BMJ

BMJ 2011;342:d2333 doi: 10.1136/bmj.d2333

Patient participation groups

NHS reforms offer new and wide ranging opportunities

Shobhana Nagraj *academic clinical fellow in general practice*, Stephen Gillam *general practitioner*

Cambridge Centre for Health Services Research, Institute of Public Health, University of Cambridge, Cambridge CB2 0SR, UK

Involvement of patients and the public is meant to be at the heart of the coalition government's health policy. *Liberating the NHS* claims to "strengthen the collective voice of patients and public."[1] Patient participation groups are one way in which the views of patients might be heard more clearly in future. Such groups emerged more than 30 years ago but have been slow to gain hold. In 2007, 41% of practices were reported to have a patient participation group,[2] but the true proportion of active groups is probably lower. Their role has always lacked clarity, but the current NHS reforms in England offer new opportunities for these groups.

Patient participation groups are voluntary and usually based around a general practice.[2] Activities undertaken by these groups come under three broad categories.[3] The first concerns health education—for example, running educational meetings for patients. The second role is that of "critical friend"—giving advice and feedback on services provided by the practice. Thirdly, some groups generate material support for practice developments—for example, through fundraising or providing voluntary services.

Surveys carried out by the National Association of Patient Participation have shown that patient participation groups are more common in rural than in urban communities. Barriers to establishing a patient participation group include lack of time and a perceived lack of interest from patients.[2] The two most important determinants of success are strong leadership and enthusiasm for the group's work by the members themselves. Other prerequisites of success include support from the practice team, selection of appropriate participants, clarity of purpose, and resourcing. Among many obstacles to progress, perhaps the most important is the difficulty, especially for smaller practices, of sustaining commitment among busy staff and members of the group.

Champions of patient participation groups say they benefit individuals who participate and the practices to which they are affiliated. They also suggest that these groups have the potential to enhance social networks. Social cohesion may be indicative of underlying psychosocial risk factors that are known to be closely associated with health.[4] Community participation in health is at the heart of the World Health Organization's strategy and the Healthy Cities agenda.[5] Patient participation groups provide a means of increasing community engagement on local health matters. Could they play a stronger role in primary care in the future?

Liberating the NHS presages the creation of HealthWatch England, a new independent consumer champion within the Care Quality Commission.[1] Local involvement networks, funded by and accountable to local authorities, are supposed to ensure that the views of patients and carers are integral to local commissioning.[1] Exactly how general practice commissioning consortiums are to be held accountable to the public is unclear. Charities fear that local HealthWatch bodies will not have the resources to ensure that patients have a say in local service development; they will need to be strengthened.[6]

Some patient participation groups already have the experience to contribute to this new agenda. In particular, they could undertake a more formal role in scrutinising practice services. Secondly, they could assist the new commissioning bodies—for example, by helping to assess local healthcare needs and set priorities. Currently, practices are not required to support patient participation groups but new contractual incentives will reward practices "for routinely asking for and acting on the views of their patients."[7] Under the terms of a Directed Enhanced Service, practices can be paid for establishing a "patient reference group," undertaking a local practice survey, and publicising actions taken as a result.

Few patient participation groups are currently equipped for a more formal scrutiny role. Members face conflicts of interest overseeing their personal doctors and local practices. They may not be representative of the communities they serve. They may lack relevant training and expertise to inform commissioning. Sustainability is a central concern; can these groups serve multiple practices?

The government extols the "Big Society," a call for the decentralisation of power and more public involvement in managing local communities.[8] The concept is destined for continuing ridicule at a time of increasing austerity and cuts in public sector spending. However, the themes that underlie the Big Society (and the similarly ill fated "Third Way" that preceded it)—of voluntarism, localism, and transparency—are not without merit.[9] They are consistent with attempts to place greater control in the hands of patients and users. They can be aligned with the core values of mutuality and fairness that are embodied in the NHS. Empowered patients are the best defence against threats to the integrity of the NHS.

Patient participation groups need clear goals, incentives, and resources, and practices now have further guidance on how to establish and sustain them.[7] An expanded role for patient participation groups could provide a means of increasing public involvement in the NHS while offering democratic legitimacy to the commissioning process.

Competing interests: All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

Provenance and peer review: Not commissioned; externally peer reviewed.

1 Department of Health. Equity and excellence: liberating the NHS. 2010. www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117794.pdf.
2 Box G. Patient participation groups: the national picture. *Qual Prim Care* 2009;17:291–7.
3 Liverpool NHS Primary Care Trust. A practical guide for developing patient participation groups, 2007. www.centralliverpoolpct.nhs.uk/Library/Your_PCT/Hearing_your_voice/PPG_pack.pdf.
4 Wilkinson RG. Income inequality, social cohesion and health: clarifying the theory. *Int J Health Serv* 1999;29:525-43.
5 Heritage Z, Dooris M. Community participation and empowerment in Healthy Cities. *Health Promot Int* 2009;24:i45-55.
6 Wise J. NHS reforms do little to empower patients, charities say. *BMJ* 2011;342:d903.
7 Department of Health. Primary medical services (Directed Enhanced Services) (England) (amendment) directions 2011. www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_125877.pdf.
8 Prime Minister's speech on the big society in Liverpool, UK, 19 July 2010. www.number10.gov.uk/news/speeches-and-transcripts/2010/07/big-society-speech-53572.
9 Taylor M. The left and the big society. 2010. www.opendemocracy.net/ourkingdom/matthew-taylor/left-and-big-society-iv-matthew-taylor.

Cite this as: *BMJ* 2011;342:d2333