The Health Committee's Report on Patient and Public Involvement in the NHS

Government Response to the Health Committee's Report on Patient and Public Involvement in the NHS

Presented to Parliament
by the Minister of State for Health Services
By Command of Her Majesty
June 2007

Cm 7128 £5.00

Contents

Introduction

1. The House of Commons Health Select Committee (the Committee) published its report on Patient and Public Involvement (PPI) in the NHS on 20 April 2007. The principal areas covered by the report were patient forums, the Commission for Patient and Public Involvement in Health (CPPIH), the proposed Local Involvement Networks (LINks) and Section 11 of the Health and Social Care Act 2001 – the duty on the NHS to involve and consult patients and the public. This Command Paper sets out the Government's response to the recommendations in that report.

2. The Government welcomes the Committee's report which makes a number of important and constructive recommendations.

3. Our aim is for user and public involvement to be a mainstream activity, one which health and social care commissioners, providers and regulators perceive as a powerful means by which services will be improved to meet the needs of local people.

4. A change in the mechanisms for patient and public involvement has been made necessary by the significant changes that are taking place in the nature of health and social care system, including the greater choice of service delivery and the increase in joint commissioning across health and social care. It is no longer appropriate to have a system which is based around the scrutiny of individual institutions. We wish this new system to be able to consider both health and social care, so that arrangements to promote and amplify the voice of users and the public can be joined up across the entire service user journey.

5. We wish to build on the good work of patient forums. We acknowledge that people who have been actively involved in patient forums, have worked very hard to further the cause of PPI. We believe that the experience developed by forum members, as well as the good working relationships that many have established with the health service, will be essential to the success of LINks.

6. We are also keen for other voluntary and community groups as well as individuals with experience of different methods of engagement to participate in LINks, bringing expertise from other areas. There is a wealth of established user engagement within the social care field, particularly in the area of independent living, and we believe that service users and carers will be eager to share their experience and skills within LINks.

7. We know that more people want to have a greater say about their local services – but in ways that suit them. LINks will give real opportunities to those who are willing to dedicate their time as well as those who want to dip in and out of involvement, enabling genuine involvement of a far greater number of people than is currently available.

The Government's response to the Health Select Committee's

Conclusions and Recommendations

Recommendation 1 (Paragraph 32)

Patient and public involvement in the health service happens in many different ways, of which patient and public involvement structures such as PPIfs are only one. There is an important distinction to be made between the involvement of patients and of the public which have tended to be confused. We agree with Harry Cayton's distinction (see para 10) between patient and public involvement. Current or recent NHS patients are likely to bring different perspectives to bear from those held by the general public. All these distinctions should be taken into account.

The Department agrees with the Committee that patient and public involvement (PPI) is not a single, simple concept. It delivers a number of objectives and for this reason, activities to support effective PPI should be designed and delivered in ways that are fit for purpose. For example, mechanisms to seek the views of patients on a particular service should be different to those seeking the views of the public about priorities and service reconfiguration. It is in this context that the Government has moved away from a single 'one size fits all' PPI system, to a comprehensive range of structures and mechanisms[1] to strengthen the ways by which patients, the public and their representatives can influence the services that they use and for which they pay.

We also agree with the Committee in recognising that although the focus is often on the institutions dedicated to securing and promoting PPI, in reality patients and the public are involved in decisions about health and healthcare in many other ways. One of the key aims of the recent review of PPI was to try to address this point. We acknowledge that the creation of a truly patient-led NHS, centred around the needs of both individuals and communities cannot be achieved without a constant commitment to ensuring that people have opportunities to influence services in ways that are relevant and meaningful to them and in ways which will make a difference to services. This message is also clearly reflected in the *Commissioning Framework for Health and Wellbeing*[2] which places individual and community engagement at the centre of the commissioning decision making process.

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[1] As set out in the supplementary evidence submitted to the Committee in March 2007 (PPI 01F in Volume III of the Committee's report)

[2] Published by Department of Health, 6th March 2007

Recommendation 2 (Paragraph 33)

The purpose of public involvement is also often confused and conflated. Two main purposes need to be distinguished: improving the design and provision of services and increasing accountability. In a publicly funded service, patients and the public are in a sense the NHS's shareholders as well as customers and their views on larger decisions about spending priorities and service design must also be taken into account.

As we stated in our evidence to the Committee, we believe that the ultimate purpose of user and public involvement is the delivery of improved services, which better meet the needs and wants of service users. Patients, carers and users of services are experts in the care they both need and want, their input is therefore essential to create the user led health and social care system people want, and towards which this Government is driving.

We also feel that it is essential to involve users, as well as the groups that represent them, in the commissioning decisions that are taken, to ensure they have an input into what services are provided in their locality. This involvement in needs assessment, in prioritisation, and decision-making will create and support local ownership of the NHS, delivering transparency and accountability for the multi-million pounds being spent at the local level.

Patient and user involvement also assists in the scrutiny of services through representing people's views, and allowing users a route to assuring the quality of the services they use.

We agree with the Committee that enhancing accountability for public spending is also important. As users and funders of the services, patients and the public should be able to directly influence the services provided for them.

Recommendation 3 (Paragraph 34)

Patient and public involvement should be part of every NHS organisation's core business. As patient choice becomes established this will become even more crucial to service provider organisations' success. However, a separate, independent, patient and public involvement mechanism provides an important back-up until patient and public involvement is better established within NHS organisations. Any independent patient and public involvement structure should attend to the differing needs and views of both NHS patients and the wider public.

We agree with the Committee, the health and social care system exists for the benefit of people who need care, now and in the future, so it is essential that we put the needs and preferences of patients, service users and citizens at the centre of all we do. We recognise, as does the Committee, that although there is evidence that patient and public involvement happens successfully in many areas, that this is not the case across the board. The development of a stronger local voice needs to be understood as part of the long-term programme of culture change and service transformation for health and social care which we are working towards, as it is a fundamental foundation of the health reform process.

Some argue that choice makes voice redundant. However, we believe the introduction of choice makes the public voice more, not less, important. As the Committee mentions, the health and social care market is still limited in opportunities for choice. Choice does not exist at the commissioning level, although practice based commissioning may introduce new opportunities. Choice therefore needs to be re-enforced by voice particularly for the vulnerable and for those who experience health inequalities. Voice also shapes and extends the choices on offer. This is particularly the case in community care, compared with the acute sector, and for people with disabilities and chronic illnesses, where there are fewer opportunities for service users to choose. Voice is also important in its own right as it allows citizens to have real influence over the services for which they have paid.

The Government is quite clear that although PPI must be embedded in everything that health and social care bodies do there remains a critical role for an independent patient/user led structure to guarantee a strong voice for local people. We believe the establishment of LINks will provide an independent PPI structure that will gather and amplify the differing needs and views of patients, users, carers and the wider public. What's more, LINks will strengthen the voice of local people in much more flexible ways, recognising that people want to express their views in ways that are meaningful and relevant to them.

Recommendation 4 (Paragraph 97)

Several witnesses argued that PPIfs should remain. They may have a small, unrepresentative membership, but this could be improved and, in any case, there was not a large number of people willing to do work of this type. Moreover, they could develop to take account of changing circumstances. The balance of evidence suggests that these witnesses may be right. Once again the Government has abolished an institution a few years after its establishment. We are concerned that the Government has taken insufficient account of the cost of change. Abolishing established structures and creating new and untested institutions has not proved successful in recent years.

We know from the feedback we received at the *Your health, your care, your say* deliberative events that more people want to have a greater say about their local services – but in ways that suit them. We want to be able to give real opportunities to those who are willing to dedicate their time as well as those who want to dip in and out of involvement.

LINKs are very different to forums. They have been designed to be able to adjust to changing circumstances. Forums are rather rigid structurally and highly prescribed in legislation. It would simply not have been possible to adjust the legislation to achieve our vision of a locally determined and flexible PPI system.

Not only do we believe that LINks will provide much more flexible arrangements for supporting 'stronger local voice', we are also clear that they will provide the opportunity for those not currently involved in PPI activity to participate as well as for those committed volunteers already in the PPI system. Additionally, unlike forums, LINks will enable the active involvement of many voluntary and community sector organisations to add their considerable influence to bear in improving services for the patients, users of care services and the public they represent.

There are not huge costs associated with this change; they will all be contained within the current budget. However, we recognise that change is unsettling, which is why we are so keen that LINks are flexible bodies that will be able to adapt to changing circumstances both locally and nationally more easily than PPI forums. The prescriptive nature of the PPI forum legislation has meant we needed to start again. However, we see this as an evolutionary step, building on the best of PPI forums and wider involvement activities. We acknowledge that those people that have been actively involved in PPI forums have worked very hard to further the cause of PPI and in doing so, have improved local health services. We are sure that LINks can really build on this experience by drawing in a much wider range of people in ways that are meaningful to them.

Recommendation 5 (Paragraph 111)

We welcome the 'early adopter' projects, but we are concerned that they are taking place after the Bill has been published which means that LINks cannot be evidence based. We are also concerned that the Department is drawing up guidance before 'early adopter' projects have been evaluated.

As Meredith Vivian, Head of Responsiveness and Accountability at the Department of Health stated in his evidence to the Committee, the early adopter projects are not pilot sites. Their aim is to provide LINks and those organisations responsible for establishing, supporting or working alongside them with information, advice and guidance on how to maximise the effectiveness of LINks and relationships with them.

The learning and evidence towards the project objectives is being collected and disseminated on an ongoing basis as the project progresses. A comprehensive evaluation framework and research strategy is in place, which is being developed by researchers from the NHS Centre for Involvement (NCI) and the Office for Public Management (OPM). This learning and evidence will be available on the NCI website and will be available through the DH website as well as being disseminated via existing networks and bulletins. More detailed information such as project group notes, monthly update reports against objectives, flyers and so on are available via the CPPIH website as a reference for other early adopter sites as well as wider interested stakeholders.

The Healthcare Commission lead for their two test sites has produced an early learning report based on their experience over the last twelve months. This report details key learning points for the other early adopter projects and LINks in general.

All Department of Health guidance currently under development for LINks is being directly informed by the experience and feedback of the early adopter projects. A number of sites have established dedicated sub-groups to consider products currently under construction such as the model contract specification for local authorities to use when contracting with host organisations for LINks and participating in specific workshop sessions held by the Department to feed their views directly to officials.

Recommendation 6 (Paragraph 112)

The 'early adopter' projects appear less an objective trial than a discussion with stakeholders, and a key point – what can be expected from Hosts – is not being addressed. We recommend that there should be full trials of LINks to assess practical requirements for running them.

As stated above, the early adopter projects are not pilot sites nor are they meant to be full-scale trials. Each project has been given significant freedom to work with local partners in the most appropriate way to look at the issues for LINks. Some of the projects are looking to establish and test shadow LINk arrangements, whereas some of the projects are taking a specific health or social care issue and examining it from a LINk perspective to gain a better understanding of how the LINk approach may work and what may be involved.

One of the key objectives of the early adopter projects, set out in point four of the project objectives, as part of the supplementary evidence submitted to the Committee in March, is to evaluate:

(a) what activities the 'host' must undertake to bring about the creation of LINks, e.g promotion of opportunities, where best to advertise, what messages work and don't work etc;

(b) the nature of staffing support necessary for LINk effectiveness, eg. Administrative resources, community development, analytical and facilitation skills etc; and

(c) physical facilities including premises, equipment and their cost etc.

We feel that these objectives will address what can be expected from host organisations. We do not feel it is necessary, nor desirable, to run full trials of LINks. We know that a network model can work, indeed as many PPI forum members who gave evidence to the Committee stated, many of them already work in a networked way. We want to build on the best work of PPI forums, bringing together the vast array of wider involvement activities and experience of voluntary sector organisations to strengthen and widen the way that people's views are gathered and fed into the commissioning, planning and development of health and social care services. The learning gathered from the early adopter projects will be used to inform the implementation process for LINks.

Recommendation 7 (Paragraph 113)

There is no fixed budget for each 'early adopter'. At Medway money is being supplied as it is needed. This is symptomatic of the Department's failure to focus on what LINks will realistically be able to accomplish with the resources available to them. We recommend that the 'early adopters' should be given the same budget LINks will have once they start so that it is possible to establish what can be achieved with the money that will be available.

As previously stated, the early adopter projects are not pilot sites nor are they meant to be full-scale trials. It would therefore not be appropriate to give the projects the same budgets as LINks will receive.

Another one of the key objectives of the early adopter projects, set out in point seven of the project objectives as part of the supplementary evidence submitted to the Committee in March, is to evaluate levels of resourcing, both financial and staffing, necessary to support effective LINks. The evidence and learning on the amount of resources required to fulfil the potential role and functions of LINks, is emerging through the project on an ongoing basis.

One of the key aspects of the Healthcare Commission's early learning report, based on their experience over the last twelve months in their two test site areas, focuses on capacity and resources. The report sets out a number of useful learning points for LINks, and on the issue of funding it states:

> 'the test site work is already beginning to demonstrate that for relatively modest investments, the community and voluntary sector can facilitate good links out into local communities that can add real value to the Healthcare Commission's assessment and regulation processes. The issues, challenges and resources required to take forward these focused activities over the forthcoming year, will provide important intelligence for the Healthcare Commission as it prepares to work with LINks in 2008 and will provide a baseline for planning the time and resources required for successful engagement, particularly around the Annual Health Check process.
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> Traditionally resources are allocated centrally and, within the context of the health service, PPI tends to be considered as a function that needs to be "administered". The test site community development approach has moved away from this model and is exploring different ways of allocating resources, including the use of a more "enabling budget" provided to the local community, so that engagement activities are negotiated or brokered in partnership with local people who in turn, are seen as genuine assets that can be tapped into.'

We recognise that it is, of course, important to be realistic about what can be achieved with the level of funds available. The experience gathered by the Healthcare Commission has shown that those involved in these activities need to address what they can achieve with the available resources at the earliest stage.

Recommendation 8 (Paragraph 150)

There are serious concerns about both of the models for LINks. It is feared that under the 'PPIf Plus' model, the existing weaknesses of PPIfs would remain. We found some of the arguments for the 'network' model vague and woolly. This model would lack the means to hold the NHS to account, might duplicate existing networks and tend to give greater weight to existing pressure groups rather than those who are not organised such as healthy working people.

The committee is right that the LINks model has developed over the last year. This model has been informed by the comprehensive range of ideas, recommendations and experiences expressed to us since the publication of *A stronger local voice*, in July 2006. We believe that the provisions underpinning LINks currently before Parliament in the Local Government and Public Involvement in Health Bill do indeed build on the original recommendations of the Expert Panel and in doing so we feel confident that the lessons learnt from PPI forum activity can really inform the process of establishing LINks.

The major differences between forums and LINks remain. LINks are flexible, their structure and ways of working are entirely open to the determination of local people. LINks will cover social care as well as health and will be networks of individuals as well as user groups and those from the voluntary and community sector – engaging groups that represent every sector of the community, and have experience of involving all different types of people. And, perhaps most importantly, LINks will be able to adjust over time to suit the changing nature of health and social care.

LINks are about bringing individuals, user-led groups and voluntary and community sector organisations together, it is not about duplicating effort – we believe that by coming together, they will be able to create a wider evidence base of views and experience and add more legitimacy in influencing those who commission, provide, regulate and scrutinise health and social care services.

LINks will have the means to hold health and social care organisations to account through the powers they will have to:

- make reports and recommendations and receive a response within a specified timescale;
- request information and receive a response within a specified timescale;
- refer matters to both health and social care Overview and Scrutiny Committees and receive a response within a specified timescale; and
- enter and view health and social care facilities.

The aim of LINks is to create a means for far greater numbers of people to express their views and influence local services. There are many people who do not currently have the opportunity to have their say. As the Committee itself illustrated, healthy working people also want to have a say – but in ways that suit them. So rather than having to commit to joining a committee, or becoming a member of a body, they should, for example, be able to log onto a website to express their views, or perhaps attend a meeting on a specific area of interest, such as maternity services.

Recommendation 9 (Paragraph 151)

The Department's present view of LINks may produce not the best of both models but the worst. There are so many things LINks could do. There is a danger that LINks will attempt to take on far too much and undertake work which is best done by others. We are concerned that

LINks will duplicate the work of foundation trust Boards of Governors if they focus on service delivery. There is a great deal of high quality information relating to the health service and public attitudes to it. There is a risk that LINks will waste time duplicating this research. There is also a risk that LINks will spend time and money undertaking detailed research that should be the responsibility of the NHS and social care commissioners.

We agree with the Committee that these are risks which will need to be managed. This is something we will seek to flag up in guidance. When setting their priorities and work programme, LINks will need to consider carefully where they can add most value. We will advise LINks that they should use existing information, wherever possible, and identify areas where they can make a real difference to services rather than attempting to do too much.

LINks will be networks of individuals and organisations and are about bringing together work rather than duplicating it. It is likely that members of Foundation Trusts may wish to join LINks or contribute to LINk research, and it is equally likely that trusts themselves will see the benefit of developing relationships with LINks as a means of gathering additional information, to be used to inform the development of services.

We are clear that LINks are not there to carry out commissioner's responsibilities for them; they are independent bodies who will set their own agendas. This issue is dealt with more fully in the response to recommendation 15.

Recommendation 10 (Paragraph 152)

The lack of clarity about LINks role and structure is likely to create confusion and inactivity. This may mean that LINks will have difficulty deciding what they are going to do and how to do it and as a result lose the interest of volunteers. This would be particularly unfortunate at a time when significant change is occurring in the NHS and social care services.

We will ensure the guidance for LINks is clear about the outcomes we think LINks should achieve, rather than specifying how they achieve those outcomes. We firmly believe this should be for LINks to decide locally – a LINk in a sparsely populated rural area will want to work quite differently from a LINk in a built up urban area. We intend to provide models of best practice for LINks to follow on key areas such as governance structures; these will be informed by the experience of the early adopter projects as well as similar networks already established in other fields, such as Community Empowerment Networks.

Recommendation 11 (Paragraph 168)

The Minister told us that the abolition of CPPIH would result in one third more money for 'front line' spending by LINks. However, we note that much of the money will be used to replace functions currently carried out on behalf of forums by CPPIH. She also argued that there would be significant economies of scale under the new LINks arrangements, but we are not convinced this is so.

We believe that by removing a national bureaucracy we can ensure that far more funds are made available at the local level in support of a stronger voice for patients, service users and the public. For example, the cost of employing a member of CPPIH staff to assist in recruiting members to patients forums could be better spent by employing someone at the local level to facilitate a LINk's activities, including seeking members and wider public involvement.

It is our expectation that the same amount of funding will go to the new system as is currently spent on PPI, however, the £9m that is currently spent centrally by CPPIH will be distributed, along with the rest of the funds, directly to support LINks locally. LINks will of course still have administrative costs involved in undertaking their activities, however, spending money at the local level offers particular advantages, not least, that each LINk will have control of its own funds and be able to decide how best to spend them in support of their activity according to local need and circumstance.

The whole system change we are making means that the focus of expenditure should be where the action is – at the local level.

We want to stress that the CPPIH has supported forums well, and has by necessity put significant resources into performing its national centralised functions. However, we believe that the available funds will be much more effectively focused and spent through local arrangements, thus giving more targeted and relevant resources to local activity.

There will be economies of scale under the new arrangements, as there will be 150 LINks as opposed to 398 PPI forums. As a result of local authorities performing the procurement role, we will benefit from their existing infrastructure and experience rather than setting up a wholly new system as we did with CPPIH. The net effect of these changes will be more resources available per LINk area for support and engagement activity. We know from early discussions with local authorities, many of them are planning to work together in procuring host support across areas, although we cannot quantify what this will mean for the number of overall contracts at this stage.

Recommendations 12 and 13 (Paragraph 169 and 184)

PPIfs believe that there is not enough money to support them as their members think is necessary. LINks are being asked to carry out significantly more work. It is a matter of serious concern that the Department has not taken the budget LINks will have into account when deciding their remit and function. The Department will need to ensure that LINks' remit takes account of the available funding. Otherwise there is a risk, as CPPIH fears, that LINks are "being set up to fail because of the level of resources".

We welcome the Department's decision not to prescribe in detail how LINks should operate but a clear direction is required in relation to what LINks should do. This the Department has failed to give. LINks will have limited resources and will have to prioritise. Clarity about what LINks should be doing will reduce confusion, allow LINks to produce useful work faster and make it easier for Local Authorities and Hosts. The Department must issue guidance to clarify what LINks priorities should be. In its guidance the Department must also make it clear to LINks that they should avoid duplicating the work of other bodies.

All organisations need to prioritise their workload and LINks will be no different. The guidance we will be producing for LINks will make this clear. For example, the model contract specification looks to create a realistic set of essential elements that a host organisation will need to deliver and then a list of desirable elements that can be chosen to fit local circumstances and priorities.

The Local Government and Public Involvement in Health Bill sets out the activities of a LINk as follows:

- promoting, and supporting, the involvement of people in the commissioning, provision and scrutiny of local care services;
- enabling people to monitor, and review, the commissioning and provision of local care services;
- obtaining the views of people about their needs for, and their experiences of, local care services; and
- making reports and recommendations about how local care services might be improved, to persons responsible for commissioning, providing, managing or scrutinising local care services.

We believe it should be for the LINk to decide its own priorities within these parameters by focusing on areas of concern to local people and seeking to influence change in ways that can provide the most benefit, and by making the best use of the LINk's time and resources. This is also what many witnesses stated in their evidence to the Committee.

The guidance we will produce will build on the examples set out in the Government response to *A stronger local voice* published in December last year on how a LINk might go about setting their annual priorities and how they might consider a priority area. This guidance will also be informed by the experience of the early adopter sites.

We accept the Committee's recommendation that we must make it clear in guidance that LINks should avoid duplicating the work of other bodies, for example we recognise there is a lot of relevant information already available including surveys, complaints data, feedback from PALS, reports from the regulators and so on and LINks should use this where possible. Much of this information will already be held by health and social care commissioners which will also have data from many other sources upon which they can build their understanding of local needs and experiences. Once the LINk has decided its priorities, it could request relevant information on a particular topic from commissioners and consider this information in conjunction with relevant national policies, guidelines or frameworks both from Government and other bodies such as Royal Colleges or specialist voluntary sector organisations. The LINk could then use this information to inform research into the experience of service users and carers through a variety of methods, including using their power to enter and view premises, online forums, questionnaires, going out into the community to talk to relevant groups and so on and report back to the relevant providers and commissioners.

The key issue is that LINks have the flexibility to use their resources and develop their activities in ways that suit them, and to meet the needs of local people. Of course resources are finite but the model being developed will mean that LINks can adapt their ways of working to match those resources.

Recommendation 14 (Paragraph 185)

The Committee supports the Department's aim of increasing patient and public involvement in commissioning decisions. However, if volunteers are given a free choice they are unlikely to make commissioning a priority as they prefer to concentrate on the quality of the services which NHS bodies provide. This would duplicate the work of foundation trust Boards of Governors. If the Department wishes LINks to focus on commissioning it must indicate how it expects this to happen and what steps it proposes to take to make it happen.

We do think that commissioning is a key area of focus for LINks. By getting involved in the commissioning cycle,[3] from needs assessment, reviewing service provision, through to deciding priorities, designing services and influencing performance management of providers, LINks can have maximum impact on future service provision as well as how services are provided now. We believe LINks have a real opportunity to create more locally responsive services by engaging with commissioners, and they will be ideally placed being based at the local authority level, especially now that the majority of PCTs are coterminous. We will be suggesting this in guidance and will be encouraging LINks to form early relationships with health and social care commissioners, rather than compelling them to look at this – it will be for LINks to decide their focus locally. We will also continue to encourage commissioners to engage with LINks once established, highlighting the key role LINks can play in helping commissioners use people's knowledge and experience to improve the services they use.

With a shift towards stronger commissioning activity and a multiplicity of providers (supported through patient choice mechanisms) it will become even more important that LINks work closely with PCTs in order to most effectively influence the way in which services are provided locally to meet the needs of the community. LINks may also draw in people who have a different view or focus on how health services are provided, and as such may prefer to look at the overall access to, and provision of services through commissioning rather than focussing on the provider side. This will become increasingly apparent as the types of providers, including the third sector and private enterprise, develop.

There is clearly a role for LINks in looking at service provision as well as commissioning – indeed; considering provision forms a key part of the commissioning cycle. LINks will be a network of individuals and organisations and are about bringing together work rather than duplicating it.

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[3] As set out in *Health Reform in England: Update and Commissioning Framework* published by the Department of Health alongside *A stronger local voice* in July 2006

It is likely that members of Foundation Trusts may wish to join LINks or contribute to LINk research, and it is equally likely that trusts themselves will see the benefit of developing relationships with LINks as a way of gathering information, additional to their own, to be used to inform the development of services.

Recommendation 15 (Paragraph 186)

We recommend that each LINk discuss with its local NHS bodies and social care commissioners its priorities. The Department should issue guidance to clarify what the respective roles of LINks, the NHS and social care commissioners should be. We further recommend that the guidance indicate that LINks should be aware of the cost and difficulties of some of the tasks they might seek to undertake, such as reaching out to 'unheard groups' (eg. healthy working people, non-English speakers, homeless people), undertaking research and compiling scientifically rigorous data. LINks should be encouraged to ask NHS bodies and social care commissioners to carry out such work and to hold them to account for doing it. A large amount of data is already collected on a range of views. The Host should be responsible for making LINks aware of the existence of this data and helping them make use of it.

We agree with the Committee that LINks should discuss their priorities with local NHS and social care bodies. The guidance which we will produce for LINks will indeed address key relationships that a LINk will need to form. This will include the respective roles and responsibilities of LINks in relation to health and social care commissioners.

We are clear that LINks are not there to carry out commissioners' responsibilities for them; LINks are independent bodies which will set their own agenda. LINks will however, be able to play a key role in helping commissioners access people's knowledge and experience to improve the services they use. As the Committee suggests this can be done by scrutinising the research and data commissioners have collated and the engagement activity commissioners have carried out and making suggestions in the development of for example, needs assessment or priority setting.

LINks will be able to compare the commissioner's information with what they know about local people's needs and experiences from their own engagement activity and assessment of services. LINks will also be able to carry out additional work commissioned and funded by local health and social care organisations interested in finding out about particular issues from the perspective of local people. In essence LINks will be able to act as a check and balance on the activities of local commissioners.

Guidance for LINks will also address issues such as how to reach out to 'unheard groups' and undertaking research with examples of best practice and approaches they might like to take. This guidance will build on the work of forums, as well as many other examples of community development and citizen engagement already available.

Recommendation 16 (Paragraph 196)

We hope that the Department is correct and that LINks will successfully attract many new members. However, we are concerned that while there may be large numbers of people who will become involved in some campaigns related to the health service, such as hospital closures, few are prepared to make a major commitment to patient and public involvement. Many of these people are members of PPIfs. The Department should take steps to ensure that in this period of uncertainty they do not cease to be involved in patient and public involvement.

We acknowledge that those people that have been actively involved in PPI forums have worked very hard to further the cause of PPI and in doing so, have improved local health services. We also recognise that there has been a period of uncertainty and this has been unsettling for members. We would like to reiterate our commitment to PPI and to maintaining the involvement of PPI forum members, whose experience and expertise will be crucial to the success of LINks.

We are sure that LINks will provide a strong and vibrant means by which PPI forum members will be able both to contribute and have real impact and influence over services. The important issue is that LINks also provide a platform from which many other people can voice their views, needs and experiences on health and social care issues.

We are working closely with the Commission for Patient and Public Involvement in Health to ensure that PPI forum members who wish to get involved in the new arrangements have the opportunity to do so, for example in the early adopter sites, PPI forum members are central to testing out how LINks will work in future. We are also making it clear to local authorities that they should seek to involve local people, especially those already involved in user involvement in health and social care such as PPI forum members, in the tendering process to appoint a host organisation locally.

The Committee rightly suggests that whilst there are many more people who would like to have their say, they are not necessarily willing or able to make a major contribution. This is the very essence of LINks. We want people to have the opportunity to voice their ideas and issues without being put off by having to be a member of an organisation. LINks provide opportunities for highly committed volunteers, such as existing forum members as well as a means by which everyone can get involved in ways and at times that suit them.

Recommendation 17 (Paragraph 202)

It is vital that LINks have the same right of entry to places where NHS care is carried out as PPIfs have at present. There must be no diminution of the powers of PPIfs. LINks should not have to write to the regulator and wait for a reply. Ideally, LINks should have the same rights in relation to social care premises with due regard for the needs and wishes of the residents.

The Local Government and Public Involvement in Health Bill currently states that the Secretary of State shall make regulations for the purpose of imposing a duty, on service-providers (defined as an NHS trust, Foundation trust, PCT, local authority or a person prescribed in regulations), to allow authorised representatives of LINks to enter and view specified health and social care premises. The clause specifies the matters that may be addressed by the regulations. The regulations will set out the details of the LINk powers to enter and view facilities and will provide the conditions and limitations that will apply. As we have stated previously, we intend to publish draft regulations for consultation before laying them in Parliament, seeking the views of all stakeholders on this issue.

LINks' power to enter and view premises carries with it an administrative burden on service providers. Consequently, in line with the Government's overall policy to reduce the burden of inspection, there will be a need for LINks to use this power with discretion and in coordination with other inspection and regulation bodies. As part of the new 'gatekeeper' role currently being given to the main public sector regulators and inspectorates across Government, we intend to specify that LINks must write to the relevant regulator, indicating their intention to visit a facility. The regulator would then have a set time period in which to respond to the LINk if it chose and that the LINk would be required to comply with any advice received. Any advice would be to ensure that there is coordination of activity at a local level. It may be, for example, that the regulator is already aware of another visit, in which case it may ask the LINk to join in with that review. Alternatively, the regulator may be able to refer the LINk to relevant information already available from another source, which may address the LINk's specific issues without any need for further burdens on the front line service.

As Frances Hasler from the Commission for Social Care Inspection (CSCI) raised in her evidence to the Committee, rights of entry to social care premises are more complex than to NHS care. We do not believe that LINks should be able to enter all social care premises, for example, they should not have the power to enter social care services, establishments and agencies for children – including but not limited to children's homes and adoption and fostering services. There are already many mechanisms in place that deal with children separately, these include the new Ofsted, which now has a statutory duty to have regard to the views of users (including children) in conducting inspection and now includes the statutory post of the Children's Rights Director which has transferred from the Commission for Social Care Inspection. Children's trusts also seek the views of children in the development of the Children's and Young People's Plans which inform joint commissioning to create better outcomes and services for children. We also do not believe LINks should have the power to enter those facilities where there is a tenancy or licence agreement between the individual and the landlord and would be therefore classed as someone's home, unless of course invited to do so by the residents that live there.

There is also a major difference between the small membership of PPI forums and the potentially much larger and more fluid 'membership' of LINks. We do not believe that all those involved in LINks should undertake the visiting role. We are clear that those who are able to exercise the power need to:

- have received appropriate training;
- be cleared by the Criminal Records Bureau; and,
- be able to demonstrate an understanding of patient confidentiality and an appropriate level of sensitivity towards the role.

Recommendation 18 (Paragraph 208)

LINks must have a higher profile with the public than PPIfs. Advertising might be one way to achieve this; on the other hand, advertising could be a waste of LINks' limited budgets. We recommend that the National Centre for Involvement should prepare best practice guidance on advertising and publicity which LINks could request if they thought it helpful.

As stated in our supplementary evidence submitted to the Committee on 8 March, the NHS Centre for Involvement (NCI) will have a pivotal role in providing advice and guidance to local involvement networks. As such, we have asked the NCI to produce the LINks guidance which will be published post-Royal Assent of the Local Government and Public Involvement in Health Bill.

We agree with the Committee, that one of the key areas this guidance should cover is the preparation of communications tools, relating especially to raising the profile of LINks, including advertising, publicity and branding.

Recommendation 19 (Paragraph 212)

We agree with the Minister that if LINks have a large membership, not all members can be trained. However, it will be crucial that at least a core of people in each LINk is trained to ensure they have the skills to carry out their task. The provision of training centrally with an appropriate qualification for those who completed the course could be attractive to volunteers.

We agree with the Committee that it is important that a core of people in each LINk is trained, especially for example, for those who are to exercise the right of entry. We also agree that central training with an appropriate qualification could be attractive to volunteers. The NHS Centre for Involvement (NCI) is in the process of developing an accredited training course for those embarking on patient and public involvement work.

The NCI recognises that in order for patient and public involvement to be effective, there needs to be a comprehensive approach to the development and delivery of learning programmes and learner support. It is seeking to create robust learning and support for both the NHS workforce as well as service users and carers – recognising this as a key way to turn the policy rhetoric for involvement into practice in meaningful ways to embed patient and public involvement in organisational culture and practice.

The vision is to create an educational model which provides a pathway of learning and development for patient and public involvement as a profession. This will have progression routes (from NVQ to Post Graduate Education), flexible pathways for learning, be accredited and attract funding. Underpinning this framework will be the creation of core ‘principles’, guidance and curriculum creating clarity for staff, learners or public involved in learning as either providers or consumers.

Recommendation 20 (Paragraph 216)

We are concerned about social care providers acting as Hosts. It will be difficult for contracts with Hosts to be drawn up to avoid conflicts of interest. We were not satisfied with the Minister’s response to our questions on this issue. Unless the Department can provide a satisfactory way to avoid actual and perceived conflicts of interest, social care providers should not act as Hosts.

Many voluntary and community sector organisations do indeed provide health and social care services. However, this does not prevent them from also advocating on behalf of patients and users of health and social care services. We believe it is more than reasonable to expect potential host organisations to demonstrate that they are able to manage their existing responsibilities as well as take on the role of supporting a LINk.

The host will be accountable to the LINk and in its support function will be required to follow the LINks’ direction irrespective of what its own interests might be. The sort of organisations that we expect to become hosts are used to dealing with these kinds of issues all the time, as indeed are local authorities. The model contract specification currently being drafted, addresses this issue and will include a requirement for an organisation to demonstrate it can deliver the contract without any conflict of interest.

The second type of potential conflict of interest to be managed is a provider organisation which, with its user representation hat on, is a member of a LINk. This is the concern that Mr Silverman raised in his evidence to the Committee. Because LINk membership will be wide-ranging, it can accommodate special interests more readily than an organisation such as a PPI forum which has much more limited membership. LINks will be ‘broad-church’ and it will be for them to decide in forming their constitution how to tackle potential conflicts of interest. This type of issue is true of any statutory institution where interests must be declared in accordance with the standards in public life such as the Nolan principles. We will of course provide examples of best practice to support LINks in this respect.

Recommendation 21 (Paragraph 220)

Witnesses welcomed the fact that Local Authorities and Hosts will not control LINks. However we are concerned that the lines of accountability are confused. Were a LINk to be dysfunctional, the Host would be powerless to change it, and the Local Authority would only be able to hold the Host to account. The Department needs to clarify how LINks, as well as Hosts, are to be held to account.

A LINk must be accountable for its activities to the local community. We believe that to demonstrate that it is performing its role effectively; with probity and transparency, it should provide evidence that it is delivering a credible work programme, based on local priorities, that meets local needs. This will be achieved in part through the publication of the LINk's annual report. In addition, the contract between the host and local authority will require the host to report on the LINk's activities on matters including:

- the level and diversity of participation,
- the views and opinions received from contributors,
- the extent to which those views have been taken on board by commissioners and providers,
- how much money has the LINk received, and how was it spent.

LINks' governance arrangements, their constitutions and how they go about their activities will need to be open and transparent. It will be for the host of a LINk to ensure that arrangements are in place for the wider membership of LINks to be able to hold the 'Board' to account to local people and to representative organisations.

Recommendation 22 (Paragraph 229)

We welcome the Government's decision to allow LINks to set up their own national body. Unfortunately, this means that there will be no national body to support and guide LINks when they are first established. We also welcome the Government's decision as an interim measure to give this role and that of diffusing best practice to the National Centre for Involvement. The National Centre must not direct LINks but supply assistance and advice on request. We recommend that the Centre be provided with additional funds to allow it to undertake this task. We also recommend that a national website be set up to allow LINks to share best practice.

As stated in our supplementary evidence submitted on 8 March, the NHS Centre for Involvement (NCI) will have a pivotal role in providing advice and guidance to LINks. As a National Centre, one of its functions is to provide models of good practice and to share and highlight ways of working that are associated with effective involvement that makes an impact. The same can be said for the Centre's role in gathering learning and specialist expertise so that the existing evidence-base can form the basis for further development.

We are working with the NCI to consider how it can act as a repository for good practice and make available ideas and approaches for how LINks specifically can go about their work as effectively as possible. Whilst the Centre has agreed to support the emergence of LINks, through for example, their evaluation of the early adopter projects, within their existing budget in the short term, we are in discussions with it to consider the funding requirements for the longer term.

We agree with the Committee's recommendation on the establishment of a national website for LINks to share best practice and are currently scoping the possibility of establishing such a site with the aim of having this in place next year.

Recommendation 23 (Paragraph 231)

Change is particularly unsettling for voluntary bodies and, for whatever reasons, it is likely to be viewed as criticism of their work. We recommend that LINks be given a sufficient period to establish themselves before any further changes are made.

One of the main aims and major benefits of the LINK model is that they should be flexible – not only able to adapt to local circumstances and attract a wider set of people, but able to adapt to future changes to the health and social care system. Further legislative changes will be far less likely as LINks will be able to adapt to changing circumstances.

Recommendation 24 (Paragraph 271)

In theory there is a good system for consulting about important local proposals for change. In practice, there is much frustration and disappointment. Too often it seems to the public that decisions have been made before the consultation takes place. Too often NHS bodies have sought to avoid consultation under Section 11 about major issues. Unfortunately the Department of Health has supported those NHS organisations in trying to limit the scope of Section 11.

We agree with the Committee that Section 11 of the Health and Social Care Act 2001 is an important element in the Government’s drive to improve services through the involvement of local people.

The changes we are proposing to make are not about allowing NHS bodies to avoid their responsibilities in consulting on major issues that affect patients and the public. We are clear in *‘Strengthening Accountability – Policy and Practice Guidance’*[4] that the overall aim of Section 11 is to make sure patients and the public are involved and consulted from the very beginning of any process – before minds have been made up about how services could or should change and this discussion needs to continue right through the process. All stakeholders need to feel that they have had the opportunity to influence the debate at important stages, and that they have been kept properly informed throughout. We stand by that advice and this will not change with the clarifications to section 11 we are proposing.

Building a partnership between the NHS, patients and the public is at the centre of modernising the health service. As set out in *Strengthening Accountability*, patient and public involvement is not an end in itself but a way of achieving three fundamental objectives:

- strengthened accountability to local communities;
- a health service that genuinely responds to patients and carers; and
- a sense of ownership and trust.

Real patient and public involvement is not about ticking boxes, it is about NHS organisations developing constructive relationships, building strong partnerships and communicating effectively. For patients’ experience of

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[4] Published by Department of Health, February 2003

health services to really improve, NHS staff need to have ongoing and meaningful dialogue with them, their carers and the public about improving and developing services.

It is not acceptable for NHS bodies to avoid their responsibilities set out in Section 11, not only are they under a legal duty, it is one of the core standards they are judged against by the Healthcare Commission as part of its annual health check. We will ensure this message is backed up in the revised statutory guidance we will be producing on Royal Assent of the Local Government and Public Involvement in Health Bill. NHS bodies will be under a new duty to have regard to this guidance. This message will also be backed up by the work being undertaken by the newly established NHS Centre for Involvement to promote and support PPI in the NHS.

Recommendation 25 (Paragraph 272)

The Government has proposed changes to clarify when consultation should take place. We are not convinced that this will strengthen rather than weaken the consultation process. Rather than amend the law it may be better to make the existing legislation work by approaching it in the spirit of the statutory guidance in *Strengthening Accountability*. There is good practice in the NHS. It should be followed.

We agree that there is already excellent practice in this area by some NHS organisations and that some can certainly improve on their practice. However, we believe that the Local Government and Public Involvement in Health Bill makes some important changes to Section 11. Section 11 currently sets no threshold about what level of service change should be consulted upon. The lack of clarity has made it difficult for NHS organisations to know when to involve and consult patients and the public and which has left local people frustrated at being asked about what they see as trivial matters and not being listened to in addressing matters that really affect them.

We want consultation activity to be meaningful and we certainly want to avoid consultation being undertaken when there is no significant change or decision with which local people can meaningfully engage. For these reasons, we are placing a requirement for consultation only to be required when there is a meaningful impact on the range of services or the manner in which they are provided – for example, this would cover a change in opening hours, or a change of site, rather than managerial changes that do not affect service provision.

Secondly, we are placing a duty on NHS organisations to have regard to statutory guidance. We think this addition will bring about much greater consistency within the NHS on how Section 11 is fulfilled. We will be updating the current guidance set out in *Strengthening Accountability* to reflect the revised duty but also to reiterate the messages made in the original guidance (as set out above) which NHS organisations will be required to have regard to. It is also important to share the best practice that we know is out there more effectively through the newly established NHS Centre for Involvement.

Recommendation 26 (Paragraph 273)

The Secretary of State's interventions following extensive local consultations threatens to undermine public confidence in the consultation procedure system. We are also concerned that few referrals from Overview and Scrutiny Committees are subsequently referred by her to the Independent Reconfiguration Panel. We recommend that the Secretary of State refer all OSC referrals to the Panel. She should also seek the advice of the Panel before exercising her extensive powers to intervene in reconfigurations. The Panel is also available for advice before formal consultation begins and wide use of this advisory service should help to make formal consultation more acceptable.

The Secretary of State is ultimately accountable to Parliament for the NHS. It is right therefore, that she has the responsibility for taking a view on important contested service changes, where asked to do so through the local democratic process. Department of Health guidance[5] clearly states that the power of referral to the Secretary of State should not be used lightly by Overview and Scrutiny Committees and where possible, issues should be resolved locally. It also states that if a case is referred to the Independent Reconfiguration Panel, *"the IRP will wish to be satisfied that all options for local resolution have been fully explored. Only those contested proposals where it is clear that all other options have been exhausted are likely to be considered in detail by the panel"*. David Nicholson, Chief Executive of the NHS wrote to Strategic Health Authority (SHA) Chief Executives on 28 February 2007 outlining Strategic Health Authorities' role in quality assuring major changes to service provision, including the expectation that SHAs review and assess all proposals for service change in their area to ensure they are fit for purpose.

Where cases cannot be resolved locally and are referred to the Secretary of State for final decision, they are assessed on their own merits, taking into account all the relevant evidence including the views of the OSC and local NHS as well as other key stakeholders. It is for the Secretary of State to determine when she wishes to seek independent advice from the IRP.

The Independent Reconfiguration Panel is available to provide informal advice to organisations involved in developing proposals for NHS service change and is contacted each year by a number of NHS organisations, Overview and Scrutiny Committees and other interested parties. In its informal role, the Panel supports organisations in developing proposals for NHS service change and implementing good practice, thereby avoiding cases being contested and referred formally to the Secretary of State at a later date.

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[5] *Overview and Scrutiny of Health – Guidance*, issued in July 2003

Recommendation 27 (Paragraph 278)

It is crucial that national consultations cannot be open to the accusation of being 'cosmetic'. However, where patient and public viewpoints can make a genuine contribution to debate, consultation on national policy may be valuable both in terms of enhancing accountability and improving policy making, even if final decisions must ultimately rest with elected representatives. We have heard that at a national level patient and public involvement is fragmented and lacking a coherent strategy; we recommend that the Government should address this as a priority.

Whilst there are some excellent examples of involving service users and members of the public to influence national policy making, as the Committee highlights most recently seen in the *Your health, your care, your say* consultation which led to the publication of the White Paper last year. We agree with the Committee that there is not a universal approach to user involvement at a national level. The need for a strong voice for patients and service users in policy development at a national level was identified by the expert panel set up to consider the evidence collected in the review of PPI in its report to Ministers in May 2006.

It is that recognition that led us to supporting a group of representatives from national patient organisations on the 'National Voices' project.

In June 2006, Harry Cayton, the National Director for Patients and the Public at the Department of Health brought together a range of national patient organisations, and existing forums for patient involvement and provided the opportunity by which a wider discussion on national voices could be pursued. This later became the National Voices Working Group. Part-time project support was provided from the Department of Health (DH) and the project was hosted by the Long Term Conditions Alliance (LTCA).

The National Voices project was established to explore the creation of a national networked body through which the voices of patients, service users and carers can be more systematically, and consistently involved in, and influence policy development in health and social care. Well over 200 organisations, national and local, contributed their views in developing the project. National Voices published their proposals in early 2007.

The National Voices Working Group met with Ministers on 7 February 2007 to discuss its proposals. It was agreed that the DH would support the continuation of the project to develop a financially sustainable business model and governance and accountability arrangements. The working group is currently working to deliver these by end June 2007.

The aim is that National Voices could have two new and valuable roles in helping the DH to engage with users and the public in a more coherent manner. Firstly, to gather and articulate views on generic issues, such as choice, system reform or electronic patient records where it is recognised there are often gaps in engagement, as there is no obvious user group with which to initiate discussions. Secondly, to act as a broker to put the Department in touch with specialist groups and with seldom-heard voices in user groups.

The Department of Health, as part of its Capability Review, is also looking at what skills, capacity and processes it needs to produce service user centred policy and how this will enable the NHS to better deliver that policy. National Voices will be included in this work which will report in June/July 2007.

Printed in the UK by The Stationery Office Limited
on behalf of the Controller of Her Majesty's Stationery Office
ID5576426 370486 06/07 19585

Printed on Paper containing 75% fibre content minimum.

Published by TSO (The Stationery Office) and available from:

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www.tsoshop.co.uk

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ISBN 978-0-10-171282-8

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