



House of Commons  
Health Committee

---

# Patient and Public Involvement in the NHS

---

Third Report of Session 2006–07

## *Volume I*

*Report, together with formal minutes*

*Ordered by The House of Commons  
to be printed 22 March 2007*

## The Health Committee

The Health Committee is appointed by the House of Commons to examine the expenditure, administration, and policy of the Department of Health and its associated bodies.

### Current membership

Rt Hon Kevin Barron MP (*Labour, Rother Valley*) (Chairman)

Mr David Amess MP (*Conservative, Southend West*)

Charlotte Atkins MP (*Labour, Staffordshire Moorlands*)

Mr Ronnie Campbell MP (*Labour, Blyth Valley*)

Jim Dowd MP (*Labour, Lewisham West*)

Sandra Gidley MP (*Liberal Democrat, Romsey*)

Mr Stewart Jackson MP (*Conservative, Peterborough*)

Dr Doug Naysmith MP (*Labour, Bristol North West*)

Mike Penning MP (*Conservative, Hemel Hempstead*)

Dr Howard Stoate MP (*Labour, Dartford*)

Dr Richard Taylor MP (*Independent, Wyre Forest*)

### Powers

The Committee is one of the departmental select committees, the powers of which are set out in House of Commons Standing Orders, principally in SO No 152. These are available on the Internet via [www.parliament.uk](http://www.parliament.uk).

### Publications

The Reports and evidence of the Committee are published by The Stationery Office by Order of the House. All publications of the Committee (including press notices) are on the Internet at [www.parliament.uk/healthcom](http://www.parliament.uk/healthcom)

### Committee staff

The current staff of the Committee are Dr David Harrison (Clerk), Emma Graham (Second Clerk), Christine Kirkpatrick (Committee Specialist), Ralph Coulbeck (Committee Specialist), Duma Langton (Committee Assistant) and Julie Storey (Secretary), Jim Hudson (Senior Office Clerk) and Luke Robinson (Media Officer).

### Contacts

All correspondence should be addressed to the Clerk of the Health Committee, House of Commons, 7 Millbank, London SW1P 3JA. The telephone number for general enquiries is 020 7219 6182. The Committee's email address is [healthcom@parliament.uk](mailto:healthcom@parliament.uk).

### Footnotes

In the footnotes of this Report, references to oral evidence are indicated by 'Q' followed by the question number, which can be found in HC 278-III. Written evidence is cited by reference in the form 'Ev' followed by the page number; Ev x (HC 278-II) for evidence published in February 2007, Ev x (HC 278-III) for evidence published in March 2007.

# Contents

---

<b>Report</b>	<i>Page</i>
<b>Summary</b>	<b>3</b>
<b>1 Introduction</b>	<b>7</b>
<b>2 Patient and Public Involvement: Aims and organisations</b>	<b>10</b>
What is patient and public involvement?	10
Purpose of patient and public involvement	13
Improving the quality of services	13
Accountability	14
Are separate patient and public involvement structures necessary?	15
<b>3 Recent history of Patient and Public Involvement</b>	<b>17</b>
History	17
Community Health Councils	18
Patient and Public Involvement forums	19
Overview and Scrutiny Committees	21
Patient Advice and Liaison Service (PALS) and Independent Complaints Advocacy Service (ICAS)	22
Foundation Trust Boards of Governors	24
Healthcare Commission	26
The abolition of the Commission for Patient and Public Involvement in Health and Patient and Public Involvement forums	27
The Department's reasons for abolishing Patient and Public Involvement forums	27
Failings of the current system	28
The changing nature of the health service	29
Alternative views	30
Should the Commission for Patient and Public Involvement in Health and Patient and Public Involvement forums be abolished?	31
Conclusions	33
<b>4 Local Involvement Networks</b>	<b>34</b>
The Local Government and Public Involvement in Health Bill	34
Responses to reports and information requests	34
Powers: Right of Entry	35
Relations with Overview and Scrutiny Committees	35
Duties: Reports	35
Support organisations: hosts	35
Lack of detail	35
Early adopters	36
What Local Involvement Networks should do	37
The 'Patient and Public Involvement forum Plus' model	37
The 'Network' model	38
The Department's position	39

Concerns	41
Concerns with the 'Patient and Public Involvement forum Plus' Model	41
Concerns with the 'Network' model	41
Concerns with the Department's model	43
How to make LINKs effective	50
Resources	51
What Local Involvement Networks should do	54
The membership	59
Right of entry	61
Marketing and communication	64
Training	65
Hosts	66
Accountability	67
A national body	69
An end to uncertainty	72
<b>5 Major consultation</b>	<b>73</b>
Consultation about major local proposals	73
Duty to consult users of the health service.	73
Problems with Section 11 consultation	75
Government's proposals for change	78
What should happen	80
The role of the Secretary of State	81
Patient and public involvement at a national level	84
<b>6 Conclusions</b>	<b>86</b>
<b>Conclusions and recommendations</b>	<b>88</b>
<b>Formal minutes</b>	<b>93</b>
<b>Witnesses</b>	<b>94</b>
<b>Written evidence in Volume III (HC 278–III)</b>	<b>95</b>
<b>Written evidence in Volume II (HC 278–II)</b>	<b>95</b>
<b>List of unprinted written evidence</b>	<b>99</b>
<b>Reports from the Health Committee</b>	<b>100</b>

## Summary

Patient and public involvement describes a wide range of activities and has a variety of purposes. Patient involvement and public involvement are distinct and are achieved in different ways. The conflation of these distinct terms and the confusion about the purpose of involvement has led to muddled initiatives and uncertainty about what should be done to achieve effective patient and public involvement. Nevertheless, patient and public involvement has the potential to play a key role in both NHS and Social Care services by bringing about service improvement and improving public confidence. Given the lack of local accountability in the NHS, often referred to as the 'democratic deficit', there remains a role for independent patient and public involvement structures.

The first formal structures to represent the public's interest in the NHS were Community Health Councils (CHCs), which were created in 1974. CHCs were in place for almost 30 years, but in recent years there has been a flurry of changes. CHCs were abolished at the end of 2003. Their role was taken over by a number of organisations, including Overview and Scrutiny Committees (OSCs—the remit of which was extended to cover healthcare), Patient Advice and Liaison Service (PALS), Independent Complaints Advocacy Service (ICAS) and Patient and Public Involvement Forums (PPIFs). PPIFs were supported by the Commission for Patient and Public Involvement in Health (CPPIH). Our predecessor Committee warned at the time of the consequences of these changes. In July 2004, less than six months after PPIFs had begun operating, the Department announced the abolition of CPPIH. At the time it said that PPIFs would remain, but, in July 2006 the abolition of PPIFs was also announced. They are to be replaced by Local Involvement Networks (LINKs). No precise date has yet been set for the abolition of PPIFs or CPPIH.

The Department argued that LINKs would provide better value for money and be better able to take into account the changing nature of the NHS, such as the increasing role of the private sector. The other reasons given for the abolition of PPIFs are the same as those given when CHCs were abolished: there is a wide variation in performance and they are not representative of the community, failing to attract young people and ethnic minorities. We are not convinced that PPIFs should be abolished. We do not see why PPIFs could not have been allowed to evolve. The abolition of PPIFs seems to have been driven by the need to abolish CPPIH rather than a real need to start again. Merging the existing PPIFs to form LINKs would have been much less disruptive for volunteers and would have reduced the risk of significant numbers of them leaving. As most Forum Support Organisations already support several forums they could have been allowed to evolve into Hosts, keeping their experienced staff. Once again the Department has embarked on structural reform with inadequate consideration of the disruption it causes.

The Local Government and Public Involvement in Health Bill establishes LINKs. It sets out the main remit, rights and duties of the organisation, but provides very little detail. Most of this is to be set out in regulations once the Bill has received Royal Assent, although the Department did send the Committee a number of draft consultation documents. Worryingly, a number of projects known as 'early adopters', which seek to explore how LINKs would operate, were established in December 2006, after the Bill was introduced, implying

that the establishment of LINKs was not an evidence-based decision.

The Department's concept of LINKs seems to have changed. It looks as if the model was originally for a network which would act as little more than a conduit to enable health service organisations to contact a wide range of communities. Subsequently, the Department's concept for LINKs has taken the form of a 'PPIf plus model', which would involve volunteers undertaking a similar range of activities to those done by PPIfs.

There was widespread concern about the proposals to set up LINKs. It is unclear how far they are to be similar to PPIfs, how far a more nebulous network. Witnesses feared that the Department could end up with the worst elements of both models. There is a real danger that LINKs will end up trying to do too much, that there will be confusion about what they should do and that volunteers will be lost as a result.

In addition, a number of outstanding issues are unresolved. At present, LINKs are not accountable; for example, it is unclear who would call a dysfunctional LINK to account. The organisations which will provide LINKs with support are to be known as Hosts. The Government intends to permit a large number of organisations to undertake the role of a Host, including voluntary sector organisations which provide social care; this could create a conflict of interest since the organisations would be providing as well as scrutinising social care services.

While we do not believe that it was necessary to abolish PPIfs and establish LINKs and while we have concerns about the Department's proposals, we consider that LINKs could be effective. We make a number of recommendations to improve their effectiveness. The Department should:

- Clarify what LINKs should do and ensure they prioritise. LINKs will have neither the funds nor the number of volunteers to do all that the Minister suggested they might like to do. The Department is keen not to be prescriptive; it is right not to specify how LINKs should work, but must issue guidance about what they should do. This guidance should be tailored to what is achievable within their budget and should encourage LINKs not to duplicate work, including research, done by other organisations
- Ensure that the 'early adopter' projects operate with 1) a Host organisation to see how this works in practice and 2) the same budget that a LINK will have to see what can be achieved with these funds
- Clarify how LINKs will be made accountable
- Clarify how conflicts of interest arising from social care providers acting as Hosts are to be resolved
- Take steps to ensure that existing volunteers are not lost in the transition from PPIfs to LINKs since there are a limited number of people prepared to make a substantial commitment to patient and public involvement and many of those are members of PPIfs.

Section 11 of the Health and Social Care Act 2001 provides for extensive public

consultation and involvement in the case of changes to services. Its accompanying guidance, entitled *Strengthening Accountability* gives good advice on how NHS bodies should go about consulting and involving the public. In theory an excellent system is in place. However, in practice there is much disquiet: people feel that they are consulted after decisions have been made. There has also been criticism of NHS organisations' refusal to consult about major changes and of the Department of Health vigorous support of these decisions. The Bill proposes changes to Section 11 consultation.

We fear that the Bill will weaken Section 11. The change of definition it proposes may lead to confusion and could lead to more court cases when the Act is tested. We are not convinced that this change is needed. We conclude that there is no need to change the law or the guidance, which is sufficient. The problem lies with the NHS organisations, often under pressure from deficits.

The Department should encourage NHS bodies to undertake consultation in accordance with Section 11 and the associated guidance. When undertaking consultations all NHS bodies must follow the best practice that already exists in parts of the NHS; in particular, they must be clear about what can and cannot be changed, ensure that they consult early enough in the process that plans can be changed and recognise that even the best designed and run consultation will not result in public agreement. Consultations in which a large proportion of the public reject plans which go ahead anyway must not continue to happen.

A major problem with large consultations has been the readiness of the Secretary of State to intervene, often after a full consultation has been undertaken. This is threatening to undermine public confidence in the consultation process. We recommend that she refer all cases to the Independent Reconfiguration Panel before intervening.

Throughout the inquiry we heard that what matters is not patient and public involvement structures but effective involvement of patients and the public. Structures and procedures, whether LINKs, CHCs, PPIs or Section 11, will have little effect if the health service is not prepared to listen and make changes as a result of what they learn. Indeed the existence of separate structures for patient and public involvement has tended to reinforce the NHS' tokenistic approach. Effective patient and public involvement is about changing outcomes, about the NHS and social care providers putting patients and the public at the heart of what they do.

Many NHS and social care organisations have done patient and public involvement well. The existence of good practice shows that there is no reason why the NHS and social care providers cannot all effectively involve patients and the public.



# 1 Introduction

---

1. There is a long history of patient and public involvement in healthcare. Probably the longest-lasting patient involvement initiative anywhere in the world concerns the ‘Guinea Pigs’. This was a group of disfigured servicemen, mainly air-forcemen, formed towards the end of World War II by Sir Archie McIndoe, the pioneering plastic surgeon. Sir Archie provided them with support not only during the highly complex individualised surgery which helped them to heal, but also in their reintegration into civil society—in this case the street, shops, and pubs of East Grinstead where McIndoe worked at the Queen Victoria Hospital. The ‘Guinea Pigs’ still meet and celebrate their achievements.<sup>1</sup> Examples such as this show that involving patients in their treatment can do a great deal of good. Similarly, the public has been involved in the decisions made by the NHS for many years and has brought about many improvements.

2. However, although the potential benefits of involving the public and patients are considerable, the reality of patient and public involvement can be more disappointing. In practice the recent structures, currently Public and Patient Involvement forums (PPIFs), and before 2003 Community Health Councils (CHCs), have sometimes been effective, but sadly frequently ineffective.

3. There is much confusion. There is a lack of clarity about scope and purpose. Should patient and public involvement be about more accountability, better services or health promotion? A plethora of organisations are concerned with patient and public involvement and the number of organisations has been increasing. In 2003 Community Health Councils were abolished. Their place was taken by PPIFs, PALs and ICAS. The remit of Local Authority Overview and Scrutiny Committees, which were set up in 2001, was subsequently extended to cover health care. Foundation trusts, which were established in 2004, have Boards of Governors to engage the public and patients. Inevitably, these organisations, particularly the forums and the Boards of Governors, are in danger of duplicating each others work.

4. This Committee has had a long interest in patient and the public involvement. We last reported on the subject in 2003 when CHCs were abolished. In that inquiry we identified the problems associated with then reforms—the replacement of Community Health Councils by PPIFs and the creation of the new foundation trusts—and called for greater clarification in order “to avoid further confusion and uncertainty for patients and NHS staff”.<sup>2</sup> The Committee warned about the problems that would be associated with the replacement of the old system”.<sup>3</sup> Now, just over three years after they were established, PPIFs are to be abolished and replaced by Local Involvement Networks (LINKs)

5. A key aspect of public involvement is the duty which was placed by Section 11 of the Health and Social Care Act 2001 on Primary Care Trusts and NHS Trusts and Strategic Health Authorities to make arrangements to involve and consult patients and the public.

---

1 E.R. Mayhew, *The Reconstruction of Warriors: Archibald McIndoe, the Royal Air Force and the Guinea Pig Club*, 2005

2 Health Committee, Seventh Report of Session 2002-3, *Patient and Public Involvement in the NHS*, para 28

3 *Ibid.*, para 34

This is of considerable importance at a time of deficits and when there is a great deal of pressure for reconfiguration. The Government plans to make changes to this legislation.

6. Once the Local Government and Public Involvement in Health Bill which is to enact the Government's proposals was announced in the Queen's Speech, the Committee decided to hold an inquiry with the following terms of reference:

- What is the purpose of patient and public involvement?
- What form of patient and public involvement is desirable, practical and offers good value for money?
- Why are existing systems for patient and public involvement being reformed after only 3 years?
- How should LINKs be designed, including:
  - Remit and level of independence
  - Membership and appointments
  - Funding and support
  - Areas of focus
  - Statutory powers
  - Relations with local health Trusts
  - National coordination

How should LINKs relate to and avoid overlap with:

- Local Authority structures including Overview and Scrutiny Committees
- Foundation trust Boards of Governors
- Inspectorates including the Healthcare Commission
- Formal and informal complaints procedures

In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

7. Our report is intended to inform the House's consideration of the report stage of the Bill, but it goes wider than that. We investigate the system established in 2003/04 and also reflect on more fundamental problems, including:

- What does patient and public involvement mean?
- How to ensure that patient and public structures, such as PPIFs, are representative: for instance, maximum involvement or a smaller more focused group which may be better at holding the NHS to account

- How to ensure that the NHS takes patient and public involvement seriously
- Funding: what can be achieved with the available budget
- What central co-ordination is necessary.

8. We received over 170 written submissions and held four oral evidence sessions. We visited Rochester to discuss patient and public involvement in the Medway area. There we met people from PPIFs, NHS bodies, local authorities, voluntary bodies and those involved in the 'early adopter' project for LINKs. We would like to thank all who helped us in this inquiry, including our advisers, Laura Hilder and Professor Bob Sang, who provided us with valuable advice and assistance.

9. This report begins by considering the overall aims of patient and public involvement. It then describes the recent history of patient and public involvement, examining the changes already made in the last five years before considering the arguments for further reform. Next the Government's proposals for change are examined, in particular the establishment of LINKs. We consider witnesses' concerns about the proposals and make recommendations to improve the effectiveness of LINKs. The report then looks at major consultations, including the Secretary of State's interventions in such consultations, and the Government's proposals to amend Section 11 of the Health and Social Care Act 2001. Finally, we state our general conclusions, stressing the key importance of the NHS in ensuring that patient and public involvement is effective.

## 2 Patient and Public Involvement: Aims and organisations

---

### What is patient and public involvement?

10. Patient and public involvement often appears to be a nebulous and ill-defined concept, used as an umbrella term to cover a multiplicity of interactions that patients and the public have with the NHS. Discussion of patient and public involvement often focuses on institutions dedicated to securing and promoting involvement; however, in reality, patients and the public are involved in decisions about healthcare and health services at many different levels, ranging from input into individual decisions about their treatment to large scale consultations on the broad direction of national policy and health spending. Some patient involvement is spontaneous, some is systematic; some is well resourced, some depends on the goodwill of interested parties; mechanisms for involving patients and the public are as complex as the many interlacing structures that make up the NHS. And, as Harry Cayton, the National Director for Patients and the Public at the Department of Health told us, it is all too easy to collapse all aspects of patient and public involvement into a ‘single portmanteau concept’ which may not be particularly helpful:

I should like to make a distinction between patient and public involvement, which I believe is a huge spectrum of activity, from how my doctor talks to me about what treatments are available and what happens to me, to how my hospital or GP practice runs its services, to the bigger question of public involvement, which is how to engage the community as a whole sometimes in difficult decisions about service patterns, reconfigurations and so on.<sup>4</sup>

11. Professor Celia Davies reinforced the importance of attending to the distinction between patient involvement and public involvement both in terms of the type of contribution people may want to make, and the different perspectives they will bring to bear:

One of the most important things to consider is the different dimensions of patient and public involvement. All sorts of things hide under a general umbrella. For me, one of the fundamental distinctions is between involving people as citizens in hard choice decisions, maybe in commissioning, in the policy process of government and, at the other end, involving them as service users who have had the experience and can feed something back.<sup>5</sup>

12. Current or recent users of the NHS may have excellent insights into the quality and design of a particular service; their personal interest in it may also make it their top priority for spending and reform. A person from the same locality who has never used a hospital service may have entirely different views about what local health spending priorities should be. In their written evidence, the Picker Institute argued that patient and public involvement initiatives concerned with service improvement will be mainly directed

---

4 Q 42

5 Q 4

towards patients, and patient and public involvement initiatives aimed at securing accountability for NHS decision-making will be more directed towards broader groupings of the general public.<sup>6</sup> However, as Professor Davies emphasised, the two perspectives are not mutually exclusive and it is perfectly possible for individuals to become involved on both levels simultaneously.<sup>7</sup>

13. An NHS patient could exert his or her influence over the NHS at many different levels, as figure 1 illustrates, including:

- Participating in treatment decisions with their clinician;
- Exercising choice over which hospital or GP to use;
- Giving their views on specific services directly to PPI initiatives run by individual providers or commissioning organisations (for example filling in a questionnaire about a service they have used; sitting on a patient participation group at the local GP surgery);
- Giving their views on specific services to external bodies, for example PPIFs, the Healthcare Commission and Overview and Scrutiny Committees, which are charged with examining commissioning and provider organisations.

14. In addition to this, NHS patients and local members of the public can make their views on their local NHS organisations heard even if they have not been a recent patient of a particular service through:

- Giving their views on broader health policy issues to organisations involved in commissioning or scrutiny of commissioning (for example, PCT PPIFs, the Healthcare Commission, Overview and Scrutiny Committees);
- Becoming a member of a local foundation trust and voting in elections to its Board of Governors;
- Participating in Section 11 consultations on local service reconfigurations;
- Participating in national consultations run by central government; and
- Voting in local and national elections.

---

6 Ev 204 (HC 278-II)

7 Q 37

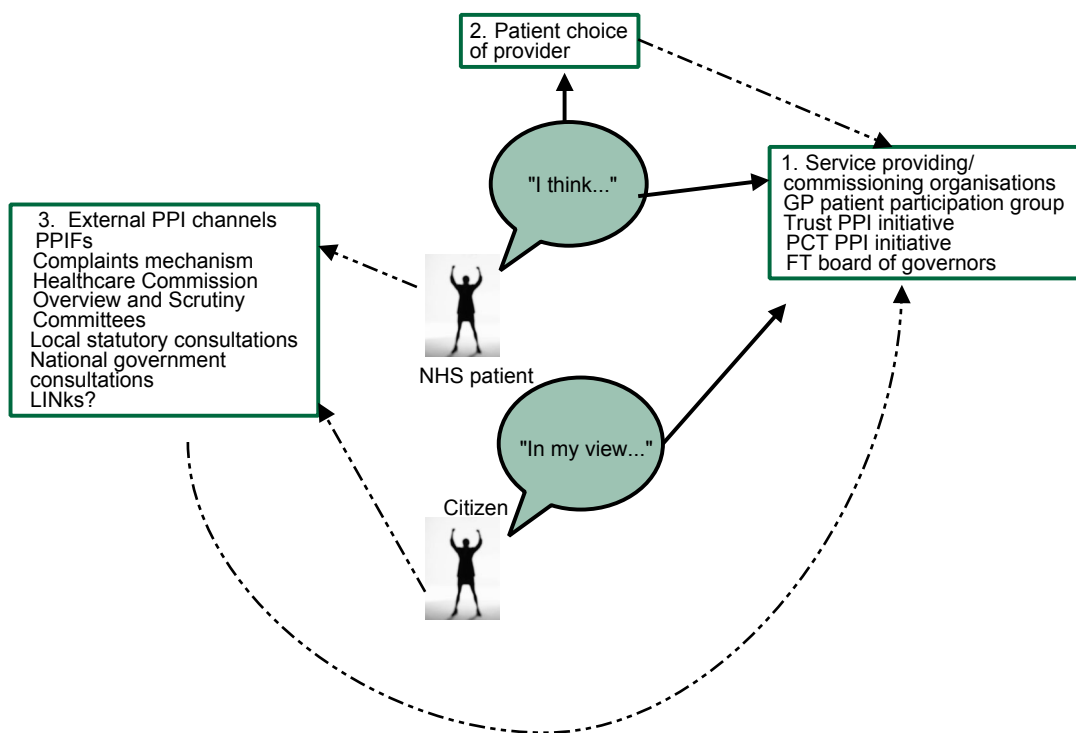


Figure 1 – Channels of influence in the NHS

15. The picture is clearly a crowded one, and Harry Cayton of the Department of Health was frank in his admission to us that despite the numerous reforms and adjustments to systems of patient and public involvement over recent years, the Department’s patient and public involvement strategy could be clearer.<sup>8</sup> Mr Cayton went on to tell us that “inevitably there are a number of bodies which have been created to solve particular problems and not necessarily all of them have been created in such a way that they are completely coherent with one another”.<sup>9</sup>

16. With service providers, commissioners, regulators and scrutiny bodies all offering patients and the public the means to get involved in decision making about the NHS, an obvious question is whether introducing a further involvement mechanism such as LINKs is really necessary or desirable. To answer this question it is helpful to consider the three broad channels of influence patients and the public currently have open to them.

17. The most obvious and direct route of influence for patients and the public is to express their views directly to the organisations charged with commissioning and delivery of services. Foundation trusts offer membership to all those who live locally and who use services, and hold elections to the Board of Governors. In addition to this, NHS trusts, PCTs and individual primary care providers can employ a variety of means through which to canvass the views of their service users and the wider populations their organisations serve.

8 Q 44

9 Q 48

18. Secondly, a further and arguably more important route of influence has been opened up through the recent introduction of patient choice of provider. Technically, patients are now able to ‘vote with their feet’, choosing providers with the highest quality services which best match their needs, and taking funding with them. As the NHS begins to function more like a market, with people able to make choices between providers and have a direct financial impact on trusts, the financial imperative to attract and retain patients by offering high quality services that match patient needs will become even sharper. Canvassing patients’ views on what they want from their local services, on what needs improvement, and, crucially, acting on these findings, will in theory become essential to the survival of trusts.

19. Thirdly, there are a myriad of independent mechanisms, set at one remove from service-providing and commissioning organisations, into which patients and the public can feed their views. Patient and Public Involvement forums are organisations which ‘shadow’ each trust and PCT and have been set up specifically for this purpose. In addition to these, patients and the public can contribute to local government scrutiny processes through Overview and Scrutiny Committees and Section 11 consultations; to the national processes such as the regulatory regime run by the Healthcare Commission; and national consultations run by government and national organisations such as the National Institute for Health and Clinical Excellence.

## **Purpose of patient and public involvement**

20. Just as the landscape of organisations through which patients and the public can express their views is complex and confusing, equally the overall aim of patient and public involvement often seems elusive, with patient and public involvement often used to serve several different purposes simultaneously. These can be broadly divided into two headings:

- i. improving the quality of services; and
- ii. enhancing accountability for public spending.

### ***Improving the quality of services***

21. The Department of Health’s written evidence lists service improvement as the first and most important purpose of patient and public involvement,<sup>10</sup> and indeed most of our evidence was in agreement that patient and public involvement can make a valuable contribution to improving services.<sup>11</sup> Patients’ views can help refocus management on things which are crucial to a patient’s experience of healthcare but which may be overlooked by conventional management approaches. Involving patients can also provide a further layer of quality assurance for things that should clearly form part of mainstream clinical and hospital management but may benefit from ongoing reinforcement—for example hygiene and cleanliness. In this respect, patient and public involvement can support the work of regulatory bodies, providing a further source of information on which to base assessment of trusts.

---

10 Ev 1 (HC 278-II)

11 For example see Q 2 and Q 107

22. The Commission for Patient and Public Involvement in Health (CPPIH) suggested in its evidence that the ultimate aim of patient and public involvement should be not improving services as an end in itself, but improving health outcomes.<sup>12</sup> There are also markedly different conceptions of what improving services actually means. For some, it is securing improvements in quality and efficiency and effectiveness; for others, it is playing a crucial role in quality assurance, supplementing the work of regulatory bodies.

23. In recent months there has been renewed emphasis on the importance of the commissioning or planning of NHS services, and patient and public involvement also has a vital role to play in this area, making local voices heard to ensure services are designed to best meet local needs and priorities.

24. Crucially, if patient and public involvement is done well, patients can challenge, and offer feedback to, the providers of services and commissioners, improving services by challenging existing assumptions and models of service delivery, and giving feedback on their experiences.

### **Accountability**

25. As well as the positive impact patient and public involvement can have on improving the quality of services, much of our evidence expressed the view that patient and public involvement can also make health service bodies more accountable to the public, who are the users and funders of services.

26. There is some confusion about the meaning of accountability. Dr Ed Mayo, Chief Executive of the National Consumers Council and co-Chair of the Department's expert panel on patient and public involvement, told us that:

Although we try to find out the answer by research, it is difficult to know what kind of accountability people want in relation to the NHS. Is it the accountability of a service provider, like Tesco or someone, that is just responsive to what people want? Is it accountability that is in some way mutual and engages them as partners in health, or is it some democratic process that has parliamentary or local councillor scrutiny? Those are very different notions of accountability and I have never heard very clear answers either from the patients we talk to or others in this field.<sup>13</sup>

27. Several witnesses stressed the importance of addressing the 'democratic deficit' by making NHS bodies in some way accountable to their local public.<sup>14</sup> The NHS has not been directly linked with local democracy since local councillors were removed from Health Authorities in the 1970s.

28. Some elements of patient and public involvement remained democratic; for instance, CHCs comprised elected members. More recently, accountability through the democratic process has been improved by the establishment of Overview and Scrutiny Committees, albeit that they do not all have sufficient resources to provide the depth and breadth of

---

12 Ev 53 (HC 278-II)

13 Q 2

14 e.g. PPI54, PPI148

coverage of NHS issues in all areas. Foundation trusts are directly accountable to their membership, which is drawn from the local population and service users, but this form of accountability is still in its infancy, with only a minority of NHS trusts having achieved foundation status. In addition the number of members of foundation trusts varies considerably from trust to trust.

29. Many of those most actively promoting public and patient involvement are concerned to tackle the ‘democratic deficit’ in the NHS. They hope that encouraging people to get actively involved in collective activity to reshape the NHS will help reduce alienation and promote a new type of community engagement.

### Are separate patient and public involvement structures necessary?

30. Given trusts’ and PCTs’ statutory obligation to involve patients and the public, and the fact that patient choice should strengthen the onus on the NHS to do this, do we really need separate, independent patient and public involvement structures? All businesses seek feedback from their customers to enable them to match their services to their customers’ demands and maximise their profits, and it is possible to argue that the NHS should be no different from other businesses, with patient and public involvement as a seamlessly integrated core aspect of the health service rather than a separate function performed at arm’s length from the organisations actually dealing with patients.

31. There seems no doubt that patient and public involvement should be an essential aspect of managing a service-providing organisation in order to improve the quality of services. There is evidence that this already happens successfully in many trusts. Equally, for commissioning organisations, patient and public involvement should be an essential part of planning services. However, good patient and public involvement does not yet happen uniformly across the health service, perhaps because it is not yet fully ingrained into NHS culture. Secondly, the NHS, although undergoing market-type reforms, is not a full market. Choice in the NHS is still a limited concept, constrained to a certain specialities; to planned care; and to certain geographical areas—there will always be patients who are not able to use choice to make their views and preferences felt. Finally, patient and public involvement initiatives run by NHS provider or commissioning organisations may not have sufficient independence and may be driven by an organisation’s agenda rather than offering a truly open forum for views. For these reasons, it seems that for the time being, at least, dedicated structures for patient and public involvement are necessary.

**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.**

**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.

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.

## 3 Recent history of Patient and Public Involvement

### History

35. Structures designed to involve patients and the public in the provision of healthcare services have been in place in some form for many years. Community Health Councils (CHCs), which were established in 1974, remained the mainstay of PPI for over 25 years. Then, around 2000 a series of changes were made. In 2001 the legislation was passed to abolish CHCs. The roles they had undertaken were divided between a number of other organisations. The inspection function and representative role was taken over by PPI forums, which were established in 2003. They were supported by a national organisation, the Commission for Patient and Public Involvement in Health (CPPIH). The complaints function was taken on by the Patients Advice and Liaison Service (PALS) and the Independent Complaints and Advocacy Service (ICAS). Local Authority Health Overview and Scrutiny Committees (OSCs) provided added scrutiny of NHS organisations. Now the Government proposes that the patient and public involvement role be transferred from forums to LINKs.

Brief History of PPI	
1974	CHCs established
2000	OSCs established following Local Government Act 2000
2001/2002	Health and Social Care Act 2001 abolishes CHCs and establishes successor organisations; extends OSCs' remit to healthcare
2003	CPPIH established to oversee a new system of PPI. CHCs cease and PPIFs begin operating at the end of the year
April 2004	First foundation trusts established with Boards of Governors
July 2004	Department of Health announces CPPIH will be abolished in summer 2006 and "stronger, more efficient arrangements will be put in place to provide administrative support and advice to Patients' Forums". The Parliamentary Under-Secretary of State for Health (Miss Melanie Johnson) tells the House of Commons that PPIFs "are the cornerstone of patient and public involvement. They will not be abolished" <sup>15</sup>
July 2005	The Department announce CPPIH abolition to be postponed until summer 2007
February 2006	The Department to conclude PPI review by setting up a PPI panel
July 2006	The Department announces the replacement of PPI Forums with LINKs

15 HC Deb, 22 July 2004, col 584

## Community Health Councils

36. The establishment of CHCs represented the first substantial attempt by Government to give the user, or potential user, of healthcare services a voice in their design and operation. CHCs had:

- a duty to represent the interests of the public, to monitor local health services and to advise, and be consulted by, Local Health Authorities on health-related matters;
- a duty to handle patient complaints and advocacy issues within NHS trusts;
- the power to veto proposals involving service re-design, such as ward closures, and to refer matters directly to the Secretary of State;
- rights of inspection to monitor services.<sup>16</sup>

The Association for Community Health Councils for England and Wales (ACHCEW) was set up to provide a national voice for CHCs and training for members.

37. CHCs had a larger overall budget than will be available to LINKs. Each CHC had a budget roughly equivalent to that planned for each LINK, approximately £150,000, but LINKs are expected to cover a larger area. For example, in an area such as Hertfordshire, there would be one LINK, with a budget of £150,000, compared to four CHCs, with a combined budget of around £600,000.<sup>17</sup> Even taking into account the fact that CHCs undertook functions now done by PALs and ICAS, this seems a substantial reduction.

38. CHCs were criticised. Their responsibilities for primary care were limited.<sup>18</sup> Some thought they lacked independence.<sup>19</sup> The Kings Fund has argued that too few council members were younger adults and individuals from non-white British backgrounds.<sup>20</sup>

39. CHCs were abolished in 2003. Many witnesses to this inquiry held them in high regard although others thought their performance variable.<sup>21</sup> Nevertheless, most criticised their abolition. The National Pensioners Convention described them as “much missed” and the Royal College of Nursing complained about the “gradual watering-down of the powers of public and patient involvement networks” since their disappearance.<sup>22</sup> Professor Angela Coulter of the Picker Institute stated:

In my view the abolition of the CHCs was a major mistake because although they could have been improved, and indeed they themselves had a review just before they

16 Kings , *Increasing the Public Accountability of Primary Care Trusts*, [not printed]

17 Q 122 [Barrie Taylor]

18 While they did not have an extensive remit within primary care services, they did have a direct monitoring role over the health visitor service and midwifery through the Health Authority. They were also required to meet Family Practitioner Committees (FPCs), which comprised GPs, pharmacists, opticians and dentists, at least once a year and these bodies had a duty to respond to CHCs' Annual Reports. In the early 1990s, when FPCs became Family Health Service Authorities (FHSAs), the relationship became closer as FSHAs were required to consult CHCs on new service developments

19 Ev 145 (HC 278-II)

20 Kings Fund, *Increasing the Public Accountability of Primary Care Trusts*, [not printed]

21 Eg. Ev 334, Ev 145 or Ev 160 (HC 278-II)

22 Ev 52 (HC 278-II)

were abolished to say, “We want to improve and make ourselves more effective”, they were abolished and we have then been reinventing and reinventing things and we have taken several steps backwards.<sup>23</sup>

40. Witnesses also argued that the abolition of CHCs reduced public involvement. Partly this was a result of destroying a long-standing institution. As David Wood from the charity Attend stated:

I think there is a loss of understanding, if that makes sense. People may have understood what they thought the CHCs did. (Whether they did it or not is another issue.)<sup>24</sup>

Mrs Jennifer Beesley, ex-chair of Great Yarmouth PPIf, commented, “[people] all still know the CHC but they have not heard about the PPIF”.<sup>25</sup>

41. CHCs were replaced by a number of organisation, including PPIfs, PALS and ICAS. In addition, about the same time, OSCs’ remit was extended to include health matters.

### ***Patient and Public Involvement forums***

42. The Health and Social Care Act 2001 gave the NHS a duty to involve the public. PPI forums were set up in response to this duty and to replace the representative elements of CHCs’ work. PPIfs became operational at the end of 2003. One PPIf was aligned to each NHS trust (including foundation trusts) and PCT in England. There were 572 in operation before PCTs were reconfigured; there are now approximately 400 PPIfs.

43. PPIf are coordinated by an arms-length body, the Commission for Patient and Public Involvement in Health (CPPIH). The Commission may speak on behalf of forums and provides training for forum members. CPPIH also runs national campaigns, such as “Fair Talk”, which raised concerns about the costs of calls from bedside entertainment units.

44. PPIfs have a number of statutory powers. These include:

- The right of access to some healthcare premises;
- The right to request written information from trusts and PCTs, which have a duty to respond to such requests within 20 days;
- The right to refer matters to the local OSC (see below).

In contrast to CHCs, the remit of PPIf included primary care.

45. PPIfs do a range of work that aims to gauge patient and public experience of health care, which is then fed back to the relevant trust in an attempt to improve services. Examples of work regularly undertaken by PPIfs include:

---

23 Q 330

24 Q 328

25 Q 218

- a) Patient surveys. For instance, the North East Ambulance Trust PPIf used surveys to examine patients' experiences and the efficiency of the Patient Transport Service. These surveys were followed by a report that made several recommendations on how standards could be raised. The trust subsequently acted upon these recommendations.<sup>26</sup>
- b) Compilation of service review reports. For example, United Bristol Hospitals PPIf examined the treatment of stroke patients and reported to hospital management. Managers subsequently took on board the recommendations and have started to implement improvements in the service.<sup>27</sup>
- c) Presence on PCT and hospital trust boards/committees. Members of PPIfs commonly act as public/patient representatives in these arenas. For example, a member of the Southwark PPIf sits alongside GPs on a committee on practice-based commissioning and on the PCT's Governance Committee.<sup>28</sup>

Department of Health officials pointed out that there was no legislation in place requiring that PPIfs should have a presence on such committees, however. Meredith Vivian stated that:

...that situation has absolutely nothing to do with the legislation or functions of the patient forums. There is nothing in the patient forum legislation that provides for that....That is nothing to do with forums; that is the NHS doing what it is supposed to do.<sup>29</sup>

- d) Visiting premises. Members of PPIfs have a right of access to hospitals and other NHS premises and use such visits to inform their reports. Witnesses stressed the value of this right as it enables them to talk to both staff and patients, gauge their views and feed back information to the organisation in question.<sup>30</sup>

46. The most common areas investigated by PPIfs are infection control, GP services, transport and parking, mental health, community involvement, out of hours services, health information, older peoples services and disability services.<sup>31</sup>

47. PPIfs have no duty to monitor or investigate social care services, and cannot examine issues unrelated to the trust or PCT to which they are affiliated. This may limit their work, as Penny Robinson, Chair of the United Bristol PPIf, described in the following example:

We were doing a survey into delayed discharge and we discovered that 60% of the delay discharges were due to problems with social services not being able to find places for elderly people, but we simply hit a brick wall with social services...

---

26 Ev 183 (HC 278-II)

27 Q 216

28 Q 235

29 Q 66

30 Q 243

31 Commission for Patient and Public Involvement in Health, *Annual Report and Accounts 2005-06*

basically we have no jurisdiction with social services and we had to abandon the project.<sup>32</sup>

48. The shift from the CHC system to PPIFs was not smooth; it was described as a “complete hiatus” by David Stout from the NHS Confederation.<sup>33</sup> Many others mentioned the need for PPIFs to “start again” following the demise of CHCs,<sup>34</sup> suggesting that much expertise and experience was lost in the move.

49. Problems associated with PPIFs included difficulties in the recruitment of members, the costs of supporting them through CPPIH (see next section), and the quality and extent of support provided by Forum Support Organisations (FSOs). PPIFs were fully operational for about six months before the abolition of CPPIH was announced in July 2004. The abolition of PPIFs was announced in July 2006 in the consultation document *A Stronger Local Voice*. There has been some uncertainty about when PPIFs will actually disappear, but it is expected that they will cease operations by the end of 2007. Many forum support organisations have been working on 6-month renewable contracts since the abolition of CPPIH was confirmed.<sup>35</sup> We look at assessments of PPIFs’ work below.

### **Overview and Scrutiny Committees**

50. Section 21 of the Local Government Act 2000 required councils to establish Overview and Scrutiny Committees (OSCs). Following the abolition of the CHCs, the Health and Social Care Act 2001 gave OSCs a role in reviewing health and social care services. These committees, which consist of elected councillors, question and evaluate the impact of executive decisions and actions as well as investigate policy issues, advise the executive and consider budgetary and other documents. Detailed implementation of scrutiny arrangements is a matter for individual local authorities.

51. OSCs have a range of powers, including the right to request information and the right to summon people before them to explain their actions. They may examine the efficacy of efforts to involve patients and the public, may request action to be taken and will then scrutinise the subsequent report. OSCs have the power to recommend an independent inspection of premises. They must be consulted by the NHS where there are to be major changes to health services and may require a public consultation when services change. Matters referred to OSCs by PPIFs may be investigated by the Committee and, where necessary, referred upwards to the Secretary of State. This may occur in the event of major reconfigurations of services but also in the case of small but intractable problems.

52. Doubts have been expressed about the effectiveness of OSCs. The 2002 report by the then Transport, Local Government and the Regions Select Committee drew attention to the weaknesses of scrutiny arrangements.<sup>36</sup> Five years later, although some PPIFs appear to

---

32 Q 220

33 Q 268

34 Ev 138 (HC 278-II)

35 Q 136

36 DTLR Committee, Fourteenth Report of the Session 2001–2, *How the Local Government Act 2000 is working*, HC 602, para 17

have good relationships with their local OSCs, other witnesses were critical of OSCs during this inquiry. The BMA stressed the limitations of their powers:

Councils have no financial hold over health service providers... OSCs have no mandatory powers to change anything.<sup>37</sup>

HealthLink pointed out:

When a local election is in the offing, OSCs can carry out no scrutiny at all because of ‘purdah’ conventions, unlike CHCs which operated irrespective of elections. There is therefore a perverse incentive for the NHS to push through unpopular changes at this time, free from challenge or referral to the Secretary of State.<sup>38</sup>

53. OSCs’ lack of independence was highlighted by other submissions. Medway Community Health PPIf stated:

Experience of Overview and Scrutiny Committees has demonstrated them as ineffective in providing local scrutiny of the NHS and are recognised as such within the Cabinet system operating within local government.<sup>39</sup>

The charity Breakthrough Breast Cancer added:

Some Breakthrough members have raised concerns that Overview and Scrutiny Committees do not currently operate as an effective check and balance on NHS Trusts because the Committees are perceived as not being independent from NHS Trusts.<sup>40</sup>

54. We were told of a number of other criticisms. OSCs can only be reactive rather than proactive.<sup>41</sup> There is no lay or public representation; local councillors fill all seats and OSCs may not reflect the political make-up of the council (ie. the majority party may choose to fill all seats).<sup>42</sup> As a result, OSCs may not exercise rigorous scrutiny.

### ***Patient Advice and Liaison Service (PALS) and Independent Complaints Advocacy Service (ICAS)***

55. The PALS and ICAS systems were set up when CHCs were abolished to absorb the advice and redress functions that were previously the responsibility of the Councils. The establishment of a PALS body in every NHS trust formed a key element of Chapter 10 of the *NHS Plan, Changes for patients*, which described a range of initiatives designed to improve patient information, patient choice and PPI in the NHS.<sup>43</sup> PALS was originally called the Patient Advocacy and Liaison Service. The advocacy element was later removed

---

37 Ev 38 (HC 278-II)

38 Ev 111 (HC 278-II)

39 Ev 156 (HC 278-II)

40 Ev 26 (HC 278-II)

41 Ev 31 (HC 278-II)

42 Ibid

43 Department of Health, *The NHS Plan: A plan for investment, a plan for reform*, Cm 4818-I, July 2000

from PALS (and the ‘A’ changed to ‘advice’), and ICAS was introduced to handle this function. PALS now aims to resolve problems reported by patients in an informal manner while the local formal complaints procedure is covered by ICAS. PALS and ICAS also pass information to PPIFs relating to complaints and other issues affecting patients which can be used to inform their work.

56. The work of PALS was criticised by several submissions to the Committee. PALS’ lack of independence was criticised by Judy Birch, from Bournemouth and Poole PCT PPIf:

PALS is not independent and patients frequently report difficulties with the non-independent nature of the latter.<sup>44</sup>

Barry Silverman, from Southwark PPIf, stated:

Complaints disappear into PALS, GP systems and hospital system.<sup>45</sup>

Mary Adams, Head of Public Involvement at North Somerset PCT, agreed that there were problems with communicating messages from patients unhappy with their treatment who report to PALS staff:

PALS services [are] not linked in well enough to other structures and feedback is under utilised in supporting NHS service improvement... People also need to know that their comments and concerns will be fed into improving services through mechanisms like PALS and complaints services.<sup>46</sup>

She added that, whereas once the service was seen as a crucial element of patient representation, PALS has become increasingly marginalised and some services have been threatened with closure due to trusts’ financial constraints.<sup>47</sup>

57. Several witnesses also expressed concern about ICAS. Some, such as the Countess of Chester Hospital PPIf, mentioned the poor standard of the current formal complaints arrangements, particularly regarding access to data on complaints. The PPIf stated that, “This has never been provided to PPI Forums in any meaningful format”.<sup>48</sup> Other submissions also commented on the poor feedback of information to PPIFs. The group Action Against Medical Accidents stated:

ICAS is also being provided in an inconsistent way across the country by three quite different providers who are not formally linked in any way to patients forums. There has been no independent evaluation of the current arrangements for ICAS.<sup>49</sup>

The London Ambulance Service PPIf added:

---

44 Ev 290 (HC 278–II)

45 Ev 263 (HC 278–II)

46 Ev 128 (HC 278–III)

47 Q 152

48 Ev 87 (HC 278–II)

49 Ev 212 (HC 278–II)

Access to ICAS services in the community is extremely poor. They have no public profile and little capacity.<sup>50</sup>

58. Problems with ICAS were also highlighted by Citizens Advice, which was a contracted provider of the service in six of nine regional areas in England. In 2005 it published a report *The pain of complaining* which looked at the NHS complaints procedure overall.<sup>51</sup> It found that patients faced:

- difficulties in accessing the complaints system, due to perceived reluctance by trusts to advertise the procedure and support services available;
- lengthy delays, as both trusts and the Healthcare Commission failed to deal with complaints within their targets;
- a culture which is defensive rather than responsive, failing to provide complainants with explanations of what went wrong, or apologies when mistakes were made.

### **Foundation Trust Boards of Governors**

59. Foundation trusts, which began to be established in 2004, have a duty to engage with their local community and encourage local people to become members of the organisation. There is also a statutory requirement for foundation trusts to establish a Board of Governors, sometimes called a Members Council.

60. The size and make-up of the Board of Governors depend on local circumstances and vary between organisations. Governors are nominated and elected by their local community. Legislation requires that the majority of places must be taken by representatives elected from the public and patient membership of the trust, there must be at least three staff governors elected from the staff membership, at least one governor from the Local Authority, one from a local PCT and, if there is a university in the area in question, a representative of that body.

61. Governors are not involved in the day to day management of the organisation; instead they ensure that the trust carries out its responsibilities as set out by Monitor. They must be consulted on future plans for the organisation. Statutory duties include:

- Appointing, or removing, the Chair and non-executive directors of the Board of Directors;
- Approving the appointment of the chief executive;
- Appointing the auditors of the trust; and
- Considering the trust's annual forward plan.

---

50 Ev 196 (HC 278-II)

51 Citizens Advice, *The pain of complaining*, CAB ICAS evidence of the NHS complaints procedure, May 2005

62. Activities designed to engage with members of the trust and other members of the public may include open days, seminar programmes, surveys and emails. Monitor gave the following example of effective public engagement by a Board of Governors:

Cambridge University Hospitals NHS foundation trust has one of the largest memberships. Governors have taken responsibility for communicating with members with monthly meetings held in local towns and villages. Meetings take place both in afternoons and evenings to make them more accessible to any member wishing to attend.<sup>52</sup>

63. According to Harrogate and District Foundation Trust (HDFT), the Board of Governors' office holds data on ways in which trust members have said they are willing to offer advice. Information is also held on patient special interest groups, expert patients, and complainants. This information allows governors to call on relevant patient expertise when it is needed. HDFT gave other specific examples of PPI work:

...the Board requires all internal plans to have input from service users or advisory groups...Service delivery and performance is routinely reported to the monthly Board of Directors; each quarter a report from the Quality of Patient Experience Group includes examples of how comments from service users have been incorporated in developing the service. That group includes members of the Foundation Trust working in a lay capacity as well as Governors.<sup>53</sup>

64. The evidence about foundation trusts' patient and public involvement arrangements is mixed. Like Harrogate and District, other trusts reported that they were doing positive patient and public involvement work. In contrast, the BMA was critical, citing the limited data on the effectiveness of patient and public involvement within these organisations, and the lack of support for lay members of the Board of Governors. The Association stated:

Foundation trusts appear to be a failing area in terms of PPI, and there is a lack of evidence to show that they may be working. From experience, there is no consistency on how appointments are advertised or made. Lay governors are unsupported, usually receiving no training or administrative support, and their role in decision making is also negligible with decisions often being made by an executive group, with no lay membership, which are then in effect rubber-stamped by the board.<sup>54</sup>

65. The powers of foundation trust Boards of Governors have not been tested to any great extent to date. Little conflict has been reported, but Monitor suggested that this may be because "governors have not yet sufficiently found their feet".<sup>55</sup> There is a proposal to establish a governors' forum, to be run by the Kings Fund, which will provide a means for governors to share information and learning and may address this issue.

66. The number of hospitals achieving foundation status will increase steadily over the next two years. There are currently approximately 60 foundation trusts, but all trusts are

---

52 Ev 157 (HC 278-II)

53 Ev 113 (HC 278-III)

54 Ev 31 (HC 278-II)

55 Ev 157 (HC 278-II)

expected to be in a position to apply for foundation status by 2008. There will therefore be an increase in public participation through the organisations' associated Boards of Governors and the potential for overlap with other groups will grow.

67. Monitor warned that the work of foundation trust Boards of Governors and other bodies concerned with PPI might lead to the duplication of effort:

Where patient and public involvement initiatives overlap there is potential for confusion as to the different responsibilities of each organisation.<sup>56</sup>

### **Healthcare Commission**

68. The Healthcare Commission, which is the main inspector of healthcare bodies, was established in April 2004 under the Health and Social Care (Community Health and Standards) Act 2003. Since its beginning, it has undertaken PPI-related work, including:

- a patient survey programme, which feeds into trusts' ratings (based on inspections carried out annually by the Commission);
- involving patient groups in the work programme through service-user consultation when examining a specific issue such as learning disabilities or services for older people.

69. The Healthcare Commission appears to place a high value on patient and public involvement, and recently held a consultation on its strategy for engaging with patients and the public. The Commission stated that effective patient and public involvement allows healthcare providers to “gain a fuller understanding” of the patient experience, and what patients need and expect from healthcare. According to the Commission, patient and public involvement allows access to expertise that clinicians and managers may not have, and gives patients more control over their care.<sup>57</sup>

70. The document *Standards for Better Health*, published by the Department, is used by the Commission to as part of its annual health check of NHS organisations.<sup>58</sup> Patient and public involvement is included as a Core Standard:<sup>59</sup>

C17 The views of patients, their carers and others are sought and taken into account in designing, planning, delivering and improving health care services.

The following Developmental Standard is also included:

D11 Health care organisations plan and deliver health care which:

- a) reflects the views and health needs of the population served and which is based on nationally agreed evidence or best practice;

<sup>56</sup> Ev 157 (HC 278-II)

<sup>57</sup> Ev 119 (HC 278-II)

<sup>58</sup> Department of Health, *Standards for Better Health*, July 2004

<sup>59</sup> Core standards and developmental standards are defined as follows: ‘core standards: which bring together and rationalise existing requirements for the health service, setting out the minimum level of service patients and service users have a right to expect; and developmental standards—which signal the direction of travel and provide a framework for NHS bodies to plan the delivery of services which continue to improve in line with increasing patient expectations.’

- b) maximises patient choice;
- c) ensures access (including equality of access) to services through a range of providers and routes of access; and
- d) uses locally agreed guidance, guidelines or protocols for admission, referral and discharge that accord with the latest national expectations on access to services.

71. As part of the annual 'health check', NHS trusts make a self-assessment of whether their organisation has achieved core standards. The Healthcare Commission seeks additional comments from patient groups and representatives, PPIfs, OSCs, foundation trusts' Boards of Governors and SHAs to check the assessment made by the trust. It will follow up any concerns.

### **The abolition of the Commission for Patient and Public Involvement in Health and Patient and Public Involvement forums**

72. The abolition of CPPIH was announced in July 2004, although the exact date on which it will cease operations has yet to be confirmed. The abolition of PPIfs was announced two years later in July 2006. Local Involvement Networks (LINKs, described more fully in the next chapter) will replace PPIfs. We discuss below what form of national body, if any, might take the place of CPPIH.

### ***The Department's reasons for abolishing Patient and Public Involvement forums***

73. The Department has given a number of reasons for the proposed changes:

- a) Failings of the current system:

- PPIfs are not representative of their communities;

- The current system is poor value for money and too bureaucratic;

- b) PPI needs to reflect the changes in the health service, including:

- The increasing diversity of providers;

- The greater emphasis on commissioning and primary care;

- The need to include social care within PPI arrangements.

Some witnesses supported aspects of the Department's argument; others suggested that there were other reasons for the changes.

## *Failings of the current system*

### **PPIfs are unrepresentative**

74. The Department of Health believes that PPIfs fail to represent their communities.<sup>60</sup> First, too few people are members of forums. The average for the country is 8 per forum.<sup>61</sup> Moreover, those people who are members tend to be older adults, often retired. There are relatively few participants from non-white backgrounds. This means that the views of working adults, those with young families and from black and minority ethnic groups are poorly represented.

75. There is also a fundamental objection to the concept of patient representatives which is that too much power is given to the few individuals who are members of forums. The Royal College of Paediatrics and Child Health stated:

It is not possible for one small group of individuals to be able to represent all the different groups who use health services...<sup>62</sup>

Some witnesses agreed. Dr Ed Mayo from the National Consumer Council stated:

I think there is a sense that [PPIf members] are representative patients rather than patient representatives. In order to do that they would need a good deal more diversity.<sup>63</sup>

The Commission for Social Care Inspection (CSCI) told us that the new plans should not, “reproduce older models of public involvement, where people speak on behalf of those who use services”.<sup>64</sup>

76. Moreover, the existence of a small group to consult makes it too easy for the NHS organisations to ‘tick the PPI box’. It discourages them from consulting widely:

Trusts should be made aware that “consultation” requires more than having a representative on a board, however, to nod through change or add credibility to its decisions.<sup>65</sup>

### *Too bureaucratic and poor value for money*

77. The Department’s proposals aim to reduce bureaucracy and increase resources received at the ‘front line’ of PPI. CPPIH agreed that potential members were discouraged from joining PPIfs by the bureaucracy associated with the regulatory framework.<sup>66</sup> Meredith Vivian, Head of Responsiveness and Accountability at the Department, also told us that better use could be made of the money:

---

60 Ev 1 (HC 278-II)

61 Commission for Patient and Public Involvement in Health, *Annual Report and Accounts 2005–06*, p 11

62 Ev 221 (HC 278-II)

63 Q 32

64 Ev 62 (HC 278-II)

65 Ev 328 (HC 278-II)

66 Ev 53 (HC 278-II)

What we can do with the available funds is make them go much further by stripping out part of the current bureaucracy between the Department of Health and the front line, ie. activity by patient forums. We want much more money to get into the hands of those people who will actively engage in this kind of activity.<sup>67</sup>

## *The changing nature of the health service*

### *Diversification of providers*

78. Services are now obtained from a range of providers within the NHS and from the private and voluntary sectors. The Department suggested that these changes meant that a different type of PPI was now needed:

In the future there will be an increasing mix of providers, meaning that the old system of user involvement, that was focussed around individual NHS institutions is no longer appropriate.<sup>68</sup>

### *Increasing emphasis on primary care and commissioning*

79. The Department also argued that increasing emphasis on primary care and the increase in commissioning carried out directly by PCTs means that public involvement at this level is more important now than when PPIs were first introduced. Harry Cayton, National Director for Patients and the Public at the Department of Health, stated:

Because government policy is very strongly to devolve responsibility for commissioning down to PCTs it is absolutely essential to ensure that they have a mechanism by which they engage with their communities about the commissioning decisions they make; otherwise, they will be detached.<sup>69</sup>

80. Moves to strengthen PPI in commissioning were welcomed by witnesses. We were told that it was of central importance for new structures to be integral in commissioning decisions. This view was strongly endorsed by HealthLink:

The commissioning of services without public and patient involvement is commissioning with one hand tied behind the commissioners back—statistics can be used to determine what services are required but the way they should be provided will be largely guess work by commissioners without patient involvement<sup>70</sup>

The NHS Alliance stated:

We also think that PPI needs to be promoted in practice based commissioning (PBC); at the moment despite exhortation PPI is poorly represented in PBC. Local

---

67 Q 86

68 Ev 1 (HC 278-II)

69 Q 49

70 Ev 111 (HC 278-II)

people should be involved in defining PBC cluster priorities, improving pathways, spending savings [and] monitoring quality.<sup>71</sup>

### *Inclusion of social care*

81. The inclusion of social care in the remit of the new PPI structures is another key change from earlier arrangements. Meredith Vivian told us:

There is a great deal to be said for adjusting and revising the whole system for representing views at local level to make things more relevant and capable of being more inclusive and to widen the remit to include social care.<sup>72</sup>

82. Most witnesses welcomed the inclusion of social care in the remit of LINKs. Dr Tritter stated:

[The new arrangement] provides a different opportunity because it links health and social care. In that sense it is about improving the transition and integration of those services potentially from the perspective of local communities.<sup>73</sup>

We were also told:

Within the wider Bill and subtle changes going on at local government level one sees opportunities for connecting health and social care and reconnecting public health with some of these other areas which I believe are genuinely exciting.<sup>74</sup>

### *Alternative views*

83. Some witnesses did not believe that the Department had given the real reasons for the changes and provided other explanations for the abolition of PPIFs. Chief among these was the poor performance of CPPIH. Many thought that the Department had decided to abolish CPPIH and subsequently abolished PPIFs almost as an afterthought. While the Department was concerned that PPIFs were 'unrepresentative', they would not have been abolished had it not been for the need to deal with CPPIH.

84. The evidence we received was overwhelmingly critical of the Commission. CPPIH's lack of response to problems experienced by forums was mentioned by frustrated PPIFs:

We are on our second Forum Support Organization [support officer] and when we are surveyed about their support for us we have always been highly critical. We have also made extensive efforts to go to CPPIH with our concerns without success.<sup>75</sup>

Others pointed out the poor communication, training opportunities and levels of support provided by CPPIH:

---

71 Ev 165 (HC 278-II)

72 Q 59

73 Q 2

74 Q 10 [Dr Ed Mayo]

75 Ev 293 (HC 278-II)

Communication and support from the Commission has been lamentable and the so-called training-provision derisory. The benefit from the Commission to Forums and their work has been nil. The Commission has misrepresented Forums' views and wishes and has often actively abetted initiatives to restrict and hamper them.... This is a disgrace.<sup>76</sup>

85. In response to questioning, the Commission's Chair, Sharon Grant, told us that CPPIH was born into "difficult circumstances". She indicated that the displacement of large numbers of people following the abolition of CHCs and the speed at which the new structures were set up contributed to the problem.<sup>77</sup> David Stout of the NHS Confederation concurred:

The shift from CHCs to PPI forums was done on the face of it in quite a hurry with perhaps less detailed planning for what exactly these forums were there to do, so there has been some degree of ambiguity about role and function.<sup>78</sup>

### Should the Commission for Patient and Public Involvement in Health and Patient and Public Involvement forums be abolished?

86. There is a widespread feeling that many PPIfs had done the best job possible given the circumstances they faced. Beatrice Rogers, Chair of the Leeds Teaching Hospital PPIf, summed up the feelings of many:

Any actual failure has been within the Commission itself, its inadequate leadership and the excessive cost. Their current inefficiencies have to be seen to be believed.<sup>79</sup>

87. Others stressed the variability of PPIfs.<sup>80</sup> It is possible that such variability is part of the nature of voluntary organisations, including PPI structures. CHCs were also of variable quality and there is no obvious reason why LINKs should be different.

88. Witnesses countered the Department's arguments. No one argued that PPIfs were fully representative of the communities they served. However, some witnesses suggested that a lack of representation of all races and religions on the PPIf itself did not matter as long as the work done was beneficial to the whole community. Professor Celia Davies argued that the actions of a group were more important than its composition:

Once somebody asks whether it is representative the whole argument collapses, because it never quite is. What one must do is ask whether the organisation will find ways to get to hard-to-reach groups and learn how to do that. Will it run events that bring together people from hard-to-reach groups in ways they find amenable?<sup>81</sup>

---

76 Ev 68 (HC 278-II)

77 Q 108

78 Q 266

79 Written evidence from Beatrice Rogers (PPI 35) [not printed]

80 Ev 31 (HC 278-II)

81 Q 32

89. Dr Brian Fisher of the NHS Alliance suggested that obtaining representative information from local people on a specific issue was in any case a “chimera”.<sup>82</sup> Eastern and Coastal Kent PPIf member Nora Warner stated simply:

There have been claims that we are too white, too middle class, too old...who else has the time, the income and the experience to devote chunks of their free time to wading through lengthy and verbose reports; sitting through and making sense of countless meetings; instigating inspections; calling PCTs or Trusts to account; carrying out surveys; suggesting solutions to problems?<sup>83</sup>

90. The presence of PPIf representatives at meetings is an easy way for patients to have a role in NHS decision-making. It also allows PPI at every stage of the process with no information being hidden or decisions made in secret. The long-term relationship allows for true engagement as both sides learn about each others’ views. Many written submissions spoke of the vital role this kind of representation plays.<sup>84</sup>

91. Several witnesses argued that PPIfs need not be abolished but could develop to undertake effectively the work that is proposed for LINKs. Penny Robinson told us:

I feel that the present system, if it was encouraged and developed and better resourced, if it just widened its remit a little, would be far more successful than dismantling everything and starting again from scratch.<sup>85</sup>

92. Witnesses argued that PPIfs roles could be extended. Some PPIfs, such as Southwark, are already involved in monitoring commissioning. More were keen to see greater patient and public involvement within commissioning. For instance, Richmond and Twickenham PCT forum stated:

Forum members...are committed to progressing the agenda for public and user involvement in the planning, commissioning and provision of local care services.<sup>86</sup>

93. Moreover, even those who accepted that LINKs might be a slight improvement, argued that the Government should not ignore the costs of change. A Forum Support Organisation stated:

It feels like any lessons learnt from the abolition of Community Health Council’s have been quickly forgotten.<sup>87</sup>

94. Finally, it was argued that the switch from PPIfs to LINKs would create a hiatus in patient and public involvement arrangements which would be convenient for the Government at a time of major and often unpopular change in the NHS.<sup>88</sup>

82 Q 251

83 Ev 221 (HC 278-II)

84 eg, Ev 128 (HC 278-III)

85 Q 228

86 Ev 212 (HC 278-II)

87 Ev 305 (HC 278-II)

88 Q 122

## Conclusions

95. For many years CHCs were the main forum for patient and public involvement in the health service. Following their abolition, PPI functions were taken over by a number of successor bodies, including PPIFs, PALs and ICAS. About the same time OSCs were established and subsequently their remit was extended to include health. Soon after the first foundation trusts were established with their Boards of Governors having a patient and public involvement role. Some aspects of patient and public involvement work are also carried out by the Healthcare Commission. The number of organisations now involved in patient and public involvement has led to concerns about overlap. In general the record of the successor bodies have been similar to that of CHCs: some good, some bad and some middling.

96. The Department provided a number of reasons for the decision to abolish PPIFs and CPPIH. There was a need to adjust to changes in the NHS, including the increasing diversity of providers, the growing emphasis on commissioning and primary care and the need to include social care within patient and public involvement structures. There were also concerns that PPIFs had too few members and were not representative of the communities they served. The present system is also too bureaucratic and does not provide value for money. According to other witnesses, the Department decided that it had to abolish CPPIH because of its manifest failings and subsequently abolished PPIFs as well, almost as an afterthought.

**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.**

## 4 Local Involvement Networks

---

### The Local Government and Public Involvement in Health Bill

98. The Local Government and Public Involvement in Health Bill gives effect to the Government's proposals for reform of the local government system in England and for reform of the current arrangements for patient and public involvement in the provision of health and social care services.<sup>89</sup> Part 5 of the Bill seeks to improve co-operation between local authorities and “local partners”, including “persons from the voluntary and community sector and local businesses”. Together they will come to Local Area Agreements, which include local improvement targets, and agree community improvement strategies. The Bill also seeks to strengthen Overview and Scrutiny Committees (OSCs) which, as we have seen, scrutinise the health service as well as local government. Thus, greater public engagement in local government is proposed to complement the changes to PPI arrangements within the NHS.

99. The Bill abolishes CPPIH and PPIFs and replaces PPIFs with LINKs. PPIFs are to be abolished before LINKs are established. The Bill provides some information about LINKs, including their:

- functions
- duties
- powers
- relationships with other organisations
- support organisations

However, there is little detail as we discuss below.

#### *Functions*

100. The Local Government and Public Involvement in Health Bill gives the remit of LINKs as:

Promoting, and supporting the involvement of people in the commissioning, provision and scrutinizing of local care services (including health and social services) obtaining the views of people about their needs for and their experience of local care services And making such views known and reports and recommendations to persons responsible for commissioning, providing managing and scrutinizing of local care services.

#### *Responses to reports and information requests*

101. The Bill provides that NHS bodies or in the case of social care, the Local Authority, must respond to LINKs' reports or requests for information. The independent sector

---

<sup>89</sup> See Explanatory Notes to the Local Government and Public Involvement in Health Bill [Bill 16 (2006–07)—EN]

(including the private and voluntary sector) will have to respond to requests for information but not to LINKs' reports or concerns about their services.

### ***Powers: Right of Entry***

102. The Secretary of State may impose a duty on service providers to allow an “authorised representative” entry. The Secretary of State has the right to limit the numbers, and “description of” visitors, and the hours during which they can visit. The Secretary of State has the right to impose restrictions on which members of the LINK can be authorised representatives, and in what circumstances the duty to allow entry applies. The Department stated in written evidence to the Committee that members would need criminal records checks and LINKs would not be allowed entry to facilities providing social care to children.<sup>90</sup> Draft documents supplied to us by the Department indicate that the Department intends to extend this duty to the independent sector by insisting on the requirement in their contracts.

### ***Relations with Overview and Scrutiny Committees***

103. A LINK has the power to refer social care matters to the Local Authority's OSC. The OSC must acknowledge receipt and keep the LINK informed. While it is obliged to take account of the information supplied by the LINK, it can decide whether or not to exercise any relevant powers it has. The Department has told us that LINKs will also have the power to refer healthcare matters to the OSC, but there is no reference to the power in the Bill since it does not require primary legislation.

### ***Duties: Reports***

104. The LINK must produce an annual report detailing their activities, how they have spent their money, and “such matters as the Secretary of State may direct”.

### ***Support organisations: hosts***

105. The Bill places a duty on local authorities to set up a ‘Host’ to run a LINK. The role of a Host is similar to that of a Forum Support Organisation, the bodies which support PPIFs. The Bill also states that Hosts, Local Authorities, NHS trusts, foundation trusts, PCTs, and SHAs cannot be LINKs.

### ***Lack of detail***

106. The lack of detail in the Bill about the form of LINKs or Hosts has been much criticised. There is no mention of membership, organisational structure or of how LINKs will be made accountable. The Department did provide the Committee with draft documents relating to Local Authorities' contracts with the Host, and on their powers of entry and to request information. However, the documents also indicate that the Government will consult about these powers, so the details will not be finalised until after the Bill has received Royal Assent.

## Early adopters

107. There are nine ‘early adopters’ or LINKs pilots. Two are run by the Healthcare Commission and seven by CPPIH.<sup>91</sup> The pilots started in December 2006. Inevitably, therefore they have had no input into the Bill and presumably very little input into the any guidance now being drafted.

108. On our visit to Medway we met Stephanie Goad and Jessie Cunnett from the early adopter project there. At that time they had had one meeting but had not decided whether to set up a LINK; further meetings with stakeholders were planned to decide what to do. They were discussing membership, structure and governance. After this consultation they might or might not go on to set up a ‘shadow’ LINK. When we asked about evaluation criteria we were told that the evaluations of the projects were being carried out formally and were being lead by the NHS Centre for Involvement and Office of Deputy Prime Minister. The project did not have a fixed budget, but was supplied with money as needed, for example to hire a venue. The people running the project did not know if there was a cap on the money they could spend. The project was being run by staff from CPPIH. There was therefore no Host organisation. Difficulties with contracting Host staff, accountability and conflicts could only be discussed rather than trialled.

109. We subsequently questioned Meredith Vivian about the ‘early adopters’. He told us:

They are not pilots; pathfinders might be a better word. They are testing out ways of working. All of them have been given a set of objectives which are asking them to focus on particular aspects. The Minister has mentioned one, what would make an effective governance arrangement, and others include how we can make sure we reach as many people as possible and are as engaged as possible with voluntary community sectors, how we can make sure that what we do is well-known in terms of communication and visibility, and there are other issues around how we can make sure the procurement process is as informed as possible.<sup>92</sup>

He added that these groups had been given a set of objectives by which they could be judged.<sup>93</sup> The early adopters will be evaluated, but the evaluation process cannot begin until after April when a baseline is to be established.

110. Mr Vivian stated that pilot studies had not been set up because the Department wanted LINKs to start work soon, rather than having, “to hang around for a long time waiting for instructions as to what we do next”.<sup>94</sup>

**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.**

---

91 Department of Health, *Local Involvement Network (LINKs) Bulletin*, Issue 1, March 2007

92 Q 454

93 Qq 455, 456

94 Q 461

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.

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.

### What Local Involvement Networks should do

114. The lack of detail in the Bill has led to confusion about what exactly LINKs are supposed to do, and what form they should take. Witnesses to the Committee had very different ideas about what form LINKs should take. Broadly these ideas fit into two models:

- The ‘PPIf Plus’ model
- The ‘Network’ Model

Most witnesses saw LINKs are having elements of both models and thought the Department had changed its position, moving away from the ‘network’ model, forming what might be described as:

- The Department’s Model.

### *The ‘Patient and Public Involvement forum Plus’ model*

115. One model for LINKs is similar to the best practices of PPIfs. In this model a core group runs the LINK. They make decisions about the LINK’s activities, can sit in on trusts’ boards and meetings, and undertake surveys or visits. They produce reports and challenge trusts if they are unhappy with the response. Members of the core can develop expertise on NHS issues and personal relationships with NHS managers and organisations.

116. They would also do everything they could to connect with local groups and find out a wider public view. Elizabeth Manero of HealthLink told us why she supports this model:

I totally accept the principle that there should not be an elite of people in the local community who are able to influence the Health Service and others who are not. That is a principle which I think we would all acknowledge but with LINKs, the proposal is to have a very, very large, “perhaps thousands of people”, involved in the Health Service. My worry about that is that it focuses on a process; it focuses on broadening a process rather than refining an outcome, because if you have thousands of people all saying the same thing, I am not quite sure why that is better than having a very focused approach, with a number of people who are trained and supported, one of whose obligations is to go and consult more broadly in the

community. If a smaller group of people can achieve something that everybody wants, I am not quite sure why we need everybody to be involved in the process.<sup>95</sup>

117. Several witnesses informed us that this was what good PPIs do already. Barrie Taylor of Westminster City Council OSC told us:

**Dr Taylor:** Would you agree as a sort of design idea with Elizabeth’s idea of a central group that feeds out into the others as a way to go?

**Mr Taylor:** Yes, but let us not fool ourselves as to what exists already. Honestly, I just think there is already a large amount of that going on.

**Dr Taylor:** This is exactly what PPIs are doing at the moment, is it not?

**Mr Taylor:** That is right. We cannot ignore that. That is really good work.

**Dr Taylor:** The good PPIs have already formed their own LINKs.

**Mr Taylor:** Of course they have, yes<sup>96</sup>

### **The ‘Network’ model**

118. The second model sees LINKs as a ‘true network’. Someone facilitates or runs the network, but there is no real core. The concept of membership does not really apply. Anna Coote of the Healthcare Commission was a powerful advocate of this model:

rather than the LINKs being there in the community, saying, “We are the patient voice. Come to us. We can speak for the patient in the community”, they are a network, a sort of junction box or a sort of facilitative mechanism, so it is not quite the same process as just going to the forum and saying, “Tell us what you think”, because we will need to know that the LINK has actually brought in the views of those organisations that are part of that network and I think that makes it more inclusive.... I feel the virtue of the LINK mechanism is that it is not a kind of entity in itself, a body that feels it speaks for the community.<sup>97</sup>

119. While several witnesses to the Committee agreed with the idea of a network, Anna Coote took it further than most by arguing that they should not have statutory powers:

if you say the LINK can inspect, who is going to do the inspecting? If the LINK is a network, it is not really a body that is designed to carry out an inspection, but it is a body that is designed to identify, and provide a conduit to, all the interest groups in the community, say, an open invitation to participate in follow-up enquiries as part of the regulatory process<sup>98</sup>.

---

95 Q 116

96 Qq 119–121

97 Q 175

98 Q 175

120. This model moves away from people speaking for others, but it sees LINKs as very passive organisations which the NHS has to make an effort to involve, thereby forcing the NHS to actively engage with the public.

I have always seen the LINK not as a body with independent rights and status, but as a facilitative mechanism, as a conduit, so that it is the place where the trust goes in order to be able to reach out to the community. Then the duty is on the trust to ensure that it has good relationships, that it does listen, that it does respond, and it is the duty of the Healthcare Commission to make sure that it does that.<sup>99</sup>

...part of the idea of LINKs is that it is really a permission slip to open up ways to involve people. Responsibility must be on the providers to open the door. If the door is shut it is very hard for people to be heard at all. The duty must be there and there must be an inspection of the extent to which they are involving people and that involvement makes a difference.<sup>100</sup>

The best thing I can say is that, if LINKs are working well, ..., a sort of amorphous, dynamic creature, well, it is drawing information from a whole series of areas which, within the provider area, we may not have access to, so, for me, the best thing is to be able to tap into another resource that has got antennae going all over the place.<sup>101</sup>

121. The Bill also provides for LINKs to refer matters to OSCs which would hold inquiries and publish reports. This opens the way to LINKs to feed their concerns into the OSC to investigate rather than undertaking investigations themselves.

### ***The Department's position***

122. Over time the Department has released more information about its plan for LINKs. It now appears that it is taking a position part way between the two models. On the one hand Meredith Vivian talked about patients representatives;

My guess is that LINKs will probably support that way of working (patient representatives sitting on boards) even more effectively because they will have a far wider range of people from which it can draw that kind of additional activity.<sup>102</sup>

On the other hand, Harry Cayton, the National Director for Patients and the Public at the Department of Health, told us:

It gives the patient participation group (active in many general practices) the ability through the LINK to speak with a united voice to other practices that have some experience of commissioning across the whole system. We talk about networks. All we are doing is helping to create networks where people are empowered. We know from all sorts of community action that little groups of people get together and the

---

99 Q 183

100 Q 38 [Dr Mayo]

101 Q 208 [Dr Day]

102 Q 67

more they do that and form larger groups the more influential and effective they become, and that is how community action works.<sup>103</sup>

Rosie Winterton MP, the Minister of State, confirmed that LINKs would be a mixture of the two models.

123. The Department was, however, reluctant to talk about ‘membership’ of a LINK. This and the focus on ‘dipping in and out’ implies that the Department is closer to the network model, with only some elements of the PPIF model. The draft documents supplied to us make this clear:

The governance structure should always seek to involve and communicate with the wider LINK membership in all its activities. It should not itself act as a consultative body or speak on behalf of the LINK without its involvement and consent.<sup>104</sup>

124. Whether this approach represents the best of both models or some confusion is unclear. We have heard from Sharon Grant of CPPIH that the Department has certainly changed its position in the long term:

We wanted to build something which we called “Our Health”, which involved a group of people around the forum, who were not forum members but who nevertheless wanted to be involved in some of those aspects and they could be formally belonging to this link. At that time that proposal was pretty much rejected by the Department as not being the direction of travel that was required at that time. We were not resourced to develop that at that time but now it seems the emphasis has shifted back to this idea of networking.<sup>105</sup>

125. The Department seems to have changed its position again more recently. Anna Coote told us that the Department was originally planning a ‘true network’, but this has since changed:

One of the important ideas behind the shift towards the LINKs was initially—I do not know if this has got lost—the idea that, rather than setting up an “us and them” arrangement, one emphasised the point that trusts themselves should take their responsibilities seriously to engage with patients and the public and that they should be the ones that really felt it was their duty, that they did not just have to respond to a body that was there in the community but that they had to do it, they had to make it happen and it was very important not just because it was a good thing in itself but it was actually good for them to achieve their objectives as providers of healthcare.<sup>106</sup>

126. As there are still many aspects of LINKs about which the Department has yet to provide information, it is hard to tell how far the Department’s view has changed. It should, however, be noted that the original proposals did not include a right of entry, but

---

103 Q 65

104 Draft document circulated by the Department

105 Q 121

106 Q 160

this has since been included, which supports Anna Coote's view that the Department is moving away from the network model.

## Concerns

127. Some witnesses were optimistic about the reforms, but there were concerns about all three models for LINKs.

### *Concerns with the 'Patient and Public Involvement forum Plus' Model*

128. It is feared that the PPIf plus model would have many of the weaknesses of PPIfs, which were described in the previous chapter: PPIfs were often unrepresentative and failed to attract volunteers; because NHS bodies were able to fulfil their PPI responsibilities by meeting the PPIf, a tick box culture was encouraged and wider consultation was discouraged; and the PPIf system was bureaucratic and poor value for money (although the abolition of CCIPH might largely remove this objection).

### *Concerns with the 'Network' model*

129. Witnesses also had a number of worries about the 'network' model:

- It will be less effective at holding the NHS to account;
- It will duplicate networks which already exist; and
- Involving a network of groups means that, by definition, it involves those who already have a voice.

### *Holding the NHS to account*

130. The aim of LINKs is to collect the views of a large number of people, but this could have disadvantages, in particular a loss of focus:

with LINKs, the proposal is to have a very, very large, "perhaps thousands of people", involved in the Health Service. My worry about that is that it focuses on a process; it focuses on broadening a process rather than refining an outcome, because if you have thousands of people all saying the same thing, I am not quite sure why that is better than having a very focused approach, with a number of people who are trained and supported, one of whose obligations is to go and consult more broadly in the community. If a smaller group of people can achieve something that everybody wants, I am not quite sure why we need everybody to be involved in the process.<sup>107</sup>

We are a small forum. On the other hand, I think being a small group makes us more effective in many ways in that we can work together effectively.<sup>108</sup>

---

107 Q 116

108 Q 216

The more time a LINK spent reaching out to the public, the less time it would have to scrutinise the NHS, compile reports and hold trusts to account for their actions. PPIf members told us that this was the type of work that produces results:

It really is very difficult for anyone to see, if it is going to involve thousands of people, how it is going to be organised. It will put a greater burden on the support organisation than there is at the moment. The wider you go I think the more disseminated, dissipated, the whole effort is going to be and there is not going to be the room for the close focus that is the only thing that produces results.<sup>109</sup>

the proposal I put to our forum which was adopted was that each member takes responsibility for a certain number of briefs and studies them, and is accountable to the rest of the forum for what he does in that area. That allows us to go across the breadth of the PCT and deep down into it because all of us cannot go, for example, to all the meetings of the Nursing Improvement Committee or the Urgent Care Committee, or whatever.<sup>110</sup>

131. If LINKs were to operate effectively as a ‘network’, NHS bodies would have to come to it to find the views of the public. One of the potential strengths of the network model is that it forces the NHS and providers of social care to be more proactive. Since there are no forum members to sit on boards and no forum which can be easily consulted, NHS bodies must make the effort to consult the wider community. However, this is also a potential failing. As we discuss in more detail elsewhere in the report, many witnesses thought that NHS organisations talked enthusiastically about PPI, but in practice many were not committed to it. If an NHS organisation chose not to make the effort to consult, there would be little pressure on it to do so.

### *Duplicating existing networks*

132. On our visit to Medway we heard that the Council had established a network of voluntary bodies which it consulted on a range of issues. There was a danger that the LINK would just duplicate this network. Other witnesses informed us that an existing network could become a LINK and receive its allocation of funding. Barrie Taylor of Westminster Council Overview and Scrutiny Committee told us:

I have a little bit of concern from the local authority point of view that what we might be putting into place is something that I think currently exists in a good format within their terms, and if you look at the evidence I have presented, you will find a series of agencies that are already in forums, are already in networks and they are very targeted. My worry is that what is likely to happen is that some local authorities may well find this government initiative and ability to try and form a LINK, fund it and you may well find that local authority reviews how it is currently working with its existing structures with the voluntary sector. So if, for instance, the monies that have been floating around, which is about £150,000 for LINK, a grant—I believe it is a three-year grant that is being proposed—what you may well find then is local

---

109 Q 227 [Ms Robinson]

110 Q 236

authorities reassess whether or not they are actually funding those other networks that currently exist. That is a reservation. It is not the way forward, obviously.<sup>111</sup>

### *A voice for those who already have one*

133. Witnesses also expressed their concern that a network would amplify the voice of existing organisations, but ignore the opinions of those who were not represented by an organisation.<sup>112</sup> LINKs would tend to seek the views of patient groups while ignoring the opinions of other groups of people such as healthy, working people. This is a group which the NHS is already unresponsive to; for example doctors' surgeries are mainly only open during working hours.

134. In some areas there are likely to be few organisations to participate in a LINK or those that exist may be short of money or have few volunteers:

Where there are few community development organisations in a locality, there is only a limited prospect for a meaningful LINKs to emerge. While it is vital for LINKs to retain their independence, it is also vital for the voluntary sector locally to be properly funded and supported in order to support the development of LINKs.<sup>113</sup>

### *Concerns with the Department's model*

135. As well as the problems with the two different models, we heard a number of additional concerns about the Department's plan to combine them, including:

- Trying to do the work of both models will result in too much work (and much of that work will be duplicating that of other bodies);
- There will be considerable variations between LINKs; and
- The lack of clarity will confuse volunteers, the public, Hosts and local authorities.

### *Doing too much*

#### **The scale of LINKs**

136. A major risk with the Department's model for LINKs is that they could end up trying to do too much. We received a considerable body of evidence pointing out how difficult it would be to run a network on the scale of a LINK.

I believe LINKs could be good because you are going wider and you are going to be looking at different sectors, more of the voluntary sector. My only worry is it could be too big and not manageable. If you take a county and bring all of the voluntary sector in, it could be unmanageable. I hope it is not but that is my biggest concern.<sup>114</sup>

---

111 Q 118

112 Written evidence from Albert Chapman (PPI 153) [not printed]

113 Ev 199 (HC 278-II)

114 Q 225

there would be one LINK for Hertfordshire. How many people? Over a million people. There are two PCTs, six or seven trusts and another 20 or so independent hospitals, 186 GP practices, and the LINK is supposed to be able to collect the views of all of those people, a million people in that particular county, about their needs, about their experience of all these services and to be the main conduit whereby all those views should go back to commissioners, to providers and, importantly, the regulator. At £150,000 apiece, it is very hard to see how those tasks could even be attempted, to be quite frank with you, and it is very important that people understood understand the scale of what LINKs are being asked to do.<sup>115</sup>

137. Yet the Department has also made it clear that as well as running an extensive network, LINKs would continue to undertake the work PPIFs currently do, including:

- Questionnaires and surveys;
- Community / citizen panels;
- Consultation and involvement workshops;
- Focus groups;
- Events and campaigns;
- Meet, listen to and record the views and experiences of local people.<sup>116</sup>

[source: draft document supplied to us by the Department]

In addition the Department wants LINKs both to focus more on overseeing commissioning than PPIFs do currently, and to cover social care.

### **Duplicating the work of foundation trust Boards of Governors**

138. Several witnesses expressed fears that were LINKs to focus on service delivery (as many PPIFs do now) they would duplicate the work of foundation trust Boards of Governors:

**Sandra Gidley:** It sounds to me as though LINKs will not have much impact on what you do?

**Dr Day:** Frankly, it will not. I do not want to make that too much of a negative comment because we have a very good patients forum and I would be very sad to see that disappear. If LINKs is its successor body then let us grab, as I have said in my evidence, the very best of the Community Health Councils and the patients forums and put those into LINKs and build on it. Let us not reinvent the wheel. Let us grab what we have got which is good.<sup>117</sup>

---

115 Q 121

116 Draft document circulated by the Department

117 Q 164

He continued:

I am going to sound like a cracked record because most of what I have heard from a lot of people this morning is a function of the foundation trust, of the board of governors and I am struggling because I am trying to think of what added value I can look for.<sup>118</sup>

Nigel Edwards from the NHS Confederation made a very similar point:

we have all been very taken by how foundation trusts and their governors and members have really taken that model perhaps to some extent to a level of involvement and engagement that was not fully anticipated by some of us when the policy was first introduced. So there are other dynamics as this process is evolving other than just the LINKs. The LINKs potentially could add some real value to that by providing over-arching structure and some input into commissioning but there are all of these other mechanisms too and we need to be encouraging providers and using methods like the Healthcare Commission standards and their inspection process to ensure that people are being able to demonstrate that they are fully engaging their local public and their patients.<sup>119</sup>

### Duplicating existing research

139. The NHS Alliance and NHS Confederation warned that LINKs should not waste time collecting data since a great deal of it on a wide range of issues was already available:

**Dr Fisher:** I agree that the data on which recommendations from local people are made should be as robust as possible. There are lots of different ways of getting that information; there is a huge amount of national and international data on things that patients would like in general; the Picker Institute delivers a lot of information about that, for instance. There are lots of surveys that have been done in similar populations to the ones in one's own PCT. So there is quite a lot of robust general information on which you can base decisions.<sup>120</sup>

**Chairman:** You did say that you should have the data and the data is available, but the real question is do they, in practice and in your experience, have the data as opposed to it being available and they should have it?

**Dr Fisher:** Yes, it is available. A good PPI forum or a PPI part of the PCT should be able to get that within 15 minutes. It is not difficult to get it. The King's Fund will provide it; lots of places will provide the data. Again, even if you provide it you could provide a very efficient set of information to the PCT.<sup>121</sup>

Professor Coulter was of the same opinion:

---

118 Q 208

119 Q 256

120 Q 251

121 Q 252

I do not think they should collect it [data on public opinion]. I think it would be a terrible waste of time to have them collecting it because it already exists. For example, in this country, which is unique in the world, we have a national patients' survey programme. Every single NHS organisation has to survey their patients on an annual basis. There is quite a bit of public money spent on that programme and it is terribly badly used. ... Since those surveys get quite a good response rate, including from the groups who, as I say, would not dream of coming to a committee, from people in disadvantaged groups, people from minority ethnic groups and so on, they are all represented in these surveys, there is a lot of meat there that can be used to ensure that the LINKs have access to a much wider view than they are ever going to be able to be in touch with face-to-face.<sup>122</sup>

### Work the NHS should do itself

140. We have also heard that in cases where detailed data was not available, LINKs were not the right organisation to collect it; responsibility should lie with the NHS. The two representatives from the NHS Confederation made this argument:

I think there are some issues about the rigour you need to do the sorts of studies, such as the quite impressive sounding one we heard described, which are methodologically demanding as well as having some quite significant resource implications but, if these are important questions that either providers or commissioners should be asking, then it might well be that if there is an issue about, for example, waiting times in a genitor-urinary medicine clinic and the need to go and find user opinion, a commissioner or provider that was presented with some early signs that there was an issue would be well advised to go out and research that properly themselves, maybe through helping the patient's forum or the PPI machinery to do that.<sup>123</sup>

We need to be clear who is responsible for what. To expect PPI forums or LINKs to do everything that your question suggested I think is a little unrealistic. To expect a PCT and commissioning services, as Nigel says, to undertake effective review of data and get hold of information having been alerted to a problem by a PPI forum or a LINKs is entirely reasonable. ... You want the patient/clinician relationship to be absolutely based on anecdote; you want big commissioning decisions to be influenced by the stories you hear and then followed through with a slightly more robust objective assessment. We are in danger of doing what we said earlier and seeing PPI is one thing when it is many things.<sup>124</sup>

141. The Committee also heard concerns from Professor Coulter that LINKs might not be best placed to research the views of "hard to reach groups":

LINKs are supposed to have a broader focus but they are going to have very tiny resources, they are going to have very little in the way of support as I see it, and these issues are so much more important. It is going to be incumbent on the statutory

---

122 Q 335

123 Q 253 [Nigel Edwards]

124 Q 253 [David Stout]

organisations to make sure that they go and, for example, consult the people who are seldom heard, the people who have multiple needs that span health and social care. Hopefully LINks will be in there too but I really do not think LINks are going to be the answer to all of this.<sup>125</sup>

142. In contrast to this we heard from Mrs Beesley, a former member of a PPIF:

I think the best thing that our forum has done was our GP survey. That was the most wonderful experience, meeting the public. We did 687 individual questionnaires and we evaluated 1,477 comments.<sup>126</sup>

Mr Silverman a member of Southwark Patients Forum for Primary Care expressed a similar opinion:

the issue that arose was that there was a cultural and religious need amongst some communities to be able to choose a woman doctor, and when we made some inquiries we found this was not just a religious and cultural issue ... Now, we are looking at the right of women to choose the gender for access. For example, what practices have women doctors? Are those women doctors of equal seniority to the male doctors if you choose a woman doctor? ... There is no pathway through patient choice that gets you along to a woman doctor, so we are trying to find funding—and this is very important—to do some research on woman's attitudes into the gender of the health professional they need... we will make it happen until we get something we can take to the PCT and it should be an influence on commissioning.<sup>127</sup>

143. Clearly PPIFs are currently doing work that is far more detailed than some witnesses consider necessary. The question arises as to whether the role of LINks should be to identify issues and press for action or undertake detailed research. Dr Fisher of the NHS Alliance stressed the importance of the former:

But I would like to make a point about practice-based commissioning in that you might be able to provide to the practice-based commissioning group but at this point there is no onus on them necessarily to have to do anything about it. The data is important, but however good the data is there is still another question about whether people respond and whether they are in any sense accountable.<sup>128</sup>

144. It seems unlikely that the Southwark PCT is unaware that there is a need for patients to be able to choose the gender of their doctor. If the role of LINks was to raise the issue rather than to substantiate it, their workload would be reduced and they would have more time to hold the NHS to account.

---

125 Q 325

126 Q 216

127 Q 243

128 Q 252

### Local variation

145. As LINKs are to have a wide remit, and will have to choose which areas to focus on, some witnesses expressed concern that there would be wide variations between LINKs. Some were concerned that this would be both unfair and that it would make it hard for the public to know what LINKs were for. Sharon Grant of CPPIH told us:

One of the drivers behind the move to the system we have now was the need for some kind of uniformity, for there to be a recognised entity at every local level in which patients and the public could have a say on health and social care. We now seem to be moving away from that, which is worrying, and it seems to be the objective that we do not have consistency, that we let a thousand flowers bloom.<sup>129</sup>

On the other hand, other witnesses saw this state of affairs as a natural outcome of local decision making, rather than a weakness.<sup>130</sup>

### Confusion

146. The Committee also heard that the radical changes to the system of PPI, and lack of clarity about what was expected, would create difficulties for volunteers and for the Hosts. Ms Robinson of United Bristol Hospitals Trust Forum told us:

any new organisation is going to start again from scratch and is wasting so much experience and so much good practice that I cannot see that there is going to be a smooth transition, and I think it is very hard on the forum support organisations who have been doing a good job within, as you say, terrible financial constraints.<sup>131</sup>

She continued:

It really is very difficult for anyone to see, if it is going to involve thousands of people, how it is going to be organised. It will put a greater burden on the support organisation than there is at the moment. The wider you go I think the more disseminated, dissipated, the whole effort is going to be and there is not going to be the room for the close focus that is the only thing that produces results.<sup>132</sup>

These concerns were echoed by Sharon Grant:

You will have to have 150 simultaneous commissioning processes, tendering processes going on at the same time in order to make sure that every LINK is supported, and if it is anything like our set-up period, it will take some time for the host to learn what their function is, and it will take time for them to undertake the necessary community development work to grow LINKs as an organisation and to decide how in that particular area, going back to Dr Taylor's point, it is going to be

---

129 Q 134

130 Q 38

131 Q 224

132 Q 227

structured and governed, et cetera. There will be all these processes going on separately at a local level without any overall co-ordination guidance or advice.<sup>133</sup>

Barrie Taylor of Westminster Council OSC told us:

It will come back to variability again. Let us assume that local authorities have some grasp of knowing what it is they are going to expect from the LINK host. Competition will then exist between agencies as to what they will propose for that.... There are no set standards ...and then local authorities will have a complete morass of proposals, some of which may look good but there will be no basic standards set for them; they will be interpreting for themselves how that operates.<sup>134</sup>

147. This confusion could have an effect on volunteers. As David Stout stated.

I think there is a risk of that. What I would be looking for in order for this to work effectively is, as far as one can, to minimise that risk by welcoming existing forum members into the new structures and (which I think is happening) having a proper debate about how the new structures will be set up rather than rushing straight into it. I grant you there is a bit of a conflict there. The longer you take over setting the new structures up the more uncertainty you create and potentially the more people walk away, so I think we have to have a balance there.<sup>135</sup>

148. On our trip to Medway we heard that some of those involved in the ‘early adopter’ project thought that the lack of a clear purpose or governance structure was causing problems for the project site. The desire not to impose any structure on people appeared to be making the start-up process very slow, although we were told that the project had only been running since the start of the calendar year. With no information on how a LINK will make decisions, or who could make them, it was proving hard to make progress in relation to the LINK. We are not convinced that those taking part in this early stage of the project seemed clear about either what they were supposed to achieve or how they were to achieve it.

149. The result may be an absence of PPI at a crucial time for the NHS, as Sharon Grant of CPPIH told us

We would be in favour of development rather than scrap, have two years further gestation to grow capacity, and then start again. The point is that that two years is going to be a critical two years in the context of system reform, particularly in the context of commissioning, which it is said that LINKs are going to be focusing on. By the time LINKs get to be functioning, one is concerned that a huge number of huge commissioning decisions will have been made and contracts will be let which are for five or 10 years and from which the public has been by and large excluded.<sup>136</sup>

---

133 Q 137

134 Q 137

135 Q 268

136 Q 122

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.

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.

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.

### How to make LINKs effective

153. As we saw in Chapter 2 there are good reasons for separate PPI structures such as LINKs to supplement the work of OSCs, PALs, ICAS, foundation trusts and the Healthcare Commission. In the previous section we looked at the different possible models for LINKs and the potential problems they may face. Here we consider what must be done if they are to be effective and what issues need to be resolved, including:

- Clarity about what LINKs should do;
- Membership;
- Marketing and communication;
- Training;
- Hosts;
- Accountability;
- A national body;
- A period of stability.

First, however, it is important to establish what resources are available to LINKs. Only then will it be possible to determine what LINKs should do.

## Resources

### *The cost of LINKs*

154. As we have seen, many witnesses stressed that, despite their small scale and small membership, PPIfs were under-resourced. Mr Silverman of Southwark Patients Forum for Primary Care told us:

We have a job to do but there have never been the financial resources to allow it to be done and that has an impact on recruitment because you need to go out and make people aware that you exist, understand what you do, and that leads to a healthy recruitment. Without those kinds of financial resources and without the support, which there has never been, those things have faltered.<sup>137</sup>

He continued:

Our allowance in time [support provided by FSO staff] is roughly about 12 hours a week, and if you want to be a proactive forum engaged on a lot of fronts, as we are rapidly beginning to be, then it can be overwhelming. There just is not enough support resource to do the job properly.<sup>138</sup>

155. If LINKs are to be a network along the lines the Department has proposed they are likely to cost considerably more than PPIfs. Secretarial and administrative support will be required as well as facilitators, i.e. people with expert people skills and a knowledge of the NHS who can bring people together and help them reach agreement. As Frances Hasler of CSCI told us:

The facilitation that is needed, and whether it is training I do not know, is helping to map people through what can be changed and how it can be changed.<sup>139</sup>

156. If, as the Government hopes, a much larger number of volunteers take part there will be a significant increase in costs to cover, for example, more volunteers' expenses, more administrative support, more publications. Money will also be needed to hire large venues for people to meet, as well as employing staff to keep in touch with all those involved in the LINKs. In addition, the Department is proposing that LINKs provide training and mentoring to some of the voluntary organisations which would also be expensive.<sup>140</sup>

157. Whatever form a LINK takes, it could have nearly 200 NHS organisations in its area. Keeping in touch with all these organisations, let alone contributing feedback to them will be a massive undertaking.

158. We were also told that LINKs would need assistance both to enable them to make use of the huge amount of research data which is available. Dr Fisher told us:

---

137 Q 216

138 Q 223

139 Q 338

140 Draft document from the Department

There are data crunchers that should be available to LINKs or PPI forums... the local authority should be providing statistical support and so on, so there are people around to do it.<sup>141</sup>

159. CPPIH agreed that LINKs would be expensive:

if you are serious about involving people, it costs money, and if we really mean what we say about the importance of patient and public involvement in our National Health Service and our social care services and if it is as important as everything else, we have to resource it, particularly if you are using volunteers. They expect to have their expenses paid, they expect to be trained and they expect to have administrative support for all that they are doing. It cannot be done on the cheap.<sup>142</sup>

### *The Department's position*

160. The Minister told us that the abolition of CPPIH would see £9 million redirected to the front line and this would result in one third more money for LINKs than PPIs received directly:

We know at the moment that for example something like £16.5 million goes out to forum support organisations to assist with servicing their patient forums. On top of that there is about £9 million that currently we spend on the Commission on CPPIH. What we want to do is put that money out there at the front-line so that it is going direct through the local authorities to the LINKs themselves. That will increase the amount of money which is spent on servicing the LINKs themselves.<sup>143</sup>

She repeated the £9m figure several times during the evidence session.<sup>144</sup>

161. In contrast, CPPIH calculated that the actual saving would be “approximately £1.5 million” since a number of CPPIH functions, such as contracting with, and the performance management of, FSOs (which will be replaced by Hosts), running websites, training volunteers, and undertaking criminal records checks of those who wished to use the ‘right of entry’, would still have to take place.<sup>145</sup> If LINKs choose (as seems likely) to set up a national body the saving would be even less.

162. Harry Cayton seemed to agree that the functions would have to be performed and paid for:

of course everything the Commission does is to support forums. What we are saying is that the majority of the money should be able to get into the front-line rather than supporting big infrastructure.<sup>146</sup>

---

141 Q 253

142 Q 110

143 Q 411

144 Qq 411, 418, 419

145 Ev 111 (HC 278–III)

146 Q 425

Presumably, he meant that Local Authorities, Hosts and LINKs could do the job more cost-effectively than CPPIH.

163. In addition, the Minister told us there would be “economies of scale” since there would be fewer Hosts than FSOs:

I think where it will be an improvement is because there will be fewer contracts... Rather than each little patient forum just having a little bit of money, you will have one LINK with considerably more money<sup>147</sup>

She added:

Also, as I have said, the number of patient forums themselves goes down from 398 into the LINKs of which there will be 150, so a lot of the duplication actually ceases and can be put, as I have said, more into servicing people on the front-line.<sup>148</sup>

164. Others claimed that the opposite would be the case. Many FSOs support several (often 10 or 15) PPIFs, thus creating considerable economies of scale. There are likely to be more Hosts than FSOs: since each Local Authority will contract separately for a Host, there may well be a different Host for each LINK.

165. The Department argued that PPI did not have to be expensive; Harry Cayton pointed out that it would cost him nothing to walk to Trafalgar Square to speak to the homeless.<sup>149</sup> The Minister told us:

We have got a meeting tomorrow in Durham where 120 people are coming along to discuss how they want to get involved in patient and public involvement. We know there are voluntary organisations out there in all our constituencies, whether it is Rethink, the Alzheimer’s Society or Age Concern, all of which would be interested in contributing to the process. That does not have to be enormously expensive.<sup>150</sup>

However, CPPIH told us that support to enable three deaf people to attend a meeting cost £1,200.<sup>151</sup> Other witnesses provided examples of expensive projects. For instance, finding out the views of black and minority ethnic residents in Westminster cost £10,000,<sup>152</sup> CSCI is spending £64,000 gathering the views of 10 care leavers.<sup>153</sup>

166. Nevertheless, the Department is certain that LINKs will have enough money. Harry Cayton told us:

It is always possible to add up all the things that you might possibly want to do and come out with a headline figure. That is what people do when they are applying for

147 Q 428

148 Q 419

149 Q 440

150 Q 412

151 Ev 111 (HC 278–III)

152 Kensington Chelsea and Westminster BME forum, *Minding the gaps, Are BME groups partners or substitutes in health provision*, July 2006

153 The children’s champions: Youngsters raised in care could soon play a vital role in assessing the local services that have shaped their lives, *The Guardian*, 28 February 2007 [www.guardian.co.uk](http://www.guardian.co.uk)

grants. What any decent organisation does is look at the money it has got available and does the best that it can with those funds. I believe that the kind of sums we are talking about are adequate. I would not say they are riches beyond the dreams of avarice but they are adequate for a good organisation to run a decent service.<sup>154</sup>

However, subsequently he seemed to slightly modify his view:

and I am sure that as time goes on we will look at the product that comes out of LINKs and think about whether the resources are indeed the resources that they need.<sup>155</sup>

CCIPH, on the other hand, costed the proposed LINKs at £64 million, or more than double the current budget of £28 million.<sup>156</sup> In view of this, the organisation fears that LINKs “are being set up to fail”.<sup>157</sup>

167. Given the concern about costs it is surprising that the ‘early adopter’ projects do not have a set budget to discover what can be achieved with the money (see Chapter 4).

**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.**

**169. 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”.**

### ***What Local Involvement Networks should do***

170. Some witnesses were reluctant to specify what LINKs should do.<sup>158</sup> This is not surprising since LINKs are to be ‘bottom up’ organisations which are not controlled from the centre. As we have seen, some witnesses do not believe LINKs should have an ‘output’; rather, the LINK would be consulted; any output would come from the NHS or other body making use of the LINK.

171. However, other witnesses thought that there should be an output and LINKs should know what they were expected to do. Mr Stout of the NHS Confederation told us:

---

154 Q 419

155 Q 419

156 Ev 106 (HC 278–III)

157 Q 110

158 Q 38

Clearly some of the devil is in the detail and the specification for what LINKs has to do is pretty critical...I do not think that specification should be saying how to do it, but what should be clear to the local authority commissioning the Host organisation is what it is we are supposed to be commissioning, what is the output we are trying to get out of this, and the more that is defined clearly the more effective LINKs are likely to be.<sup>159</sup>

172. Most witnesses agreed that the Government should clarify what LINKs were expected to do. Recommendations included ensuring that LINKs:

- focus on areas where their work can be of the most use to the NHS and therefore provide the most benefit for patients; and
- make the best use of their members' time and a limited budget: this would mean that they should:

avoid duplication with the work of other bodies (particularly foundation trust Boards of Governors); and

ensure that research was undertaken by groups with the right skills.

### *The Department's view*

#### **The most useful work: commissioning**

173. The Department stressed that it did not want to prescribe what LINKs should do, but thought that commissioning should be their priority. In its written evidence the Department explained why:

PCTs and other commissioners are the power base of the new NHS, with 80% of budgets being devolved to them. In the future there will be an increasing mix of providers, meaning that the old system of user involvement, that was focussed around individual NHS institutions is no longer appropriate.<sup>160</sup>

174. Many witnesses supported this proposal. Elizabeth Manero of HealthLink thought this could be popular:

We have had people working with carers in dementia saying to us “We do not want relatives to be treated in acute hospitals where the nurses do not know anything about dementia and think people with dementia are just stupid.” That is a very important quality standard which should be put into commissioning.<sup>161</sup>

175. However, other witnesses stressed that overseeing commissioning was not very attractive to volunteers. In Medway we heard how the local PCT forum tried to recruit members but nearly all of them preferred to join the Acute Trust's forum and oversee service delivery. We heard similar accounts from other witnesses:

---

159 Q 25

160 Ev 2 (HC 278-II)

161 Q 132

In our experience patients and their carers describe that they are keen to be involved at a local level where they can see the benefits and changes that occur as a result of their actions or feedback.<sup>162</sup>

there is no doubt volunteers find it far easier for very obvious reasons to focus on service provision because you can see what is going on. You can go in, you can monitor. When you are talking about commissioning there are quite difficult concepts to doing that<sup>163</sup>

176. The idea of commissioning being very complex is supported by others. Mike Sobanja of the NHS Alliance told the workforce planning inquiry:

I think it was in 1990 that I was appointed director of commissioning in a health authority. I observed at the time that I did not know what the job was, and I do not know that much better what it is now.<sup>164</sup>

Dr Jonathan Tritter told this inquiry:

...Commissioning decisions made at local level have to take into account national targets, local priorities, existing epidemiological evidence and also different communities of interest. It is the balancing of those different tensions which makes those decisions so difficult. Greater transparency will help to justify and provide an account of how those decisions are reached.<sup>165</sup>

177. When Harry Cayton was asked whether patients would want to get involved in commissioning decisions he replied;

I have attended a lot of patient participation groups in practices and many have a constructive engagement with their GPs. There is bound to be variability when we give local responsibility to people. There will be variability in the commitment, far-sightedness and imagination of GPs and also in the quality of patient participation groups and LINKs, but I argue that unless we allow these mechanisms to be created and have incentives of various kinds in the system to achieve good quality we will not develop anything like the kind of dynamic dialogue that we would like to happen. with volunteers one always needs to start from where people are.<sup>166</sup>

178. Dr Mayo told the Committee:

I agree that the issue of commissioning is more obscure to ordinary people and patients and yet it is key to whether services are delivered in responsive ways. One needs to build up the involvement so that one can take people voluntarily into that,

---

162 Ev 155 (HC 278-II)

163 Information from *Anatomy of Accountability*, Centre for Public Scrutiny Conference, 30 November 2006

164 Health Committee, Fourth Report of Session 2006–7, *Workforce Planning*, HC 171-II, Q 862

165 Q 5

166 Q 64

but, as with the public at large, when dealing with volunteers one always needs to start from where people are.<sup>167</sup>

179. It would be possible to conclude from those two answers that while it is felt that PPI could add a lot to commissioning not enough thought has gone into how to make it attractive to the public. As Sharon Grant stated:

We are at the very early stages of starting to look at exactly how that can be done. Commissioning is a highly complex process at one level, and we are not here trying to turn patients and the public into experts but we are going to try and find a level at which the public can usefully engage and influence the way in which commissioning is carried out. We have just started to do that.<sup>168</sup>

### **Making best use of LINKs' members' time**

180. As we saw earlier, there are strong arguments that LINKs should avoid duplicating work which has been done by other organisations or of undertaking tasks which other organisations were better equipped to do, including research, contacting 'hard to reach' groups and the work undertaken by foundation trust Boards of Governors, in particular service delivery. Questioned about this, the Minister again refused to be prescriptive. She told us:

So it is giving the LINKs the ability to look from the point of view of the patient as to what happens to them during that journey, going through all the different stages of care, which means that they have got much greater power over that patient journey and what they can look at, but it involves also the social care side. As you know, that is another new power we are giving to LINKs, but it is up to the local LINK to decide what it wants to prioritise. We are not saying you have to look at every single thing.<sup>169</sup>

She was also unwilling to prevent or discourage LINKs from looking at certain areas to prevent duplication.<sup>170</sup>

181. However, she seemed to think that rather than reaching out to unheard groups themselves, LINKs should ensure PCTs were doing so:

If a LINK was working well I hope it would have service users and people who are members of, and in touch with, local organisations like Rethink or MIND, and I hope they would become members of the LINK so they would be contributing to the process whereby the LINK says, "That is interesting. You are telling us that you do not feel that the mental healthcare services are reaching out enough at the moment to help people within the community. PCT, what have you got to say about that?" and the PCT has a duty to respond to that and say... "we have invited them [Rethink and MIND] in to discuss why people are facing these problems".<sup>171</sup>

---

167 Q 37

168 Q 133

169 Q 410

170 Q 438

171 Q 439

Later she seemed to move away from this slightly:

All in all, it is a kind of general approach. You cannot necessarily pigeonhole things and say, “That is the job of the PCT, that is the job of the LINK”. If a LINK is going to be effective it has to be working closely with the PCT. It is an iterative process, if you see what I mean.<sup>172</sup>

182. We asked the Minister whether LINKs should collect information themselves or seek to make use of existing information. She replied:

Probably a mixture. My feeling is that we do have quite massive amounts of information collected but whether we use it as effectively as we ought to is rather different.<sup>173</sup>

But she continued

I would not like to say to LINKs “you can only use this information”, because they might say, “Yes, but we would like to go and have our own views, thank you very much.”<sup>174</sup>

183. The Minister agreed that the lack of prescription would inevitably mean that different LINKs would do different types of work:

We do want them to produce an annual report as to what they have done and we do want to say, “These are your new powers which we believe are much extended,” but we do not believe that within that it is necessary for them in every different part of the country to do exactly the same thing.<sup>175</sup>

**184. 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.**

**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.**

---

172 Q 439

173 Q 441

174 Q 441

175 Q 410

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.

### *The membership*

#### *Optimists and pessimists*

187. Witnesses disagreed about whether there was a large number of people and organisations who would be keen to get involved in LINKs. One group, which might be termed the optimists, argued that people were potentially keen, but were discouraged by a variety of considerations. Harry Cayton told us:

If being a member of a LINK is a miserable activity—a bit like, I fear, being a member of a forum today when it has been through such a difficult time—why would somebody bother? Any organisation that wants to build its membership needs to provide support, encouragement and love for its members.<sup>176</sup>

Richard Stein of Leigh Day and Co Solicitors agreed:

There are lots of people in the community who will give their time and who have the skills and the expertise to make a valuable contribution. What the NHS needs to learn to do is to make it feel worth their while.<sup>177</sup>

He continued:

It is not that they are not interested but they think to go along to the meetings and the framework and the way it operates is not going to make it worth their while being there because they will not be heard in a significant or appropriate way.<sup>178</sup>

188. On the other hand, another group, the pessimists, believe that PPI work is by its nature boring and that very few people would want to do it. Professor Coulter told the Committee:

we have heard a lot, and it is an important issue, about the extent to which people do or do not want to get involved in hospital friends or in sitting on LINKs or PPI

---

176 Q 85

177 Q 385

178 Q 383

forums or whatever. That is a real problem because it is only a tiny proportion of the population that does want that<sup>179</sup>

She added

It is the people who have the time. Other people with more problems in their lives just do not have time to sit on committees or to do some research into what patients think about their practices or whatever.<sup>180</sup>

189. The BMA's evidence suggested that it not be easy to find suitable people to play an active role in LINKs:

There are few people who have the capacity to really engage, and to find ways of engaging others. Capacity is about having time, self-confidence, access to technology, the ability to spend hours reading lengthy and often turgid official documents, political skills, committee experience and the availability to attend meetings during working hours as well as outside them.<sup>181</sup>

190. The pessimists pointed out that hopes that voluntary organisations will make a major contribution to LINKs may be disappointed. According to the West Sussex PPIf Chairs:

the CHCs were established to include direct membership of voluntary organisations and in West Sussex at least, had difficulty in recruiting people with sufficient time and interest. Our PPI Forums have endeavoured to gain support and input from voluntary organisations, but generally unsuccessfully. Voluntary organisations and their active members are concerned with their 'cause'. Trusts do consult and include them in specific subjects but there is no evidence to suggest that their members feel isolated from the NHS or would wish to broaden their contribution to it.<sup>182</sup>

In Medway we were only able to meet a representative from one voluntary organisation as members of the other three organisations we had hoped to meet were unable to attend.

191. Many people are very concerned about hospital closures and will campaign against them. The optimists thought this showed the potential for a wider involvement in patient and public involvement; the pessimists did not.

### *Keeping the volunteers*

192. A few witnesses were concerned about some of the members of PPIfs. Richard Stein told us:

unfortunately my experience, which is again usually when these things do not work very well, is that there is a handful of busybodies, to be rather blunt, who have their own obsessions that are not necessarily the ones that most people care about and who, understandably, are the kind of people who, when you have to have meetings

---

179 Q 330

180 Q 334

181 Ev 31 (HC 278-II)

182 Ev 276 (HC 278-II)

with them, are not really helping at all. In that situation, it is a spiral of decline. They will end up being there, but they will not have anything to say, so you will not involve them.<sup>183</sup>

193. Mary Adams argued for a rapid turnover of members:

It is just this idea of keeping freshness... I am just thinking of the people that might come forward and what they are like...I think in that way, if you limit it to three years, you will always have a kind of freshness so that people do not become institutionalised and become the kind of usual suspects that always are there contributing. It is a way of limiting that from happening.

**Mr Amess:** So you want to get shot of them if they become absolute bores and a bit of a nuisance? It is probably not a bad idea!

**Ms Adams:** If they become too professionalised, if they stop being as lay in their perspective as they might be.<sup>184</sup>

194. Others, however, were far more worried about losing volunteers. David Wood from the charity Attend told us that overall numbers of volunteers are falling.<sup>185</sup> This will become more acute as more hospital trusts achieve foundation status and the new bodies try to encourage individuals to join their Boards of Governors. As Nigel Edwards told us:

I just see a real hazard here, first of all, of cannibalising a relatively small number of people. We already have a bit of an issue in some areas where, if you have a mental health trust and an acute trust, there are a limited number of people you want to get involved in this way, and that we have cannibalised people's willingness between different and overlapping (and often maybe unhelpfully overlapping) bodies.<sup>186</sup>

195. There are such a small number of people prepared to take part it is important they are looked after, both to prevent them leaving and to enable them to make the most of their time.

**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.**

### **Right of entry**

197. Many witnesses argued that LINKs should have a right of entry. Elizabeth Manero told us:

---

183 Q 385

184 Qq 198–9

185 Q 326

186 Q 275

I see the visiting rights not as inspection but as the furtherance of a dialogue and relationship between the community and the Health Service... if you are going to exclude forums or LINKs from actually going into NHS premises, you are saying that the views of the population on the Health Service are not relevant if they are using the Health Service at the time.<sup>187</sup>

Mrs Robinson from United Bristol Hospitals PPIf said that:

one of the things that forums can do is support hospital staff when they visit. It is not just a question of patients. Often staff take us on one side and say: “We have been pressing and pressing for this, we would really appreciate it if you could put a good word in”, and we do find sometimes that tips the balance.<sup>188</sup>

She continued:

I think this has already been said but we do not want any dilution of our statutory rights. They are the basic minimum with which we can function. We must be able to go into premises and see what is going on. Whether you call it inspections or visiting or whatever, we have to be able to go and talk to people.<sup>189</sup>

198. The Department’s draft document provided more details about LINKs’ right of entry. LINKs will not be able to visit:

until they have written to the relevant regulator, indicating their intention to visit a facility, and received a reply—this is to ensure that there is coordination of activity at a local level; it may be that the regulator already plans a visit in which case it will have the ability to request that the LINK holds off, or just as possible joins in with its review.

199. LINKs will be allowed to visit not only places providing NHS care, but also some social care providers, including communal areas of nursing homes, respite care, and day centres, However they will not be able to visit the homes and hostels of those with disability, mental health problems and learning disabilities, or any institutions providing social care for children.

200. CPPIH was unhappy with the draft document, particularly as it applied to the NHS:

In effect the proposals make a mockery of the visiting rights of the new LINKs. It appears that before any visit can take place, they will have to write to, and obtain a reply from, the regulator, i.e. the Healthcare Commission! This gives the lie to any notion that LINKs will be able to be free and independent in the way that they work, and other proposals will severely curtail the locations which they will be permitted to enter and observe services in delivery.<sup>190</sup>

CPPIH went on to claim that:

---

187 Q 131

188 Q 219

189 Q 240

190 Ev 140 (HC 278–III)

This would have the effect of preventing LINKs carrying out informal visits and unannounced formal visits, because of the requirement to give written notice of a visit. It also enables the regulator to place barriers in the way of LINKs making use of any right to visit premises, creating unnecessary bureaucracy and potentially preventing the LINK from following up concerns raised with them by service users or concerns raised in the media in a timely manner.<sup>191</sup>

201. Rights of entry to social care premises are more complex than to NHS care. Frances Hasler from CSCI was concerned that:

Social care takes place in people's homes, either in a residential care home or in their own private homes, which is very different from the vast majority of healthcare that people have been talking about today which takes place in public spaces, so one of our concerns was the absolute control of this ought to rest with the people whose homes are being talked about. . . . . In the proposals that we had seen it was not very clear how this would look and feel different from inspection from the provider viewpoint, or indeed sometimes from the viewpoint of people who live in care homes. One of the things we know from talking to people is that they can quite often feel they are the ones who are being examined when someone goes in. Although that is not the intention of inspection it can often feel that way.<sup>192</sup>

However, she did not think LINKs should be banned from visiting social care premises:

**Dr Taylor:** I think you said it might be possible for residents to invite LINKs in?

**Ms Hasler:** I would like to hope it would be. Again, in open institutions, and many, many care homes are very open to the local community and very vibrant, and sometimes you go to some care homes and no-one is at home because they are all out doing things in their local community, in those sorts of places there are already good links. I would hope people who live in care homes would sometimes want to influence the commissioners of services through the LINK and that is one way they can do it.<sup>193</sup>

CPPIH agreed, informing us:

Clearly the LINK should not be able to enter the home within a care facility of a service user without his or her permission, but it should be the service user who is able to refuse entry not the provider or owner of the facility. There may be cases where service users wish the LINK to visit.<sup>194</sup>

**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,**

---

191 Ev 140 (HC 278–III)

192 Q 346

193 Q 352

194 Ev 141 (HC 278–III)

**LINKs should have the same rights in relation to social care premises with due regard for the needs and wishes of the residents.**

### **Marketing and communication**

203. PPIfs have suffered from a low profile. Optimists took the view that with better marketing and communications LINKs could have a much higher profile and attract many more members. Money spent on advertising could be well-spent, as PPIf members told us:

We have a job to do but there have never been the financial resources to allow it to be done and that has an impact on recruitment because you need to go out and make people aware that you exist, understand what you do, and that leads to a healthy recruitment.<sup>195</sup>

When you ask your support organisation: “Can we advertise to try to get it in the paper?”, it is always “There is not enough money”, so apart from knocking on doors I really do not know the answer. I would like to see more put into recruitment.<sup>196</sup>

Nobody knows what forums are and if they do not [know] what forums are after three years how are they going to know what LINKs are when they are first set up?<sup>197</sup>

204. It was claimed that advertising in the press would also attract new people who had not previously been engaged in PPI. In addition, a higher public profile would give LINKs’ reports more clout with the NHS and make it easier to get media coverage, which PPIfs struggle to achieve at the moment.<sup>198</sup> NICE’s experience demonstrates the effectiveness of advertising:

NICE’s national advertisement for its Citizens Council asked whether people wanted to improve the NHS. NICE received initially 35,000 expressions of interest which to me is absolutely stunning. Four thousand people followed it through by filling out application forms and so on.<sup>199</sup>

205. On the other hand, if the pessimists are right, and few people want to be involved in PPI work, advertising might not attract many new people and might be money poorly spent.

206. The Minister told us that prospective Hosts could include advertising when putting forwards proposals to Local Authorities but:

It will vary from area to area as to how people feel they want to use a budget in terms of advertising for people to join.<sup>200</sup>

---

195 Q 216

196 Q 218

197 Q 231

198 Q 232

199 Q 18 [Professor Davies]

200 Q 445

If the early adopter projects do not involve Hosts, it is unclear whether the projects will examine the effectiveness of advertising.

207. Some thought that LINKs would be able to generate publicity by a better communications strategy, encouraging local press coverage, but others were sceptical, arguing that the local press was not interested in stories about PPI. Penny Robinson told us that the local press tend to only take notice of bad news stories:

A forum doing a little bit of good work is not news in the same way as a postponed operation or some kind of hospital scandal is.<sup>201</sup>

**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.**

### **Training**

209. PPIf members told us that they needed training on a wide range of issues. One submission from PPIfs operating in Bath and North East Somerset, Bristol, Gloucestershire, North Somerset, South Gloucestershire, Swindon and Wiltshire suggested training should be provided on

- 'what is a LINK';
- Statutory duties and rights;
- How to conduct and behave in a meeting objectively;
- How to communicate with the public;
- Calling on experts;
- Health and social care education;
- Time management;
- Leadership training;
- Job description for volunteers and training on this;
- Understanding NHS structures;
- Training for specialised areas e.g. visiting; PR; checking trust literature etc; public meetings eg. use of microphones.<sup>202</sup>

---

201 Q 232

202 Ev 18 (HC 278-II)

Other submissions argued that there should be training on legal issues, auditing accounts, and training on specific parts of the NHS.

210. We received evidence that some training should be provided centrally, both to ensure its quality and to allow volunteers to gain a nationally recognised certificate. We were told that obtaining such a qualification would be attractive for volunteers and could encourage employers to allow employees to take time off work for LINK activities.<sup>203</sup>

211. On the one hand, the Minister told us that LINKs would have to be realistic about how much training they could do:

It will be for individual LINKs to decide how much training is necessary...if people are on a board then it may be that there are particular bits of training that are necessary. I think we have to be realistic. I do not envisage a problem. For example a LINK might say to the local Age Concern or Alzheimer's Society, "Why don't you as an organisation join our LINK so that all your volunteers and all your interested people become part of that?" The idea that you would then train every one of those people would be, first of all, unrealistic and, secondly, probably unnecessary.<sup>204</sup>

On the other hand, the Department proposed that :

some groups are particularly disadvantaged or vulnerable to breaches of their human rights. LINKs should have a role in providing capacity building support to those people who are not accustomed to having their views heard or indeed conveying their views, through training or mentoring.<sup>205</sup>

This seems to imply that a LINK would be expected to provide training for voluntary organisations rather than for just a few members of the LINK, as the Minister suggested. The Department also stated that anyone who exercised the right of entry would need to be trained.

**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.**

### **Hosts**

213. We heard a range of concerns about conflicts of interest which might arise if social care providers can act as Hosts as the Government proposes. For example:

- The Local Authority might punish or reward the Host when awarding a social care contract;

---

203 Ref? check

204 Q 413

205 Ev 1 (HC 278-II)

- The Local Authority might not take LINKs' recommendations seriously if there were clear financial benefit to the Host;
- The Host might seek to encourage the LINK to refrain from criticising the Local Authority, or indeed its own service provision;
- Local people, volunteers, and the NHS might lose faith in the LINK or Host.

214. Mr Silverman told us:

I am a trustee of a local charity and 80% of our funding comes from public sector commissioning. Quite frankly, as a member of a LINKs, if I was involved I would be extremely hesitant about challenging the commissioners, and I think there is going to be some real conflict of interest in a situation with local charities. ...I promise you, if you are sitting on a LINKs, you are not going to be upsetting your commissioner.<sup>206</sup>

The Minister attempted to reassure us:

I would want to be very clear that there should not be that kind of conflict of interest. If somebody was a direct service provider, the LINK is likely to be investigating the services and I think we do need to be absolutely clear in the way that the contracts would be let to make sure that any worries about conflicts of interest were dealt with. I would want that to be part of the discussions that we are having with local authorities as to how they would manage that situation.<sup>207</sup>

215. We asked her how the conflicts of interest should be dealt with. She told us that Hosts would be accountable to LINKs for their behaviour which should ensure that Hosts acted properly. Other witnesses suggested a number of other measures to deal with the potential conflicts of interests. A register of interests would improve transparency, but would be unlikely to allay concerns.

**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.**

## **Accountability**

217. Meredith Vivian explained the accountability arrangements relating to LINKs:

The local authority will contract with the Host. The specification that the Department of Health is now establishing will set out what the Host needs to do. The Host will be accountable to the local authority for the money it has spent and will need to show how it is meeting the contract. There is, however, dual accountability for the host. The Host is also the support provided to the LINK, so it is the LINK which says how much money should be spent on certain activities, decides priorities

---

206 Q 233

207 Q 432

of activity and what reports need to be sent to the PCT or the local authority. The power base is the LINK but it is the Host which must say how it is meeting the contract specification. The LINK is certainly independent of the local authority; it does not have to do what the local authority tells it.<sup>208</sup>

The Bill states that the local authority must require the Host to ensure that the LINK compiles an annual report and sends it to the Secretary of State. However in draft guidance for Hosts the Department has indicated that neither Hosts nor local authorities are to have any control over LINKs:

The LINK will operate independently of the local authority, within its own governance structure and decision making processes.

A regular performance review meeting will be organised by the local authority to ensure the host is performing and as a result meeting the LINK's need and ensuring its success locally. It is essential that the LINK inputs into the local authority's performance management of the host.

LINK governance arrangements are a matter for the LINK membership and do not come under the control of either host or local authority.

It will be for the LINK to decide what work it does, when and how and how to spend its funds. The purpose of a host organisation is to enable, support and guide the LINK in their activities.

The document also stressed that LINK decisions should not be taken by a small group:

The governance structure should always seek to involve and communicate with the wider LINK membership in all its activities. It should not itself act as a consultative body or speak on behalf of the LINK without its involvement and consent. The governance structure will carry out its function with the support of the Host.

218. However, there seems to be no mechanism to ensure that LINKs do what they are supposed to do or that they act appropriately. It is not difficult to envisage a situation arising in which a LINK failed to agree an annual report. The Secretary of State would presumably take this up with the Local Authority, which would take it up with the Host. But the LINK is not accountable to the Host.

As with any organisation there is potential for it [a LINK] not to carry out its functions properly. At present there appears to be no robust mechanism for performance management or for managing a situation in which a LINK has become dysfunctional other than to enforce the contract with the Host organisation.<sup>209</sup>

219. The draft document also says:

---

208 Q 93

209 Ev 141 (HC 278-II)

LINks should develop a strategic focus, looking at for example, service commissioning.<sup>210</sup>

As we have seen LINks are unlikely to choose to do this. It is hard to see how a Host could be required to ensure that this took place when they are to have no control over the governance or work programme of the LINK.

**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 national body***

221. The Bill abolishes CPPIH and the Department does not plan to replace it. The Department's written evidence states:

Whilst LINKs are independent and will have the power to develop their own priorities and agendas, they will need to develop relationships with a number of stakeholders to fulfil their statutory role effectively. In certain circumstances LINKs may want to work in partnership to scrutinise services across local authority boundaries. LINKs may also wish to work together in regional groups, or even nationally to share experience and findings. We believe there is nothing to prevent LINKs establishing a national body to share and co-ordinate their work if they so wish.<sup>211</sup>

222. With the notable exception of UNISON,<sup>212</sup> as we have seen, witnesses had little positive to say about CPPIH. However, we received a considerable amount of evidence which argued there needed to be some form of national body for LINKs. For example, Elizabeth Manero told us:

We do not have anything at all as a national organisation, which I think is the most extraordinary proposal. It is not a reform if you take something apart and only put something back to replace half of it. I think there is a very significant gap.<sup>213</sup>

223. A number of different functions were proposed for the national body, including:

- To be a conduit for funding (so that it did not go through Local Authorities);
- To oversee LINKs and step in if things go wrong;
- To share best practice;
- To provide training; and

---

210 Draft document circulated by the Department

211 Ev 1 (HC 278-II)

212 Ev 268 (HC 278-II)

213 Q 135

- To be a national voice for LINKs.

224. Witnesses did not agree which of these functions they wanted a national body to perform. Some wanted a body which undertook similar tasks to CPPIH:

The potential is that you will get a fragmented process in which there will be variable sets of standards and the likelihood is that, should there not be some sort of co-ordination or base the standards sorted out, for membership, the way in which the membership appointments process will operate and how then that member is expected to perform, that is when you are going to start to see a complete fragmentation because individual agencies, individual LINK organisations will take their own direction, which will not help the process of either the public knowing what to expect or to be engaged.<sup>214</sup> [Barrie Taylor]

if you take out an overarching body, you end up with 150 different kinds of training and support, it is not very efficient and neither will you get the learning being shared from one LINK to another on this issue as on so much else, or any national conclusions being drawn about how it is all working. It is all going to be done very much at a local level and it is hard to see how the best is going to come out of it in that very localised context.<sup>215</sup> [Sharon Grant]

225. Most witnesses however wanted a body different from CPPIH:

There should be a national organization to which LINKs affiliate, and this needs to be adequately funded. What it does not need to be is a controlling mechanism for the LINKs, or—in short—similar to the CPPIH.<sup>216</sup>

A national body is needed to oversee all LINKs and share best practice.<sup>217</sup>

There is mechanism for gathering ‘collective wisdom’ in order to drive changes in national policy.... The point being that opportunities to share local work more widely is very valuable. This is distinct from national ‘co-ordination’ that would not sit well with the flexibility that is suggested for the way LINKs are established and run.<sup>218</sup>

226. Elizabeth Manero of Healthlink was very clear about how a new national body might differ from CPPIH:

The issue about a national voice is actually quite a difficult one, because there are two types of national voice and it is a question of deciding which one you need and how to do it. Do you need a bottom-up national voice? That means that a LINK can be confident that, if they agree with all the other LINKs in their region that they want a particular issue taken up on their behalf nationally because they do not feel they can resolve it locally, that would be a bottom-up organisation which is led by its

---

214 Q 135

215 Q 128

216 Ev 328 (HC 278-II)

217 Ev 216 (HC 278-II)

218 Ev 45 (HC 278-II)

members and accountable to its member LINKs, which I think is necessary. The top-down type of national organisation, which is what the Commission is currently, is one which performance-manages the patient forums, deals with their governance, their training, their standards and so on.<sup>219</sup>

227. The Department takes a similar view and stated that LINKs would be free to set up their own national body if they so wish. The Department added that the National Centre for Involvement might perform some of the functions of a national body:

**Sandra Gidley:**...Is there not a role for some sort of overseeing body that can help to monitor and spread best practice as well?

**Ms Winterton:** That is what we are having.

**Sandra Gidley:** That will effectively be the structure?

**Ms Winterton:** As I say, the National Centre for Involvement will be doing exactly what you have described in terms of spreading best practice and being able to give advice to the new LINKs organisations about good ways of operating.

**Mr Vivian:** It has an additional £2 million on top of the existing £28 million, just to say that that resourcing is an additional factor.<sup>220</sup>

The Department later clarified that the £2 million is not money to support LINKs; it is the Centre's total annual budget. The Department also told us that the Centre:

...will additionally provide advice and guidance to local involvement networks. It will act as a repository for good practice and make available ideas and approaches for how LINKs can go about their work as effectively as possible. I do not think this role could be described as a monitoring role but clearly there will be a degree of evaluation of practice to enable it to determine whether that practice is good or not.<sup>221</sup>

228. There will be a particular problem when the LINKs begin. At this stage they will be most in need of guidance and advice, but presumably it will take time before they can establish their own effective national body. At this stage the National Centre for Involvement could have an important role to play, but there is concern that it will not have adequate funds to so.

**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**

---

219 Q 135

220 Q 430–431

221 Ev 100 (HC 278–III)

**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.**

### ***An end to uncertainty***

230. There is widespread concern that the frequent changes to the PPI system have had a detrimental effect. Several witnesses stressed that continuity is particularly important for volunteers:

You had members joining these organisations who were not quite clear how they were going to work and then becoming disillusioned and leaving and a constant turnover of membership, which obviously does not lead to very effective development of the sorts of partnerships you are talking about. More latterly, I think the point raised again by our colleagues from the PPI forums earlier about the uncertainty about the future of these organisations for a relatively extended period has not helped any of that.<sup>222</sup>

I think it is about an overall awareness and changing things frequently. In the voluntary sector two or three years is frequent. It takes a while for people to understand the change and for volunteers to contribute. Frequent changes of the nature that we are experiencing actually put people off.<sup>223</sup>

Each time you change, in the volunteer's view, particularly if they are volunteering, there is an evaluation that there is something wrong. It is making a judgment. Although that may not be the judgment, my whole experience of working with volunteers is that they read it as an implied judgment that somehow it is an evaluation that their volunteering is not good.<sup>224</sup>

**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.**

---

222 Q 266

223 Q 327

224 Q 328

## 5 Major consultation

---

### Consultation about major local proposals

#### *Duty to consult users of the health service.*

232. Under Section 11 of the Health and Social Care Act 2001 there is a duty to consult users of health services. Subsequently, Section 11 of the 2001 Act became Section 242 of the National Health Service Act 2006, but consultations are still commonly known as Section 11 consultations and in this report we continue to refer to them in this way.

233. Consultation may cover:

- the planning of the provision of those services;
- the development and consideration of proposals for changes in the way those services are provided; and
- decisions to be made by the body affecting the operation of those services.

234. 'Policy and practice' guidance on Section 11 of the Health and Social Care Act 2001, entitled *Strengthening accountability*, was issued by the Department in February 2003. This gives guidance to NHS trusts on how they should undertake their role of involving and consulting patients and the public.

235. Under Section 7 of the Health and Social Care Act 2001 Local Government OSCs have the power to review and scrutinise matters relating to the health service in the authority's area, and to make reports and recommendations.

236. The Secretary of State has extensive powers to intervene in the NHS under the National Health Service Act 1977. In addition, cases can be referred to the Secretary of State by an OSC. The Local Authority (Overview and Scrutiny Committees Health Scrutiny Functions) Regulations 2002 state:

In any case where an overview and scrutiny committee considers that the proposal would not be in the interests of the health service in the area of the committee's local authority, it may report to the Secretary of State in writing who may make a final decision on the proposal and require the local NHS body to take such action, or desist from taking such action, as he may direct.<sup>225</sup>

In coming to a decision the Secretary of State may refer the case to the Independent Reconfiguration Panel for advice.

237. In principle, an effective and comprehensive system of statutory consultation has been established, as Candy Morris of the South East Coast SHA told us:

---

<sup>225</sup> The Local Authority (Overview and Scrutiny Committees Health Scrutiny Functions) Regulations 2002 (SI 2002, No. 3048)

As a minimum, Section 11 of the Health and Social Care Act 2001 places a duty on Primary Care and NHS Trusts and Strategic Health Authorities to make arrangements to involve and consult patients and the public:

- not just when a major change is proposed, but in ongoing service planning;
- not just in the consideration of a proposal, but from the outset in the development of that proposal; and
- in decisions about general service delivery, not just major changes....

Section 7 of the Health and Social Care Act 2001 gave powers to Local Authorities to establish Overview and Scrutiny Committees to:

- take on the role of scrutiny of the NHS—not just for major changes but for the ongoing operation and planning of services;
- refer contested service changes to the Secretary of State;
- call NHS managers to give information about services and decisions;
- report their recommendations locally;
- be consulted by the NHS where there are to be major changes to health services.

Section 11 requires that the NHS engage people in all circumstances when the NHS are changing and improving services, since this is a constant process of improvement for any public service. In the NHS as in other public services there are many and varied ways for patients, staff and the wider public to improve the way the NHS and other providers offer health and social care services.<sup>226</sup>

Other witnesses expressed similar views:

The wording of Section 11 of the Health and Social Care Act 2001 is, perhaps, rather incoherent and repetitive, but on any reading the intention is plain. Patients or their representatives are to be ‘involved’ in virtually any deliberations within the NHS which might impact on what is delivered, how it is delivered and by whom. The obligation is notably framed in very wide terms—it goes beyond a simple (and more traditional) obligation formally to consult before taking decisions. The fact that consultation is required across the full range of planning and from the earliest point in the development of ideas.<sup>227</sup>

238. Thus in theory the system of statutory consultation is excellent; however, in practice there is much disappointment with its operation of both Section 11 and Section 7. Many submissions to the inquiry addressed such disappointments. We also questioned representatives of the NHS Alliance and NHS Confederation and the Minister and officials about the subject and held an evidence session with the two experts quoted above, Candy Morris, who is in charge of reconfiguration in the South East Coast SHA, and Richard

---

226 Ev 233 (HC 278–II)

227 Ev 116 (HC 278–III)

Stein from Leigh Day and Co Solicitors who has challenged several Section 11 consultations.

### **Problems with Section 11 consultation**

239. There are a number of criticisms relating to Section 11 consultation namely:

- consultation is or is thought to be insincere or dishonest;
- even when undertaken honestly, mistakes are made, often because of lack of time;
- too often NHS bodies seek to avoid consultation.

240. We heard many complaints about trusts undertaking consultations after the decision had already been taken. As the Patients Forum stated:

It is still too often the case that communities are presented with a fait accompli, and the NHS simply uses inadequate consultation mechanisms to effectively rubber-stamp a decision that has effectively already been taken.<sup>228</sup>

241. This conclusion is perhaps inevitable when a large majority of people reject a proposed reconfiguration but their views are ignored. For example, in Hertfordshire people were presented with two options relating to . 82% of people preferred option two, but the trust is going ahead with option one anyway.<sup>229</sup>

242. Witnesses argued that the situation was becoming worse as trusts deal with financial deficits. Richard Stein told us “that in a climate of hospital closures, service reductions and staff redundancies, to achieve spending reductions, it became even less attractive to NHS managers to involve patients or their representatives in their decision-making”. He gave an example of how consultation could be avoided:

In many cases, where Trusts are short of money, they will run down the staffing levels so that the only safe step they can take is to close a ward or a service. Such steps are frequently taken without patients being involved in the decisions. Once such services have been closed, albeit on a supposedly temporary basis, they very rarely re-open and the decline takes place without any patient involvement as to the appropriateness of the change. This is seen by many NHS Trusts as a useful device for avoiding their responsibilities to involve patients and public.<sup>230</sup>

243. Even where consultation is undertaken sincerely, mistakes are made, as the consultation (albeit not a formal consultation) described in Box 1 shows.

---

228 Ev 199 (HC 278–II)

229 *Traffic Study over A&E decision*, Emma Clark, 24 November 2006, [www.thisishertfordshire.co.uk](http://www.thisishertfordshire.co.uk) ; see also [www.westhertshospitals.nhs.uk/consultation](http://www.westhertshospitals.nhs.uk/consultation)

230 Written evidence from Volunteering England (PPI 159) [not printed]

**BOX 1**

**244.** Before amalgamation with Kent & Medway SHA to form the South East Coast body, Surrey & Sussex SHA carried out a public consultation on healthcare services in the area.<sup>231</sup> This was not a formal consultation under Section 11 of the Health and Social Care Act, however. The document, *Creating an NHS fit for the future*, was instead referred to as a ‘discussion document’. It examined why changes to healthcare were needed and made proposals for improvements to services in Surrey and Sussex. The document was aimed at patients, carers and NHS staff as well as the general public. In addition to circulating the document, meetings were held to discuss the issues.

**245.** 6,226 people responded to the discussion document and 2,575 wrote with a more detailed response to the issues raised. Most of the responses were sent by members of the public (87%). The majority (81%) were about concerns at the possible closure of St Richards Hospital in Chichester. A company called TwoCan Associates was commissioned by the SHA to analyse the responses in more detail. They found:

Overall, people agreed with the reasons for change outlined in the document, and the desire to improve health services. However, they were concerned that the changes would not lead to any improvements in the quality of health care, and felt that the real reason for the proposed changes was to save money. Many did not seem to trust that the SHA was telling them the truth.<sup>232</sup>

**246.** Concerns relating to the closure of the hospital included longer journey times to hospital for patients and visitors and delayed treatment. There were also fears about reduced capacity with the growing population of the South East. The researchers commented:

Overall, the discussion document seemed to frighten many people—perhaps needlessly.<sup>233</sup>

**247.** A common point raised was that too many consultations were being held within a short space of time and several respondents stated that “in spite of these consultations no one felt any better informed”. In addition:

These discussions were thought to have had a very negative impact on staff morale and caused distress to the public. Overall the community felt let down and shared a great deal of cynicism regarding the whole process.<sup>234</sup>

**248.** Furthermore, respondents said the document was too vague to give constructive feedback, did not help move the debate on and was a waste of money. Comments included:

Consultation is urgent but it is maddening to see all this money being spent on ‘glossy magazines’ when we have no budget for training, nor sufficient stationery to

231 Ev 256–260 (HC 278–II)

232 Ev 132 (HC 278–III)

233 Ev 133 (HC 278–III)

234 Ev 133 (HC 278–III)

do our jobs. [member of NHS staff]

The glossy brochure and lack of space to return comments creates the impression this is a publicity stunt and not a genuine consultation. [Member of the public]

**249.** Many were sceptical that their views would be listened to and a common response, which echoes comments made in previous evidence sessions, was that people thought the major decisions had already been made so the exercise was pointless.<sup>235</sup>

**250.** Questioned about this case, Candy Morris argued that in a proper consultation, people must be involved from the beginning when nothing was ruled out. Inevitably therefore staff would be scared and the consultation would appear vague; this is a sign of things being done correctly:

one of the effects of Section 11, however well it is undertaken, is that engaging rightly patients and staff, communities, local government, voluntary groups and so on right from the beginning of a process which lays out the reasons why change might need to happen, what the benefits are, what the risks are and trying to work together on solutions over a long period of time means that everything is out on the table and nothing is off the table for a long period of time, so it is not possible right at the beginning to say, “But of course this place will be all right”, or, “Of course that place will be all right”, because, otherwise, you are not actually undertaking Section 11 properly.<sup>236</sup>

**251.** We also heard from several witnesses that too many NHS organisations are trying to narrow the range of situations in which they have to consult under Section 11. Witnesses argued that the Department of Health had certainly not acted in the spirit of Section 11 and its accompanying guidance. Rather it had done its utmost to support the NHS organisations which rejected demands to consult. Richard Stein told us:

I know you are aware of the example in Derbyshire last year around the GP practice in Langwith and Creswell where it was clear that the need to involve the community was one which the community themselves had been crying out for which was not done. That would seem exactly the kind of case where one would hope that the Strategic Health Authority or the Department of Health would have said, “Hey, this is a good example where better practice would have been so and so”. Rather than that, they were in court doing everything that they could do to try and bolster what had happened locally, so, from my perspective, they are all in it together and there is not really a pressure to introduce, to support or encourage that culture of involving patients through the whole process.<sup>237</sup>

The Department is also taking the lead in arguing that Section 11 does not apply to ISTCs. Mr Stein added:

235 Ev 132 (HC 278–III)

236 Q 359

237 Q 358

I understand your Committee has looked at ISTCs and one of your concerns is the lack of consultation on them and then the comment from the Minister in response that there would be consultation. ... but [in Bristol] the clear direction came from the Minister that one does not consult before the conclusion of the contract on ISTCs. I think that is wrong in law, but the reason why it is important that it is also wrong in policy terms is that clearly, even though the ISTCs might be commissioned at a national level by the Department of Health, the way that they impact on the provision of healthcare is obviously local.<sup>238</sup>

He continued:

I think that the trouble with Section 11 itself is that, when you get the Department of Health lawyers in court picking through it and trying to make it say that it does not cover things like the GP contracting process in Derbyshire or currently that it does not cover the need to consult about introducing an ISTC as part of a development in the Bristol area, then you could say that it is not clear, but the intentions are very clear from the guidance.<sup>239</sup>

In the North Derbyshire case the courts found that the PCT did have a duty to consult, which it had breached.

### ***Government's proposals for change***

252. The Department stated in its evidence to the Committee:

We will simplify, clarify and strengthen the current legislation on health service consultation.<sup>240</sup>

To this end the Government proposes to amend Section 11. Section 11 currently states that there must be consultation on all proposals and decisions. This will be amended to “significant proposals” and “significant decisions”; “significant” is defined as “having a substantial impact on the manner in which services are delivered to users or the range of services available to those users”.<sup>241</sup>

253. Several witnesses expressed concern about this change; CPPIH stated:

We are concerned that the proposed amendments in clause 163 of the Local Government and Public Involvement Bill narrow the range of issues on which consultation is required to proposals which would have a substantial impact on the manner in which the services are delivered to users of those services, or the range of health services available to those users only. The Committee will recall there was no requirement to consult under Section 11 over the recent PCT reconfigurations as these were classed as managerial and administrative decisions by the Department of Health and considered to have no connection to service delivery. The consequence of

---

238 Q 371

239 Q 364

240 Ev 1 (HC 278-II)

241 Local Government and Public Involvement in Health Bill [Bill 77 (2006/07)]

this was that objections that such changes could adversely impact on service delivery were overridden. CPPIH recommends that there should be a requirement to consult on major structural change such as large scale reconfigurations of organisations charged with securing the delivery of public services.<sup>242</sup>

254. A number of witnesses approved of the change. We questioned Nigel Edwards of the NHS Confederation about this issue:

**Dr Taylor:** So, going back to the word “significant”, should we be trying to change it, delete it, or what word should we put in instead?

**Mr Edwards:** I think “significant” will do and maybe it is the guidance that is the issue here and it might be helpful to have some worked case studies...From our point of view “significant” must relate to a change in patient experience or convenience, so saying that I produce the same amount of healthcare but I have moved from Grantham to Lincoln would count as significant if it makes a big impact on patients, but if you change the GP practice between one practice and another or between a GP practice and a private company, for example, as we have seen recently in north east Derbyshire, as long as the same experience is there that probably does not count as significant. It is a really quite slippery concept and I think we may run into trouble with it as time goes on.<sup>243</sup>

255. In contrast, other witnesses were strongly opposed to the use of “significant”. The group Keep Our NHS Public stated:

[The Bill] would limit consultation under Section 11 to (a) the planning of the provision of services and (b) to changes that significantly affect the range or manner of delivery of services at the point of use. Such legislation would allow an NHS organisation to by-pass public consultation on substantial changes, including the awarding of contracts to multinational corporations, if managers could argue that the proposals would not affect the delivery or range of services on offer at the point of use.<sup>244</sup>

256. There is concern that the Department’s real aim is to remove the case law relating to Section 11. Since the Department has lost a number of the legal cases involving the interpretation of Section 11 a change in wording would remove the precedents and give the Department a better chance in court. It would also allow them to rewrite the guidance, which has also caused them trouble:

I have been in really extraordinary situations, usually when I am trying to disagree with government representatives, where they rely on their guidance for the interpretation of the legislation. What happened here in the case last summer in Derbyshire was that they were saying, “We don’t need to look at the guidance. The guidance doesn’t help”. Now, what they mean is that the guidance gives the wrong

---

242 Ev 53 (HC 278-II)

243 Q 215

244 Ev 134 (HC 278-II)

slant on where they now want the legislation to be which is restrictive rather than expansive.<sup>245</sup>

257. Clearly, there will be some circumstances in which formal Section 11 consultations should not take place either because they would be a waste of money or because they would compromise safety. However, there is little agreement as to exactly what these circumstances should be.

258. Ms Morris noted that where a change is proposed for strong clinical safety reasons, it may not be possible to alter plans on the basis of consultation findings. There was a risk that the public would feel that consultation was pointless as no other decision could realistically be made:

This kind of situation can then damage genuine engagement and consultation processes where there is a real choice to be made and flexibility about the way forward which patients', partners and the wider public can influence. Maybe there should be a different name for an 'informing' type 'consultation' where urgent changes need to be made to differentiate from more interactive processes where there is mutuality in finding potential solutions.<sup>246</sup>

According to Ms Morris, public consultation might also be unnecessary when it involved minor matters such as a small number of beds or the transfer of a specialist service to another site. In such cases:

whilst there should be discussion with key stakeholders around the reasons for such adjustments, full scale public consultation on such issues does not usually seem the best use of resources, or conducive to the NHS operating most effectively.<sup>247</sup>

259. However, Mr Stein thought that a case could be made for consulting in both sets of circumstances. Safety issues, which could sometimes be resolved with moderate expenditure, were used as an excuse for closure. A series of small scale closures could amount to a major reconfiguration. Moreover, consultation about small changes which only affected a few people would not be expensive.<sup>248</sup>

### **What should happen**

260. Candy Morris and Richard Stein both agreed that there was no need to amend the law relating to the duty to consult. Existing legislation could work perfectly well if the NHS and Department of Health approached it in the right spirit. The NHS should stop trying to avoid consultations or undertake sham consultations and approach consultation in accordance with the guidance accompanying Section 11.

261. Candy Morris stressed the need for much wider engagement:

---

245 Q 364

246 Ev 233 (HC 278-II)

247 *Ibid.*

248 Q 400

NHS organisations need to ensure they invest the appropriate time, commitment, resources and drive to deliver good PPI throughout all the services they provide. This will lead to the desired cultural change, putting patients in a position to truly shape and influence service to improvements for themselves and other people.<sup>249</sup>

She added that PPI could not be seen as an ‘add on’ by the NHS and that it must be integral to the day-to-day working.

262. Harry Cayton, National Director for Patients and the Public at the Department of Health told us:

I believe that there are five stages to good public involvement. The first is to go where the people are; the second is to share all one’s knowledge with them. Usually, people are suspicious and distrustful of consultation when they think the other side is holding its cards to its chest. One needs to put out all the information and be honest about performance and say why something is not safe and something else would be safer; one needs to say what one is doing about public transport and talk seriously about the costs. One needs to share with the public all the information that one has as professionals, listen to them, act and finally tell them what one has done and why. If people try to rush that process, or miss out part of it, or not take any part of it seriously, it will not work.<sup>250</sup>

We heard similar views from other witnesses,<sup>251</sup> while many thought that there was no need to amend the legislation relating to Section 11. This does not mean that there will not be disputes about exactly when to consult, but they should be decided by the establishment of precedents and by following the guidance in the right spirit. Essentially, if there is a strong public feeling that there should be consultation, consultation should take place.

### ***The role of the Secretary of State***

263. There is much concern about the role of the Secretary of State in consultations, in particular in relation to:

- Overturning decisions arrived at following a long period of consultation;
- Her failure to refer cases to the Independent Reconfiguration Panel; and
- The timing of her interventions.

The effect is to undermine public confidence in the consultation process.

264. Richard Stein complained that most referrals to the Secretary of State concerned objections to the implementation of the Department’s own policies. She was, so to speak, acting as a judge in her own case:

---

249 Ev 233 (HC 278-II)

250 Q 72

251 eg. Q 357

The position is that there are the referrals to the Secretary of State, there are the appeals to the Secretary of State to do something and, unfortunately, ...that has no credibility whatsoever, and most of the things they do not like are driven by the Secretary of State, so to appeal against their implementation locally to the Secretary of State will not deliver anything, and that is a real shame because that is potentially a mechanism...You do not find that the Secretary of State says, or through the strategic health authority, if that is the way it would happen, "Oy, you can't do that. Go back and do it properly".<sup>252</sup>

265. The NHS Confederation thought that in a number of cases the Secretary of State had made illogical interventions, presumably for political reasons

A major problem with staffing in a Special Care Baby Unit led the Trust to decide that it needed to close the Special Care Baby Unit and consequently the Maternity Unit under emergency powers. The then Secretary of State intervened to order a review, which confirmed that the Trust was correct. The Secretary of State then requested a second review from an independent expert. This broadly confirmed the results of first. A third review by a government agency made some suggestions about managing the interim but did not lead to any substantially different conclusions. Several months later the Unit did close but in the meantime services had been very unsafe.<sup>253</sup>

266. Questioned about referrals, the Minister told us that the threat of referral to the Secretary of State was an important part of the system:

so by the time it gets up to the Secretary of State, the Secretary of State will be looking at a whole range of things that have happened, the overview and scrutiny committee has said, "We don't mind them doing this but the reason why we are referring it on is because we think that is wrong" and in the meantime because of the process the position might be, "Actually, since the overview and scrutiny committee made that referral the strategic health authority has worked with the local primary care trust and addressed that issue, so that particular service is no longer provided over there where it was objected to, but it is going to be provided here". The intervention, if you like, can indirectly work because the process means that people will try to find an agreement so that when it goes up to the Secretary of State it may well be that there has been a compromise.<sup>254</sup>

267. A number of proposals were put forward to improve the situation. Decisions at all levels should be taken transparently. As Nigel Edwards told us:

There have been some examples where sometimes those interventions have seemed to run quite counter to both logic and local opinion and, therefore, I think we should be asking whoever does intervene to be willing to be held to account for the same

---

252 Q 388

253 Ev 127 (HC 278–III)

254 Q 475

tests about is it fair, is it logical, is it transparent and is there no spin, which I think were your words, Richard. That seems to me to be a sensible test to apply.<sup>255</sup>

268. One way to do this would be for the Secretary of State to refer all cases to the Independent Reconfiguration Panel and publish their advice, which she does not do at present; indeed, the Independent Reconfiguration Panel is underused:

the independent reconfiguration panel is an interesting idea, although, frankly, it seems to be more an idea than anything else, and it can deal with difficult projects but my understanding is that it has only dealt with a handful, it is completely up to the Secretary of State when she refers to it and it is then up to the Secretary of State what she does with its recommendations—if there was something that was more properly independent and was there on a more regular basis and was more robust ...clearly if it was done properly it would be a good thing.<sup>256</sup>

269. When challenged on why the Secretary of State sent so few cases to the reconfiguration panel the Minister was not able to give a clear answer:

Something like 23 referrals have been received from overview and scrutiny committees and that is out of hundreds of changes that will have gone on with local NHS services. I think four have now been referred to the Independent Review Panel. In making those decisions, the Secretary of State obviously receives advice from strategic health authorities and from the Department. I do not feel that system is working badly.<sup>257</sup>

270. We also heard complaints that the Secretary of State intervenes at too late a stage. Nigel Edwards told us:

I think the point is that there should be a clear set of rules about at what point you intervene and that where possible that intervention should come much earlier in the process than it currently does. It tends to be rather late in the day and in some cases intervention is already in many ways too late because staff have started to leave, consultant posts cannot be filled. I can think of one particular example where, despite the Secretary of State's intervention, the service effectively fell apart and all the Secretary of State did in that particular case was keep a service that was probably dangerous continuing to run, so it did not actually achieve what he had set out to do in the first place.<sup>258</sup>

He continued:

If the question is about intervention on whether the answer is the correct one, many of the interventions have come too late in the day and could and should be made significantly earlier. Last minute intervention is generally unhelpful and on the whole

---

255 Q 312

256 Q 388

257 Q 469

258 Q 320

should be discouraged, but it would be hard for us to argue from where we sit that the Secretary of State does not have some rights in this.<sup>259</sup>

**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.**

**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.**

**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.**

## **Patient and public involvement at a national level**

274. Recent years have seen increasing involvement of patients and the public in national policy making, beginning with the *NHS Plan* in 2000, which involved many organised consumer and patient groups. Most recently, the *Your Health, Your Care, Your Say* White Paper was the product of a very large-scale consultation.

275. By their nature national policies tend to be broad and far reaching in their scope, and are often controversial, with a heavy political overlay. Because of this, there may be a particular danger that consultation is seen merely as window dressing, as a means of achieving post-hoc justification for decisions that have already been taken behind closed doors. Professor Davies described this “cosmetic” type of exercise as giving consultation “a really bad name”.<sup>260</sup> However, this raises the difficult issue of exactly how much weight it is desirable to give to the views of patients and the public in decision-making of this scale. While on the one hand paying insufficient heed to the views of patients and the public that have been sought makes a mockery of the consultative process, on the other hand certain key decisions about public spending and the direction of national policy may be more appropriately taken by elected representatives. According to Professor Celia Davies, her experience of running a citizens’ council for NICE, the national advisory body on the

---

259 Q 321

260 Q 8

efficacy and cost effectiveness of different drug treatments, demonstrated that the public in many cases do not want the responsibility for final decision making, but simply to have had their views taken account of in that process:

We found that people were really keen to understand what the issues were and the hard choices that the NHS faced. They wanted to be assured that they had been heard; they wanted to see their arguments in the final document. They did not want to take the final decision; they wanted it to be taken elsewhere.<sup>261</sup>

276. So it seems that national consultation may be a valuable tool, even when final decision-making needs ultimately to rest with elected representatives. However, Professor Davies argued that despite individual “initiatives about which people become enormously enthusiastic”, efforts to ensure involvement in regional and Department of Health decisions remain “fragmented” and lack a coherent strategy:

I think that there is still not a clear strategy or map ... there is perhaps over-enthusiasm and under-thinking.<sup>262</sup>

277. According to Ed Mayo, the voluntary sector “has real life and energy when it comes to engaging in national policy making” but is sometimes constrained because of a lack of resources. He described the Long Term Medical Conditions Alliance as “operating out of a large shoebox”.<sup>263</sup> Proposals for a coalition of voluntary organisations to give a national voice with which to engage in national policy making might help address this.

**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.**

---

261 Q 5

262 Q 7

263 Q 8

## 6 Conclusions

---

279. PPI describes a wide range of activities and has a variety of purposes. Patient involvement and public involvement are distinct and are achieved in different ways. The conflation of these distinct terms and the confusion over the purpose of involvement has led to muddled PPI initiatives and uncertainty about what should be done to achieve effective PPI. Nevertheless, PPI has the potential to play a key role in both NHS and social care services by bringing about service improvement and improving public confidence.

280. Public trust has to be earned and is easily broken. In some places, consultations have been a sham, elsewhere NHS bodies have sought to evade their duty to consult entirely. The Department needs to take a lead and make it clear that such behaviour will not be condoned.

281. When undertaking consultations all NHS bodies must follow the best practice that already exists in parts of the NHS; in particular, they must be clear about what can be changed, ensure that they consult early enough in the process that plans can be changed and recognise that even the best designed and run consultation will not result in public agreement. Consultations where huge percentages of the public reject plans which go ahead anyway must not continue to happen.

282. We fear that the Bill will weaken Section 11. The change of definition it proposes may lead to confusion and could lead to more court cases when the Act is tested. We are not convinced that this change is needed.

283. The Secretary of State's interventions in consultations, especially when done at a late stage in the process, both threaten to undermine public confidence and lead to illogical decisions. Before intervening the Secretary of State should refer cases to the Independent Reconfiguration Panel.

284. The establishment of LINKs provides an opportunity to improve and strengthen the PPI system. However, we do not see why PPIFs could not have been allowed to evolve. The abolition of PPIFs seems to have been driven by the need to abolish CPPIH rather than a real need to start again. Merging the existing PPIFs to form LINKs would have been much less disruptive for volunteers and would have reduced the risk of significant numbers of them leaving. As most Forum Support Organisations already support several forums they could have been allowed to evolve into Hosts, keeping their experienced staff. Once again the Department has embarked on structural reform with inadequate consideration of the disruption it causes.

285. Nevertheless properly designed and resourced LINKs provide an opportunity to improve the quality of PPI and allow people to have a much bigger input into services in their area. In order to achieve this, it is crucial that LINKs use their funds in the most effective way. LINKs need clarity about what they should focus on and what work they should produce. This will provide clarity for volunteers, allow LINKs to start up quickly, and avoid duplicating the work of other bodies.

286. There need to be clear lines of accountability for LINKs as well as for Hosts. Hosts needs to be carefully managed to ensure there is not the inconsistency found in FSOs.

287. Organisations like LINKs, PPIFs, PALS, ICAS along with formal processes like Section 11 and Section 7 are not the most crucial aspects of PPI. Indeed the existence of separate structures for PPI has tended to reinforce the NHS's tokenistic approach to PPI. Effective PPI is about changing outcomes, about the NHS and social care providers putting patients and the public at the heart of what they do.

288. The Department needs to recognise that the work of LINKs will be hard to evaluate and measure. If the NHS does not listen, LINKs, however well designed and run, will fail as volunteers see that their work is not having an effect.

289. If NHS bodies are to involve the public effectively, they need to do so at an early stage and before any options are drawn up or decisions are made. This means it may be difficult to determine exactly what changes their involvement has brought.

290. Many NHS and social care organisations have done PPI well. As Candy Morris said "NHS is a real mosaic of good and less good practice".<sup>264</sup> The existence of good practice shows that there is no reason why the NHS and social care providers cannot all effectively involve patients and the public. NHS providers and commissioners must not assume that they know what people want. They should go out and ask them.

## Conclusions and recommendations

---

1. 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. (Paragraph 32)
2. 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. (Paragraph 33)
3. 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. (Paragraph 34)
4. 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. (Paragraph 97)
5. 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. (Paragraph 111)
6. 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. (Paragraph 112)
7. 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. (Paragraph 113)

8. 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. (Paragraph 150)
9. 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. (Paragraph 151)
10. 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. (Paragraph 152)
11. 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. (Paragraph 168)
12. 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”. (Paragraph 169)
13. 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. (Paragraph 184)

14. 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. (Paragraph 185)
15. 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. (Paragraph 186)
16. 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. (Paragraph 196)
17. 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. (Paragraph 202)
18. 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. (Paragraph 208)
19. 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. (Paragraph 212)

20. 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. (Paragraph 216)
21. 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. (Paragraph 220)
22. 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. (Paragraph 229)
23. 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. (Paragraph 231)
24. 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. (Paragraph 271)
25. 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. (Paragraph 272)
26. 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. (Paragraph 273)

27. 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. (Paragraph 278)

# Formal minutes

---

**Thursday 22 March 2007**

Members present:

Mr Kevin Barron, in the Chair

Charlotte Atkins

Jim Dowd

Sandra Gidley

Mr Stewart Jackson

Dr Doug Naysmith

Dr Howard Stoaite

Dr Richard Taylor

The Committee considered the draft Report [Patient and Public Involvement in the NHS], proposed by the Chairman, brought up and read.

*Ordered*, That the Chairman's draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 290 read and agreed to.

Summary read and agreed to.

*Resolved*, That the Report be the Third Report of the Committee to the House.

*Ordered*, That the Chairman do make the Report to the House.

*Ordered*, That embargoed copies of the Report be made available, in accordance with the Provisions of Standing Order No. 134.

*Ordered*, That the Memoranda received by the Committee be reported to the House.

[Adjourned till Thursday 19 April at 9.30 am]

## Witnesses

---

### Thursday 1 February 2007

Page

**Professor Celia Davies**, Visiting Professor, London School of Economics, **Dr Ed Mayo**, Chief Executive, National Consumer Council, and **Dr Jonathan Tritter**, Chief Executive, NHS Centre for Involvement Ev 1

**Harry Cayton**, National Director for Patients and the Public, and **Meredith Vivian**, Head of Responsiveness and Accountability, Department of Health Ev 12

### Thursday 8 February 2007

**Sharon Grant**, Chair, Commission for Patient and Public Involvement in Health, **Councillor Barrie Taylor**, Chair, City of Westminster Health Scrutiny Task Group, and **Elizabeth Manero**, Director, Health Link Ev 25

**Mary Adams**, Head of Public Involvement, North Somerset PCT, **Dr Albert Day**, Chairman, Harrogate and District NHS Foundation Trust, and **Anna Coote**, Head of Engaging Patients and the Public, Healthcare Commission Ev 36

### Thursday 22 February 2007

**Mrs Jennifer Beesley**, Former Chair, Great Yarmouth PPI Forum, **Penny Robinson**, Chair, United Bristol Hospitals NHS Trust PPI Forum, and **Barry Silverman**, Chair, Southwark Patients Forum for Primary Care Ev 48

**Nigel Edwards**, Director of Policy, **David Stout**, Director, PCT Network, NHS Confederation, and **Dr Brian Fisher**, PPI Lead, NHS Alliance Ev 55

**Professor Angela Coulter**, Chief Executive, Picker Institute, **David Wood**, Chief Executive, Attend, and **Frances Hasler**, Head of User and Public Involvement, Commission for Social Care Inspection Ev 67

### Thursday 1 March 2007

**Candy Morris**, Chief Executive, South East Coast Strategic Health Authority, and **Richard Stein**, Partner, Leigh Day & Co, Solicitors Ev 74

**Rosie Winterton**, a Member of the House, Minister of State for Health Services, **Harry Cayton**, National Director for Patients and the Public, and **Meredith Vivian**, Head of Responsiveness and Accountability, Department of Health Ev 84

## Written evidence in Volume III (HC 278–III)

---

	<i>Page</i>
1 Department of Health (PPI 01D)	Ev 100
2 Department of Health (PPI 01E)	Ev 100
3 Department of Health (PPI 01F)	Ev 102
4 Attend (PPI 163)	Ev 104
5 Commission for Patient and Public Involvement in Health (PPI 109A)	Ev 106
6 Commission for Patient and Public Involvement in Health (PPI 109B)	Ev 107
7 Commission for Patient and Public Involvement in Health (PPI 109D)	Ev 111
8 Healthcare Commission (PPI 107A)	Ev 111
9 Dr Albert Day, Harrogate and District NHS Foundation Trust (PPI 156)	Ev 112
10 Health Link (PPI 121A)	Ev 115
11 Richard Stein, Leigh Day & Co (PPI 169)	Ev 116
12 NHS Alliance (PPI 81A)	Ev 121
13 NHS Confederation (PPI 142A)	Ev 127
14 Mary Adams, North Somerset PCT (PPI 154)	Ev 128
15 South East Coast Strategic Health Authority (PPI 112A)	Ev 131
16 TwoCan Associates (PPI 162)	Ev 132
17 Cllr Barrie Taylor, Westminster City Council (PPI 158)	Ev 134
18 Professor Celia Davies (PPI 157)	Ev 137
19 Commission for Patient and Public Involvement in Health (PPI 109E)	Ev 140

## Written evidence in Volume II (HC 278–II)

---

	<i>Page</i>
1 Department of Health (PPI 01)	Ev 01
2 Action against Medical Accidents (PPI 40)	Ev 04
3 Arthritis and Musculoskeletal Alliance (ARMA) (PPI 149)	Ev 07
4 Arthritis Care (PPI 130)	Ev 07
5 Association of the British Pharmaceutical Industry (PPI 79)	Ev 13
6 Asthma UK (PPI 103)	Ev 15
7 Avon, Somerset and Wiltshire area PPI Forums (PPI 89)	Ev 18
8 Barnet and Chase Farm Hospitals NHS Trust PPI Forum (PPI 13)	Ev 23
9 BLISS (PPI 09)	Ev 24
10 Breakthrough Breast Cancer (PPI 42)	Ev 26
11 United Bristol Hospitals NHS Trust, North Bristol NHS Trust and Bristol Primary Care Trust PPI Forums (PPI 63)	Ev 29
12 British Medical Association (PPI 148)	Ev 31
13 Canterbury City Council Health Scrutiny Panel (PPI 113)	Ev 42
14 Centre for Public Scrutiny (PPI 62)	Ev 45
15 Cheshire and Wirral Partnership NHS Trust PPI Forum (PPI 33)	Ev 49

16	Civil Service Pensioners' Alliance (PPI 34)	Ev 52
17	Commission for Patient and Public Involvement in Health (PPI 109)	Ev 53
18	Commission for Social Care Inspection (PPI 144)	Ev 62
19	Contact a Family (PPI 08)	Ev 65
20	Community Investors (PPI 128)	Ev 68
21	Countess of Chester Hospital PPI Forum (PPI 87)	Ev 71
22	County Durham and Darlington Acute Hospitals PPI Forum (PPI 04)	Ev 72
23	Craven, Harrogate & Rural District Patients' Forum Group (PPI 12)	Ev 74
24	Diabetes UK (PPI 100)	Ev 75
25	Disability Rights Commission (PPI 137)	Ev 79
26	Dr Foster Intelligence (PPI 125)	Ev 80
27	Ealing PCT PPI Forum (PPI 133)	Ev 82
28	East of England Ambulance PPI Forum (PPI 124)	Ev 82
29	Epilepsy Action (PPI 36)	Ev 84
30	Epsom & St Helier University Hospitals NHS Trust and Sutton and Merton PCT PPI Fora (PPI 93)	Ev 85
31	South East Essex PCT PPI Forum (PPI 136)	Ev 87
32	West Essex PPI Forum (PPI 29)	Ev 90
33	Family Planning Association (PPI 82)	Ev 91
34	Gateshead Hospitals PPI Forum (PPI 02)	Ev 91
35	General Medical Council (PPI 147)	Ev 96
36	Hammersmith and Fulham Service User Network (PPI 68)	Ev 97
37	Hampshire County Council Health Overview and Scrutiny Committee (PPI 48)	Ev 99
38	Health Advocacy Partnership (PPI 99)	Ev 101
39	Health Foundation (PPI 117)	Ev 109
40	Health Link (PPI 121)	Ev 111
41	Healthcare Commission (PPI 107)	Ev 119
42	Help the Hospices (PPI 17)	Ev 124
43	Herefordshire's Health Overview and Scrutiny Committee (PPI 86)	Ev 125
44	Hull and East Yorkshire Hospitals Trust PPI Forum (PPI 30)	Ev 126
45	INVOLVE (PPI 98)	Ev 130
46	Keep Our NHS Public Campaign (PPI 66)	Ev 132
47	Kensington & Chelsea PCT Forum and Chelsea & Westminster Foundation Trust Forum (PPI 14)	Ev 134
48	Kettering General Hospital PPI Forum (PPI 07)	Ev 135
49	Kingston PCT Forum (PPI 80)	Ev 136
50	Leicester City, Leicestershire County and Rutland, The Leicestershire Partnership and The University Hospitals of Leicester PPI Forums (PPI 64)	Ev 138
51	Local Government Association (PPI 108)	Ev 139
52	London Network of NHS Patients' Forums (PPI 96)	Ev 142
53	PPI Forums for Hounslow PCT, W Middlesex University Hospital, Ealing Hospital, Ealing PCT, Hillingdon PCT, Hillingdon Hospitals and West London Mental Health Trust (PPI 141)	Ev 145
54	West London Mental Health Trust PPI Forum (PPI 45)	Ev 146
55	LMCA (PPI 126)	Ev 146
56	Macmillan Cancer Support (PPI 111)	Ev 149

57	Macmillan Patient and Public Involvement (PPI 56)	Ev 155
58	Medway Community Health PPI Forum (PPI 53)	Ev 156
59	Monitor (PPI 118)	Ev 157
60	Moore Adamson Craig Partnership (PPI 39)	Ev 160
61	Motor Neurone Disease Association (PPI 55)	Ev 162
62	National Cancer Research Institute Consumer Liaison Group (PPI 32)	Ev 163
63	National Pensioners Convention (PPI 25)	Ev 165
64	NHS Alliance (PPI 81)	Ev 165
65	NHS Confederation (PPI 142)	Ev 169
66	NHS National Centre for Involvement (PPI 129)	Ev 174
67	National Consumer Council (PPI 114)	Ev 176
68	National Institute for Health and Clinical Excellence (NICE) (PPI 61)	Ev 177
69	National Association for Patient Participation (PPI 83)	Ev 180
70	Norfolk & Norwich University Hospital PPI Forum (PPI 27)	Ev 181
71	North East Ambulance Service PPI Forum (PPI 16)	Ev 183
72	North Tyneside PPI Forum (PPI 51)	Ev 184
73	Northern Group of Oxfordshire PCT PPI Forum (PPI 65)	Ev 186
74	Oxford Radcliffe Hospitals NHS Trust PPI Forum (PPI 46)	Ev 187
75	Oxon & Bucks PPI Forum for Mental Health (PPI 71)	Ev 188
76	Oxon & Bucks Area of South Central Ambulance Service PPI Forum (PPI 135)	Ev 190
77	Parkinson's Disease Society (PPI 120)	Ev 191
78	Patient Opinion (PPI 88)	Ev 194
79	Patients' Forum for the London Ambulance Service (PPI 78)	Ev 196
80	Patients Forum (PPI 92)	Ev 199
81	Peterborough Primary Care PPIF and The Peterborough and Stamford Hospitals PPIF (PPI 03)	Ev 202
82	Picker Institute Europe (PPI 97)	Ev 204
83	Redcar and Cleveland PPI Forum (PPI 49)	Ev 211
84	Richmond and Twickenham PCT PPI Forum (PPI 140)	Ev 212
85	Royal Brompton PPI Forum (PPI 59)	Ev 216
86	Royal College of Nursing (PPI 134)	Ev 217
87	Royal College of Paediatrics and Child Health (PPI 119)	Ev 221
88	Royal College of Radiologists (PPI 50)	Ev 223
89	Royal College of Surgeons of England Patient Liaison Group (PPI 85)	Ev 225
90	Shaw Trust (PPI 127)	Ev 226
91	Sheffield Children's Hospital NHS Foundation Trust PPI Forum (PPI 52)	Ev 228
92	Socialist Health Association (PPI 123)	Ev 228
93	South East Coast Strategic Health Authority (PPI 112)	Ev 233
94	Southwark Patients Forum for Primary Care (PPI 54)	Ev 260
95	St Mary's NHS Trust PPI Forum (PPI 145)	Ev 263
96	Tower Hamlets, Barts and the London Hospital and the East London and the City Mental Health PPI Forums (PPI 70)	Ev 265
97	UK Clinical Research Collaboration PPI Project Group (PPI 91)	Ev 265
98	UNISON (PPI 105)	Ev 268
99	University College London Hospital Acute Trust Forum (PPI 75)	Ev 271
100	Wandsworth Primary Care PPI Forum (PPI 69)	Ev 272

101	Warwickshire PPI Forum (PPI 05)	Ev 273
102	Westminster PCT PPI Forum (PPI 102)	Ev 274
103	West Sussex PPI Forum (PPI 67)	Ev 276
104	Which? (PPI 106)	Ev 278
105	Whipps Cross University Hospital NHS Trust (PPI 116)	Ev 280
106	Winchester and Eastleigh Healthcare Trust PPI Forum (PPI 44)	Ev 282
107	Worcestershire County Council Health Overview and Scrutiny Committee (PPI 115)	Ev 283
108	Yorkshire and Humberside Specialist Forums (PPI 28)	Ev 286
109	Louise Bate (PPI 95)	Ev 288
110	Mrs Jennifer Beesley (PPI 41)	Ev 289
111	Judy Birch (PPI 101)	Ev 290
112	Susan Booth (PPI 94)	Ev 292
113	Malcolm Budd (PPI 84)	Ev 292
114	Judie Collins (PPI 10)	Ev 293
115	Mike Cox (PPI 21)	Ev 294
116	Seton During (PPI 24)	Ev 299
117	Ron Eskdale (PPI 43)	Ev 300
118	Ray Evans (PPI 37)	Ev 301
119	John Fearn (PPI 22)	Ev 302
120	Barry Fineberg (PPI 151)	Ev 302
121	Tony Fletcher (PPI 60)	Ev 305
122	Trevor Gash (PPI 146)	Ev 307
123	Gerald Gilbert (PPI 138)	Ev 309
124	Dr Martin Gorsky, London School of Hygiene & Tropical Medicine (PPI 90)	Ev 316
125	Nick Green (PPI 77)	Ev 322
126	James Halsey (PPI 20)	Ev 324
127	Mr U Hawtin (PPI 57)	Ev 325
128	Dr John Hyslop, Consultant Radiologist, Truro, Cornwall (PPI 11)	Ev 326
129	Robert Jones (PPI 18)	Ev 328
130	John Kapp (PPI 31)	Ev 330
131	Mandy Lawrence (PPI 26)	Ev 332
132	Jean Lewis (PPI 23)	Ev 332
133	Brenda O'Neill (PPI 143)	Ev 334
134	Jean Nunn-Price (PPI 139)	Ev 334
135	Len Roberts (PPI 74)	Ev 337
136	Peter Robinson (PPI 15)	Ev 338
137	Mike Tiernan (PPI 110)	Ev 339
138	Paul Brian Tovey (PPI 47)	Ev 340
139	Nora Warner (PPI 19)	Ev 343
140	John Wigley (PPI 104)	Ev 344

## List of unprinted written evidence

---

Additional papers have been received from the following and have been reported to the House but to save printing costs they have not been printed and copies have been placed in the House of Commons Library where they may be inspected by Members. Other copies are in the Record Office, House of Lords and are available to the public for inspection. Requests for inspection should be addressed to the Record Office, House of Lords, London SW1. (Tel 020 7219 3074). Hours of inspection are from 9:30am to 5:00pm on Mondays to Fridays.

North of Tyne Forum (PPI 58)  
Beatrice Rogers (PPI 35)  
Bob Maggs (PPI 73)  
Patients' Forum for Mayday (PPI 132)  
Fareham and Gosport (PPI 6)  
Hammersmith and Fulham NHS PCT (PPI 166)  
Help the Aged (PPI 160)  
Albert Chapman (PPI 153)  
Mr B N Green (PPI 168)  
Mr Gerald Gilbert (PPI 138A)  
Keep Our NHS Public Greenwich (PPI 164)  
Staffordshire PPI Forums (PPI 161)  
Volunteering England (PPI 159)

## Reports from the Health Committee

---

The following reports have been produced by the Committee in this Parliament. The reference number of the Government's response to the Report is printed in brackets after the HC printing number.

### Session 2006–07

First Report	NHS Deficits	HC 73 (Cm 7028)
Second Report	Work of the Committee 2005–06	HC 297
Fourth Report	Workforce Planning	HC 171

### Session 2005–06

First Report	Smoking in Public Places	HC 436 (Cm 6769)
Second Report	Changes to Primary Care Trusts	HC 646 (Cm 6760)
Third Report	NHS Charges	HC 815 (Cm 6922)
Fourth Report	Independent Sector Treatment Centres	HC 934 (Cm 6930)

The following reports have been produced by the Committee in the 2001–05 Parliament.

### Session 2004–05

First Report	The Work of the Health Committee	HC 284
Second Report	The Prevention of Thromboembolism in Hospitalised Patients	HC 99 (Cm 6635)
Third Report	HIV/AIDS and Sexual Health	HC 252 (Cm 6649)
Fourth Report	The Influence of the Pharmaceutical Industry	HC 42 (Cm 6655)
Fifth Report	The Use of New Medical Technologies within the NHS	HC 398 (Cm 6656)
Sixth Report	NHS Continuing Care	HC 399 (Cm 6650)

### Session 2003–04

First Report	The Work of the Health Committee	HC 95
Second Report	Elder Abuse	HC 111 (Cm 6270)
Third Report	Obesity	HC 23 (Cm 6438)
Fourth Report	Palliative Care	HC 454 (Cm 6327)
Fifth Report	GP Out-of-Hours Services	HC 697 (Cm 6352)
Sixth Report	The Provision of Allergy Services	HC 696 (Cm 6433)

### Session 2002–03

First Report	The Work of the Health Committee	HC 261
Second Report	Foundation Trusts	HC 395 (Cm 5876)
Third Report	Sexual Health	HC 69 (Cm 5959)
Fourth Report	Provision of Maternity Services	HC 464 (Cm 6140)
Fifth Report	The Control of Entry Regulations and Retail Pharmacy Services in the UK	HC 571 (Cm 5896)
Sixth Report	The Victoria Climbié Inquiry Report	HC 570 (Cm 5992)
Seventh Report	Patient and Public Involvement in the NHS	HC 697 (Cm 6005)
Eighth Report	Inequalities in Access to Maternity Services	HC 696 (Cm 6140)

Ninth Report	Choice in Maternity Services	HC 796 (Cm 6140)
<b>Session 2001–02</b>		
First Report	The Role of the Private Sector in the NHS	HC 308 (Cm 5567)
Second Report	National Institute for Clinical Excellence	HC 515 (Cm 5611)
Third Report	Delayed Discharges	HC 617 (Cm 5645)