Editorial

Involving patients: representation or representativeness?

In the UK and in several other European countries, attempts are being made to engage patients and citizens in monitoring the quality of health services and determining policy priorities. The Department of Health in England wants to 'move away from a system of patients being on the outside, to one where the voices of patients, their carers and the public generally are heard and listened to through every level of the service, acting as a lever for change and improvement'.[1] The plans include various mechanisms for increasing direct patient participation in oversight of provider performance, including the establishment of Patients' Forums in every acute and primary care Trust which are intended to be 'truly representative of a broad sweep of the community.'

The dangers of tokenism in patient representation on committees are well recognized and the plans envisage a much greater number of lay representatives than ever before. Where are the members going to come from? There is a plethora of organized patient groups, but many are small and poorly funded and the majority represent patients with specific diseases. Some patient groups were established with funding from pharmaceutical companies as part of their 'disease awareness' strategies, and others were set up by clinicians to support their efforts to raise funds for research. The representativeness of many of these groups is open to doubt. The relatively few umbrella or general groups cannot be expected to supply members for all the new committees and, anyway, since most patients are not members of organized groups, these groups cannot be said to represent the views of the majority. There are fears that the new Patient Forums will not be sufficiently independent from Trust management, that they may attract people with a particular axe to grind, and will not represent the views of disadvantaged members of local communities who are unlikely to put themselves forward for membership.

While welcoming the new commitment to user involvement, it is important to recognize the limitations of direct participation. While most patients want providers to take account of their views and experiences, only a small unrepresentative minority will want to be actively involved in committees to achieve this. It will be crucial to ensure that the Forums have access to regular feedback from representative samples of patients and citizens to balance the views of the special interest groups. The new National Health Service (NHS) survey programme will serve a useful purpose here. Every Trust in England is now required to survey their patients annually. If these surveys are carried out in accordance with recognized standards for high quality research, they could provide a legitimate basis for arguing for quality improvements which carries more weight than the opinions of lay representatives. Patients Forums should monitor the conduct and results of these surveys and ensure that appropriate action is taken to address any problems identified. The next step should be to supplement the surveys of patients' experience with robust techniques to identify citizens' views on health care priorities to ensure that the public involvement programme has a sound evidence base on which to build.[2]

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References

1 Department of Health. *Involving Patients and the Public in Healthcare: Response to the Listening Exercise*. November 2001. www.doh.gov.uk/involvingpatients.

2 Mullen P, Spurgeon P. *Priority Setting and the Public*. Abingdon: Radcliffe Medical Press, 2000.