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A social enterprise working on patient and public involvement

1. About Health Link - Health Link is a not for profit social enterprise working in patient and public involvement, particularly with people at risk of health inequalities or social exclusion.

1.1. History: It was formed in January 2004, as a successor to London Health Link, the regional association of London Community Health Councils (CHCs) by Elizabeth Manero, ex Chair of London Health Link. The management committee is made up of patient representatives with many years experience in patient and public involvement (PPI). Health Link also operates a network of 125 lay people across all London boroughs, which have a wealth of knowledge and expertise about their local health service and about patient and public involvement. Most are ex-CHC members and many are now on Patients Forums, Overview and Scrutiny Committees or local involvement groups.

1.2. Activities: Health' Link's work is project based, mainly under contract to DH, NHS Connecting for Health and NHS organisations, with some grant funding:

- **Running a Choose and Book Patient Reference Group** for NHS Connecting for Health, to advise on implementation in London.
- **Setting up the NW London Patients' Parliament** for NW London Strategic Health Authority (STHA), recruiting and training members from 8 boroughs, designing governance materials and Code of Conduct.
- **Outreach consultation for London Patients Choice project**, on the choice information needs of socially excluded groups. The resulting *Taking Soundings* recommended how to avoid Choice inequalities.
- **Acting on Taking Soundings:** with 4 STHAs, the DH and NHS Connecting for Health, we developed a Patients' Information Tool, to enable patients to compare hospitals, in response to *Taking Soundings* findings.
- **Cross-government Partnership for Patients:** Setting up 9 library pilots to test the role of libraries in patient choice, as suggested by *Taking Soundings*, through a Partnership led by ourselves and comprising the DH, DEFRA, the Museums, Libraries and Archives Council, the London Libraries Development Agency and London Health Libraries.
- **Health and Homelessness:** involving homeless volunteers in monitoring and improving A & E services from the homeless perspective, in partnership with Whittington and Homerton Patients Forums. This Project was independently evaluated and funded by the Kings Fund. With funding from the Halley Stewart Trust, we are now implementing the resulting recommendations.
- **PPI in the determinants of health:** working with the London Health Commission to help grass roots community groups to engage with pan-London decision-making bodies on the determinants of health and health

inequalities.

- **PPI in specialised services:** supporting a Patient Reference Group for the London Specialised Commissioning Group,
- **Connecting Patients' Forums to their communities:** developing a 'Community Connections' approach for two London Patients Forums, facilitating dialogue between the Forums and local community groups supporting disadvantaged people, so the Forums' work could be socially inclusive.

1.3 Our Evidence: This range of patient and public involvement activity has informed our evidence. Our various projects on Patient Choice demonstrate that we have been able to take the public and patient view to policy makers and get policy and practice adapted. In response to *A Stronger Local Voice*, we undertook a survey of our Network to gather evidence on the lay visiting to the NHS, which the government was proposing to remove when Patients Forums were abolished. We sent out 125 surveys to our London Network and received 420 responses from all over the country reflecting the strength of feeling on this matter. Results of the survey are attached at the Appendix and summarised in paragraph 4.6 below.

2. What is the purpose of public and patient involvement?

In the 21st century, it is no longer acceptable for public services to be designed for the public – they need to be designed with the public. A paternalistic approach to public services, where a minority decides for the majority, is inappropriate to a modern diverse, democratic society. We consider that patient and public involvement has two purposes:

- a) to bring a general patient and public perspective to the design, monitoring and scrutiny of health and social care services,
- b) to use the perspective of people at risk of health inequalities to ensure services better meet their needs, and help reduce health inequalities

If the first objective is met, services will meet the needs of most people and match the expectations of most of the public. For example, hospitals will meet the standards for accessible services which the public expects from the NHS (e.g. waiting times). If both objectives are met, some of the health inequalities which hold the NHS back in its goal of improving health will be alleviated. For example, the perinatal mortality rate for black African women, including asylum seekers and newly arrived refugees is seven times higher than white women. Where these inequalities are caused by inaccessible or culturally inappropriate services, patient and public involvement which draws in the perspective of these women can help make such services accessible to them.

2. What form of public and patient involvement is desirable, practical and offers good value for money?

2.1 Desirability: The desirability of patient involvement is implicit in the recommendations of the Bristol Enquiry and the Wanless Report:

- In 2001 the Bristol Inquiry¹ (which investigated the high number of deaths of babies and young children after heart surgery at the Bristol Royal Infirmary between 1984 and 1995) recommended: *"The involvement of patients & the public must be embedded in the structures of the NHS & permeate all aspects of healthcare in the NHS."*
- In 2002, the Wanless Report² (a Report commissioned by the Treasury into the viability and sustainability of the NHS) required *"more effective partnership between health professionals & the public"*

Based on our experience, three types of patient and public involvement are needed:

- Prospective – in planning services
- Contemporaneous – in monitoring services
- Retrospective – in scrutinising whether what was promised has been delivered

2.1.1 Prospective: The planning of services operates at both strategic and commissioning levels:

- **Strategic** – strategies for health and social care need to be aligned to health improvement. For example, if young people are involved in designing health strategies then they will expect to be involved in the same way as they grow older, tying future strategic development to a public and patient perspective. If people at risk of health inequalities are involved in strategic decision-making, their interests are more likely to be advanced by those decisions. We are facilitating contact for NHS London with people with mental health problems and homeless people, so they can consider their needs in developing the no smoking strategy for London, improving enforceability of the forthcoming legislation.
- **Commissioning** - the commissioning of services without patient and public involvement is commissioning with one hand tied behind the commissioner's back – statistics can be used to determine what services are required but the way in which they should be provided will be largely guesswork by commissioners if they work without patient input. For example, statistics may inform a health service commissioner that there are high levels of diabetes in an area but only effective patient and public involvement in commissioning diabetes services will help make sure that some Asian groups, who have a greater predisposition to this condition, find these services culturally appropriate.

¹ *Learning from Bristol: the report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984 -1995*

² *Securing our future health, Taking a long-term view. London HM. Treasury:*

2.1.2 Contemporaneous: monitoring of services as part of patient and public involvement is important in ensuring that a fair view is obtained of the performance of those services. Visiting rights are vital for this and we are very pleased that the Department of Health reconsidered its decision to remove these. Without such rights, LINKs may ask patients what they think of local health services - unless they are using them at the time. They can ask local marginalised groups what they think of health services - unless they are so marginalised by mental illness for example that they are receiving inpatient care. They can ask patients their views about their experience of waiting for services - unless they are actually waiting in a waiting room at the time.

Much more consistent training and accountability standards are required to ensure that lay visiting is responsive and of high quality and has clear outcomes. For example, government targets require that patients are seen and transferred or treated from A & E within four hours. Only regular monitoring by patients and the public can give a fair view of the quality of the patient experience of that process and the quality of the environment in which it is delivered. This will enable patient representatives to maintain a dialogue about how it can be improved. This kind of monitoring has the capacity to reduce the amount of inspection required because local services are under constant patient review, making it less likely that problems will build up.

2.1.3 Retrospective: Scrutiny is conducted by elected officials, councillors at local level and MPs at national level, and is the way in which the Department of Health or local health and social care providers are held to account on behalf of the electorate for the commitments made to the population, locally or nationally. It is developing slowly in some areas, hampered poor resourcing and the interruptions of local elections. These reforms would be an opportunity to address some of the problems surrounding scrutiny:

- Failure to make Overview and Scrutiny in health a duty on local authorities and include it in performance management of local authorities has led to patchiness in scrutiny and to its complete absence in some areas.
- Lessons must be learned from this 'postcode democracy' on health, where some communities have their interests represented in the health service by their locally elected councillors, and some do not. The planned duty to host a LINKs should be coupled with a duty to undertake scrutiny so that local citizens get best value from the patient and public involvement framework, rather than only half the system as happens currently where scrutiny is poor.
- There is no incentive on local authorities to be transparent about any political bias operating in the way in which they would handle the funding for LINKs or the way they currently operate scrutiny (if they do). Political bias was predicted before the establishment of the Scrutiny role for Local Authorities³ and has been demonstrated now that this role has started, as reported to

³ *Abolition of CHCs: A Blueprint for Failure* London Health Link 2000

CPPIH by Patients Forum members⁴. This problem could be addressed by including an explicit obligation on local Councillors to act without political bias in scrutiny, enforced through the Standards Board.

- 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. This interruption in public accountability could be addressed by prohibiting the NHS from undertaking change at a time when scrutiny committees are in suspension, a period which should be strictly limited. Patients' needs do not change because of elections so election arrangements must reflect those needs.
- The scrutiny of contested reconfigurations remains weak because, even if OSCs use their power to refer such matters to the Secretary of State, she has apparently complete discretion in whether to seek advice from the Independent Reconfiguration Panel and whether to disclose why she has not. This is a serious accountability gap, at a time when such reconfigurations are becoming increasingly common and contentious. A duty on the Secretary of State to give reasons for any failure to call in the IRP would preserve her discretion but make its use more transparent and accountable.

2.2 Practicality

Making decisions with patient and public involvement is more likely to result in outcomes which meet patient and public needs. This is a concept which is mirrored in commerce where market research and feedback are essential components of offering what customers want and need, to have the best chance of succeeding in giving it to them. There are some changes which could improve the practicality of the system:

2.2.1 Integration with scrutiny: Scrutiny by elected officials is the way that this success in health and social care, is monitored. It is impractical to expect scrutiny to be effective without close links with patient and public involvement, so the two have to be integrated. The current arrangement where Patients Forums have powers to refer issues to local OSCs or refer to national bodies if local action has been absent or ineffective, provides this integration and should not be lost.

2.2.2 Integration with management: Well designed involvement need not act as a brake on effective management and decision making. Patients Forum members can and do sit on clinical governance committees, audit committees, NHS boards (although less consistently than CHCs for whom this arrangement was enshrined in Department of Health Guidance), tendering panels and recruitment boards. The practice of mental health service users being involved in the recruitment and training of health service professionals is well established. Maternity service users influence maternity strategy through Maternity Service

⁴ August PPI Review Special Forum Focus. Commission for Patient and Public Involvement in Health August/September 2006

Liaison Committees. Integrated patient and public involvement is practical and well established, although it is true that there have never been any systematic evaluation of its benefits.

2.2.3 Triangulation with the views of people at risk of health inequalities: it is not practical to postpone all strategic decision-making for outreach consultation with people who are socially excluded. A more practical approach is for the views of people who have joined Patients Forums to be informed by their outreach work (such as the Community Connections project described above) with local community groups supporting disadvantaged people.

2.2.4 Equality of Opportunity: Government policies which do not permit equal access to patient and public involvement for disabled people and people from different ethnic groups and health services which are discriminatory for either group can be challenged. For this reason, it is important that people in the relevant population groups are supported to access patient and public involvement. It is impractical to expect the NHS to meet the needs of disabled people and to provide culturally appropriate services without the direct involvement of people affected who have the expertise to help.

None of these components of effective ppi can be delivered without acceptance that

- **Some people will act as proxies for others:** Providing there are proper accountability arrangements for patient representatives as well as training that meets consistent standards, the risk of 'usual suspects' unintentionally distorting services to suit their own ends, can be avoided. It is the work of patient and public involvement that must be representative, not necessarily the people.
- **Suitably trained and accountable patient representatives should have access to wherever patients go in the NHS:** to monitor services from their point of view and talk to them while they are actually using services without fear of reverberations. This way full integration with management can be achieved because judgments are based on a shared understanding of reality. OSCs would be able to scrutinize with the benefit of first hand reports on what is happening in services, which they would not have time to obtain for themselves given the breadth of the scrutiny remit and the other demands on Councillors.

2.3 Value for Money

As patient and public involvement traditionally depends largely on volunteers, value for money is high. Competent staff support is essential and enables the best value to be obtained from the system. There is a clear cost benefit to the NHS if there are quality and health improvements as a result of effective patient and

public involvement. The Treasury Guidance⁵ on Inspection of Services makes the important point that the threat of inspection is a valuable benefit achieved at the cost of merely having the inspection system in place, irrespective of how frequent inspections are: *'Would the service worsen if there were no direct inspection or no threat of inspection? Potentially, there could be no difference, or at worst, fraud and corruption could become endemic, service quality could spiral downward and public confidence in the whole political system could decline markedly.'* Knowledge of the mere possibility of lay visiting would have the same effect.

3. Why are existing systems for patient and public involvement being reformed after only 3 years?

This remains somewhat of a mystery.

3.1.1 Patients Forums: It is true that the reshaping of the NHS requires a different focus, with the shift to commissioning, plurality of providers and integration with social care. However, the necessary changes could be achieved with legislative amendment to functions of Forums so their wholesale removal is not necessary.

3.1.2 CPPIH: It seems that an undue level of resources is tied in up the infrastructure of the Commission for Patient and Public Involvement in Health, with its regional offices and staff. The contract management process of the Forum Support Organisations has also not inspired confidence with Patients Forums.

3.1.3. Budgetary responsibility: The peculiar way in which the budgets of Forums have been managed lacks transparency and raises questions about accountability. For example, we were present at a meeting of a Forum where the Chair was required to sign off Accounts in public, with '0' as the only entry because the Forum support Organisations held the budget and refused to disclose how it had been spent, citing commercial confidentiality. This could be addressed by proper application of commercial confidentiality. In our view, disclosure of this sort of financial data involving public money under procurement is largely a matter of timing. Whilst a procurement process is continuing, the amount to be charged by bidders is commercial in confidence. However, once the contract has been awarded, the way in which the public money funding the contract, is spent, should be transparently and freely reported and open to challenge. We suggest that this interpretation be used to make sure that the procurement of host organisations for LINKs is transparent and accountable. The bill before Parliament does little to improve matters as it preserves this substitution of contractual accountability for public accountability and leaves budgetary responsibility for the money spent on LINKs unclear.

A consequence of removing these elements of the system might well be that Patients Forums would be incapable of survival. As the support system for the

⁵ *Assessing The Costs And Benefits Of Government Inspection Activity: Guidance.* HM Treasury and Office of Public Services Reform. 2003

Forums is vested in the Commission, it would be necessary to transfer these roles (training, support, performance monitoring, budget management) to another bodies or bodies.

3.2 Substitute arrangements supporting patient and public involvement under the Local government and Public Involvement in Health Bill:

3.2.1 Support Arrangements: Both local authorities and local commercial or voluntary sector organisations have potential roles substituting for the Commission's support functions in the bill. The bill before Parliament imposes a duty on authorities to make arrangements for LINKs and it is envisaged that they will commission local organisations for this role. There seems to be an element of government 'washing its hands' of the troublesome issue of managing transparent patient and public involvement and offering to local authorities and 'the market.' In doing so, greater variability will be introduced making performance monitoring, insofar as there will any performance monitoring, harder to implement.

3.2.2 National Voice for patients: It is unclear what role the Centre for Patient and Public Involvement and the proposed loose grouping of voluntary sector organisations styled as 'National Voice' will have. The other clear consequence of the fragmentation of the CPPIH function to local authorities is the loss of a national statutory voice for patients, which the CPPIH so signally failed to deliver. This result needs to be challenged as it is a significant subtraction from public accountability. The most significant example of how such an independent public body can contribute was Casualty Watch – a national inspection of waiting times in A & E which highlighted some difficult patient experiences and led to the introduction of the 4 hour target in A & E.

3.2.3 Local Authorities: It seems unlikely that local authorities would be sufficiently remote from LINKs to undertake the role of contracting for 'arrangements' to support LINKs, especially given the very welcome extension of the LINKs role to social care which is the statutory responsibility of local authorities. We note that the funding for LINKs is to be given to local authorities. Whilst appreciating this is a cost effective way of managing the budget for LINKs, we are concerned that this means the funds will be vulnerable to being diverted by local authorities to their other activities. For example, in an area where a local authority is experiencing an increased demand for social services, what would be the brake upon them diverting funding from LINKs to the direct provision of services? In the absence of such a brake, there is no guarantee that LINKs would continue to be provided or that they would be adequately resourced. Thus the very means of finding out what users thought of social care services in difficulties would be removed. With the current bill before Parliament which includes provisions on the standards for Councillors, there may be an opportunity to address some of these matters in the Code of Conduct and to strengthen the protection of funds for involvement.

3.2.4 Local Voluntary or commercial organisations: it is envisaged that such bodies will contract for arrangements to host LINKs from local authorities. On the face of it, there seems no reason why commercial organisations such as market

research companies should not be granted contracts to support LINKs. This would run counter to the whole spirit of patient and public involvement, but may be difficult to prevent under procurement rules.

There is a risk of conflict of interest under the new proposals. With the introduction of plurality of providers there is a tangle of vested interests operating in the health service, with provision of services and monitoring of services increasingly both vested in the voluntary sector. It is a clear principle that the person who carries out a function should not be the only arbiter of the quality of the performance of that function. The government agency, the NHS, which provides health care, has never been responsible for exclusively judging its own performance. If the function of delivering health care is to be transferred to a plurality of providers under contract, the function of scrutiny must not be transferred to the same organisations. Although OSCs have a leading role in scrutiny, they cannot perform this alone and must have the benefit of disinterested input from patient and public involvement bodies. To avoid conflict of interest for bodies which may be both delivering services under contract and contributing to scrutiny of those services by hosting a LINKs, we feel that a new model of contractual accountability is needed as follows:

- It is essential that there is a guarantee of independence incorporated into the new 'contractual arrangements' with voluntary sector organisations, for them to have any credibility with the public. This might be achieved through eligibility criteria, a Code of Conduct and a transparent, independent complaints process which permits the removal of members of LINKs who display bias or commercial interest.
- Contractual relationships with the voluntary sector should be based on the Compact, which includes the following undertaking by government: *'To recognise and support the independence of the sector, including its right within the law, to campaign, to comment on Government policy, and to challenge that policy, irrespective of any funding relationship that might exist, and to determine and manage its own affairs.'*
- The spirit of this undertaking needs to colour the relationships between the voluntary sector and the NHS, contractual and otherwise. Voluntary sector organisations need to feel secure that they are not compromised in any procurement process because they are active members of LINKs and may have come into some sort of conflict with their local NHS. Equally, the local community needs to be confident that its interests are being promoted in an unbiased and transparent way through an independent LINKs. This could be achieved through transparent procurement processes and appropriate provision in contracts for service provision.

3.3 Issues for consideration in connection with the reform decision:

3.3.1 Risk Assessment: Under Guidance from the Prime Minister's Strategy Unit⁶, all policy reforms are required to be subject to a risk management, following on from the recommendations after the BSE crisis: *'All decisions and processes need to take account of risk. These include policy making, programme and project management, and operational management and decision making;'*

The same Guidance requires *'openness and transparency'*, *'a precautionary approach'* where risks to the public are involved and that all decisions *'are based on all relevant evidence.'* It is not clear that this approach has been taken to the abolition of Patients Forums.

The continual disruption to patient and public involvement of sequential reform and the loss of motivation to individual people who have great expertise in ppi and who volunteer their time and commitment to undertake this activity at local level, must clearly be a factor in any such risk assessment. We are pleased that the very considerable risk pose by the proposed removal of lay visiting to NHS facilities, has been reversed. In the absence of draft regulations on visiting, it is of course impossible to judge how restrictive these might be of independent monitoring.

3.3.2 Cost Benefit analysis of the proposals. A cost benefit analysis should be undertaken of the latest reforms, taking account of all the costs incurred to date. We understand that there may still be empty CHC premises in the country that have not been redeployed or disposed of, suggesting a financial penalty on the taxpayer of this continuous reform of patient and public involvement. Such a cost benefit analysis would have to take account of:

- Parliamentary time spent debating the legislation to set up Patients Forums
- Parliamentary time spent abolishing Patients Forums and legislating for LINKs
- Cost of closing CHC offices and disposing of the estate, including any premiums for the surrender of leases
- Costs of disposing of CHC equipment (including disabling and junking of computers)
- Human resources support and redundancy costs for CHC staff
- Set up costs for CPPIH
- Redundancy costs for CPPIH staff
- Costs of disposing of CPPIH premises and equipment (including disabling and junking of computers)
- Set up costs for Patients Forums
- Recruitment and training of Forum members
- Procurement costs for Forum Support Organisations
- Costs of disposing of Patients Forum offices and equipment (including disabling and junking of computers)
- Recruitment and training of LINKs members

⁶ *Handling risk: A user's guide to the Strategy Unit report.* Prime Minister's Strategy Unit November 2002

- Procurement costs for hosting and subsequent contract management, multiplied by the number of local authorities in the country required to undertake the procurement and subsequently manage the contracts
- Opportunity costs of the management time in local authorities, the NHS and the Department of Health in implementing these proposals, when the previous set has not been evaluated.

We are not sure what evidence the Department of Health has used to cost the benefits of abolishing Patients Forums but no doubt this can be factored into the analysis.

4. How should LINKs be designed?

4.1 Remit and level of independence

4.1.1 Remit: the extension of the remit of patient and public involvement to social care with the plans for Links is very welcome. However, we do not understand how this is to be achieved given the different governance for social care and the extra resources required. A draft specification for a host organisation would be useful in determining the adequacy of the proposals to meet the important objective of integrating involvement in health and social care.

4.1.2 Independence: Sufficient independence is needed to enable the LINKs to have credibility with the public and to be in a strong enough position to create a meaningful position of influence with local care providers. This standard could be met through

- Training and standards for LINKs member activity
- The contracting arrangements we have referred to above for host organisations
- Accountability for Councilors on political bias, through the Standards Board
- Removal of any possibility for health service employees to be part of LINKs.

Currently, regulations on membership are not strong enough to exclude NHS employees from influencing the work of Forums and the recommendations they make, which is clear conflict of interest. We are aware of one case where a consultant from a Foundation Trust has become a member of a Patients Forum for an adjacent NHS Trust Patients Forum.

4.2 Membership and appointments: it is clearly essential for governance purposes that there be some form of core membership of a LINKs. Otherwise LINKs is merely an amorphous fluctuating group of people and groups with no leadership and little accountability, which would effectively put all power in the hands of the host organisation. This is not patient and public involvement but a classic talking shop, where gathering a plethora of views meets the requirement - but doing something about those views is not required. The bill is silent on both membership and appointments. In the absence of draft regulations it is very hard to judge the LINKs proposal at all. Patients Forum members who are interested in being part of

LINks should be considered for the core role if they undertake appropriate compulsory training.

4.3 Funding and support: as explained above, in the absence of a model specification for the host organisation and for LINks in an area and of an indicative budget, it is impossible to judge the adequacy of funding. We have commented about on the proposed support arrangements.

4.4 Areas of focus: the resources, infrastructure and competence required to seek views, and interpret these into dialogue across the whole of health and social care will be huge. Nonetheless, these functions are very important. We suggest different groups within LINks covering different aspects, so that specialist expertise is developed without losing the overview maintained by the core members.

4.5 Statutory powers: all the existing legal rights of Patients Forums must be retained as they constitute the backbone of arms length scrutiny. We welcome the extension of a power of referral on social care for OSCs. The findings of our survey of 237 Patients Forum or ex-CHC members are detailed below and the full extract from our Response to A Stronger Local Voice is attached at the Appendix.

4.5.1 Conduct of Visits: there was evidence of close engagement by lay people in the management of their local NHS through lay monitoring

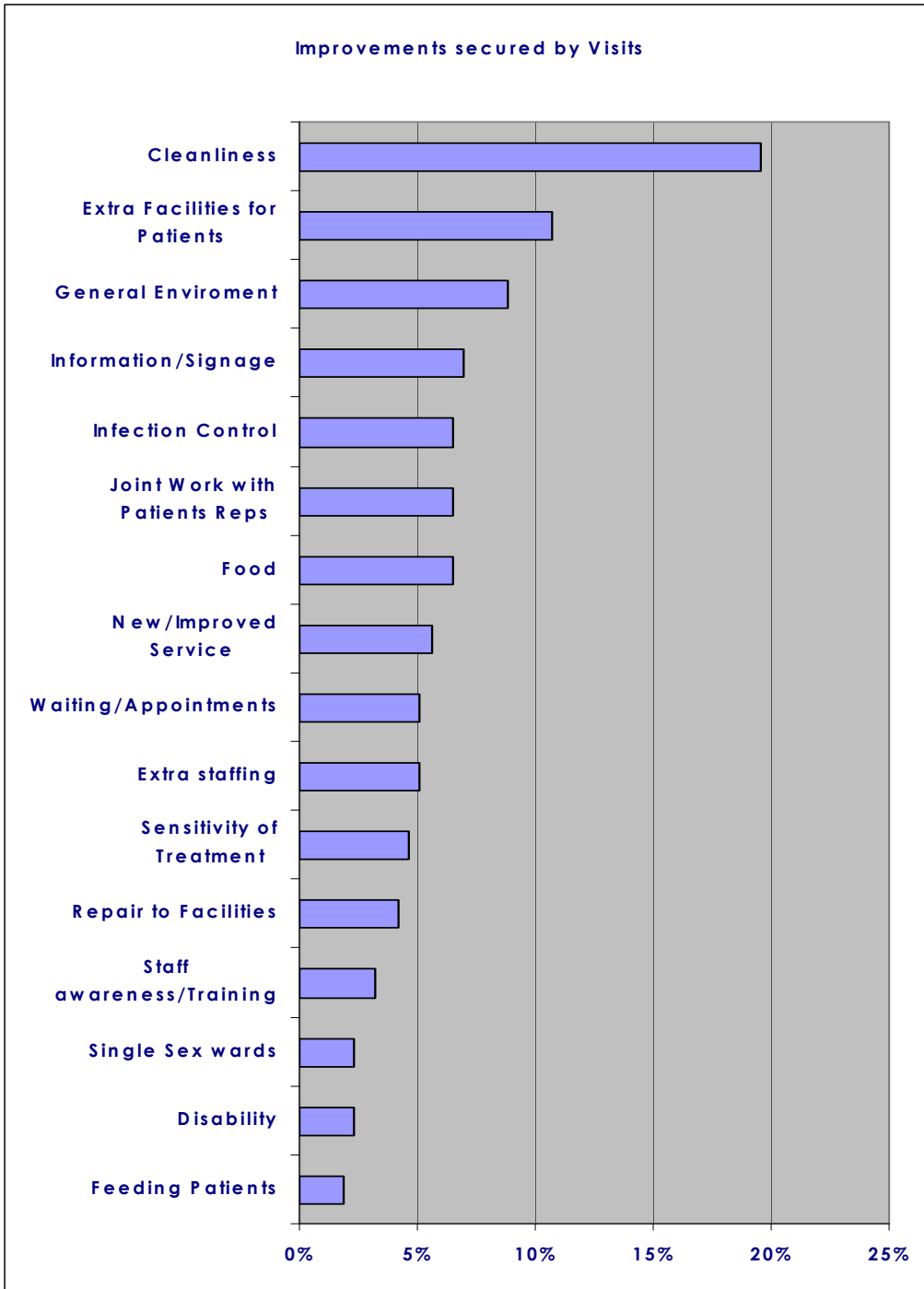
- 76% usually or always talked to patients about their views of the service
- 81% usually or always talked to staff about their views of the service
- 55% said their visits were rarely or never unannounced

4.5.2 Shortcomings Highlighted: 77% of respondents said that their visiting had highlighted shortcomings in services. Issues raised are grouped for Acute (hospitals), Primary Care and Mental Health Services. In terms of the patients' interest, it is striking that issues highlighted would all have a powerful effect on the quality of the patients' experience, including cleanliness, infection control, security, single sex wards and waiting times in hospitals and GP surgeries.

4.5.3 Improvements made as a result of visits: The range and diversity of improvements reported by respondents as a result of visiting, across all sectors are illustrated on the bar graph overleaf. Improvements to the cleanliness, feeding of patients, to sensitivity of care and to patient information, signage and disabled access clearly relate very closely to the patient's experience of care and issues such as infection control relate to the quality of clinical outcome. In addition, there is a clear link between shortcomings highlighted and improvements secured, with 92% of visit reports highlighting shortcomings also suggesting improvements and improvements claimed in 72% of cases. The purpose of the visits was not just to pick holes in the NHS and complain – real improvements were negotiated as a result. This is illustrated on the graph overleaf.

5. Formal and informal complaints procedures

Independent Complaints Advocacy Service (ICAS), the statutory complaints support service set up in 2001 to replace CHCs' informal role, seems to be a largely invisible service. So far as we are aware there has been no formal evaluation of it. After the Shipman tragedy it is essential that complaints are carefully tracked by those who commission and monitor services. We suggest that ICAS has an obligation to feed in anonymised complaints data to commissioners, LINKs and OSCS. There will obviously be a resource issue for this additional role.



6. 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?

6.1 Section 7: The legal duty to consult the public, with the OSC as the statutory consultee, is the means by which major changes in infrastructure of local services are tested with local communities. Because changes consulted upon will be by nature 'substantial', the right to refer to the Secretary of State for the OSC, is an important one. Since *Shifting the Balance of Power* transferred more power to PCTs, it is one of the few ways in which the DH can intervene when unwise or damaging plans are proposed locally. The only change we propose to this system is that the referral process is more transparent, as described above. Section 7 is essential because it preserves local NHS infrastructure and avoids services departing from national policy. Unfortunately, it cannot be triggered if the OSC refuses to respond to a consultation in the first place.

6.2 Section 11: We welcome the planned amendment of S.11 to relate to 'significant' operational and planning activities. It is not clear however, what this would mean in practice. There is case law on substantial variations under section 7 but the difference between significant and substantial is unclear. It is important to make S.11 practical for the NHS to implement but not to reduce its remit to such an extent that they can avoid it all together. Some guidance needs to be developed on what significant means, in consultation with users and health and care providers. It is also not clear how the two sections are intended to relate to one another. If thorough consultation under the new Section 11 has resulted in a consensus solution, how could an OSC subsequently disagree under a Section 7 public consultation on that proposal and refer it to the Secretary of State?

Conclusion: there is no clear evidence of the need for reform on quite the scale proposed. The undoubted faults of the current system may well be due to poor implementation of the last set of reforms, rather than poor design of those reforms. Properly designed and implemented ppi, which recognises and builds upon current skills and commitments, has the right powers and governance framework and has the capacity to add measurable improvement to the patient and user experience of health and care.

Elizabeth Manero
Director
Health Link
10.01.07

APPENDIX

Extract from Health Link's Response to A Stronger Local Voice

Evidence on lay visiting – the Health Link Survey

1 Background to the survey

To contribute evidence to the debate on ppi reform, Health Link carried out a survey to seek the views of Health Link's London PPI Network members, all lay people with real experience of volunteer patient and public involvement. A copy of the survey and accompanying letter is attached at Appendix 2. Issues covered in the survey included:

- Experience of participation in monitoring visits
- The number of visits participated in
- Type of health service premises visited
- How the visit was conducted (e.g. whether visitors spoke to patients and staff)
- Whether the visit planned or unannounced
- Whether shortcomings were found and what type
- Any improvement made to the services as a result of recommendations
- Views on the new arrangements for visiting

1.2. Methodology

The self completion survey was distributed by post to our Health Link Network, with our Freepost address. The Network comprises 125 patient representatives across 31 London boroughs, who are familiar with the front line of Patient involvement. Given their experience, we felt that they might well have participated in visiting NHS services. In the event we received numerous requests to allow the survey to be forwarded to people outside the Network and finally received 380 responses (including 6 by email) from all parts of the country. 237 were received before the deadline and the results are incorporated into this Report. We will produce a final survey Report in the next few weeks where we will include all the surveys, to give as balanced a view as possible.

The areas from which responses were received within the timeframe are shown in Appendix 3, and cover a large part of the country. As our original purpose was to consult our London network, we have grouped the numbers of responses by London boroughs and areas outside London. Where we only have details of the Patients Forum to which the person belongs, we have included that name under the appropriate section.

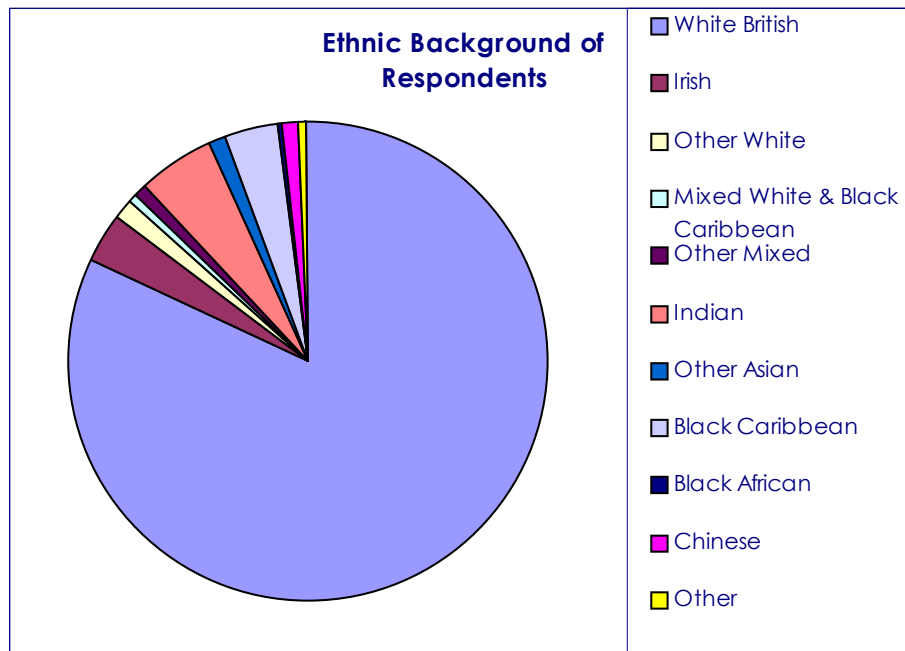
1.3. Survey Respondents Overall

53% of respondents were male and 47% female.

The majority of the respondents were over 60. Two thirds of hospital users are over 65. Most participants who responded to our survey had visited hospitals, reflecting their interest in the part of the NHS which they use.

Age of Respondents by %					
16-19	20-29	30-39	40-49	50-59	60+
0	0	1%	6%	15%	78%

Ethnic background of respondents is shown over the page. 77% of the respondents were White British, which compares with 91.2% of the UK population who are White British.



2. Findings

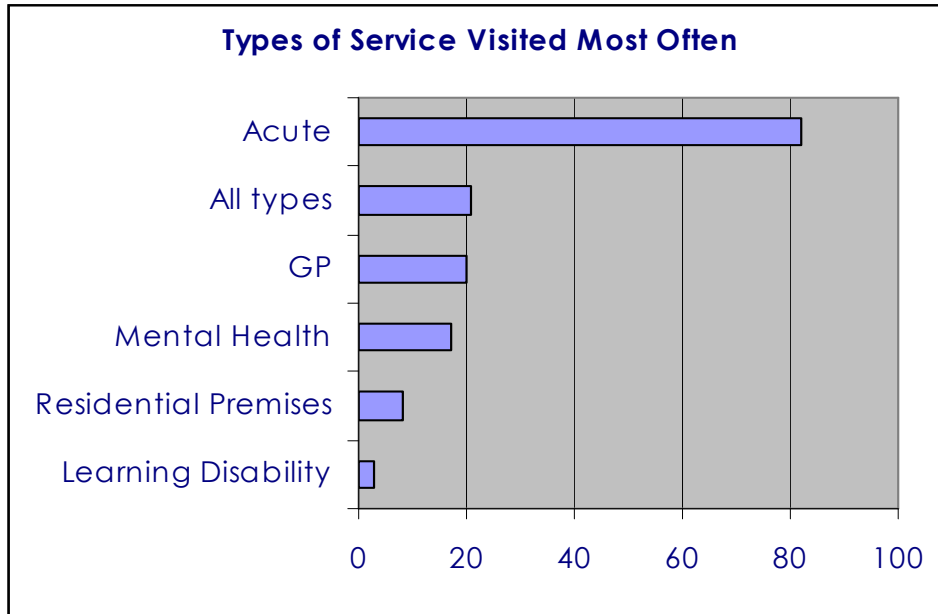
Findings from our survey are divided into various sections:

- How and Where visits were conducted
- Shortcomings found or improvements secured
- Views of respondents to the survey on the plan to remove local lay led visiting

85% of respondents had experience of visiting and were therefore well qualified to contribute to our evidence gathering on the subject, with 37% having conducted more than 10 visits.

2.1. How and Where Visits were conducted

The whole range of NHS facilities was visited by respondents, from residential premises to hospitals and GP premises, with 57% visiting acute hospitals most often and 14% visited GP surgeries and clinics most often. The Table overleaf ranks types of facility by frequency of visit.



It was very much usual practice for visitors to talk to both patients and staff to get their views on services and environment. The opportunity for front line staff to talk informally to visitors about issues, such long standing repairs or staff shortages, has traditionally been an important benefit of lay visiting. The visitors' report highlights the issue and the management is obliged to respond and often addresses the issue, short circuiting internal processes.

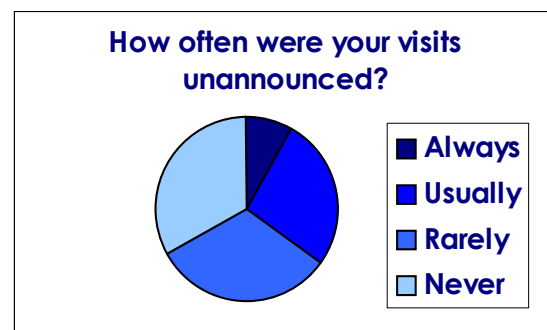
- 76% usually or always talked to patients about their views of the service
- 81% usually or always talked to staff about their views of the service

Amongst respondents to our survey, it was not uncommon for visits to be unannounced, but they were usually by prior arrangement:

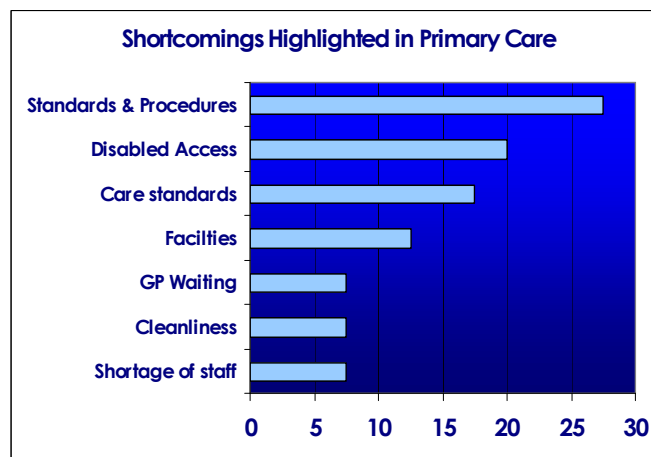
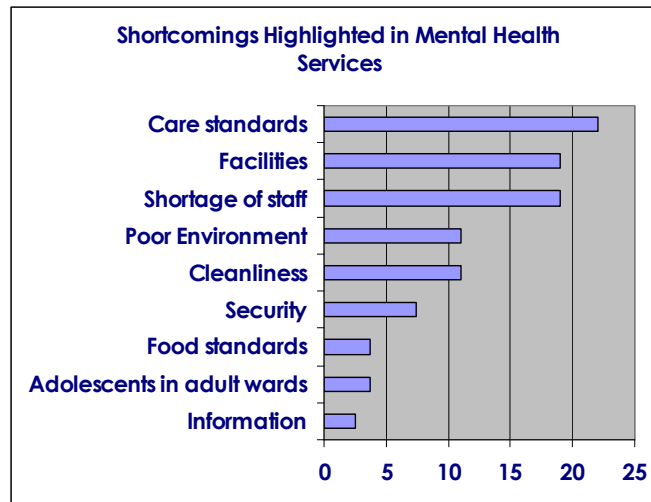
- 30% said visits were usually or always unannounced
- 55% said visits were rarely or never unannounced (15% did not respond)

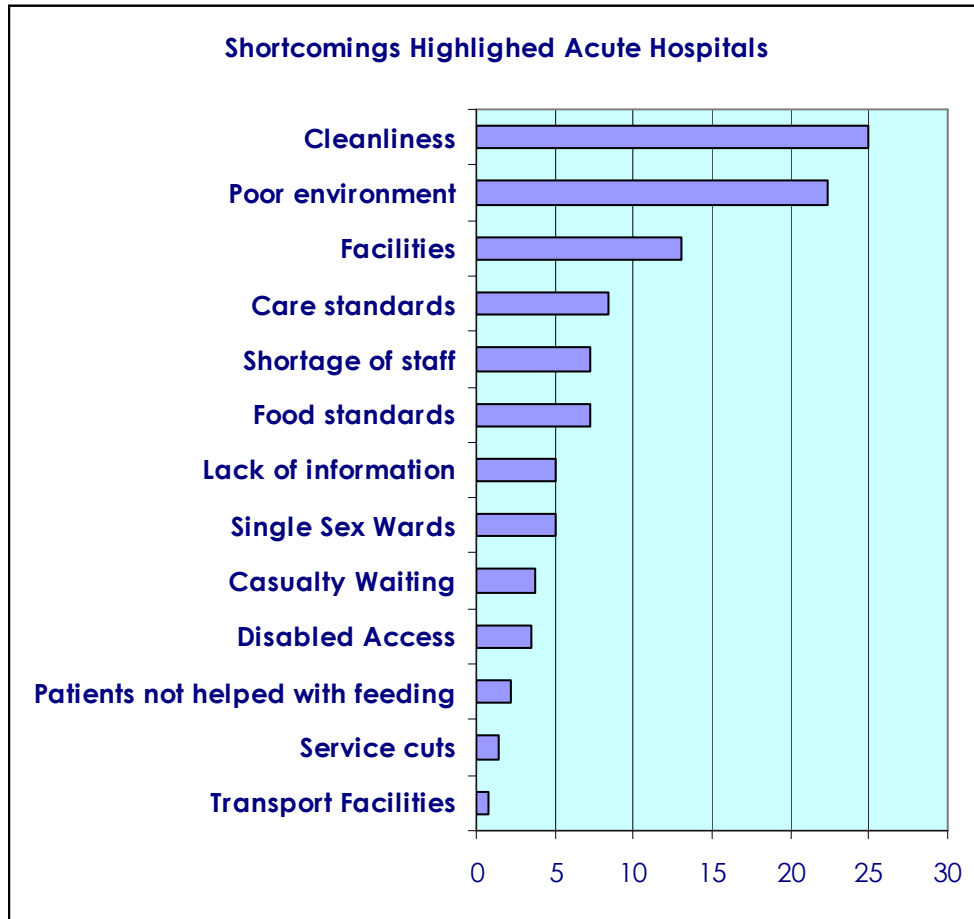
2.2 Shortcomings highlighted by Visits

77% of respondents said that their visiting had highlighted shortcomings in services. Issues raised are grouped for Acute



(hospitals), Primary Care and Mental Health Services. In terms of the patients' interest, it is striking that issues highlighted would all have a powerful effect on the quality of the patients' experience, including cleanliness, infection control, security, single sex wards and waiting times in hospitals and GP surgeries.

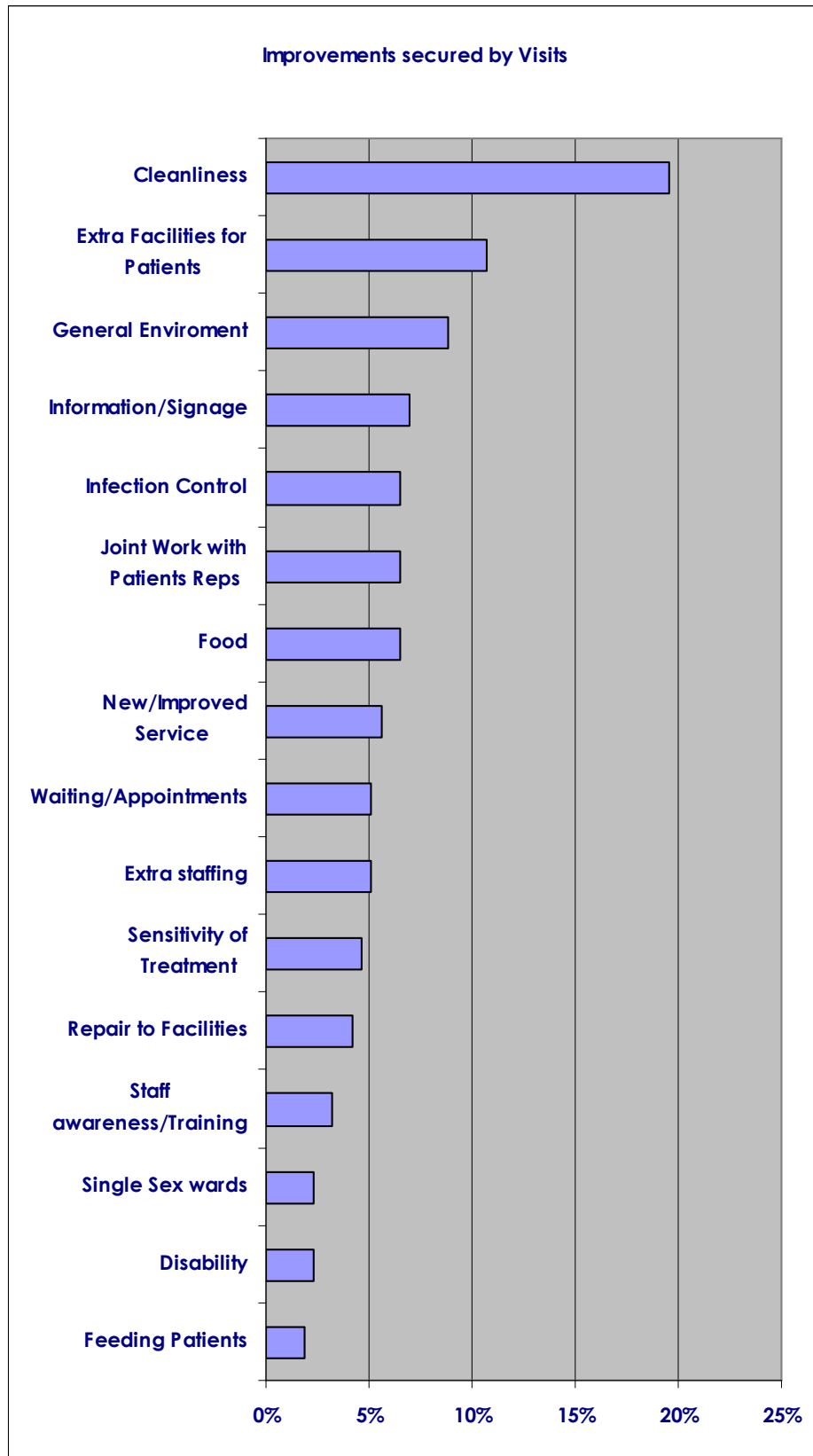




2.3 Improvements made as a result of Visits

Not all respondents reported improvements. When considering abolishing the local lay inspection system, it is also important to note the range and diversity of improvements reported by respondents as a result of visiting, across all sectors. These are illustrated on the bar graph overleaf. Improvements to the cleanliness, feeding of patients, to sensitivity of care and to patient information, signage and disabled access clearly relate very closely to the patient's experience of care and issues such as infection control relate to the quality of clinical outcome. In addition, there is a clear link between shortcomings highlighted and improvements secured. The purpose of the visits was not just to pick holes in the NHS and complain – real improvements were negotiated as a result.

- Where shortcomings were highlighted, 92% (161/175) of people recommended how each shortcoming identified could be improved.



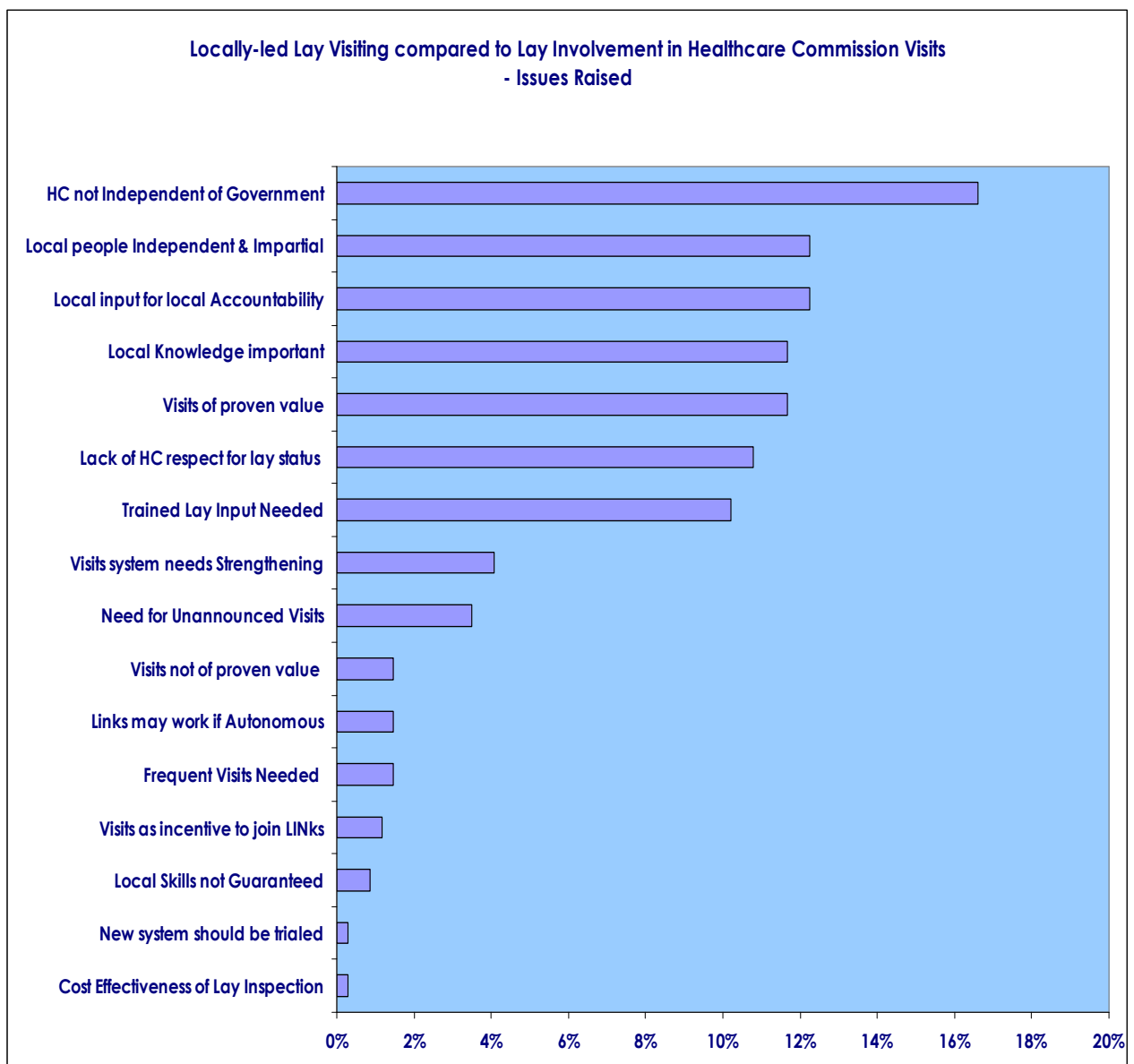
- Where shortcomings were highlighted, improvements were made by the Trust as a result of the visits made in 77% (135/175) of cases.

2.4 Views of respondents on abolition of locally-led lay visiting

Very strong views were expressed by respondents against the abolition of locally led lay visiting, and its replacement with involvement in Healthcare Commission visits, with 83% opposed, 3% in favour and 5% unsure.

- 3 people who supported the change, had never taken part in a visit, whilst 4 had
- Conversely, 73% (144) of those who opposed it had visiting experience.

Reasons given for views are set out in the Table below.



Conclusions

There is no evidence of a proper process in the development of these proposals. The Expert Panel's Report is instructive and its publication is useful. However, we do not see any views from actual patients on what is proposed. The argument in the Report on visiting rights reveals a complete lack of understanding about how this works and what it has achieved. We hope our survey will go some way to filling that evidence gap. There does not appear to have been a Risk assessment of the abolition of the forums nor of the removal of locally-led inspection, nor so far we can tell, any Cost Benefit Analysis of either. In the absence of these we see no justification for either decision. It is clear that lay visiting adds hugely to the inspection and accountability of the NHS and that it would be foolhardy to remove the process.

The functions of Patients forums undoubtedly need updating to take account of changes in the NHS, but this can be done by amending their functions and reforming their structures, without outright abolition. The way that volunteers have been treated in these proposals, as with the last abolition of patient and public involvement structures just two years ago, sits ill alongside the commitment of government under the Compact to value volunteers and volunteering and to 'involve volunteers when developing new policies and ideas; and 'consult the sector so that proposed legislation or regulation, guidance and policies take account of the ways they may affect volunteers and volunteering activities.' We suggest that the Department revisits its proposals.