Viewpoint

User involvement and the NHS reforms

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Summary

The policy of 'user involvement' in the UK National Health Service emerged during the 1990s along with the reforms that created an internal market. Despite the official rhetoric, progress has been limited. Critics suggest that, not only was the policy flawed in its conception by the construction of service users as consumers and the conflation of consumerism with empowerment, but collaborative models of involvement have tended to legitimate rather than challenge existing provision. Some commentators have questioned the value of user involvement initiatives and proposed that alternative approaches, such as a strengthening of procedural rights or alignment with broader political campaigns, would be more appropriate. The low prominence given in the recent Government White Paper *The New NHS*[1] to the contribution of service users, however, represents less of an ideological shift than a concentration on other, in the Government's view, more pressing priorities: namely, a concern to address the problems of public legitimacy and low staff morale by engaging in greater public participation and giving health professionals a more central role. The result has been a weakening of the users' voice by a conflation of user involvement with public participation and giving health professionals the authority to define users' needs for them. Service users risk, not only having their contribution devalued, but losing the right to an independent and distinctive voice. There is a real danger that the issues of user involvement will not be included on local agendas and the disparities between provision and need and between professionals' and users' views will increase.

Introduction

Given that the 1997 Government White Paper, *The New NHS: Modern, Dependable,*[1] is heralded as 'a new model for a new century', its failure to give service users a stronger voice with regard to the design of health service strategies is disappointing. At the local level, at least, user involvement seems to have been subsumed by the more pressing policy concern for the Government of public accountability. Although the role of service users is acknowledged, there is little recognition of users' separate and distinctive contribution. More worryingly, in strengthening health professionals' role by giving them the authority to speak on behalf of patients, *The New NHS* is in danger of signalling a return to the paternalistic attitudes that have been so

heavily criticized in the past.[2–5] In its enthusiasm to court professionals' goodwill, it risks 'throwing the baby out with the bathwater'.

The New NHS was drawn up against a background of high expectations on the part of both the general public and health service staff and it is in this context that its priorities need to be understood. There is a real danger, however, that failure to give sufficient weight to the contribution of service users will result in input from users not being included on local agendas as an item that requires special attention. Far from services becoming more sensitive to patients' wishes and needs, the gap between provision and need is in danger of widening and the well-documented discrepancies between professionals' and service users' views[6–9] are likely to increase. This is particularly disappointing given the increasing recognition in recent years of the need for greater user involvement in service planning and delivery.

In this paper we trace the history and progress of user involvement as a contemporary policy initiative in the UK NHS, and consider the context in which *The New NHS* white paper was drawn up. We then discuss the form in which issues of user involvement appear in *The New NHS*.[1]

Recent developments

A policy of 'user involvement', by which health service managers were required to pay greater attention to the wishes and views of individual service users and carers as well as to the views of the wider public, emerged as a policy initiative in the UK National Health Service during the 1990s (see Box 1). The introduction of market principles to the NHS[10] cast recipients and potential recipients of health care in the role of consumers. The dominant conception of service users was, therefore, one of consumers, and the notion of consumer choice underpinned a number of policy initiatives, including *The Patient's Charter*[11] and the publication of hospital performance league tables. Consumer choice was also the driving principle behind the policy document, *Local Voices*,[12] which exhorted health service managers to consult with their local populations. The

development of the policy has been linked to the need to impart legitimacy to a system which was increasingly suffering from 'democratic deficit'.[13–15] Patient choice was also seen as a necessary counter to the professional power and authority perceived to be primary impediments to organizational change. While an individualist approach to health care may not necessarily weaken the decision-making power of professional or managerial staff, the introduction of customer choice to the NHS nonetheless presented the possibility of consumer authority coming into direct conflict with professional authority.[16] The whole edifice of professionalism on which such authority is legitimated – the training, qualifications, membership of peer associations, peer regulation and supervision – was thereby undermined.

Box 1 Selected policy developments in the UK

White Paper, WORKING FOR PATIENTS (1989)
- separated service providers from commissioners and created an internal market in health care

THE PATIENT'S CHARTER (1991)
- set out a set of rights and basic service standards for patients

LOCAL VOICES (1992)
- indicated how health commissioners could involve local communities in the purchasing process

White Paper, THE NEW NHS (1997)
- announced the phasing out of the internal market and establishment of primary care groups with commissioning responsibilities for their local populations

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Progress in user involvement

Progress over the past decade, however, has been patchy. Despite the promises of the official rhetoric, user involvement initiatives have often taken low priority.[17] An evaluation by the NHS Executive of progress on *Local Voices* found that only 21% of health authorities could be categorized as 'good' in that:

> …they had consulted widely, involved local people… made tangible changes to plans and contracts… and established arrangements for feeding back decisions'.[18]

The remainder had made little progress and 22% were categorized as 'unsatisfactory'.

The rhetoric of the reforms implied improvement in patient choice but many believe that the reality was to improve operational processes and control costs. This was often at the expense of patient choice, which was reduced through the curtailment of GPs' referral freedom. Although purchasers have embarked on public consultation projects, patients' views have had little, if any, effect on major decisions. Patients still have very little choice and decisions are taken on their behalf by doctors or managers.[19] Furthermore, there was widespread confusion between the *Patient's Charter*, which was about rights for people at the point of use, and *Local Voices*, which was about wider public involvement.[20]

Such discouraging outcomes are attributable, not just to a failure to involve users, but to the types of user involvement adopted. Commentators have pointed to the risks of tokenism, service users becoming co-opted onto managers' agendas, and collaborative models of involvement which suppress critical questioning.[3,21] Such was the fate, for example, of patient and user councils. These councils were originally set up as a 'state endorsed model of action in hospital self-advocacy groups', but were often co-opted by the system itself, with workers employed by health authorities rather than directly by ex-patients and with advisory groups 'above' the user group.[3] Pressure for change has, therefore, often come largely from outside participatory debates and structures.[21]

Where user groups have engaged in challenging the system, health service managers have been able to question the legitimacy of such groups by reference to their unrepresentative nature and/or unsatisfactory character as formal organizations.[13,22] Harrison *et al.* note that managers have appeared to support user involvement as a means of securing legitimacy along the lines of participatory democracy while, at the same time, evading the consequences of challenge from users.[13]

Criticisms of the consumerist model

The rationale for increasing choice was to give greater power to users. In practice, patients have been given little opportunity to exercise real choice.[23–25] In any case, choice will be of little value if none of the options is appropriate.[23] Moreover, if the contexts in which choices are made are dissociated from the contexts in which power in society is exercized, increasing choice cannot, in itself, be a means of empowerment. Far from empowering service users, the need to choose can create confusion and stress, irreconcilable dilemmas, risk and a sense of inadequacy.[23] Moreover, by concentrating on individuals' needs, a consumerist approach fails to recognize the role of public services in addressing the collective needs of society. Crucially, a true market would require the consumer to have: adequate information and a practical range of alternatives; competence to make rational choices; the opportunity to exercise free choice; readiness to make quality comparisons; protection by legal rights and the possibility of redress.[26] Within the context of the NHS, these conditions are rarely met in their entirety.

Consumerism or empowerment

A useful distinction has been drawn between a commercial or economic approach, in which consumers exercise individual choice in a market-driven system, and a political model, in which users are given a voice in a system which ensures their participation in service planning, organization and delivery.[27] The NHS approach to the involvement of service users has remained locked within the consumerist mould, reflecting, in Saltman's view

> '...a fundamentally different understanding of the role of the patient than does direct decision-making about appropriate providers made by the patient as *user*.[27]

Many management initiatives, including customer care training for staff and patient satisfaction surveys, were, arguably, designed less to empower patients than to increase the market share of organizations.[27] A similar point is made by Croft and Beresford,[28,29] who see a fundamental conflict between the emphasis on consumer choice, aimed at achieving improvement in efficiency, effectiveness and economy along

the lines of consumer satisfaction, and the politics of empowerment or liberation, aimed at giving users greater control over their lives by giving them a direct say in agencies and services.

Some commentators have questioned the value of the whole user involvement enterprise and suggest that a more profitable approach would be to focus on securing legally enforceable procedural rights for users.[21] Others see greater scope for change in community-based initiatives with wider popular appeal.[21] It has been argued that a definition of users that is specifically linked to the particular experience of service usage marginalizes what users themselves want,[21] limits definitions of need to the narrow perspective of what services can provide,[21,30] excludes those who have been denied or are unable to access services,[31] and fails to acknowledge the unequal power relations that underlie service transactions between the agency and users.[21] In addition, a generic definition of 'user' conceals the diversity of user experience and the heterogeneity of users, and obscures other sources of disadvantage and discrimination, such as gender, class, disability and race.[21,29]

Such criticisms, however, do not militate against arguments for user involvement. Rather, they emphasize the need for an approach that is both receptive to users' views and genuinely allows those views to influence the service planning process. By virtue of their particular experience and knowledge, service users have a distinctive perspective from which to comment on the process by which services are delivered and the definition of desired outcomes and to participate in the research process. In so doing, they can help to ensure that services are efficient and relevant and that compliance with treatment plans and research protocols is enhanced.

Many examples already exist of ways in which user involvement can be usefully carried out. General practitioners' patients, for instance, have been involved in focus groups on specific aspects of primary care, as well as in broader-ranging patient participation groups or consultations on practice plans.[32] The King's Fund Nursing Development Unit has undertaken projects on user involvement in oncology services, rehabilitation, mental health advocacy and choices for people with learning difficulties.[33] Consumer audits have been carried out by the College of Health as a complementary approach to clinical audit[34] while, elsewhere, service users have been involved in the clinical audit process itself.[35] Mental health service users have conducted interviews with other users as part of monitoring the care programme approach.[36] Focus groups of patients have been involved in developing protocols for clinical trials in breast cancer care.[37] Pilot projects under the *Patients Influencing Purchasers* initiative have involved people with long-term medical conditions in service planning, development and monitoring.[38]

The examples of user involvement are many and varied, and there is no single 'best' model. What is needed, though, is a commitment to the principle that users have a right to be involved in shaping the services that are designed to meet their needs. The rhetoric of the reforms placed the involvement of service users firmly on the policy agenda. It thereby opened a window of opportunity for health agencies interested in developing new approaches. Importantly, user involvement enables health agencies to take greater account of users' experiences and to plan and provide services that will meet users' needs more appropriately.

Background to the *The New NHS*[1]

A primary objective of the new Labour government is to rebuild public confidence in a service that had been radically restructured under the previous Conservative administration and whose democratic mandate had been progressively weakened.[39] Among a number of contributory factors was the gradual erosion of the local democratic credentials of health authorities and other NHS institutions,[40,41] along with the dismantling of the old bureaucracies and their reconstitution into smaller organizations. Legitimacy was further weakened by the introduction of the internal market and a competitive market ethos, rising costs and demands for health care

requiring more explicit prioritization and rationing of services, and an increasingly critical questioning of 'old style' professional paternalism.[13]

The election of a new government in 1997 was welcomed enthusiastically by a health service workforce alienated and demoralized by 18 years of relentless organizational change and ensuing uncertainty, the introduction of the disciplines of the internal market and consequent undermining of the traditional values of welfare. The health service reforms forced a move away from lifetime professional careers under national terms and conditions of service, to time-limited contracts with locally determined pay and conditions. 'Professional solidarity' was undermined by professionals working for rival providers forced into competition with each other, and an expectation to support the corporate image and refrain from public criticism led to conflicts between allegiance to employers and to professional bodies.[42] Towards the end of the Conservative administration, morale in the NHS had sunk dangerously low, with difficulties of staff retention and recruitment in many areas.[43,44] A second objective of *The New NHS* was therefore to regain professionals' goodwill and support by reinvesting them with an authority which, previously, had been persistently challenged and undermined.

The New NHS[1]

The White Paper was thus concerned both with addressing the problem of public legitimacy and courting the goodwill of health professionals. Although it gives some acknowledgement to the potential contribution of service users to local health service planning, there is no specific discussion of how this might be achieved. *The New NHS* contains no real discussion of users' distinctive role and gives no direction or guidance as to how that role might be enhanced by building on past experiences and avoiding past failures. In consequence, there is a danger that, as other priorities take precedence, it will not be included on local agendas as a separate issue requiring special consideration.

The emphasis in the *The New NHS* on broad public accountability and participation is evident in statements such as:

> Openness and public involvement will be key features of all parts of the new NHS. (para. 2.23).

A variety of measures are to be implemented to enhance public involvement. Health authorities will be required to:

- involve the public in developing the Health Improvement Programme;
- ensure that Primary Care Groups have effective arrangements for public involvement;
- publish agreed strategies, targets and details of progress against them
- participate in a new national survey of patient and user experience (para. 4.19, also see Box 2)

Box 2 Summary of points in *The New NHS* relating to public/user involvement

- Health authorities are to involve the public in developing health improvement programmes
- Primary care groups must have effective arrangements for public involvement
- A national survey will be undertaken of patient and user experience
- The boards of NHS Trusts must be more representative of the local community
- New ways are to be explored of securing informed public involvement in decisions about local service planning
- Health Action Zones will be established, providing new opportunities to involve local people
- Patients and carers are to be represented on proposed new national bodies: the National Institute for Clinical Excellence and the Commission for Health Improvement

Furthermore, all NHS Trusts will be required to open their board meetings to the public (para. 2.23) and to ensure that board membership is more representative of the local community (para. 6.39). New ways of securing informed public and expert involvement in decisions about local service planning are to be explored and a clear set of principles for decision-making and criteria for ensuring that due process is observed are to be drawn up (para. 4.20). Primary Care Groups will be required to have

clear arrangements for public involvement, including open meetings (para. 5.15). Finally, Health Action Zones will offer opportunities to explore new ways of involving local people (para. 4.19).

There is, however, no real recognition of the distinctive contribution of service users. It is not enough simply to interpret public involvement to include service users, who are also members of the public. Public participation and user involvement represent overlapping but potentially conflicting strands. People have a dual relationship with the NHS: as patients, concerned about what happens to them when they use the service, and as citizens, with a broader interest in what happens to the wider community. These two interests may conflict, not least in decisions about the allocation of finite resources.[45] In particular, it is important for the views of low incidence, high needs groups and unpopular or minority user interests to be heard and recognized. In focusing just on a community in a geographical area, communities of interest or concern may be neglected.[46] In any case, the remit of user involvement is wider than questions of resource allocation and priority setting: it also has an important contribution to make in relation to issues of service quality and the definition of desired outcomes. In any consultative exercise, the most appropriate target group will depend on the aims of the consultation and the issues to be addressed.[47]

The second area likely to have a serious impact on the potential for service users to have an independent voice is in the authority of health service professionals to speak on their behalf. Service users' independent and distinctive voice appears to have been largely subsumed under the newly reinstated authority of professionals to speak for them.

Where, previously, many professionals felt side-lined from health service decision-making,[41,48] under Labour they are to be rehabilitated into a central role (para. 6.31) and a series of measures has been set out to ensure staff involvement. These include: the establishment of a task force on improving the involvement of front-line staff in shaping new patterns of healthcare (para. 6.32); a requirement for NHS Trust Boards to review regularly whether they are doing enough to involve staff, and to outline in their annual reports their local policy on staff involvement and the outcomes of any negotiations or local initiatives which have been undertaken during the year (para. 6.32).

By empowering health professionals, the Government clearly believes that not only will services become more responsive to patient needs:

> By empowering local doctors, nurses and Health Authorities to plan services we will ensure that the local NHS is built around the needs of patients (para. 2.6),

but public confidence will be increased:

> Greater involvement among staff in NHS Trusts will help rebuild public confidence in the NHS (para. 6.37).

The intention is to redress the balance of power between professionals and managers. Where, in the 1990s, managers were exhorted to become 'Champions of the People',[16] professionals are now being recast in that role.

Central to this newly strengthened role is the authority to speak on patients' behalf. *The New NHS* is peppered with references to the belief that professionals are best placed to represent patients' interests:

> …decisions about how best to use resources for patient care are best made by those who treat patients – and this principle is at the heart of the proposals in this White Paper (para. 1.22).

There is little room for the view that patients themselves might be best placed to articulate their own needs and wishes and thereby to contribute to the discussion. Even while recognizing that professional and other staff may well be service users at various times, their contribution to service planning is likely to rest primarily on their occupational roles and this cannot be a viable substitute for consulting with service users directly. Pressures on resources are always likely to occur, and an ability to take account of the opinions of all interested parties (including different groups of service users) is essential when determining priorities. This will not re-

solve difficult problems of equity or definitions of need, although the decision-making process will be more transparent when participants' various opinions are made explicit. The emphasis, Miller noted:

> …is on the way in which a process of open discussion in which all points of view can be heard may legitimate the outcome when this is seen to reflect the discussion that has preceded it, not on deliberation as a discovery procedure in search of a correct answer.[49]

Although there is reference in *The New NHS* to 'the important part played by Community Health Councils in providing information and advice, and in representing the patient's interest' (para. 4.20), there is no mention of means to involve individual patients and carers directly. Direct input seems to be limited to the complaints procedure. The underlying assumption seems to be that input from individual service users and carers can be adequately interpreted by practitioners on the basis of personal interactions between patients and staff:

> Of course, service quality is essentially determined at local level, through the personal interaction between NHS staff and patients (para. 7.4).

Where *The New NHS* talks of 'partnership', the concept is generally limited to partnership between health and social care organizations rather than partnership with service users.

At a national level, there are a number of provisions for the participation of service users' representatives on newly proposed national bodies, such as the National Institute for Clinical Excellence and the Commission for Health Improvement (paras. 7.12, 7.14), but there are no details of formal mechanisms for involving users and carers directly at a local level.

The primary mechanism for tapping users' views is to be the new national survey of patient and user experience (para. 8.10). According to the *The New NHS*,

> The survey will give patients and their carers a voice in shaping the modern and dependable NHS (para. 8.10).

However, for the purposes of giving users a voice, a satisfaction survey is a rather blunt and inflexible instrument which is likely to constrain users' comments to predetermined questions and areas of interest[50] and, in view of the need to standardize questions for the purposes of comparisons between different parts of the country, is unlikely to be sufficiently sensitive to local needs and conditions.[51] Furthermore, it is not clear what weight users' views will be given or exactly how they will feed into policy decisions. It is more likely that the survey will be used as a management tool for assessing service performance than as a means to give service users a genuine voice in shaping services.

Conclusions

According to some analysts, the contemporary policy of user involvement in the UK health service is flawed by basic contradictions, and attempts to involve users have met with only limited success as a result of entrenched resistance to the politics of empowerment and an inability to incorporate an oppositional voice into the planning process. Disillusionment with the failures of the past has led some to suggest that current collaborative models should be abandoned in favour of what they believe to be more effective means of achieving change, including the strengthening of procedural rights and alignment with broader political struggles.

The 1997 White Paper, however, signals less of a change in ideological emphasis on the Government's part – it still pays lip service to notions of user involvement – than a by-product of somewhat muddled thinking in this area. Not only is it in danger of conflating the distinctive contribution of service users with issues of general public participation but, in its zeal to court professionals' goodwill by reinvesting them with some of their old authority, it seems to have inadvertently opened the door to a return to professional paternalism. The Government seems to have forgotten that the critique of professional paternalism and unresponsiveness originated not only from the political right but had a long-standing history on the political left[42] and was primarily initiated by service users themselves.[2–5]

Most commentators seem to agree on the principle of increasing the involvement of service users in decisions about their own treatment and care and in consultations about service planning and delivery. There is less agreement about the means, with the most trenchant criticism levelled at the attempt to introduce the principles of consumerism into welfare provision. According to this criticism, it was the central rationale – the construction of service users as consumers in a market – rather than the policy of user involvement itself which underlay many of the failures of implementation in the past.

Given the unequal power relations between service agencies and users,[21] there will always be a danger that agencies will subvert user involvement initiatives to their own agenda. The dangers of incorporation or marginalization, however, do not invalidate the aims of user involvement: no enterprise is free from risk. User involvement is not a substitute or replacement for other forms of action and challenge: it is one of several strategies for achieving change. Service users have a right to a strong voice in decisions about service planning, organization and delivery, given that they are likely to be directly affected. They also have a unique and important contribution to offer, based on insights and knowledge which can be gained only from the direct experience of using services. In the words of Toby Harris, director of the Association of Community Health Councils for England and Wales:

> Above all, patients must be put first – their needs, expectations and choices'.[52]

In *The New NHS*, patients' contribution is relegated to a poor second, even third, place.

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