Patient and public involvement in the restructured NHS

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Abstract

Purpose - As it is now some time since the publication of the Health White Paper, and there is currently a pause in the progress of the Health and Social Care Bill through Parliament, it seems timely to look at how the proposed changes to patient and public involvement (PPI) may develop. This paper seeks to address these issues.

Design/methodology/approach - The paper examines the proposals for PPI set out in the legislation and uses the findings of the authors' recent research to examine them.

Findings - The paper argues that the legislation, as currently written, contains nothing that will guarantee a more effective engagement with either patients or the public.

Originality/value - This is a fast moving field at present, and the eventual outcome of this major reorganisation is unclear. This paper uses evidence from previous studies to provide an overview of the issues relating to patient and public involvement in the National Health Service and highlights the potential problems in the proposals as they stand at present.

Keywords Patient and public involvement, Health White Paper, Health and Social Care Bill, Commissioning, National Health Service, Organizational restructuring

Paper type General review

Introduction

The recent Health White Paper "Equity and excellence" (Secretary of State for Health, 2010) and the Health and Social Care Bill (House of Commons, 2011), propose major changes affecting both the National Health Service (NHS) and local government. In response to sustained criticism of the proposals, the government announced a six-week "pause" in the legislative timetable in order to allow a "listening exercise" to take place (www.dh.gov.uk/en/ MediaCentre/DH_125865). It is, therefore, timely to look at what is proposed in relation to patient and public involvement (PPI) and to reflect on how far official aspirations to put patient and public voices at the heart of the system are likely to be realised by the proposals as they currently stand. Although all public bodies still have the duty to consult under Section 11 of the Health and Social Care Act (House of Commons, 2001), many have struggled with the notion of PPI in the past. Difficulties arise from many sources, not least the fact that much commentary on this subject fails to clearly distinguish between the involvement of patients and the involvement of the wider public.

This paper will look at some of the mechanisms which are currently being proposed for taking PPI forward, examine their potential impact and set out some of our current reservations. In doing so this article brings up to date our previous piece, which suggested that those involved in commissioning health services should:

 $[\ldots]$ think deeply about the meaning of public involvement in their context, while at national level strategies should be flexible enough to allow diversity of approaches which may ultimately allow PPI to flourish (Coleman et al., 2009a, p. 23).

The earlier article was written at a time of relative stability in the NHS, but the coalition government elected in summer 2010 has subsequently proposed major changes.

Proposals for change

The coalition government's proposals (set out in the *White Paper* and *Health and Social Care Bill*) for the future commissioning of health services place a great deal of emphasis on individual patient influence ("no decision about me without me") through four main avenues (detailed in the *Health White Paper*, Secretary of State for Health, 2010):

- 1. Free patient choice of GP (and therefore of commissioner) from 2012 (p. 53).
- 2. Free patient choice of hospital and "consultant-led team" for elective secondary and tertiary care (from April 2011, pp. 3 and 52).
- 3. An aspiration to make patient-reported outcome measures a central element in the NHS performance regime, extending them across the NHS wherever practicable (p. 14).
- 4. Promoting personalisation and extending patient choice of what treatment, where and by whom, including personal health budgets where appropriate (p. 31).

In addition, the Health Service Ombudsman's national report (PHSO, October 2010) on the handling of complaints by the NHS (www.pals.nhs.uk/CmsContentView.aspx?ItemId= 2129) has highlighted the need for improvements in this area.

Against this background, the government proposes that local authorities will commission NHS complaints advocacy services (Independent Complaints Advocacy Services (ICAS)) from 2013. The *Health and Social Care Bill* (House of Commons, 2011) provides flexibility concerning, who these services can be commissioned from: this could be either Local HealthWatch[1] or other independent organisations, with HealthWatch providing information signposting potential complainants to these services and providing advocacy and support, in order to help people access and make choices about services. According to the *Health White Paper* (Secretary of State for Health, 2010, p. 19) they will:

[...] support people who lack the means or capacity to make choices; for example, helping them choose which General Practice to register with.

The National Association of Local Involvement Networks (LINks) members (NALM) and National PALS Network (NPN) have been exploring future collaboration and their main proposals include:

- Developing local coalitions between Patient Advice and Liaison Service (PALS) and LINks as they develop into HealthWatch, and a triangular relationship with ICAS when the HealthWatch model evolves.
- Developing methods for sharing information from issues raised by patients through PALS, LINks and ICAS, and raising common problems as policy and campaigning issues with local hospital and primary care.
- Ensuring that local information systems are effective so that members of the public can easily access PALS, LINks and ICAS (www.pals.nhs.uk/cmsContentView.aspx?ItemId= 2161).

In addition to these proposals relating to *individual patient responsiveness*, the government's reform proposals also make claims that the new organisational arrangements will be more responsive to *collective* public and patient opinion. The *Health White Paper* (Secretary of State for Health, 2010, p. 4) contains a whole chapter entitled "Putting patients and the public first" where it is suggested that:

To strengthen democratic legitimacy at local level, local authorities will promote the joining up of local NHS services, social care and health improvement.

This aim has been espoused by many governments in the past, but it remains far from clear how local authorities, at a time of constrained budgets and other ongoing changes, such as the introduction of the *Localism Bill* (House of Commons, 2010), will be able to carry

out this role effectively. Indeed, the 2010 Health White Paper is relatively silent about the mechanisms by which this responsiveness to collective public opinion will occur. Health and Wellbeing Boards are charged with undertaking a joint strategic needs assessment (JSNA), and GP commissioning consortia (GPCC) are supposed to take this into account in their work, but there is no clear mechanism proposed by which local authorities can challenge commissioners who are not following its recommendations. Local HealthWatch will be charged with ensuring that patient voices are heard, but again, concrete powers are lacking.

Past history does not cause us to be sanguine in this regard. Despite PPI mechanisms in the NHS dating back over three decades (with the introduction of Community Health Councils in 1974 (Klein and Lewis, 1976) or the 1992 "local voices" initiative (NHS Management Executive, 1992)), there is little in past experience of PPI in the NHS to suggest that it has been effective in creating change in services or organisation (Harrison et al., 2002; Coleman et al., 2009a). Eight leading health charities including Alzheimer's Society, Asthma UK, Breakthrough Breast Cancer and Diabetes UK have expressed similar concerns about the probable effectiveness of the current reforms, writing an open letter to the Times (8 February 2011). In the letter, the charities argued that "Plans to make GP consortia accountable to the public are far too weak" and also raised concerns that Local HealthWatch bodies would neither have the powers nor the resources to ensure patients have a say in local services (Wise, 2011). How justified is this pessimism? In the following sections, we will examine the proposed changes and discuss their potential impact.

Areas of concern relating to PPI

Boxes 1 and 2 set out the principal changes that will impact upon PPI in the NHS. In this section we set out our concerns relating to these changes:

1. Despite GPCCs having a duty of PPI (Secretary of State for Health, 2010, p. 29), there is at present no requirement for them to have non-executive directors in their governance mechanisms or for their meetings to be open to the public except for an Annual General Meeting, an issue raised in the House of Commons Health Select Committee Report (2011). Moreover, we have evidence from our past research into practice-based commissioning (PBC) that PPI has not been a central concern for GPs and PBC consortia in the past:

The involvement of patients and the public in commissioning was an area with which most of our study sites struggled (Coleman et al., 2009b, p. 34).

[...] whilst many [PBC consortia] acknowledged the importance of consulting and involving the public, we did not observe any really successful models at work (Coleman et al., 2009b, p. 35).

However, the introduction of the new Patient Participation Directed Enhanced Service[2] (introduced in April 2011), which is intended to promote proactive engagement of patients through Patient Reference Groups and local surveys (lacobucci, 2011), may encourage greater attention to patient participation by GPs by giving out payment. On the other hand, GPCCs will have many issues competing for their attention, and there is a danger that PPI will remain a low priority as they struggle to develop new structures, processes and systems of governance over a relatively short timescale.

Box 1. Major changes in the *Health and Social Care Bill* (2011)

- The establishment of an independent NHS Commissioning Board to allocate resources and commission some services.
- Increasing GPs' powers to commission services for their patients.
- Strengthening the role of the Care Quality Commission.
- Developing Monitor, the body that currently regulates NHS foundation trusts, into an economic regulator to oversee aspects of access and competition in the NHS.
- Cutting the number of health bodies to help meet the government's commitment to cut NHS administration costs by a third, including abolishing Primary Care Trusts and Strategic Health Authorities (Summary of the Bill, http://services.parliament.uk/bills/2010-11/healthandsocialcare. html.

Box 2. Responsibilities relating to PPI under new structures

- 1. NHS Commissioning Board:
 - To promote PPI.
 - To provide guidance for GPCC in relation to PPI.
- 2. GPCC:
 - To involve the public in their decision making.
 - To commission services that are responsive to patients.
- 3. Health and Wellbeing Boards:
 - To perform a comprehensive assessment of local needs.
 - To work with GPCC in ensuring that services are responsive to patients.
- 4. Local authority:
 - To commission a health advocacy and complaints service.
 - To undertake Overview and Scrutiny of any planned service changes.
- 5. Local HealthWatch:
 - To provide advocacy and support for individual patients.
 - To ensure that patient voices are an integral part of local commissioning.
- 6. National HealthWatch:
 - To support local HealthWatch.
 - To propose CQC investigation of poor services.
- 2. It is claimed that new structures and processes will ensure greater accountability (to the local population). However, the legislation before Parliament appears to equate "consultation" with the provision of information about service changes. Thus, for example, on p. 43 of the *Health and Social Care Bill* it states that:

The consortium must make arrangements to secure that individuals to whom the services are being or may be provided are involved (whether by being consulted or provided with information or in other ways) – (a) in the planning of the commissioning arrangements by the consortium, (b) in the development and consideration of proposals by the consortium for changes in the commissioning arrangements where the implementation of the proposals would have a significant [emphasis added] impact on the manner in which the services are delivered to the individuals or the range of health services available to them, and (c) in decisions of the consortium affecting the operation of the commissioning arrangements where the implementation of the decisions would (if made) have such an impact".

Furthermore, this section of the Bill does not define what constitutes a "significant" change. For example, does a significant change in management arrangements (e.g. subcontracting functions) constitute a "significant" service change? Previous experience with the local authority overview and scrutiny (O&S) process suggests that such ambiguities can cause significant problems. For example:

What constitutes substantial development or variation is not defined in the legislation and health OSCs [Overview and Scrutiny Committees] with their local health bodies have needed to establish working definitions (Coleman and Harrison, 2006, p. 12).

Most of the sites had attempted to define SDVs [Substantial developments and variations to services] and joint health scrutiny work over the fieldwork period. This proved problematic at times and caused much discussion about what constituted a "SDV" and how best "health" OSCs should be involved in such consultations (Coleman and Harrison, 2006, p. 28).

If GPCC accountability to the public for service changes is to be meaningful, such definitions will need to be clarified.

3. Whilst GPCC will have an approximate geographical "footprint", they will be funded on the basis of their registered patients, whose residence may not correspond to the "footprint".

The local authority, public health, JSNA and Joint Health and well-being strategy, by contrast, will be focused upon spatially-defined populations, which will not necessarily match with the populations covered by GPCC. In some areas, these complexities will be minimal, where GPCC populations and local authority boundaries coincide. In other areas, however, Health and Wellbeing Boards and Local HealthWatch will potentially be required to develop relationships with a number of GPCC, and it remains to be seen how effectively these bodies will be able to gather and represent the collective views of the public in these circumstances. Furthermore, the Bill is lacking in detail about the powers that Local HealthWatch will have in representing those collective views, and it remains unclear how, for example, public disquiet about a service change proposed by a GPCC might be expressed, and what impact it would have.

4. Whilst it is claimed that the new structures will enhance the accountability of health services to democratically elected local councillors, the mechanisms by which this will occur are unclear. GPCC will have a duty to work with their local Health and Wellbeing Boards, but these latter bodies will have no powers to intervene in the work of consortia. Local authority O&S functions are to be retained and "enhanced", but it seems likely that the reorganisations within the NHS (as described in Boxes 1 and 2) and potentially arising from the Localism Bill (House of Commons, 2010) will at the very least interfere with the development of relationships that are so important in the scrutiny process. Disruption to working relationships due to such changes has been observed in previous research:

Officers also had to work in different ways and build and maintain relationships with scrutiny and executive councillors, with service officers from within the local authority and with health representatives (Coleman and Harrison, 2006, p. 46).

It could be argued that health scrutiny faces some special difficulties in becoming embedded as a process, or "institutionalized", due to the external nature of the work. This is made especially hard if organisational units, and individuals within them, are regularly changing, as this disrupts relationships and inhibits organisational learning (Johnson et al., 2007, p. 8).

Furthermore, Health and Wellbeing Boards will operate at the top-tier of local authorities. Where there are unitary authorities, this will be relatively straightforward, but where there are also district councils it seems likely that the tensions that were present within the O&S process in the past will continue. Our previous research (Coleman and Harrison, 2006, p. 31) demonstrated that O&S in two-tier councils was both resource and time intensive, and it seems likely that this will continue to be an issue in the new system.

5. Watts (2011) raises additional concerns in relation to the tightening of budgets, suggesting that councils have historically "cream-skimmed" budgets for local LINks, and that they may do the same with funding for HealthWatch processes, thus potentially limiting their effectiveness. Overall, therefore, it seems that, whilst the new system may provide adequate opportunities for the individual patient voice to be heard, mechanisms to involve the wider public appear to be weak. Triggle (2011) puts it thus:

It [the new system] has the potential to score well on the individual patient voice with regards to needs assessment and monitoring, but less well on ongoing engagement of patients in service improvement and commissioning decisions. But the big gap at the moment is the absence of any vehicle to include the citizens' voice, democratic accountability should not just be left to Overview and Scrutiny Committees.

Local authorities are currently coming to terms with huge reductions in their budgets plus additional responsibilities (e.g. Public health, Health and Wellbeing Boards), and GPCC are wrestling with a myriad of new powers and responsibilities. In this climate, it seems unlikely that the resources required to effectively engage with the collective public voice will be found.

Concluding remarks

In general, there are two arguments that can be made in favour of the involvement of patients and the public in health services. First, it is argued that such involvement will improve the services provided. Whilst this is an attractive idea, there is little concrete evidence that this has ever been successfully achieved in the NHS (Harrison *et al.*, 2002). Second, an argument can be made that, in a publicly funded system, PPI is necessary in order to achieve democratic legitimacy. This latter issue has been an important strand of Liberal Democrat policy, and the 2010 *Health White Paper* includes a rhetorical commitment to increasing democratic accountability.

One of the problems with assessing the potential impact of the current reorganisation on PPI is that the Health White Paper (Secretary of State for Health, 2010) fails to make a clear distinction between the involvement of individuals in decisions about their own care, and the wider involvement of the public in decision making about services. Whilst the former is desirable, and may contribute to the overall goal of improving services by making them more "consumer" orientated, it is the latter that is most important in ensuring that those who spend public money are accountable to the public for the decisions that they make. This form of accountability is difficult to achieve, as it requires decisions to be made about whose voice should be heard (patients or "the public" as a whole) and requires extensive efforts to ensure that those involved have the information that they need to make a decision (Harrison and Mort, 1998). In this context, involving locally elected councillors is superficially attractive, as they already have a democratic mandate. However, we have demonstrated here that, as they stand (April 2011), the proposals contained in the Health and Social Care Bill (House of Commons, 2011) fall far short of ensuring real accountability to the public via this route. It is possible that GPCC will show a real commitment to involving the public in their decision-making processes, and it is possible that Health and Wellbeing Boards' needs assessment processes (and the development of a joint health and wellbeing strategy locally) will work effectively, whilst Local HealthWatch and the overview and scrutiny process hold GPCC effectively to account. However, we can see nothing within the Bill as it is currently formulated to ensure that this is the case. In addition, the House of Commons Health Select Committee (2011) have recommended scrapping the idea of Health and Wellbeing Boards and GPCC, instead creating local commissioning authorities, an idea the Local Government Association (LGA) strongly opposes due to a lack of local democratic legitimacy (Evison, 2011). There also remains a real danger that, as the new bodies (once structures are finally decided upon) wrestle with their complex and expanding responsibilities, "patient and public involvement" is equated with providing information and allowing choice, and the opportunity to embed meaningful democratic accountability is lost.

It does seem as if criticisms such as these have had some impact on policy makers. At the time of writing the government had just launched The NHS Future Forum (6 April 2011). According to the Department of Health (http://healthandcare.dh.gov.uk/nhs-engagement-exercise/) the forum's role is, amongst other things, to consider "how to ensure public accountability and patient involvement in the new system". It remains to be seen, however, what changes relating to public accountability this forum might recommend, and whether any recommendations will be subsequently followed.

Notes

- 1. HealthWatch is described as a consumer champion at local and national level. Local HealthWatch organisations (from 2012) should ensure that the views and feedback from patients and carers are an integral part of local commissioning across health and social care (Secretary of State for Health, 2010 p19). Local involvement networks (LINks) will become the local HealthWatch. Local HealthWatch will be funded by and accountable to local authorities.
- 2. GPs are contracted to provide core (essential and additional) services to their patients. The extra services they can provide on top of these are called enhanced services. Enhanced services plug a gap in essential services or deliver higher than specified standards. Directed enhanced services (DES) must be provided or commissioned by the PCT for its population www.dh.gov.uk/en/ Healthcare/Primarycare/PMC/Enhanced/index.htm

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