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Patient and public involvement: What next for the NHS?

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Abstract

Introduction Patient and public involvement is the cornerstone of the 'patient-led' National Health Service (NHS). Though the UK has had state sponsored arrangements for patient and public involvement since 1974, they have become fragmented and unstable. Patients' forums and the Commission for Patient and Public Involvement in Health replaced community health councils (CHCs) and their national association in England in 2003, but now will be replaced by local involvement networks (LINks) and the Commission will be abolished in 2007.

Learning from history This study provides an overview of research on the effectiveness of arrangements for patient and public involvement and reviews the debates about accountability, independence, ensuring consistency of performance, representation and how arrangements for the NHS fit within the wider agenda of citizenship and renewal of democracy. It explores key themes and areas for learning to inform the debate about how LINks might work effectively to improve the health of local people, in particular addressing issues of equity, representation and citizen engagement.

Conclusions The proposed LINks provide the opportunity to integrate patient and public involvement into wider initiatives for local democracy and citizen engagement. But debates and key issues about user and public involvement in the 1970s remain current and unresolved. If the new LINks are to succeed where forums and CHCs are considered to have failed, the strengths and weakness of both need to be understood and addressed.

Introduction

There is much talk about patient and public involvement in England – it is the cornerstone of the 'patient-led' National Health Service (NHS) and among the standards for which NHS will be audited by the Healthcare Commission, the inspectorate for England. However, in spite of government commitment and additional resources, the formal arrangements for the involvement of patients and public, which have existed in the UK since 1974, have become fragmented and unstable following the abolition of community health councils (CHCs) in 2003. Within 2 years the Government announced that the successors to CHCs, patients forums and the

Commission for Patient and Public Involvement in Health (CPPIH), would also be abolished and replaced by local involvement networks (LINks).

This is an important time to ask what we can learn about the nature of participation from the experiences of the last 30 years. The debates of the 1970s have an eerie similarity to current debates. If the new LINks are to succeed where forums and CHCs are considered to have failed, the strengths and weakness of both need to be understood.

Formal arrangements for patient and public involvement

Community health councils

CHCs were set up in 1974 as local bodies representing the interests of local people to managers of the NHS.[1] In the 1970s there was great interest in CHCs and many thought that they might provide a model for other public services. Dr David Owen, the Minister of Health in 1974 who oversaw their birth, wrote: *The decision to establish community health councils will probably be looked back on by social historians as the most significant aspect of the whole of the NHS Reorganisation Act 1973. For the first time there exists a strong consumer body to both criticize and champion the NHS.*[2]

CHCs were a radical new idea. They started with enthusiasm and commitment, working in different ways. Early assessments, such as that of the Royal Commission on the NHS in 1979, were largely supportive, indicating the need to strengthen CHCs rather than questioning their role or efficacy.[3] However, the world had already moved on and subsequent years saw a gradual reduction in CHC's rights, accelerated by the introduction of the internal market in 1990. The workload had increased, but not their resources and CHCs were reluctant to give up non-statutory duties such as information, advice and complaints work or restrict their role to working with health authorities as purchasers, which the Department of Health wanted.[4,5]

CHCs survived until 2003. They were local, autonomous and independent and they needed an external agent to bring about change, if they were to be part of a 'modernized' service and operate in line with a managerial agenda set by government. By the late 1990s, CHCs agreed that they wanted reform.[6] However, the NHS Plan in 2000 proposed abolition not reform.[7] The battles as legislation went through Parliament resulted in political damage for the government and the end result was muddled legislation, a complex, expensive and fragmented system that was an inheritor of acrimony and anger.[8] CHCs had been one-stop centres providing scrutiny of local services, information and advice, helping complainants as well as identifying community needs. A range of new arrangements replaced them. Local authorities were given the power to monitor the NHS with overview and scrutiny committees (OSCs); patient advice and liaison services (PALS) were set up in every trust to help resolve problems for patients; and voluntary organizations were contracted to provide independent advocacy for complainants. CHCs and their national association were replaced by patient and public involvement forums and the CPPIH in 2003.

Patients forums and the NHS Plan

In December 2003, 572 forums replaced 185 CHCs. Unlike CHCs they were linked to institutions – NHS trusts and primary care trusts. The CPPIH was set-up as a non-departmental public body with responsibility for promoting patient and public involvement, recruitment and appointment of members of patients forums, providing staff and funding for patients forums, setting standards and performance management; as well as undertaking national reviews of policies and services and putting forward the views of patients and the public at national level.

After 18 months the abolition of the Commission was announced as part of the government's review of arms length bodies in 2004, followed by the announcement in 2006 that LINks would replace patients' forums. Though they had not been given much time to evolve, forums were not seen as effective replacements for CHCs and there were concerns about the way that CPPIH had approached its task.[9–11]

Local Involvement Networks

In July 2006, it was announced that 152 LINks would replace patients' forums and be based on a different model (see Table 1). Like CHCs they were to be based on localities rather than institutions but cover both health and social care, not just the NHS and focus on commissioning rather than providing services. Funding would be channelled to local authorities who would commission a 'host organization' to develop the LINk, including recruiting members and developing and managing the governance structure.[12] LINks were to have no statutory rights. CHCs and Forums had rights to information and to inspect NHS premises. CHCs also had the right to observer status on trust boards as well as to be consulted about changes of use and to appeal to the Secretary of State in a dispute, a right inherited by OSCs. Little further detail is given on how the LINks might operate and the intention is to leave local areas to decide how they should be set up and managed locally.

If the new local networks are to be more successful than their predecessors, they will need to address several issues: what they will actually be expected to achieve; how will they be accountable; how will they represent the population they serve; how will their independence be maintained and will they be able to raise issues at national level?

What do governments want from involvement?

Why should anyone with power want to share it? The reasons why governments promote patient and public involvement have changed over time. Governments in the 1970s were frustrated that national policies were not being implemented locally, resources were unfairly distributed between geographical areas and between acute and long-term and community services, in particular for disabled and elderly people and people with mental health problems and learning disabilities. The obstacle was seen to be professionals who were reluctant to accept change. A consumer voice might help to shift the balance of power. This was a time when social rights and entitlements were accepted, but it was realized that the welfare state had not eradicated poverty. CHCs were expected to be an advocate for deprived communities. It was also hoped that CHCs would provide a bridge between the NHS and local authorities to improve the co-ordination of services and planning between the NHS and local authorities through members, half of whom were appointed by the local authority. It was also hoped that CHCs would increase the involvement of the voluntary sector in the NHS, with one-third of their members elected by voluntary organizations.

In 2000, the NHS Plan had a different vision – this was for patients to take part in decisions, as 'insiders' to help to make providers more responsive to patients' experiences through patients' forums attached to every trust. The public would be involved separately through independent local advisory forums of residents to provide a sounding board for determining health priorities and policies.

It is not clear what Government wants from LINks once you look beyond the rhetoric, but two possible benefits can be seen. The first benefit is that LINks could contribute to local democracy by integrating patient and public involvement into civil renewal and active citizenship and the new localism. The policy reforms in the health service, local government and other sectors since 1990 have been oriented towards fostering active citizenship, overcoming social exclusion and promoting public participation in decision-making at local level. The 'new localism' aims to develop local decision-making within a framework of national standards.[13]

The NHS has always followed a separate path; perhaps partly because it was looking to individual 'consumers' to drive change through choice and promote the market in health care, whereas active citizenship and civil renewal were promoted because of concerns about the antisocial behaviour arising from alienation in

Table 1 Comparison of arrangements for patient and public involvement in England

	Community health councils	Patient and public involvement forums	LINks
Number	185	572	152
Establishing body	Regional NHS office	CPPIH	Local authority
Coverage	Locality based	All NHS trusts and primary care trusts	Local authorities
Remit	NHS, including public health	NHS, including public health	Health and social care
Number of members	15–25	Minimum of 7	To be decided locally
How members appointed	1/2 by local authorities, 1/3 elected by voluntary sector, remainder by NHS regions	By application to the CPPIH	By local host organization
How accountable	Not clear, but nominating organizations had power to remove them	To CPPIH	To be decided locally
Staff	Staff selected by members and employed by the NHS	Staff employed through voluntary organizations contracted to provide support	Staff employed by local host organization
Access and premises	Local office in each district	No local offices	Local host organization
Rights and powers	Rights to information, visits NHS premises, observer status on health authority boards, to be consulted on major changes and appeal to the Secretary of State	Rights to information and visit NHS premises	To be decided

NHS, National Health Servicel CPPIH, Commission for Patient and Public Involvement in Health; LINks, Local Involvement Networks; OSC, overview and scrutiny committee.

disadvantaged urban communities.[14] This is an opportunity to question and address this separation. The LINks might be extended beyond health and social care to provide a framework for consultation and engagement on many areas of local concern. The boundaries between health, social care, housing and the environment are often meaningless and confusing to the public and there are opportunities to take a wider view of citizen engagement, looking at services that have implications for health run by local authorities as well as the NHS. With all public bodies having a duty to consult under Section 11 of the Health and Social Care Act 2001 there is a danger of overlap, duplication and 'consultation fatigue' and disillusionment within the voluntary sector and increasing difficulties in recruiting volunteers.[15,16]

Can local networks contribute to an increase in local democracy? It is increasingly recognized that for democracy to work at a local level there must be a variety of organizations so that citizens have an opportunity to be involved in decisions about services and judge the capacity of different institutions to deliver. Users of a particular service and those concerned with a particular policy issues form a legitimate political community as well as those that come from particular localities. Local networks will need to address accountability and see their role as facilitators for the community to enable the many different voices to be heard.

The second potential benefit, which is not explicit, is that LINks may provide a way of determining local priorities for services – rationing by another name. A critical issue for health and social care in the next decade will be about eligibility for services and treatments, which are decisions Governments may wish to avoid making at national level. If LINks are to advise on local priorities, they will need to operate in the public interest rather than the 'patient' or consumer interest. They may be reluctant to do this as it might lead to conflict as the major pressures for new drugs and new services come from patients and patient groups, often funded by the pharmaceutical industry.

Most CHCs were unwilling to engage explicitly in the debates on rationing, and LINks may be no more enthusiastic for this thankless task.

An important lesson from history is to be clear what involvement is to achieve and how it relates to management and decision-making. Tensions and confusion between roles of management and representation are recurrent themes in debates on patients and public involvement. In the 1970s the Conservatives were clear that management and representation could be separated in their design for CHCs, but the incoming Labour Government in 1974 disagreed. *Our whole national democratic process as it has evolved over the years is a complex interweave of management and representation.*[17] They gave CHCs greater independence, additional rights and new tasks which duplicated those of health authorities. This set up a basic ambiguity and conflict at the heart of the CHC movement that became a recurrent source of misunderstandings and conflict throughout their lifetime.

The NHS Plan proposed that forums should be more involved in management and be able to elect a member as a non-executive director of each trust.[18] This was not implemented because of opposition from all sides.[19] The 'interweave of management and representation' is integral to the running of foundation trusts, which were introduced in the Health and Social Care Act 2003. Foundation trust status, which will apply in future to all hospitals, is based on the model of mutual societies. Central control is replaced by boards of governors, chosen by patients, the public and staff from the trust. There has been a duplication and confusion about the role of Forums and members in foundation trusts.[20]

Local networks will be community-based and focussed on representation rather than management. While this clarifies their role, the power to influence decisions will need to come from other sources. There is no point for individuals to participate unless they can see a result. Consultation does not necessarily result in change, particularly where NHS bodies are driven by the market and the need to keep within their budgets.

It is not known whether LINks will have statutory rights, but it will be up to the Healthcare Commission and its inspection powers to ensure the NHS works with the new bodies, but this will not address the way that local authorities play their role as the 'establishing body' or themselves relate to the LINk. Without explicit rights there is a danger that either the LINk will be ignored by the community or it will feel that the only way it can be 'heard' is by confrontation with the NHS and local authority and through the media, rather than working in partnership, which is the intention.

The abolition of forums will leave a gap in provider units when statutory forums are abolished. There will be a particular gap in services that cover more than one Primary care trust area, such as mental health and ambulance trusts. Forums in provider units could carry on their activities, integrated with the role of foundation trust members or be affiliated and supported by the LINks. Alternatively the government could revert to the NHS Plan that saw each trust setting up and supporting its own 'insider' user council or forum.

Accountability and governance

CHCs were autonomous and their accountability was never explicit. Members were appointed by local authorities and elected by voluntary organizations with links, though not explicit accountability, to their appointing bodies. Members could be removed if they did not attend a meeting for 4 months. CHCs were required to be transparent: to hold meetings in public, make papers publicly available and produce an annual report.

Forums' accountability was also not explicit, but in practice was to the CPPIH that was responsible for their performance. Forums' relationship to their local communities was also not explicit and members were recruited as individuals following a national recruitment campaign and application to the Commission. There were no formal mechanisms for removing members for inactivity, only for misconduct. Forums must produce an annual report but were not required to hold meetings in public or make available their working papers to the public.

The accountability of LINks to their local communities needs to be explicit from the start and mechanisms set up to ensure transparency, including meetings held in public and annual reports. It needs to be addressed in the way that members are elected or appointed and how they are held to account.

Who are members to represent?

In both CHCs and forums there was confusion about the representative nature of the members. First, are members to represent patients or the public? If members are individuals and representatives of the wider community, the composition should reflect the community in social class, education, ethnicity and demographic factors like age. As Klein and Lewis pointed out in 1976 this 'mirror of the community' approach treats representative bodies as though they were the permanent sample in an on-going public opinion poll. The fact that people are prepared to put themselves forward suggests that they may be unrepresentative of the network from which they are recruited. They may not voice the values, attitudes and experience of those being represented which is why public opinion surveys use large samples.[1]

However, if the relevant community is seen to be users rather than the public there are also difficulties. Do you weight representation towards the intensity of use of services? In which case older people and children would need high levels of representation. Appointments to patient forums put value on the experiences of the individual user or patient rather than on the groups that might represent them. This did not deal with the problem of how you get the views of people who are not part of established networks and are not organized.

There is little information about how members for LINks will be selected or how many there might be. There will, however, be a mix of individual and voluntary organization members. One model that may be followed is that of foundation trusts where members are drawn from the wider community and elect the council and hold them to account. This is a model that meets some criteria for openness but, as with foundation trusts, there is a danger that pressure groups and single issue groups could come to dominate. Elections could be undertaken with places reserved for people with particular interests – children, mental health, older people or from particular communities. This generally achieved a good mix of representation for CHCs. CPPIH tried to develop *Our Health* that was a wider network of individuals who could contribute online without the commitment of being a forum member.[21] However, this was not followed through, but could be developed as a framework for wider involvement.

What number of members on the decision-making body for the new networks would be appropriate? CHCs initially had been 22–35 members, but this was reduced in 1982 to a maximum of 18–25 members. CHCs felt that the reduction in membership decreased the direct representation of different sections of the community as well as the volunteers available to carry out CHC business.[22] To increase the volunteers available to them, many CHCs had several co-opted members.[23] Forums were required to have seven members and many had no more than this because of recruitment difficulties. The CPPIH based on experiences of forums has suggested a minimum of 15 members, but by the end of 2004 only 50 forums had 15 members.[24] There is also the question of how big a pool of volunteers there is who will wish to devote their spare time to the local network.

What is required of members

The way the LINk defines its role and the relationship between staff and members will affect the commitment required of members. If they see their role as generating their own information and relying less on NHS sources, more is expected of members and their networks. If the network is member-led, seeing staff as administrators, it will be up to members to generate new ideas and explore new areas of work.

The skills required of members were not clarified for CHCs, though for patients forums the skills required were listening and communication. Forum members were not to speak just for themselves but be a conduit for the views of wider groups of patients or public.[25] This proved a tough task. It is one thing to turn up to meetings once a month and give your views, quite another to collect other peoples views, especially without strong staff support. CHCs and Forums both depended on a small proportion of active members, but there were also inactive members, whether from lack of commitment, other priorities or ill health. A survey of CHC members in 1995 found that just under 50% stated that CHC work was taking an average of around 4–6 h a week, 21% that CHC work took between 8 and 12 h a week.[26] Forums aimed for a similar level of commitment.

The role of staff has important implications for the role of members. The limited research on CHCs showed that the effectiveness of individual CHCs depended largely on the energy and commitment of its paid officers.[1,27,28] Staff identified with their council and the community and were committed to the work, often over many years. This was important not only for links with the community, but also to build up trust with NHS managers which is essential for constructive, but critical dialogue.

Forums were a different model – they were to be 'member-led' and so the skills of staff were seen to be less important. CPPIH faced with staffing 572 forums decided to contract voluntary and non-profit bodies to support forums. It seemed like a fresh approach and in keeping with the mood of the times. In practice it was probably the single decision that contributed to the failure of forums. The relationship between staff and members was very different from CHCs where the staff were interviewed and selected by the CHC, even though employed by the NHS. Forums had no choice in either their forum support organization or the staff provided for them. Some organizations contracted to provide staff support had no experience in health or local knowledge. Many staff appointed to work with Forums were inexperienced and had no knowledge of either the NHS or the local community. They were not therefore in a position to advise or support members and help them to contribute in the most helpful way. This was particularly felt by organizations working with mental health service users.[11] Staff skills are particularly critical in supporting and encouraging new people who want to get involved.

Forums also lacked formal arrangements for leadership. They were not required to elect a Chair, though most did. As a result forum chairs did not have the status of the Chair of the CHC who was formally elected annually and provided leadership as well as mediating or diffusing difficulties and disputes between members and with the NHS.

Independence

Can users become 'insiders' and partners of managers and retain their independence and credibility? The vision for the new forums saw them as an insider group with individuals rather than representatives, staffed by the NHS body to which they related. However, the government accepted the argument that to have credibility with the local community, independence was important and CPPIH was established to ensure their independence.

State sponsored participation is always open to the accusation that it is manipulation – a cynical attempt to get support for management rather than enhance participatory democracy.[29] Essential for independence is have your own staff and control your own money – and, very important, stability. The new networks will be hosted by a local organization commissioned by the local authority. There is a potential conflict in that the LINk will be commenting on the services provided by the local authority. Furthermore, local authorities vary in their support for the voluntary sector and some areas do not have co-ordinating councils for voluntary service. The terms on which LINks are established and how funding is provided will be critical for stability and public credibility.

Variable standards

CHCs from the early days were criticized for their inconsistency and variability.[30] The problem was that CHCs were autonomous and no one was in a position to deal with failing CHCs or externally review their performance. This issue was addressed structurally in the legislation for forums. Forums had clearer and more restricted core tasks and the Commission was able to set standards and review their performance. However, their performance has been even more variable than CHCs.[9,10] The outsourcing of staff support meant that different levels of support were provided and accentuated inconsistencies between local areas.

Local networks will, however, be expected to be different in each local area. Inconsistency, rather than a weakness, is seen as a strength that demonstrates the responsiveness to the locality. However, they will receive public funding and will need monitoring to ensure that they do what they are supposed to and meet standards of probity. Local network will require clear terms of reference, standards and arrangements for review, and lines of accountability and methods of reporting back to the community to which the network relates. There are examples of good practice that local networks can draw on. Considerable work was undertaken in the 1990s to develop performance standards and review and achieving explicit accountability to the community.[31] A report commissioned by the Department of Health concluded that peer review and a multifaceted approach, involving external stakeholders, was the best way to performance manage CHCs.[23]

Funding and review can be linked to the process – how the networks consult their communities, but not the outcomes or their popularity with the NHS, local authority or sectional interests. An active and effective network is likely to have allies and also enemies from time to time.

A national voice?

Will local networks need a national voice? In the 1970s the government wanted a strong national patients voice in order to counteract the power of professionals at national level and proposed a national council for CHCs to act as a pressure group for patients and public. However, CHCs chose a membership, bottom–up organization that would represent them rather than a body imposed on them by the Government.[32]

The benefits for the government now of a national voice are less clear. The attraction for the government of setting up the CPPIH was not the potential 'national voice', but its functions in appointing members, employing staff, training and performance review in order to ensure that forums were not so variable as CHCs had been. CPPIH had the remit to undertake policy reviews from a user perspective, but never got round to this. A major failing of the CPPIH was that it was a top–down organization.[11] The best principles of user involvement require a bottom–up rather than top–down approach.

The local networks will need a way of feeding their experiences to influence national policy, but this will need to emerge from the networks and not imposed on them. There is also an argument for integrating LINks with voluntary sector voices at national level.[33]

Conclusions

Patient and public involvement in England is to undergo a further period of instability and the risks of getting it wrong again are high, with the threat of the loss of further goodwill among the public and the NHS as well as the waste of resources. One theme that emerges is the confusion underlying arrangements for patient and public involvement in the NHS. CHCs were initially community advocates embedded in the culture of the 1960s and 1970s when the welfare state and social rights were accepted. There were tensions between the ideology of new social movements and the traditional role of the volunteer in civic service. The health-care market introduced the individual consumer as the force for change, rather than community participation. Patients' forums were based on a mixture of consumerism and participatory models. The nature of representation, accountability and governance were never addressed, leaving them open to criticisms of being undemocratic, unrepresentative and inconsistent. Unless these issues are explicitly addressed, LINks will not contribute to increased local democracy.

LINks provide an opportunity to integrate patient and public involvement into wider initiatives for local democracy and citizen engagement. The challenge is considerable. Many questions need to be addressed as to who they are, what they will do, what powers they will have, how they will be set up and held to account. Particularly important is how their stability can be assured. They may not deliver what the government wants now and what the government wants may well change in the future. After the bitter battles over the abolition of CHCs, there was no willingness to build on their legacy or learn from their experiences. There are many lessons that we can learn and ignoring them risks a further loss of credibility in systems for patient and public involvement and a waste of resources that might be better spent.

Note

The author was a CHC Chief Officer (1974–80) and as an independent consultant, has worked on public involvement for the Association of CHCs for England and Wales, the Department of Health and the CPPIH. This paper draws on these experiences as well as the current research study.

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