

Making good use of patients' views

This month sees the first anniversary of Patient and Public Involvement forums in England. But does involving the public in health related decision-making and planning through such initiatives really make a difference to the provision of health services? Zoë Gross investigates

Patient and Public Involvement (PPI) forums have been up and running in England since the beginning of December last year. The aim of these forums, currently supported by the Commission for Patient and Public Involvement in Health (CPPIH), is to raise awareness of the needs and views of patients and the public, placing them at the centre of health services. Another initiative involving the public is the National Institute for Clinical Excellence (NICE) Citizens Council. The council was established in November 2002 to try to find out what the public think about key issues that inform the development of guidance issued by the institute. The question is, do these initiatives really achieve anything?

Sharon Grant, chairman of CPPIH, says that patients and the public need a channel by which they can have their views heard and acted upon. By creating PPI forums, steps have been taken to ensure that patients and the wider public are increasingly involved in decision-making. She adds: "Any major organisation, or service organisation, the size of the NHS that does not routinely and seriously involve the people that it serves in how it works, is heading for serious trouble."

Mrs Grant believes that the CPPIH's budget last year of £33m, funded by the Department of Health, has been well spent on setting up these forums. Examples of work that PPI forums have been involved in include: preventing the closure of facilities, such as wards and clinics; helping raise awareness of teenage girls with diabetes in Southern Derbyshire who end up in casualty as a result of refusing to take their medication because of fears that it will make them fat; and monitoring public opinion on pharmaceutical services in the Doncaster area.

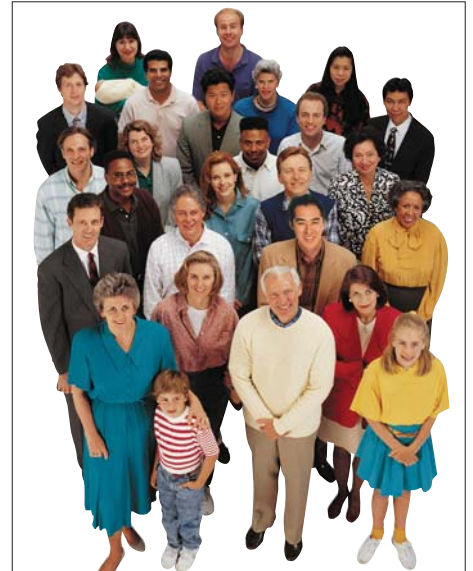
Chairman of North Tees and Hartlepool Hospitals PPI forum, Linda Shields, agrees with Mrs Grant that the money is well spent. She says: "It is impossible for clinicians to

make the kind of contact with the public that [PPI forums] can." One of the most important roles that the forums play is being a voice for the public. In addition, she says the more the public become aware of the forums and the work that they do, the more they are taking ownership of health issues.

According to Sir Michael Rawlins, chairman of NICE, it is important "to capture the views of the public". He strongly believes that since health care is provided under general taxation, the thoughts of the general public about how their money is being spent need to be taken into account. One example Sir Michael gives of where the Citizens Council has influenced NICE guidance is for the treatment of hepatitis C with ribavirin and interferon alfa. He says that NICE had specifically recommended, in its guidance, that drug abusers who were still misusing drugs should not be offered treatment. However, the council "reckoned we should discriminate on the basis of the causation of peoples' illness", he says and the guidance was amended.

Nevertheless, Sir Michael is not convinced that determining the public's view by means of the council is good value for money. He says that each council meeting costs about £100,000 and he is "conscious that it is actually a lot of money" to be spending. But, if the money was not spent in this way, it would be spent doing something else instead, he says. He does not favour opinion polls or focus groups as alternatives, and suggests that cost cutting initiatives could include addressing money spent on hotel accommodation for three nights during council meetings and shortening the meetings. NICE has commissioned the Open University to evaluate the work of the council and a report is expected over the next few months.

Last month, the council met to discuss the management of rare diseases and the use of ultra-orphan drugs in the NHS. Council member Paddy Storrie, deputy head of a secondary school, who attended the meeting, says that the council did not give NICE a black and white answer about whether these exceptionally expensive drugs should be paid for by the NHS. However, the balance of opinion was a conditional "yes". He says that the council was confronted with the possibility that if on one hand it said "no" to paying premium prices to treat patients with rare diseases, then these people would suffer. If on the other hand, it said "yes", then people in the wider population with more common ailments would find themselves suffering badly in terms of delayed treatment or even not receiving treatment. The outcomes are to be published in a report to be presented to the DoH in spring 2005.



Public involvement helps plan services

Other initiatives

Last month, the Government announced a number of measures to help make the Medicines and Healthcare products Regulatory Authority (MHRA) and the pharmaceutical industry operate more openly (*PJ*, 20 November, p734). One such measure was a new structure for a commission for safety and efficacy of medicines (bringing together the Committee on Safety of Medicines and the Medicines Commission). There will be two lay representatives as well as patient representatives on the new commission and its bodies and groups. The aim is to give patients a greater involvement in the regulation and safety of medicines. Harry Cayton, national director for patients and the public, DoH, comments that this initiative "brings a new level of expertise into the thinking within the commission". It also makes sure that public interest is broadly represented in the way the commission works, he says. "My hope is that by bringing in the expertise of patients and by opening the processes up to the public, first of all we might get a better process, but secondly we will get greater accountability and greater confidence."

Mr Cayton says there is still quite a long way to go before being convinced that public involvement improves health services. However, he says that the DoH report "Patient and public involvement in health — the evidence for policy implementation", shows that public involvement does help people to design and plan better services. In terms of expenditure on such initiatives, he says that any money is well spent if it leads to a health service centred around the people who use and pay for it.

The patient voice

PPI forums: There are 572 Patient and Public Involvement forums, one for every NHS Trust and primary care trust in England. Further information can be found at www.cppih.org.

Citizens Council: The council consists of 30 members of the public who reflect the age, social circumstances, ethnic background, regional difference and abilities of a cross-section of the population of England and Wales. Further information can be found at www.nice.org.uk