



*The national voice for LINks'
members*



Increasing Local Democratic Legitimacy in Health

**Consultation response on the future of LINks
and the Development of HealthWatch**

A NALM Report
September 2010

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



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THE AIMS OF NALM

The aims of NALM are to:

1. Provide a national voice for LINKs' members.

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

3. Promote the capacity and effectiveness of LINks' members to monitor and influence services at a local, regional and national level and to give people a genuine voice in their health and social care services.

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

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

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

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

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Introduction

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. In each case there have been great concerns about opportunities for communities to influence access to ... and the quality of, services. The effectiveness and performance of each PPI systems has been highly variable.

NALM welcomes HealthWatch at a local and national level. We believe this development could substantially increase the power and influence of local people, enable communities across the country to monitor services more effectively, provide a voice that will be heard 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 is intended to 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 on 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 NALM Conference on July 8th 2010 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. But this requires current legislation to be modified so that relevant government Departments, statutory bodies, Local Authorities and providers and commissioners of health and social care have a duty to involve HealthWatch in decision making, commissioning and service development.

To be successful, the new system must be widely advertised and a duty placed 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.

Key Recommendations to the Government on HealthWatch

Location in the CQC

- 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.

Holding regulators, providers and commissioners to account

- 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.

Guarantor of rights and independence

- National HealthWatch should be the guarantor of the rights, duties and independence of local HealthWatch.

Local of statutory duties

- 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.

Accountability of HealthWatch

- 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.

Expert advice for local HealthWatch

- National HealthWatch must promote and share good practice, be a source of responsive and expert advice.

Sources of good practice

- An information system of successful HealthWatch work should be maintained by the National HealthWatch, to show what can be achieved. It should also hold the PPI specialist library and have access to DH and other department libraries.

Legal and policy advice

- 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.

Governance advice

- National HealthWatch must provide draft governance documents and guidelines to Local HealthWatch for local modification.

Independence from Local Authorities

- Local HealthWatch should be fully independent of Local Authorities and must not be accountable to any body that it monitors.

Ring-fenced funding

- Local HealthWatch must have centrally provided ring-fenced funding. They are unlikely to survive without secure funding.

Powers to enter and view

- 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 and in the interests of patient and service users;

Publicising the role of HealthWatch

- There should be a statutory duty for all health and social care commissioners and providers to advertise Local HealthWatch. 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.

Statutory power to refer commissioning decisions

- 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.

Calling providers and commissioners to account

- 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.

Focus on outcomes

- Local and National HealthWatch should ensure that their work is outcome focussed and their achievements well publicised to the public, local and national government.

LINKs involvement in transition

- LINK Members must be actively involved in all aspects of the transition to HealthWatch.

1. Developing HealthWatch – Local Perspective

Training of HealthWatch members and staff

- 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 LINks members and staff require to operate effectively and training should be certificated.

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

- In collaboration with directors of public health, HealthWatch should take a lead in preventative health campaigns in relation to both health and social care.
- As a component of their work with Health and Wellbeing Boards, HealthWatch should monitor local health policies for evidence that social care implication have been considered.
- HealthWatch must have a major role in the development of commissioning arrangements, both in relation to PCT, GP/practice based commissioning and specialist regional and national commissioning. Each commission board and committee should have 50% representation from HealthWatch members as participant observers.
- HealthWatch 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

- HealthWatch should be centrally funded through National HealthWatch, and resources must be ring-fenced.
- Funding through Local Authorities has **not** been successful in many parts of the country and should be abandoned. There are major conflicts of interest as Local Authorities provide and commission services that will be monitored by HealthWatch.
- Where HealthWatch and Hosts agree that the relationship has successful, support from the Host should continue. Where the relationship has not worked, HealthWatch should have the option of choosing its own staff or hosts.

- HealthWatch must not be accountable to Local Authorities for the reasons given in bullet two.
- HealthWatch should become legal entities in their own right, able to employ staff and fund projects.
- All local resources for patient and public involvement should be centralised in the HealthWatch budget, so that HealthWatch can support, initiate and carry out community research, community development and outreach work.
- HealthWatch must be completely independent of government, government quangos and other bodies that provide and commission services
- Mentoring arrangements should be developed to support poorly performing LINks to assist them transformation into HealthWatch.
- National HealthWatch should provide model governance documents that local HealthWatch can adapt to their local circumstances.

Advocacy for complainants

- ICAS (Independent Complaints Advocacy Services) should be fully integrated into HealthWatch in every part of the country.
- Feedback from complaints following investigations is essential data for HealthWatch. This should include all recommendations made following complaints investigations by health and social care agencies and evidence of enduring improvements following implementation of recommendations.
- Initially the Independent Complaints Advocacy Service (ICAS) could be located within National HealthWatch and gradually develop capacity in HealthWatch for a local complaints advocacy service.

How should LINks build and promote diversity and inclusion?

- HealthWatch should work consistently and strategically with all communities, and ensure that they have the opportunity through the HealthWatch to influence health and social care in their area.
- Where specific groups or communities have a low level of participation in service development, proactive outreach work will be essential for HealthWatch
- HealthWatch should be supported to develop of culturally sensitive services and the most effective methods of promoting diversity and inclusion.

2. What's in a name ... HealthWatch or CareWatch?

- Agreement must be reached on whether the new system is best called CareWatch to reflect the major role in social care activities. The focus on social care is always minimal in discussions about the role of HealthWatch.

3. Developing National HealthWatch

Influence on health and social care

- HealthWatch must not be part of the CQC because this would create a major conflict of interests and increase the risk of future major disasters of the type that occurred at the Mid Staffordshire Foundation Trust. In view of the government's plan to abolish overview and scrutiny committees the full independence of HealthWatch is essential.
- National HealthWatch must be wholly independent and seen to be so. This would help 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 national policy debates, e.g. about personalisation and care pathways, and ensuring the local views have impact on the national agenda must be a very high priority for HealthWatch.
- The Board of HealthWatch must be elected from local HealthWatch.
- For National HealthWatch to be credible, NALM must have a major role in its development and fully funded for this task. NALM, National Voices and ICAS are critical partners in this development.
- National HealthWatch must have an intelligence gathering role and should identify and promulgate best practice from and to local HealthWatch. National HealthWatch should be a source of best practice in involvement and consultation practice and strategy.
- HealthWatch nationally must hold the NHS and arms length bodies, e.g. the Care Quality Commission (CQC) and the National Commissioning Board to account.
- National HealthWatch must give advice to local HW on public involvement and influence deficit issue, relation people living in rural areas, specific cultural groups and communities and in relation to the six equality strands in the Equalities Act.

National HealthWatch 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 HealthWatch.
- Working with MPs to brief them on key issues about the role of HealthWatch and policies issues raised by HealthWatch.
- Briefing Ministers and opposition leads on health and social care issues generated by HealthWatch locally and nationally.
- Providing evidence to the Health Select Committees and other select committees.
- Working with the parliamentary All Party Group on Patient and Public Involvement.
- Establishing of regional HealthWatch based on needs of local bodies.
- Working with the Department of Health and Local Government Association to develop effective scrutiny of local government health and social care services.

Specific roles of National HealthWatch

- Receiving and disseminating information to and from local HealthWatch.
- Inform, advise and advocate at a national level for local HealthWatch on national health and social care issues.
- Be a source of specialist advice, expertise and support for local HealthWatch.
- Develop accredited training for HealthWatch members to a national standard.
- Provide legal advice and support when issues arise about involvement and consultation procedures and access to treatment.
- Develop research capacity at national and regional level in relation to public involvement issues.
- Policy development work in relation to issues raised by local HealthWatch and the wider public.
- Collation and assessment of Annual Reports.
- Acting as a source of advice and conciliation for local disputes including conflict resolution with local HealthWatch and Local Authorities.
- Providing indemnity for HealthWatch members.

Organisation form of National HealthWatch

- Run by a nationally elected council of HealthWatch members to ensure that local voices are heard at a regional and national level and that the National HealthWatch is directed by HealthWatch.
- Constitution agreed by the members of HealthWatch
- Development of a Service Handbook to ensure that HealthWatch know exactly what they can expect from the national body.
- Statutory powers to be created through the bodies National HealthWatch monitors and held to account, e.g. the legislation would require the CQC and National Commissioning Board to consult with, respond to issues raised and be held to account by National HealthWatch.

4. Developing the capacity to monitor social care

- Training packages and skills audits to build the capacity of HealthWatch to monitor social care, must be developed. Training should include 'knowledge' of safeguarding, the assessment process and how resources are allocated, equality, inclusion and diversity.
- HealthWatch recruitment should include a strong focus on people with social care knowledge or experience
- Local Authorities be required to identify on their website and in their literature social care officers responsible for service quality, recording accidents, incidents and risks.
- HealthWatch 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.
- Private agencies/companies providing social care services should be required to share information about standards of care and risk management with HealthWatch.
- Building relationships with Experts by Experience will create enormous shared capacity in the monitoring of care homes.

Working with carers and relatives

- HealthWatch will 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.

Monitoring care homes

- HealthWatch 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.

HealthWatch 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 HealthWatch through website and bulletins.
- Developing a research strategy to build HealthWatch 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 HealthWatch has a good knowledge of local cultures which it obtains first hand.

5. Transformation Board

- A Transformation Board is being established by NALM to influence the development of local and national HealthWatch.
- A key aim of the Board is 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 document produced by the Board shall be placed in the public arena.
- Accountability of the Board shall be agreed by its members at its first meeting.

Transformation Board objectives and Terms of Reference

Terms of reference

- 1) To consider key objectives for the establishment of effective HealthWatch and to make recommendations.
- 2) To make recommendations and advise Ministers, parliamentary committees, parliamentarians and key DH policy makers on key issues in relation to the development of HealthWatch.
- 3) To propose how the public's voice, including LINk and voluntary sector members, can have a major influence on the development of HealthWatch.
- 4) To receive evidence from key players with front- line and policy experience of effective PPI in health and social care on the development of HealthWatch.

Objectives

Governance

1. To consider the governance, accountability and transparency arrangements for Local HealthWatch and National HealthWatch including elections to the board of National HealthWatch.
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Independence

2. To consider arrangements and guarantees for the independence of National HealthWatch and Local HealthWatch.
 3. To consider potential conflicts of interest in relation to the funding and accountability arrangements for HealthWatch.
-

Powers of Local HealthWatch and National HealthWatch

4. To consider what additional statutory powers will be required by Local HealthWatch to increase its effectiveness.
 5. To consider what statutory powers will be required by National HealthWatch.
-

Commissioning, funding and staffing of LHW

6. To consider the most effective arrangements for the funding of Local HealthWatch.
 7. To consider arrangements for the employment of Local HealthWatch support staff.
-

Inclusion and diversity

8. To consider arrangements for the supply of information about the activities of HealthWatch to communities and individual.
 9. To consider the arrangements to ensure that HealthWatch has a proactive duty of inclusion of all communities in relation to activities and membership.
-

Mechanisms of Influence

10. To consider arrangement for Local HealthWatch to be involved in and to influence to the commissioning of services at local, regional and national levels.
 11. To consider arrangements for National HealthWatch to raise issue of public concern and on behalf of Local HealthWatch with national health and social care bodies and their regulators
 12. To consider circumstances in which National HealthWatch would raise issues on behalf of Local HealthWatch with Ministers and parliamentary committees.
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13. To consider the building of relationships between NALM and National HealthWatch/Local HealthWatch.
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ICAS

14. To consider arrangement for the integration of HealthWatch with ICAS (health advocacy).
15. To consider access arrangement and publicity to Local HealthWatch/ICAS
-

National HealthWatch support for Local HealthWatch

16. To consider how the effectiveness of Local HealthWatch might be enhanced and supported through NationalHealthWatch.
17. To consider how National HealthWatch should support Locla HealthWatch in respect of its independence and the fulfilment of its duties.
18. To consider support arrangements by National HealthWatch for a poorly performing Local HealthWatch.
19. To consider arrangements for providing arbitration in case of disputes in or between Local HealthWatch or their members.

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 agreement of LINKs and voluntary sector bodies. The period of consultation would be no more than three months.
- The Board will attempt to communicate a vision of the role of HealthWatch and HealthWatch to the widest possible health and social care community and the wider public.
- The final Board report will be submitted to Health Ministers and to a Conference for LINK and voluntary sector members.

HealthWatch will need:

- **Greater powers and more clout, e.g. a veto over local decisions in the health and social care economy, to ensure public involvement in all major local decisions.**
- **Advice and support is needed to ensure successful engagement with diverse communities.**
- **Community development work be promoted to enhance the effectiveness of HealthWatch 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 HealthWatch (e.g. large rural counties and smaller urban unitary authorities).**

APPENDIX ONE

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 will 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 will 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 to access and to 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 – as described in Chapter 4. To reinforce local accountability, Local Authorities will be responsible for ensuring that Local HealthWatch is 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.

APPENDIX TWO

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.

APPENDIX THREE

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.”

APPENDIX FOUR

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 in 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.

APPENDIX FIVE

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 LA, 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
Establishing Body	RHA/RO/HA	CPPIH	LA
Funding	DH regional allocations	DH allocation to CPPIH	LA area based grant
Support Staff	Employed by NHS	Employed by FSO or by default directly by CPPIH.	Employed by Host
Premises	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
Membership	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.
Main Functions	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.

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

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