



House of Commons
Health Committee

Patient and Public Involvement in the NHS

Third Report of Session 2006–07

Volume I



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Report, together with formal minutes

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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.

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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.

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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.¹ 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”.² The Committee warned about the problems that would be associated with the replacement of the old system”.³ 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.⁴

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.⁵

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.⁶ 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.⁷

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

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,¹⁰ and indeed most of our evidence was in agreement that patient and public involvement can make a valuable contribution to improving services.¹¹ 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.¹² 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.¹³

27. Several witnesses stressed the importance of addressing the 'democratic deficit' by making NHS bodies in some way accountable to their local public.¹⁴ 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" ¹⁵
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.¹⁶

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 £600,000.¹⁷ 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.¹⁸ Some thought they lacked independence.¹⁹ The Kings Fund has argued that too few council members were younger adults and individuals from non-white British backgrounds.²⁰

39. CHCs were abolished in 2003. Many witnesses to this inquiry held them in high regard although others thought their performance variable.²¹ 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.²² 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.²³

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.)²⁴

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

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.²⁶
- 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.²⁷
- 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.²⁸

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.²⁹

- 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.³⁰

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.³¹

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.³²

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.³³ Many others mentioned the need for PPIFs to “start again” following the demise of CHCs,³⁴ 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.³⁵ 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.³⁶ 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.³⁷

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.³⁸

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.³⁹

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.⁴⁰

54. We were told of a number of other criticisms. OSCs can only be reactive rather than proactive.⁴¹ 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).⁴² 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.⁴³ 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.⁴⁴

Barry Silverman, from Southwark PPIf, stated:

Complaints disappear into PALS, GP systems and hospital system.⁴⁵

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.⁴⁶

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.⁴⁷

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”.⁴⁸ 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.⁴⁹

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.⁵⁰

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.⁵¹ 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.⁵²

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.⁵³

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.⁵⁴

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".⁵⁵ 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.⁵⁶

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.⁵⁷

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.⁵⁸ Patient and public involvement is included as a Core Standard:⁵⁹

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;

⁵⁶ Ev 157 (HC 278-II)

⁵⁷ Ev 119 (HC 278-II)

⁵⁸ Department of Health, *Standards for Better Health*, July 2004

⁵⁹ 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.⁶⁰ First, too few people are members of forums. The average for the country is 8 per forum.⁶¹ 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...⁶²

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.⁶³

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”.⁶⁴

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.⁶⁵

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.⁶⁶ 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.⁶⁷

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.⁶⁸

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.⁶⁹

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 involvement⁷⁰

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.⁷¹

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.⁷²

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.⁷³

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.⁷⁴

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 PPIs. Chief among these was the poor performance of CPPIH. Many thought that the Department had decided to abolish CPPIH and subsequently abolished PPIs almost as an afterthought. While the Department was concerned that PPIs 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 PPIs:

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.⁷⁵

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.⁷⁶

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.⁷⁷ 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.⁷⁸

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.⁷⁹

87. Others stressed the variability of PPIFs.⁸⁰ 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?⁸¹

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”.⁸² 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?⁸³

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.⁸⁴

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.⁸⁵

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.⁸⁶

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.⁸⁷

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.⁸⁸

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.⁸⁹ 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

⁸⁹ 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.⁹⁰ 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.⁹¹ 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.⁹²

He added that these groups had been given a set of objectives by which they could be judged.⁹³ 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”.⁹⁴

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.⁹⁵

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, yes⁹⁶

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.⁹⁷

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 process⁹⁸.

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.⁹⁹

...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.¹⁰⁰

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.¹⁰¹

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.¹⁰²

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.¹⁰³

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.¹⁰⁴

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.¹⁰⁵

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.¹⁰⁶

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.¹⁰⁷

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.¹⁰⁸

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.¹⁰⁹

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.¹¹⁰

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.¹¹¹

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.¹¹² 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.¹¹³

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.¹¹⁴

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.¹¹⁵

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.¹¹⁶

[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.¹¹⁷

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.¹¹⁸

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.¹¹⁹

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.¹²⁰

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.¹²¹

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.¹²²

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.¹²³

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.¹²⁴

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.¹²⁵

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.¹²⁶

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.¹²⁷

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.¹²⁸

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.¹²⁹

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

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.¹³¹

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.¹³²

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.¹³³

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.¹³⁴

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.¹³⁵

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.¹³⁶

133 Q 137

134 Q 137

135 Q 268

136 Q 122

