying expenses efficiently to volunteers is essential for the successful operation of Local HealthWatch.
- National HealthWatch should provide model governance documents that local LINKs/HealthWatch can adapt to their local circumstances.

### **Should LINKs become advocates for complainants?**

---

- Local HealthWatch should work closely with, and be a signpost for, ICAS (Independent Complaints Advocacy Services)
- Feedback from complaints is essential data for Local Health. This should include all recommendations made following complaints investigations by health and social care agencies.

## **2. Developing the LINKs - National HealthWatch, national perspective**

---

### **Influence on health and social care**

---

- National HealthWatch must be fully independent of government and arms length bodies established by government. It should represent to government what Local are saying and what local people need.
- For National HealthWatch to be credible, NALM should have a major role in its development. A key question is - should NALM become part of HealthWatch or hold HealthWatch to account? NALM must be fully funded for the task.
- National HealthWatch must have an intelligence gathering role and should identify and promulgate best practice from and to LINKs/HealthWatch. National HealthWatch should be a source of best practice in involvement and consultation.
- LINK nationally and locally must hold the NHS and arms length bodies like the Care Quality Commission (CQC) and the National Patient Safety Agency (NPSA) to account. HealthWatch must not be part of the CQC because this would build in a major conflict of interests and increase the risk of future major disasters of the type that occurred at the Mid Staffordshire Foundation Trust.
- National HealthWatch should be represented on regional bodies to make sure that commissioners are responsive and work jointly with LINKs/HealthWatch on regional issues, i.e. it would support the development and capacity of local LINKs to work at a regional level.

- The Independent Complaints Advocacy Service (ICAS) should be located within National HealthWatch, and gradually provide for the development of local capacity in LINKs/HealthWatch to provide a local complaints advocacy service. ICAS should be required to provide information from NHS complaints recommendations to LINK/HealthWatch.
- National HealthWatch must be wholly independent and seen to be so. This is a must to ensure that the monitoring and development of health and social care is a high priority at a national, regional and local level and that the public has real influence on policy and strategy. Advocating for the public in the policy debates, e.g. about personalisation and pathways, and ensuring the local views have impact on the national agenda, is considered to be a very high priority.
- National HealthWatch should oversee the development of systems of commissioning, e.g. is GP-commissioning working for the benefit of patients
- Local and National HealthWatch must be built on the work of LINKs and NALM, not attempt to sweep them aside, as previous reorganisations of PPI have done. LINKs were set up to reach the 'seldom heard' not to be seldom heard!
- For this to happen, LINKs and NALM must continue to work together to stimulate and promote national, regional and local discussion and debate on the best ways of building more effective organisations. **All voices have a place in this debate and must be listened to.**
- HealthWatch locally and nationally must address the problems of people in rural areas, specific cultural groups and deprived individuals and communities who are not currently served well by LINKs

### HealthWatch or CareWatch?

- 
- Agreement must be reached on whether the new system is best called CareWatch to reflect the major role of LINKs/HealthWatch in social care activities.

### National HealthWatch should have the following functions:

- 
- Advising on legislation relevant to the promotion of patients and public involvement in health and social care.
  - Developing policy based on local issues raised by local and regional LINKs/HealthWatch.
  - Working with MPs to brief them on key issues about the role of LINKs/HealthWatch and policies issues raised by LINKs/HealthWatch.
  - Briefing of Ministers and opposition leads on health and social care issues generated by local LINKs/HealthWatch.
  - Providing evidence to the Health Select Committees and other select committees.

- Working with the parliamentary All Party Group on PPI.
- Establishing of regional LINKs/HealthWatch based on needs of local bodies.
- Working with Department of Health and Local Government Association to develop Overview and Scrutiny Committees in their new role.

### **Specific roles of National HealthWatch**

---

- Receiving and disseminating information to and from LINKs/HealthWatch.
- Inform, advise and advocate at a national level for LINKs/HealthWatch on all national health and social care issues.
- Be independent, employ its own staff.
- Be a source of specialist advice, expertise and support for Links/HealthWatch.
- Accredited training for LINK/HealthWatch members to a national standard.
- Legal advice and support when issues arise about involvement and consultation procedures.
- Research capacity at national and regional level.
- Policy development and policy papers for LINKs/HealthWatch.
- Collate Annual Reports.
- Act as a Court of Appeal for local disputes.
- Conflict resolution with Local HealthWatch/Hosts/Local Authorities.
- Providing indemnity for LINKs/HealthWatch.

### **Organisation form of National HealthWatch**

---

- Run by a nationally elected council of LINKs /HealthWatch members to ensure that local voices are heard at a regional and national level - and that the National HealthWatch is run by local LINKs/HealthWatch.
- Have a Constitution agreed by the members of LINKs/HealthWatch, and a Service Handbook to ensure that LINKs/HealthWatch know exactly what it can expect from the national body.
- Run at low cost as a social enterprise.
- Statutory powers would be created through the bodies National HealthWatch monitors and held to account, e.g. the legislation would require the CQC and NPSA to consult with, respond to issues raised and be held to account by National HealthWatch.



### **3. Transformation Board**

---

- A Transition/Transformation Board established by NALM to influence the development of local and national HealthWatch.
- A key aim of the Board would be to give Ministers a clear steer on the appropriate means of developing HealthWatch.
- The transition from LINK to the new HealthWatch system should be completed in not more than one year after the Board has presented its report to Ministers.
- To ensure democratic accountability, NALM will hold its regional elections in the autumn of 2010 so that NALM representative on the Board will be newly elected.
- The Board will be interactive, work in partnership with other key agencies and have a strong emphasis on social care.
- The Board will be established for not more than six months, and all documents produced by the Board shall be placed in the public arena.
- The Board may propose the setting up of a short life implementation panel to monitor the initial stages of the development of HealthWatch.
- Accountability of the Board shall be agreed by its members at its first meeting.

#### **Transformation Board Objectives**

---

- That the HealthWatch system is demonstrably independent.
- To secure the investment that has so far gone into LINKs, and advise on the most cost effective means of developing the new system at national and local levels.
- To ensure that the National HealthWatch and LINKs/HealthWatch are created as organisations with a national perspective on the local, regional and national health and social care economy.
- To ensure that the local and national powers of HealthWatch match their duties and responsibilities and enhance the effectiveness of patients and public involvement in health and social care
- Greater accountability and transparency must be paramount in the HealthWatch system.
- To convince Ministers not to introduce legislation to abolish LINKs.
- To advise government on both the successful and negative aspects of the current LINKs system.

## Membership of the Board

---

- Elected NALM representatives, including the Chair and Vice Chair
- One person who is an active member of a LINK, but not in NALM
- One person specifically representing social care interests of users
- One person to specifically represent mental health interests of users
- Two representatives for Hosts – one from a CVO and one from a large provider
- A secretary/minute taker

The following organisations will be invited to give evidence to the Board

- Local Government Association
- Centre for Public Scrutiny
- Department of Health

## Key communications

---

- The Board shall ensure regular communication and consultation with all LINKs to ensure that the widest possible views are represented.
- NALM shall prepare a consultation document on the findings of the Board for the final approval of all LINKs. The period of consultation would be no more than three months.
- The Board will attempt to communicate a vision of the role of LINKs and HealthWatch to the health and social care community and the wider public.
- The final Board report will be submitted to the Health Minister and to a Conference for LINK members.

## 4. Developing the capacity to monitor social care

---

- Training packages to build the capacity of LINKs to monitor social care, should be developed. Training should include a 'knowledge' of safeguarding, the assessment process and how resources are allocated, equality, inclusion and diversity.
- People of all ages receive social care. This should be reflected in LINKs work.
- Skills audits are a valuable way of developing the potential role of LINKs members - as in during visits, report writing and negotiating improvements.
- Recruitment should be targeted at people with social care knowledge or experience.
- Building relationships with key officers in local authority social care is essential for successful monitoring of social care services and getting access to users of domiciliary care.

- Local authorities should identify - on their website and in their literature - officers responsible for service quality, recording accidents, incidents and risks.
- LINKs should gather information from local authorities about what services are contracted, what is in the contracts, whether there are effective complaints procedures and how quality is assessed.
- The Freedom of Information Act can be used to gather information about services if local authorities are reluctant to share information.
- Private agencies/companies providing social care services should be required to share information about standards of care and risk management with LINK. Meeting and developing relationships with managers of providers will assist in the process of both visiting and obtaining information.
- Developing relationships with local Care Quality Commission managers is essential - and copies of all CQC reports for the area should be held by the LINK office.
- Building relationships with Experts by Experience will create enormous shared capacity in the monitoring of care homes.
- LINKs should develop a protocol with the OSCs to share information and alerts about service quality, incidents and problems of access to services.

### **What methods are successful in monitoring domiciliary care?**

---

- Obtaining information about systems and performance indicators used by local authorities to monitor domiciliary services should be obtained.
- Accessing to local authority reports on the performance of social care providers are essential together with any recommendations made following inspections and complaints.
- Developing ways of contacting service users, carers and relatives of those receiving care to obtain information about the standards of care.
- Establishing contact with informal carers as a major resource in assessing the quality of domiciliary care.
- Developing further, Patient Opinion, as a resource for sharing information about care homes and domiciliary care.
- Holding and sharing events where local service users, carers and relatives can exchange information about their experiences of the quality of social care.
- Generating methods to let users of domiciliary care know about LINKs, and their independence from the care provider and the local authority that commissions domiciliary care.

## **Working with carers and relatives**

---

- LINKs need to develop systems to gather information on behalf of people who have lost the capacity to evaluate the effectiveness of care being provided to them.
- Meetings should take place - formally and informally - with carers and those cared for. Some of these meeting should be exclusively with carers, and others exclusively with people being cared for.
- Recruiting carers and the Carers Association to join LINKs is a priority, as is the aim to get at least one informal carer on the LINK Steering Group.
- LINKs should ensure they have training to address the diversity of the populations they serve, e.g. the cultural and religious needs of people being cared for.
- Alliances should be developed with other organisations in the area with knowledge of and involvement in social care.

## **What are the problems associated with monitoring care homes?**

---

- LINKs should specifically share information on problems encountered in monitoring care home and consider whether the Act should be strengthened to allow LINKs greater access to all care homes and all parts of care homes.
- A clear plan of what the LINKs wants to achieve is essential before the visits and this plan should relate both to residents and staff.
- Quantitative and qualitative questions should be used to gather the information.
- All enter and view visits should explore the "dignity agenda".

<http://www.dignityincare.org.uk/BecomingADignityChampion>

### Priorities in monitoring social care

- Developing more effective systems to monitor domiciliary care.
- Creating methods to communicate with young people in the process of transition from children's to adult services.
- Developing techniques to talk to vulnerable users, and especially people who find it difficult to communicate.
- Producing publicity about the role of LINKs through website and bulletins.
- Developing a research strategy to build LINKs knowledge of local needs, and the capacity to monitor social care services within their area.
- Carrying out surveys of users of social care and carers to ascertain their needs.
- Making connections with other bodies, 'Experts by Experience, CAB and GPs.
- Ensuring the LINK has a good knowledge of local cultures which it obtains first hand.

## 5. What have LINKs achieved and what have LINK members learned?

### LINKs - some achievements

Seat at the table with Primary Care Trusts (PCT's) Boards, and Overview and Scrutiny Committees (OSCs).

Development of PCT surveys for assessment of patient need and assessment of services.

Development of dental services.

Contribution to the transformation of thinking on policy in health and social care.

Independent surveys of service users – which have influenced PCT's and social care directors.

Attending and contributing to Practice Based Commissioning Groups.

Developing a hard core of 55 dedicated activists to carry out the work of the LINK

Monitoring of hospital hygiene.

Working with local agencies to develop more effective patient transport services.

Effective monitoring of social care.

Major project to improve hospital parking.

---

Communicating to local groups through the Gurdwara (Sikh Temple).

---

Informing young people about the LiNk at a 6<sup>th</sup> Form Conference.

---

Development of projects around GP information and assessment of GP quality

---

Hospital discharge monitoring project.

---

Engagement with faith groups with an initial focus on the Islamic community.

---

Reversing a decision to close ante-natal classes.

---

Redesigning speech and language therapy services.

---

Improving access for deaf people through establishment of a user focus group.

---

Development of outpatient service for people living with dementia.

---

### **Finding and recommendations from the Workshop**

- LiNks need greater powers and more clout, e.g. a LiNk veto over local decisions in the health and social care economy, to ensure public involvement in all major local decisions.
- LiNk members must be fully consulted on any proposed alterations or changes to LiNks by the new Government.
- LiNks must be given a major role in developing a clear direction on the new structure of LiNks and HealthWatch.

After two years, many LiNks are developing well and do not want their work sabotaged by inappropriate reorganisations. Some changes are needed, e.g. the relationship with the local authority.

- LiNks need a major role in the in the appointment of Hosts.
- Advice and support is needed to ensure successful engagement with diverse communities.
- Community development work must be promoted to enhance the effectiveness of LiNk work with communities.
- More engagement of wider community/ general public e.g. through better use of media, e.g. radio and social media.
- Recognition of differences in populations served by LiNks (e.g. large rural counties and smaller urban unitary authorities).

# **The Future of local LINKs in the Context of HealthWatch:**

## **A draft NALM policy paper**

---

### **Background**

---

The new Government White Paper, *'Equity and Excellence: Liberating the NHS'* proposes the creation of Local and National HealthWatch, to represent the interests of patients and the public in relation to the commissioning and provision of health and social care services. The remit of these bodies will include:

- Representing the interests of patients and the public in the provision of health and social care in the public, private and voluntary sectors.
- Representing the interests of patients in GP commissioning and specialist commissioning at regional and national levels.
- Monitoring NHS and social care services and making them accountable through statutory powers to HealthWatch. HealthWatch will have the duty to obtain and disseminate information, make visits - and possibly call NHS and social care witnesses for questioning.
- Pursuing and referring complaints made by individuals, and referring group/collective complaints about services to the Care Quality Commission, or other appropriate bodies.
- Contributing to and influencing the public debate about the NHS and social care at a national level by voicing the concerns of patients to Ministers, statutory bodies, local authorities, political parties and the media.

### **Role of HealthWatch**

---

The role of National HealthWatch should be to support and enhance that of Local HealthWatch

The role of local Local HealthWatch should include:

- Gathering the views of local people about the services they receive by engaging with individual service users, support groups, and voluntary and community organisations through discussion, consultation and community development work.
- Building networks and strong working relationships with organisations in the health and social care sectors to ensure that the collection and dissemination of information on health and social care is effective.

- Identifying issues from people locally, regionally and nationally that impact on the commissioning of services and negotiating with commissioners to vary service specifications and contract to meet identified needs.
- Holding local service providers to account by making enquiries based on what local people have told them, raising the issues with providers and commissioners and when necessary, Overview and Scrutiny Committees and National HealthWatch.
- Raising and campaigning on significant public health issues.
- Assisting people in making complaints, by making them aware of how the process works, sign-posting them to the Independent Complaints Advocacy Service (ICAS) for support and advocacy, and passing information on complaints to National HealthWatch where appropriate.
- Ensuring that National Health Watch is aware of what is happening locally and about issues it needs to raise with Ministers, the CQC, NPSA and other national bodies.

In order to deliver this role, National HealthWatch will need to ensure that the Government, other national bodies, commissioners and Foundation Trusts have a clear understanding of its place as the statutory national representative of the public in relation to health and social care services.

Local HealthWatch will need to be given the flexibility to adopt a range of approaches to gathering information and providing challenging information by:

- Talking to groups, through consultations and web sites and new media in order to reach the widest possible population.
- Writing letters and reports and talking to commissioners and providers.
- Inspecting health and social care facilities to gather information on how care is provided.
- Contributing to debates about public health.

## **Communications with HealthWatch and organisations in other areas**

---

In order to develop a comprehensive picture of the views of local people about the services they receive, it will be necessary to develop a network of communications between HealthWatch and organisations at the local level by:

- Passing information upwards to HealthWatch so that it has an overview of concerns being raised about the way services are being delivered locally and can take action where appropriate.
- Sharing information with other local organisations “across boundaries” so that those involved have a complete view of the issues being raised in relation to specific services or providers. This might be across localities or within regions, although experience suggests that sharing information on the basis of major commissioners and acute hospitals leading on specialities will be the most useful.
- Share information among localities to ensure equity of access to services.



## Geographical Coverage

---

Local HealthWatch must have boundaries that ensure that they are accountable and accessible to local people and able to influence both commissioning and the work of the new the Health and Wellbeing Boards. They will need locality groups aligned to the areas covered by one or more practice-based commissioning consortia.

Local HealthWatch must be local so that they are in touch with local people, but the area they cover needs to be:

- Meaningful to local people. The locality groups could be based on communities in urban areas and market towns in rural areas. This would alleviate the local population's lack of familiarity with practice-based commissioning and the areas the consortia cover.
- Subject to limited change. The boundaries of the areas used for the delivery of health and social care do not coincide and are subject to frequent changes.
- Large enough to have the resources to monitor the activities of organisations such as strategic commissioners, specialist commissioners and acute trusts that provide services over a wide area.
- Appropriate for metropolitan, rural and mixed areas - what works in a big city is not necessarily suitable for a large rural county

## Support

---

Before proposals for the provision of support for the new organisations are drawn up, it will be important to learn the lessons from the experience of LINKs. However, some of the needs are already clear:

- Roles and responsibilities should be agreed between the Local HealthWatch and the Host (support provider).
- Where this relationship has not worked, a Host from a neighbouring Local HealthWatch could be shared, or Local HealthWatch could employ its own staff on contracts held by the Local Authority.
- Apparatus for conflict resolution should be included in the structure.
- The provision of high quality communications suitable for gathering critical information.

## Nationally

---

- Early national publicity regarding the existence and role of all HealthWatch organisations.
- A national set of draft governance arrangements so that time is not wasted in duplicated effort.

**Locally, there is a need for:**

---

- Host support organisations to be independent of providers and suppliers.
- The Local HealthWatch to participate in developing roles and responsibilities to meet local needs.
- The Local HealthWatch to have the ability to take action if the level of Host services is not acceptable. The variability of quality of organisations providing support at present has been a recurring theme.
- Staff of a sufficiently high calibre, experience and training to deliver the remit of the new organisation.
- Salary levels sufficiently high to attract the right staff

# NALM Conference Speeches – July 8<sup>th</sup> 2010

---

## **Joan Saddler - National Director for Public and Patient Affairs**

*Extracts from Joan's speech*

---

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

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

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

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

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

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

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

Andrew Lansley says “outcomes are more important than processes”. A focus on outcomes, reduces silo thinking. Do professionals understand communication with GPs? [GPs will have £60-80bn to spend]. Do GPs understand social care and the campaigns such as Disability Rights?

The patients' voice must be a thread through the entire system together with service users and empowered staff. Our motto should be 'nothing about us without us', not the old hamster wheel but transparency and accountability.

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

We are hearing from LINKs that their issues are:

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

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

---

### **Paul Streets Director of Patient and Public Experience**

*Extracts from Paul's speech*

---

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

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

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

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

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

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

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

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

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

---

## Questions and Answers

---

**Q** Don’t forget the carers.

**A** ‘Patients and the public’ includes carers. For every patient there is a carer. But keep reminding us. Paul Burstow, Minister for Social Services leads on carers.

---

**Q** Health is not just for the old. How can LINKs attract the young?

**A** Young persons? This is for you, you’ve got organised now, the centre won’t tell you how to do it. Work with what you’ve got. Youngsters won’t go to LINKs’ meetings. Don’t be into ‘representativeness’ but act as representatives, linking to the diversity of the community.

---

**Q** LINKs’ funding goes through the Local Authorities. Will our funding be hit?

**A** There’s no answer to this one. There’s not going to be anything ring-fenced. There won’t be. How to make it happen? NALM will work with Joan and with me.”

---

**Malcolm Alexander**  
**Chair of NALM**

---

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

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

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

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

LINKs are public guardians in health and social care.

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

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

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

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

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

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

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

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

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

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

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

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

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

---

**Ruth Marsden**  
**Vice Chair of NALM**

---

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

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

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

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

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

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

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

'NALM' is not an acronym of elegance. If it had been BASH, or JAB or even BED, it might have had more cache, and looked more slick ... but NALM didn't start with the intention of looking or being slick. It started because there were unmet needs, real needs, and then as now, no-one else was adequately addressing them. Meeting those needs is what NALM does. It explains, it informs, it connects, it updates, it supports and above all, it's responsive, it's there when called on, it does what its members ask of it. NALM is an honest organisation doing an honest job.

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

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

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



### **Equity and Excellence: Liberating the NHS**

The Government's Health White Paper - Extracts

---

#### **Patient and public voice**

---

- 2.24 We shall strengthen the collective voice of patients, and we shall bring forward provisions in the forthcoming Health Bill to create HealthWatch England - a new independent consumer champion within the Care Quality Commission. Local Involvement Networks (LINKs) will become the local HealthWatch, creating a strong local infrastructure, and we shall enhance the role of local authorities in promoting choice and complaints advocacy, through the HealthWatch arrangements they commission.
- 2.25 We shall also look at existing mechanisms - including relevant legislation - to ensure that public engagement is fully effective in future, and that services meet the needs of neighbourhoods.
- 2.26 All sources of feedback - of which complaints are an important part - should be a central mechanism for providers to assess the quality of their services. We want to avoid the experience of Mid-Staffordshire, where patient and staff concerns were continually overlooked while systemic failure in the quality of care went unchecked. Building on existing complaints handling structures, we will strengthen arrangements for information sharing. Local HealthWatch will also have the power to recommend that poor services are investigated.

#### **The role of HealthWatch**

---

##### **At local level:**

- Local HealthWatch organisations will ensure that the views and feedback from patients and carers are an integral part of local commissioning across health and social care.
- Local authorities will be able to commission local HealthWatch or HealthWatch England to provide advocacy and support, helping people access and make choices about services, and supporting individuals who want to make a complaint. In particular, they will support people who lack the means or capacity to make choices; for example, helping them choose which General Practice to register with.

- Local HealthWatch will be funded by and accountable to local authorities, and will be involved in local authorities' new partnership functions, described in Chapter 4. To reinforce local accountability, local authorities will be responsible for ensuring that local HealthWatch are operating effectively, and for putting in place better arrangements if they are not.;
- Local HealthWatch will provide a source of intelligence for National HealthWatch and will be able to report concerns about the quality of providers, independently of the local authority.

### **At national level**

---

- HealthWatch England will provide leadership, advice and support to local HealthWatch, and will be able to provide advocacy services on their behalf if the local authority wishes.
- HealthWatch England will provide advice to the Health and Social Care Information Centre on the information which would be of most use to patients to facilitate their choices about their care.
- HealthWatch England will provide advice to the NHS Commissioning Board, Monitor and the Secretary of State;
- Based on information received from local HealthWatch and other sources, HealthWatch England will have powers to propose CQC investigations of poor services.

### The Statutory Role of LINKs

---

The statutory role of Local Involvement Networks (LINKs) is described in s221 of Local Government and Public Involvement in Health Act and the accompanying statutory regulations. Each Local Authority in England with social service responsibilities must ensure that a LINK is operating in the area of the Local Authority and must contract with a Host to provide support for the LINK.

The statutory role of the LINK is to:

- (a) Promote and support the involvement of people in the commissioning, provision and scrutiny of local health and social care services
- (b) Enable people to monitor the commissioning, provision and scrutiny of local health and social care services
- (c) Obtain the views of people about their needs for, and their experiences of, local health and social care services
- (d) In relation to the above roles, the LINKs must send reports about the quality of services, and recommendations about how local care services could or ought to be improved to Local Authorities, PCTs, NHS Trusts, Foundation Trusts and other relevant commissioners and providers of health and social care, as appropriate

### Public Involvement Policy and the Legal Framework

---

LINKs are funded to monitor care services, promote involvement, improve access and quality, and to influence the commissioning of services. A key way of doing this is through the bundle of legislation and policies on PPI in health and social care. Well trained Hosts and LINK members are the key to ensuring that LINKs are able to influence local health and social care bodies effectively.

Health bodies are required to involve and consult with the public under s242 of the NHS Act 2006 (amended by the Local Government and Public Involvement in Health Act 2007).

Health and social care bodies must also comply with standards set by the Government and monitored by the Care Quality Commission – CQC (the regulators) and Strategic Health Authorities (as performance managers). The CQC will do this using 'Quality and Risk Profiles', which include all the information gathered about each care provider in relation to essential standards of quality and safety.

These are expressed as outcomes related to the experiences of people receiving services; e.g. respecting and involving people who use services.

Real Involvement (Department of Health 2008) recommends health bodies to:

- Seek people's views and taken them into account when making a decision about the service
- Carry out any research, consultation or other discussions with patients, local organisations, the LINKs and other local people
- Demonstrate proper consideration of evidence derived from users of the service or the clinicians running the service, when NHS managers make decisions to vary or change these services
- Provide information to show that any closure decision was properly made in accordance with duties under the Act or duties in relation to CQC standards
- Have representatives on committees and steering groups, co-designing services directly with people and delegating activities to users and community representatives where appropriate.

PCTs have additional duties under World Class Commissioning Competency 3, to engage with the public and patients, and to proactively seek and build continuous and meaningful engagement with them, in order to shape services and improve health. PCTs must ensure the public is involved in decisions about the allocation of public funds on behalf of patients and communities, so that services reflect the needs, priorities and aspirations of the local population.

Proactively, engaging with LINKs is fundamental to the success of PCTs in seeking out the views and experiences of the public, patients, their carers and other stakeholders - especially those least able to act as advocates for themselves.

LINKs also have a specific duty to raise issues of concern with the relevant Overview and Scrutiny Committee. Where local NHS bodies have under consideration any proposal for a substantial development of the health service in the area of a Local Authority, they must consult the Overview and Scrutiny Committee of that Authority.

If the Overview and Scrutiny Committee is not satisfied that consultation on a proposal to close or vary services has been adequate, it may report the matter to the Secretary of State in writing, who may require the PCT concerned to carry out further consultation, with the Overview and Scrutiny Committee.

## The NHS Constitution

---

The NHS Constitution underlines the fact that public and user involvement should be part of the fabric of the NHS, by setting out a right for people to be involved. It says:

“You have the right to be involved, directly or through representatives, in the planning of healthcare services, in the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services.”

### Workshop Reports

---

#### **1. Developing LINKs/HealthWatch – local perspective - powers, duties, funding, hosting and naming**

---

**Are LINKs powers about right or do they need greater powers and duties?  
What support should they get from a national body?**

---

**Should the National HealthWatch be responsible for training of LINKs members and staff?**

---

Yes, the national body should lead on the training of LINK members and staff. There should be a core national curriculum in relation to training and induction, but the training should be delivered locally. A basic skills set should be established in relation to the competencies that both LINKs members and staff require to operate effectively and training should be certificated.

**How can LINKs get the balance right between health and social care?**

---

A better balance is required between health and social care activities. LINKs should take a more holistic approach. LINKs should take a lead in preventative health campaigns in relations to both health and social care. A focus on mental health must be a high priority for all LINKs. LINKs should monitor all local health policies to ensure that they consider the social care implication for patients.

LINKs/HealthWatch must have a major role in the development of the new commissioning arrangement both in relation to GP/practice based commissioning and specialist regional and national commissioning. LINKs must have access to private and voluntary sector commissioners and providers of health and social care and rights of access to information equivalent to rights of access in the public sector.

**How should LINKs be funded?**

---

Central funding via national HealthWatch was proposed as the best way forward and funding must be ring-fenced. The total budget for LINKs (£28m) has not been increased for inflation since 2003. LINKs must be accountable for their budget to the community.

Funding through local authorities has been a serious mistake and should not be repeated.

Many local authorities have performed poorly in relation to the development of LINKs because they have seen their major role as performance managing Hosts according to

their own needs not the needs of the LINKs. There are also major conflicts of interest as local authorities provide and commission service monitored by LINKs.

LINKs should become legal entities in their own right and able to employ staff and fund projects. The budgets in some cases are too low to employ highly trained and relevant staff.

In some cases, the statutory sector could commission LINKs to carry out research and outreach work.

### **What is the best kind of relationship between LINKs and Hosts? What is the best role for Local Authorities?**

---

LINKs must be completely independent of government, government quangos and other bodies that provide and commission services.

Hosts have been variable in quality. Some have been excellent and some have failed to grasp the role and responsibilities of LINKs. In some cases LINKs have been regarded by Hosts as sub-committees, or as a source of additional funding for the Host.

Where LINKs and Hosts agree that the relationship is successful, support from the Host should continue. Where the relationship has not worked, the LINK should have the option of choosing its own staff or hosts. An arms length body can provide the 'pay and rations' arrangements, contracts of employment etc. This body could be a local authority or a specialised voluntary sector body.

Members of LINKs Steering Groups should have a clear statutory role and be elected by the most democratic means possible.

LINKs work differently; some are bottom-up, some top-down and some have flat structures. These local arrangements should be supported if they are successful. What matters are transparent and democratic relationships. Where LINKs do not work, they should be mentored by one that does. The problems are usually due to personalities, a failure to determine appropriate objectives and an inexperienced Host.

Paying expenses efficiently is essential for a volunteer based organisation.

### **Should LINKs become advocates for complainants?**

---

LINKs locally should not become advocates for complainants. This is a highly specialised area of work and would require the employment of specialised advocates. LINKs should work closely with and be a signpost for ICAS (Independent Complaints Advocacy Services).

Feedback from complaints is essential data for LINKs. This should include all recommendations made following complaints investigations by health and social care agencies.

## **How should LINKs build and promote diversity and inclusion?**

---

LINK should work consistently and strategically with all communities and ensure that all communities have the opportunity through the LINK of influencing health and social care in their area. Where groups or communities currently have a low level of participation in service development, outreach work is essential, e.g. gypsies, travellers and young men from all parts of society.

LINKs should support the development of culturally sensitive services, and to be effective in promoting this type of development, LINKs members need to have training in the most effective methods to promote diversity and inclusion.

Jointly organised events with local groups that provide information about the work of the LINK, are essential and must be repeated in new and various formats over a long period of time to build trust and promote inclusion. The use of social media is essential to include individuals and community.

## **Should all LINKs have a Governing Council or Committee and if so who should be on it and how should they be chosen?**

---

LINKs should have a Governing Committee and its members elected through the membership of the LINK. Wider membership and greater inclusion in the work of the LINKs is essential for effective growth of public involvement in health and social care.

National HealthWatch should provide model governance documents that local LINKs/HealthWatch can adapt to their local circumstances.

## **2. Developing the LINKs-HealthWatch national perspective**

---

### **Will the national body give LINKs more influence in health and social care?**

---

#### **Influence on health and social care**

---

National HealthWatch must be fully independent of government and should represent to government what LINKs are saying and what local people need. It must have an intelligence gathering role and should identify and promulgate best practice from and to LINKs/HealthWatch. National HealthWatch should be a source of best practice in involvement and consultation.

NALM has initiated a lot of the activities that National HealthWatch should be responsible for. NALM should be a major part of National HealthWatch. A key question is should NALM become HealthWatch or hold HealthWatch to account. Either way NALM must be fully funded for the task.

National bodies in the NHS, and arms length bodies like the Care Quality Commission (CQC) and the National Patient Safety Agency (NPSA), are often unresponsive to the public. A national body is needed that can require them to work effectively with local



LINK/HealthWatch and the public, and hold them to account. This would empower LINKs and reduce the risk of major disasters of the type that occurred at the Mid Staffordshire Foundation Trust.

National HealthWatch might be represented on regional bodies to make sure that commissioners are responsive and work jointly with LINKs/HealthWatch on regional issues, i.e: it would support the development and capacity of local LINKs to work at a regional level.

The Independent Complaints Advocacy Service (ICAS) should be located within National HealthWatch and provide for the development of capacity in LINKs/HealthWatch to provide a local complaints advocacy service. ICAS should be required to provide information from NHS complaints recommendations to LINK/HealthWatch.

Participants felt that National HealthWatch must be fully independent and must ensure that the monitoring and development of health and social care was a high priority at a national, regional and local level - and that the public had real influence on policy and strategy. Advocating for the public in the policy debates, e.g. about personalisation and pathways, and ensuring the local views have impact on the national agenda, was considered to be a very high priority. National HealthWatch should also oversee the development of systems of commissioning e.g. is GP-commissioning working for the benefit of patients?

Local and National HealthWatch should be built on the work of LINKs and NALM, not attempt to sweep them aside as previous reorganisations of PPI have done. But for this to happen, LINKs and NALM must work together to stimulate and promote national, regional and local discussion and debate on the best ways of building more effective organisations.

**All voices have a place in this debate and must be listened to.**

The Workshop was concerned that in the current system. LINKs cover such great geographical distances, especially in rural areas. Many people in rural areas, specific cultural groups and deprived individuals and communities are difficult to serve by the current system, and people in these group find LINKs difficult to access or may not be aware of them.

## **HealthWatch or CareWatch**

---

There was a significant debate about whether HealthWatch should be called CareWatch to reflect the major role of LINKs/HealthWatch in social care activities.

**It as agreed that a national body should have the following general functions:**

- Ability to advise on legislation relevant to the promotion patients and public involvement in health and social care.
- Vehicle for development of policy based on local issues raised by local and regional LINKs/HealthWatch.
- Working with MPs to brief them on key issues about the role of LINKs/HealthWatch and policies issues raised by LINKs/HealthWatch.

- Briefing of Ministers and opposition leads on health and social care issues generated by local LINKs/HealthWatch.
- Providing evidence to the Health Select Committees and other select committees
- Work with the parliamentary All Party Group on PPI.
- Establishment of regional LINKs/HealthWatch based on needs of local bodies.
- Work with Department of Health and Local Government Association to develop Overview and Scrutiny Committees in their new role.

## **Specific roles of National HealthWatch**

---

National HealthWatch should be a body receiving and disseminating information, which can inform, advise and advocate - at a national level - for the public on all health and social care issues. It must be independent, employ its own staff and be a source of specialist advice, expertise and support for local HealthWatch. Its role should include provision of the following services to local HealthWatch.

- Accredited training for LINK/HW members to a national standard
- Legal
- Research
- Policy development and papers
- The national body should collate annual reports and act as a court of appeal for local disputes
- Conflict resolution with LHW/Hosts/Local Authorities.

There are a range of opinions on whether National HealthWatch should become a national Host for LINK, or whether it should be the commissioning body for local Hosts. This discussion is repeated in the section on Local LINKs/HealthWatch and includes the view that LINKs/HealthWatch should have two choices: to retain their current Host if the relationship is successful, employ staff, or perhaps to share a Host where a Host in an adjacent area is recommended.

## **Organisation form of National HealthWatch**

---

It should be run by a nationally elected council of LINK /HealthWatch members. This will ensure that local voices are heard at a regional and national level and that National HealthWatch is run by local LINKs.

National HealthWatch must have a Constitution agreed by its LINKs/HealthWatch members, and a service handbook to ensure that LINKs/HealthWatch know exactly what is can expect from the national body.

Funding will need to be shared between the local bodies and nationally, and may mean volunteers taking on a bigger role. National HealthWatch could be run at a very low cost, as a company limited by guarantee or social enterprise. This would not stop

National HealthWatch from having a statutory framework. If National HealthWatch is placed in the CQC it will be very expensive and deprive LINK/HealthWatch of resources. If it is within the CQC it will not be independent and will be subject to major conflicts of interest.

### **3. Transformation Board**

---

#### **Introduction**

---

Participants agreed that there should be a Transition/Transformation Board established by NALM to influence the development of HealthWatch.

NALM's regional LINK representatives should be key members of the Board. A key aim of the Board would be to give Ministers a clear steer on the appropriate means of developing HealthWatch at a local and national level.

Transition from LINK to the new HealthWatch system should be completed in not more than one year after the Board has produced its report for Ministers.

To ensure democratic accountability, NALM will hold its regional elections in the autumn of 2010 so that NALM representative on the Board will be newly elected.

The said Board must be interactive, work in partnership with other key agencies and have a strong emphasis on social care.

The workshop felt that the name HealthWatch does not reflect the key role of LINKs/HealthWatch in social care and suggested that CareWatch was a more appropriate name.

The Board would be established for not more than six months and all documents produced by the Board shall be placed in the public arena.

The Board may propose the setting up of a short like implementation panel.

Accountability of the Board shall be agreed by its members.

#### **Transformation Board Objectives of the Board**

---

Participants felt that the purpose of the Board would be to ensure that LINKs/HealthWatch and National HealthWatch together create organisations with a national perspective and local power, which are demonstrably independent and more powerful than the current model of LINKs.

Greater accountability and transparency were felt to be paramount and should be underpinned by a more clearly defined framework for patients and public involvement.

The Board would seek to convince the government not to introduce legislation to abolish LINKs, and would advise government on both the successful and negative aspects of the current system. Potential improvements to the current system would be identified that would put power into the hands of people and give people real control in health and social care services.

A key role for the Board would be securing the investment that has so far gone into LINKs and advising on the most cost effective means of developing the new system.

## **Membership of the Board**

---

The Board will consist of not more than 24 members and must, as far as is possible, be inclusive in its membership in relation to the six diversity streams. It shall include:

- Nine elected regional NALM representatives, including the Chair and Vice Chair
- One person who is an active member of a LINK but not in NALM
- One person specifically representing social care interests of users
- One person to specifically represent mental health interests of users
- Two representatives for Hosts – one from a CVO and one from a large provider
- A representative of the Local Government Association
- A representative of the Centre for Public Scrutiny
- A representative of the Department of Health
- A secretary/minute taker

It shall be considered the duty of NALM members of the Board, to maintain the closest possible contact with all LINKs in England.

## **Key communications**

---

The Board should ensure regular communication and consultation with all LINKs to ensure that the widest possible views are represented. NALM is in regular communications with LINKs across England and would prepare a consultation document on the findings of the Board for the final approval of all LINKs. The period of consultation would be no more than three months.

Effective communications should include communicating a genuine understanding of the role of LINKs and HealthWatch to the health and social care community and the wider public.

The final report will be submitted to the Health Minister and a conference of LINK members.

## **4. Developing the capacity to monitor social care**

---

### **How can LINKs be encouraged to develop a role in social care?**

---

Prior to the establishment of LINKs, public involvement work chiefly focused on the monitoring of health care and hospitals. The introduction of social care to the work of LINKs required a change of culture, additional training and new ways of looking at the provision of care services. Added to this, the composition of LINKs did not specifically require the recruitment of people with social care knowledge or experience. Some LINKs

are very fortunate in having users of social care and carers in membership who have experience of this major area of work but for most members training is needed (see training section below).

Understanding the relationships between health and social care and care pathways is essential for LINKs, because there are many layers in the organisation of health and social care systems. Systems are often quite fragmented, because social care services are commissioned from a wide range of social care providers. Finding officers responsible for service quality, recording accidents, incidents and risks can be extremely difficult, particularly because private agencies are often unwilling to share information about standards of care and risk management. Members complained that commissioners and providers of social care services are sometimes poor communicators.

It was noted that the Care Quality Commission has a specific role in monitoring social care and that contact with them are essential. Developing local contacts with Experts by Experience is recommended – they are lay people with personal knowledge of social care, who work with the Care Quality Commission through voluntary sector agencies and brief CQC inspectors during visits to social care services.

Overview and Scrutiny Committees (OSCs) have responsibility for ensuring that social care services are working effectively. Some LINKs have developed excellent relationships with OSCs. It was recommended that LINKs develop a protocol with the OSC to share information and alerts about service quality, incidents and problems of access to services. Two LINKs' members in each area should also have the right to fully participate in OSCs as participant observers – one representing social care and one representing health care interests. The LINK observers should also be able to fully participate in 'task groups'.

There is a flaw in the relationship between local authorities and LINKs. As long as local authorities commission Hosts, LINKs will be hampered in making effective interventions in social care services.

It was recommended that LINKs form alliances with organisations that already exist in the social care field. They should participate in public events with the objective of finding out what carers and relatives need and encourage them to join LINKs, so we can remain in touch and also get them involved in work to improve access to and quality of social care.

The Workshop agreed that LINKs must have a right and duty to be involved in all stage of the commissioning cycle – needs assessment, specification, procurement and monitoring. LINKs must also have access to all relevant reports on social care services.

### **What methods are successful in monitoring domiciliary care (home care workers)?**

---

Monitoring of domiciliary care will be greatly improved if a domiciliary care reports becomes a standard item on OSC agendas. Reports should include performance indicators relating specifically to domiciliary care.

For LINK, developing effective relationships with local authorities was prioritised as a key means of getting access to users of domiciliary care. A critical understanding of the systems local authorities use to monitor domiciliary services, examining their reports and becoming familiar with local authority performance indicators used to manage providers of social care, were felt to be very important.

Obtaining copies of recommendations made following complaints to local authorities, was considered a key means of obtaining information about problems in the provision of domiciliary care. A major resource in assessing the quality of domiciliary care was establishing contact with informal carers.

It was agreed that locating the targets and standards used by the local social service department was essential. Copies of all CQC reports on local services are also an essential resource.

The use of Patient Opinion was recommended by some participants, but the main emphasis was on 'getting out there' to see what is going on, dropping in to day centres to discuss domiciliary care, using staff at events to contact people to hear about their experiences, and using a 'camper van' in various locations to make contact with people and hear about their experiences.

It was agreed that this is a difficult area as we have no rights to enter and view services delivered in people's own homes unless they give permission and getting questionnaires out to those who use services is problematic. We need to recruit domiciliary care users and informal carers into the LINK and to reassure them that we are independent of the local authorities that arrange their domiciliary care and the provider.

It was agreed that finding out how services are contracted - what is in the contracts - are there effective complaints procedures and how quality is assessed - form an essential part of the process of monitoring domiciliary care.

### **Working with users, informal carers and relatives to gather information?**

---

Working with both informal and professional carers was considered to be a major route to gathering information about how services are working - especially when the person being cared for has lost the capacity to evaluate the effectiveness of care being provided to them.

Some of these meetings should be exclusively with carers and others exclusively with people being cared for. Recruiting carers to LINKs as members – and especially as Steering Group members - was seen as a particularly important means of gathering critical information. Invite LINK membership from the Carers Association and other organisations in the voluntary/community sector representing people receiving care.

Training and development was considered essential for effective collection of information, especially when a person has dementia and/or has lost capacity. Training to understanding the cultural needs of people being cared for was felt to be a major priority.

Using the Freedom of Information Act to gather information about services was seen as useful in some circumstances. It was also agreed that having to use the Act suggested that the Local Authority was avoiding the sharing of information.

## **What are the problems associated with monitoring care homes?**

---

Concerns were expressed about the limitations on the rights of LINKs members to monitor care homes (enter and view). These limitations include parts of care homes and the rooms of those living in care homes (except by invitation). It was noted that children's residential accommodation is also excluded.

It was agreed that establishing professional contacts with care homes was essential to facilitate access. This is particularly important because LINKs are not always well known, so making an effective approach to the head of the care home, and providing good information about the LINK is important when first making contact. The information must provide details about the powers and responsibilities of LINKs. The ground rules for enter and view visits should be reviewed to make it less easy for managers of care home managers to exclude LINK visitors.

During visits when contact is made with service users, it was emphasized that gathering information about experiences of specific services provided to residents was of great importance. It was emphasized again that contact with carers and families was of great importance in getting a full picture about service quality. There is a particular problem with obtaining good quality information from residents with dementia.

It was agreed that visiting care homes is a much easier task than monitoring domiciliary care. A clear plan of what the LINKs wants to achieve is essential before the visits and this should relate to both residents and staff. Both quantitative and qualitative questions are useful to gather the information needed. All enter and view visits should explore the "dignity agenda" in its widest sense.

### **High quality care services that respect people's dignity should:**

---

1. Zero tolerance to all forms of abuse.
2. Support people with the same respect you would want for yourself or a member of your family.
3. Treat each person as an individual by offering a personalised service and show respect for their culture.
4. Enable people to maintain the maximum possible level of independence choice and control.
5. Listen and support people to express their needs and wants.
6. Respect people's right to privacy.
7. Ensure people feel able to complain without fear of retribution.
8. Engage with family members and carers as care partners.
9. Assist people to maintain confidence and positive self-esteem.
10. Act to alleviate people's loneliness and isolation.

## What training do LINKs need to improve their social care work?

---

Participants regarded the development of training in social/domiciliary care monitoring work as a major priority. The areas prioritised were:

- Having a clear understanding of what social care and social work is.
- The assessment process
- Allocation of resources

Meeting with social care workers and managers and developing a dialogue was seen as a key source of information and training for LINK members. Good contact with staff provides information about the range of services available in the area

Other **essential** areas of training included safeguarding, equality and diversity.

Practical training to support the work of LINK members included community research (action research), and techniques to learn about the demography of the target area.

It was agreed that actively recruiting members from social care backgrounds and those with a 'knowledge' of dementia and other chronic conditions would substantially benefit the effectiveness of LINKs and provide opportunities for co-learning.

It was agreed that doing a skills audit to find out about the skills and experiences of members of the LINK can potentially be a valuable, especially if members are involved in social care as recipients or carers. In some cases the resources of a neighbouring

LINKs can be useful, e.g. Sheffield LINK has a good knowledge base on the subject of social care which they are happy to share. Becoming Dignity Champions was recommended as a way of gathering a wealth of information.

<http://www.dignityincare.org.uk/BecomingADignityChampion>

## Priorities in monitoring social care

---

- Developing systems to monitor domiciliary care.
- Creating methods to communicate with young people in the process of transition from children's to adult services.
- Developing techniques to talk to vulnerable users and especially people who find it difficult to communicate.
- Producing publicity about the role of LINKs through website and bulletins.
- Develop a research strategy to build LINKs knowledge of local needs and the capacity to monitor social care services within their area.
- Carry out surveys of users of social care and carers to ascertain their needs.
- Making connections with other bodies, 'Experts by Experience, CAB and GPs.
- Ensure the LINK has a good knowledge of local cultures which it obtains first hand.



## 5. What have LINKs achieved and what have LINK members learned?

### LINKs achievements

Participants identified a wide range of activities – many LINKs now have seats at the table with Primary Care Trusts (PCT's) and Overview and Scrutiny Committees (OSCs)

In some areas, LINKs have worked with PCTs to develop PCT surveys for assessment of patient need and assessment of services. Several LINKs have been involved with the development of dental services and had seen significant improvements. The opportunity to contribute to the transformation of thinking on policy in health and social care was also a major advance in some areas. Many LINKs reported they had done their own independent surveys of service users – which had been listened to by PCT's and social care directors.

### Key achievements -

Of 11 LINKs represented in one Workshop, 9 reported that they had established good foundations on which to build their organisations.

Good cooperation with Overview and Scrutiny Committees and PCTs although some PCTs still refuse to allow LINKs representative to sit at the Board table with PCTs directors.

In some parts of the country good relationships have developed with Practice Based Commissioning Groups with LINKs attending, contributing and observing meetings.

Project work and surveys with services users.

### What are LINKs proud of?

#### **Barnsley:**

Establishment of excellent relationships with statutory sector partners and no need to refer any issues to OSC. The LINKs has a hard core of 55 dedicated activists (but no chair).

#### **Kent:**

Initial focus on getting governance right, but now concentrating on project delivery. Major pieces of work on hospital hygiene and access to services and patient's transport. Development of excellent relationships with statutory sector partners.

#### **Birmingham:**

Building on former PPI base to create effective monitoring of social care.

#### **Havering:**

Major project on hospital parking.

#### **Bexley:**

Reaching out to diverse groups, e.g. via the Gurdwara (Sikh Temple) and to the

wider community groups through the Bexley show and the 6<sup>th</sup> Form conference. Establishing rapport with the Care Quality Commission.

---

**Islington:**

Establishing contact with the wider voluntary sector. Development of projects around GP information, hospital discharge and care homes (enter and view powers used for this work).

---

**Richmond-on-Thames:**

Engagement with local MPs.

---

**Norfolk:**

Getting the big picture around health and social care. Gaining respect for the health and social care economy because of the quality of local evidence gathering by the LINK.

---

**Sheffield:**

Initial focus on procedures, but now fully engaged with communities, e.g. monthly newsletter, High Street marquee. Work with stakeholders including the Health Overview and Scrutiny Committee and the local NHS Trust patient groups.

---

**Greenwich:**

Engagement with faith groups with an initial focus on the Islamic community

---

## Examples of services which have improved because of the LINK?

---

<b>Bexley:</b>	Reversing a decision to close ante-natal classes.
<b>Sheffield:</b>	Improving hospital shower facilities.
<b>Barnsley:</b>	Redesigning speech and language therapy services
<b>Medway:</b>	Involving service users in developing services for adult social care
<b>Havering:</b>	Improved parking provision for disabled people attending hospital
<b>Kent:</b>	Input to Quality Accounts
<b>Camden:</b>	Improving access for deaf people through establishment of a user focus group
<b>Islington:</b>	Reviewing hospital discharge procedures
<b>Enfield:</b>	Improved public transport access to hospitals
<b>Norfolk:</b>	Improved communications to enable timely discharge
<b>Richmond:</b>	Development of outpatient service for people living with dementia

## What have we learned over the past two years?

Build on patients and user involvement projects and activities that are already active and successful.

Recognise that developing good relationships takes time.

The legislation has limitations.

- Can lead to domination by better funded more active groups.
- More powers are needed for LINKs to give them a veto over decisions, while matters are being reconsidered in line with current policy. This change would ensure public involvement in major local decisions.
- LINKs need more clout.
- Insufficient recognition of differences in populations served by LINKs (e.g. large rural counties and smaller urban unitary authorities)

Understanding the language of government can be difficult because the language can be confusing and sometimes obscure.

Need for more support in engaging diverse communities.

More engagement of wider community/ general public e.g. through better use of media, e.g. radio and social media.

Importance of effective project management structures:

- Leadership skills
- Costing
- Timetabling

## How can LINKs increase their influence?

Adding value to existing groups seeking help (e.g. Norfolk's ME Group) by sharing the resources/ powers available to the LINK with other groups providing a collective local voice.

Developing media skills.

Becoming recognised as the citizens' independent care champions strengthening LINK and other stakeholder engagement in both statutory and voluntary sectors

## What didn't go well for LINKs?

Participants felt that the lack of a funded national body for LINKs fundamentally weakened them, because there was insufficient national leadership and no support with the development of governance arrangements. Too much time, in the first year, was wasted finding a Host, putting structures in place and recruiting members. It was felt that if the government has sought advice from people with practical experience, the current model would not have been adopted.

It was felt that LINK 'early adopters' had an advantage of more time to develop their operational model. However, 'early adopters' all operated in different ways and provided no coherent advice, which contributed meaningfully to the development of other LINKs. Also, because of the failure of the Department of Health to provide support and advice, and the inexperience of many Hosts, LINKs spent their first year building their organisations and little time monitoring services.

Wide range different operational approaches by Hosts were identified. Some LINKs participants identified excellent Hosts, but several participants described communication problems with Hosts - particularly Host staff not listening to LINK members. A major problem identified was that some Hosts had been appointed who had no knowledge of the geographical area in which they were operating, and some retained control of finances. In some cases Hosts contracts were drawn-up and withdrawn by the local authority without consulting the LINK members.

Although the addition of social care to the work of LINKs widened their remit, LINKs had fewer powers than Patients' Forum or Community Health Councils and some participants felt LINKs had been set up to fail.

### **Comment on workshop**

---

Members in these workshops reported that the discussions had been of great value because they had gained an insight into the work of other Links – some very successful. For participants who were feeling disillusioned with their Hosts, and had experienced a lack of co-operation from Local Authorities, the workshop had provided inspiration and ideas to take back to the members of their LINKs.

### **Recommendations from the Workshop**

---

- (1) LINKs need greater powers and more clout - more powers for LINKs to give them a veto over decisions while matters are being reconsidered in line with current policy, to ensure public involvement in major local decisions.
- (2) LINK Members must be consulted on any proposed alterations or changes to LINKs by the new Government.
- (3) LINKs must be given a major role in developing a clear direction on the new structure and LINKs and HealthWatch.
- (4) After two years many LINKs are developing well and do not want their work sabotaged by inappropriate reorganisations. Some changes are needed, e.g. the relationship with the local authority.
- (5) LINKs need a major role in the in the appointment of Hosts.
- (6) Need for more support and advice in engaging diverse communities and community development work.
- (7) More engagement of wider community/ general public e.g. through better use of media, e.g. radio and social media.

- (8) Recognition of differences in populations served by LINks (e.g. large rural counties and smaller urban unitary authorities).

### **The lessons of the Transitional Advisory Board (TAB) for Department of Health involvement of stakeholders.**

---

#### **Background**

---

The TAB was set up by Hazel Blears, to involve a range of stakeholders in advising the DH on the new patient and public involvement mechanisms. With 15 members, it included equal numbers of participants from CHCs, voluntary sector, local government and the DH/health. Each constituency was asked to put forward its own nominees. It was Chaired by one of the 'patient and citizen' representatives on the Modernisation Board and supported by an independent project manager.

The work began in February 2002 and ended that December. This short report is based on a discussion at the last meeting on 4th December. Both TAB and DH officials present for the discussion deemed the TAB to have been a success but it could have been better and easier.

We hope these points may be useful for similar exercises in the future.

#### **The lessons of the TAB for future stakeholder involvement.**

---

- Make the terms of reference clear and separate change management issues from future visioning issues.
- Establish and maintain a clear link with a senior DH sponsor – in this case the Minister.
- Use independent project management, but working alongside the DH, and have an independent chair. Ensure that the selection process of members does not question the credibility and independence of the group.
- Dedicate DH staff to the process – effective consultation is a significant investment, but, if got right, has a substantial return.
- Open and transparent communication – especially around areas of uncertainty and ambiguity. The use of a larger reference group as a point of communication and consultation appears to be a good idea.
- Trust the group, make sure it is aware of important decisions made elsewhere which may affect its work and use it to address difficult as well as easy questions.
- If a group is formed to advise on transition reassess whether you still need it once the body to which the transition is being managed forms.
- Be very clear about the resource envelopes, or lack of relevance of them, right at the start.

## What went well?

---

- The idea of a fixed term **independent mixed stakeholder group**: the group was able to debate difficult issues, make recommendations on options and enrich the policy making process.
- **Communication**. Early on the TAB made a commitment to operate in an open and transparent way with minutes, an update and all reports placed on an open website. This appears to have been widely welcomed by many with an interest in the issues under discussion. The website became one of the main sources of credible information at a time of change, when the DH was not necessarily trusted. It was, however, also used to convey updates on DH policy making.
- **The use an external reference group** – made up of approximately 100 stakeholders from the 3 constituencies – to debate contentious issues.
- Having an **independent project manager**, funded by the DH, and an independent voluntary sector chair.
- The use of **sub groups** of the 15 to discuss more detailed areas of work, which also enabled a wider group of stakeholders to make a contribution.
- The Department of Health's commitment to meet participants' **travel and incidental expenses**.

## What could have been better ...

---

- **The remit of the group**. The issues under discussion were a mix of advice on the transition and advice on what the new arrangements might be. At times the former inevitably affected discussions on the latter. It may have been more productive for the Department to use the group just to help shape the new proposals, using a different group, or direct negotiation, to address issues that affected some members of the TAB very directly.
- **The DH often appeared not to trust the group during the process**. It often seemed that decisions were being made which would affect our deliberations but we were not told, or we were given only half the story.
- The brief led us to debate **structure before function** at times.
- At times we were **too inward looking** and we think that more effort should have been made to increase **diversity** amongst the group and those consulted.
- **Lack of transparency** about how the members were chosen which could have questioned our credibility – although we think the working methods chosen (see above) helped to preclude potential criticism.
- **Connecting interrelated Department of Health's reference groups**. It was not always apparent whether, an invitation to join a reference group was related to the individual's membership of the TAB, or offered in a personal capacity. Equally the reporting mechanisms, from those reference groups back to the TAB, were not always clear.

### **CHCs, PPIFs and LINKs – Lessons from History**

#### **A brief comparison of patient representative bodies**

---

#### **Community Health Councils (CHCs)**

---

Community Health Councils (CHCs) were the established body for patient representation from 1974-2003. They were established within the NHS structure by Regional Health Authorities, or later on, by one Health Authority in each region. CHCs had a Board-style membership structure (the “Council”) of between 18- 30 members from local authorities, voluntary organisations and the public, according to proportions laid down in Regulations. CHCs dealt with the NHS only and were based on health authority boundaries.

CHC staff was employed on permanent NHS contracts, to run the CHC in premises owned or rented by the NHS. They had a statutory role in monitoring local NHS services and in taking up patient and public issues regarding NHS hospitals and primary care services. Most CHCs, from the early days, assisted individuals with complex NHS complaints - although this was not a statutory role and CHCs were not given any additional funding for this.

#### **Patient and Public Involvement Forums (PPIFs)**

---

PPIFs were set up to replace CHCs, and lasted from 2003-2008. A national quango, the Commission for Patient and Public Involvement in Health (CPPIH) was established to give a national voice to PPIFs and to support them with information and training. The CPPIH contracted with a wide range of charitable and voluntary service organisations to support PPIFs locally. These were known as FSOs (Forum Support Organisations), and they provided premises and administrative services for each Patients’ Forum.

PPIF members were volunteers from the public, and the number on a Forum varied from 5 to 20. PPIFs undertook the work of gathering views and representing the patient and the public view locally.

#### **Local Involvement Networks (LINKs)**

---

Legislation, passed in 2007, required local authorities to make arrangements for the provision of LINKs to provide public and patient representation in health and social care. LINKs replaced PPIFs, but have a wider remit which includes monitoring and involvement in social care. LINKs are funded through non-ringfenced budgets via Local Authorities.



The Department of Communities and Local Government (DCLG), allocated funding for LINKs for 3 years (2008/9 to 2010/11) through the Area Based Grant given to each Local Authority. The funds are allocated to enable each local authority to commission a Host organisation to support the LINK in its area.

The commissioning of a Host organisation by the local authority is intended to enable the Host to employ LINK Support Staff to assist the volunteers to engage with patients and the public in health and social services. The LINKs remit is to monitor all publicly funded services in the local authority area, including services provided by Hospital Trusts, Foundation Trusts, PCTs, GPs, dentists, pharmacists and other independent providers. LINK's expenditure must be declared in the LINK Annual Report and the LA Annual Accounts. Local authorities have a statutory duty to monitor the contracts made with Host organisations.

*There follows a rough and subjective comparison of the 3 bodies based on my personal experience as a CHC Chief Officer, PPIF volunteer and LINK Chair. Others will no doubt have their own views but I hope this contributes to the debate.*

	CHCs	PPIFs	LINKs
<b>Establishing Body</b>	RHA/RO/HA	CPPIH	LA
<b>Funding</b>	DH regional allocations	DH allocation to CPPIH	LA area based grant
<b>Support Staff</b>	Employed by NHS	Employed by FSO or by default directly by CPPIH.	Employed by Host
<b>Premises</b>	Supplied by establishing body. Were mostly central to locality and accessible to public.	Supplied by FSO. Wide variety of premises mostly not accessible to public.	Supplied by Host. Wide variety of premises mostly not accessible to public
<b>Membership</b>	18-30 all selected. Half places for local authorities, one third for voluntary groups, one sixth for public but appointed by establishing body.	Up to 20. All volunteers from public but appointed by FSO/CPPIH.	Open to all members of public. Most LINKs have a Governing Body or Committee elected by the membership.
<b>Main Functions</b>	Monitor and review commissioning, provision and quality of NHS services in the area.	Monitor services provided or commissioned by matching PCT or NHS Trust.	Promote and support the involvement of people in the commissioning, provision and scrutiny of local health and social care services.

	<b>CHCs</b>	<b>PPIFs</b>	<b>LINKs</b>
<b>Rights</b>	Visit NHS services (not primary care contractors). To information on local NHS. To be consulted and if necessary appeal against substantial changes or closures of services.	Visit NHS services including primary care contractors. To information on matching Trust or PCT.	Enter and view NHS and social care services including primary care contractors. To information on local NHS and social care services.
<b>Duties</b>	Publish an Annual Report. Meet annually with matching health authority.	Publish Annual Report.	Publish Annual Report.
<b>Independent?</b>	Surprisingly yes despite establishing arrangements.	Yes but members severely constrained by CPPIH and FSO policies and 'templates'.	Yes but some Hosts over-manage the members.
<b>Accountable?</b>	To NHS but not to local community.	Almost none.	Yes to local community but LINK can decide how.
<b>Regional support</b>	CHCs set up informal Regional Associations to discuss common issues. Lot of Regional support to Chief Officers through regular meetings with RHA.	CPPIH had regional offices which held occasional training events for PPIF members.	No regional support other than the odd meeting through CSIP.
<b>National support</b>	Association of CHCs in England and Wales (ACHCEW) established by Regulations to provide training, legal advice and a national voice for CHCs. Funded by DH and CHC subscriptions.	CPPIH nationally issued a Newsletter and organised PPIFs to take part in a series of national reviews – Bugwatch, Foodwatch, Carewatch, Dentistrywatch.	Very little 'official' support to LINKs other than the LINKs Exchange web site.  NALM provides information and news to LINKs without any funding.

CHCs – PROs	CHCs – CONs
<ul style="list-style-type: none"> <li>• Most had shop-front premises.</li> <li>• Provided complaints advice/advocacy.</li> <li>• Overview of NHS in an area.</li> <li>• Clear budget and Chief Officer accountable for it.</li> <li>• Brilliant national support from ACHCEW.</li> <li>• Staff tended to stay and build up knowledge and expertise.</li> </ul>	<ul style="list-style-type: none"> <li>• Not social care.</li> <li>• No rights to visit primary care contractors.</li> <li>• Complaints work not part of statutory remit and very staff time intensive.</li> <li>• Not funded for complaints work.</li> <li>• Lot of staff time spent managing premises, supplies, budget, etc..</li> <li>• Few opportunities for interested members of the public to get actively involved.</li> <li>• No financial information to members and they had little budgetary control.</li> <li>• Some LA places not taken up or with little commitment to the CHC.</li> </ul>
PPIFs – PROs	PPIFs – CONs
<ul style="list-style-type: none"> <li>• Rights to visit primary care contractors.</li> <li>• CPPIH set up Knowledge management System to share good practice.</li> </ul>	<ul style="list-style-type: none"> <li>• CPPIH top-sliced a lot of funding for central and regional offices, army of highly-paid staff, etc.</li> <li>• Little practical support to PPIFs on the ground.</li> <li>• Fragmented structure made co-operation between PPIFs difficult.</li> <li>• Matched a Trust or PCT so very narrow focus with no overview.</li> <li>• Staff accountable to FSOs for every paper clip.</li> <li>• Staff had little independence or discretion in how to support PPIFs.</li> <li>• No advantages to PPIFs of FSOs being in voluntary sector as they operated PPIFs in silos.</li> <li>• No financial information to members and they had little budgetary control.</li> <li>• “Commissioners” invisible and ineffective.</li> </ul>

LINKs - PROs	LINKs - CONs
<ul style="list-style-type: none"> <li>• Overview of health and social care in an area.</li> <li>• Remit to engage with seldom heard groups.</li> <li>• More local people involved and opportunity to engage wide range of people and organisations.</li> <li>• Members have some budgetary control.</li> <li>• Some Hosts in voluntary sector using their networks to assist LINKs to engage with community organisations.</li> </ul>	<ul style="list-style-type: none"> <li>• Funding arrangements mean risk of LA or Host keeping back some LINK funding for their own use.</li> <li>• Some Hosts constrain LINK activities.</li> </ul>