How To Do It

Set up a patient participation group

TIM PAINE

Patient participation is emerging from its infancy as a new enterprise in general practice. It has become an increasingly common topic for discussion and debate at meetings and conferences, and the number of practices with a patient participation group (PPG) is steadily rising. Although there is still considerable resistance to the idea, especially among long established general practitioners, the number of doctors seriously considering it has multiplied. The principle behind it is as old as the hills: the best results occur when client and craftsman confer over the job to be done and pool their resources in carrying it out. This is the basis of counselling, and patient participation is simply counselling writ large. A PPG is not, and should not be, the only means of participation. Every consultation is an opportunity for sharing—information, insights, solutions and tasks; a PPG is merely a structured and practical method of consultation with the practice as a whole.

What is a PPG? There is enormous variety among the 100 or so in existence, but most share a basic structure. A committee of patients (who may be elected by their peers, or co-opted), together with one of the partners and one or more of the practice team, meet at regular intervals to decide ways and means of making a positive contribution to the services and facilities offered by the practice to its patients. Patient participation group activities tend to fall into five main areas: consumer feedback—a voice in practice planning and organisation; health promotion—meetings, groups, literature; community care—various voluntary activities such as transport, fetching prescriptions, and social events; providing information—practice guides, leaflets, local facilities; and fund raising—both to maintain the group and to purchase equipment and provide facilities. By no means all groups engage in all these activities; some prefer to limit their energies to one or two. It very much depends on the interests, priorities, and talents of those concerned and how much time they have to spare.

What have practices gained from having a PPG? For many who have become involved—patients and professionals—it is the atmosphere of openness and mutual respect that seems to go with participation that is the most important plus. Others will point to more tangible results, such as a woman partner, a better organised appointments system, or a more congenial waiting room—the results of feedback and suggestions. A health education programme, patient transport service, or lunch club for the elderly are further examples; the list is long. Arguments for having a PPG range from the basically practical (more involvement: better system), to the philosophical (freedom and autonomy) and the political (public service: public say).

From *How To Do It: 2*, a new collection of useful advice on topics that doctors need to know about but won't find in the medical textbooks. To be published in October 1987, this is a companion volume to the popular *How To Do It: 1*, also published by the BMJ.

Selling the idea

The first task that anybody thinking of starting a PPG should attend to is reading the subject up. This has recently become much easier since the publication of a superb little book by Ann Richardson and Caroline Bray called *Promoting Health Through Participation* (obtainable from the Policy Studies Institute, 100 Park Village East, London NW1 3SR, price £5.95). It is a concise account of the current state of patient participation in Britain, and is a mine of information for anyone about to take the plunge. It is also a valuable guide to publications about patient participation.

If you are inspired by what you have heard and read, and want to proceed, the next step is consultation—with partners, team, and maybe one or two “likely” patients. A large part of this is a selling exercise, and it may tax your powers of persuasion to the full. It is to equip you for this that background reading and thinking are so vital, so that you are sure of your facts and arguments. Of course, the other object of the exercise is to listen to people's reactions and suggestions; “bulldozing” will get you nowhere. One of the reasons groups fail (and this happens not infrequently) is that those concerned have not talked things through sufficiently before they start. This may lead to unrealistic and conflicting expectations, and eventual disillusionment. Do your best to encourage active participation from the start. This applies especially to the practice team and staff, who are all too often left out of discussions and plans, and not surprisingly show little interest subsequently. Receptionists and health visitors in particular are valuable allies in the initiation and running of a PPG, and the more opportunity they are given from the start to contribute ideas, suggestions, and their time to the scheme the better will be the prognosis for the group. To make it easier for everyone to gain a clear impression of what a PPG implies, consider inviting one or more people from a thriving group to meet your practice and talk about their experiences. The National Association for Patient Participation (NAPP) comes in useful here. The secretary (Helen Lyus, 13 Manor Drive, Surbiton KT5 8NE) will send you a “start up” package, together with details of contacts in your vicinity.

Once the preliminary discussions are under way, it won't be long before you know if you are on to a winner. It is probably wise to satisfy a few basic criteria before proceeding further: an enthusiastic doctor willing to devote several hours a month, at least initially, to establishing and supporting the group—that's you; partners who are well disposed to the scheme—or at least not antagonistic; one or two members of the practice team who are willing to help enthusiastically; and possibly one or two patients willing to act as

catalysts for the first year or two. (You may, of course, decide to delay the involvement of any patients until you are ready for the launch.) Having obtained general agreement, you will need to form a small planning group to examine logistics in detail. Perhaps the most vital aspect to consider is the operational philosophy of the PPG. If you and fellow planners have democracy and accountability at the top of your list of priorities you will probably opt for a committee elected by the practice list and totally autonomous in deciding the range of its activities—so you may decide merely to float the idea at a meeting, describe a few PPG activities and benefits, and let them get on with it. On the other hand, you may want to be a little more directive (in the interests, of course, of PPG effectiveness), and present interested patients with a structure for the group, a list of initial activities and even a constitution. If you veer towards this stance you will need to work out some practical details about how such activities as feedback, health education, and community care might be organised and put into operation.

Funding and publicity can both pose problems. Unless they become very elaborate, PPGs are relatively inexpensive to set up and run. Most groups manage on less than £500 a year, and probably need only £50-£100 to get started. Partnerships often contribute this sort of money at the start, and annually thereafter, which is, of course, tax allowable. It is well worth approaching health authorities, particularly if the group is to have a health education role; and local firms and charities are other sources of funds. Once the group is established, it may well become self financing from fundraising activities such as jumble sales, raffles, and sponsored events.

Publicity is probably the biggest headache that you and the group will have to cope with. The constraints on professional advertising are in the process of some degree of relaxation, but it is unlikely that practices will be able to publicise PPG activities other than directly to their own patients. (The one exception is a health education event, which may be widely advertised as long as the practice itself is not identified.) As you will probably be aiming for a maximal response from your patients at the start—most begin with an open meeting to discuss the scheme—it is worth making a supreme effort to circulate as many on the list as possible. This means giving serious consideration to supplementing publicity at the surgery or health centre with a distribution of letters to homes, even through the post. It is also worth putting a lot of thought into how you present your message. The wording and visual impact are crucial, and your planning group may decide that it is helpful to seek some expert advice. Experience has shown that patients respond most positively to communications directly from their doctors, so arrange for the whole partnership to sign the letter before it is duplicated.

When the planning group has done its work, it is wise to have a final practice meeting before the launch, with the proposals and details down on paper. From this stage on it is a good idea to minute discussions and decisions, if only to prevent anyone having an excuse for claiming that they were kept in the dark.

Carrying it through

By this time you and your fellow planners are likely to be somewhat excited and impatient for the huge response to the publicity that you have so carefully engineered. A note of sober caution must be sounded at this point. Patient participation is not everyone's cup of tea, and this applies to patients as well as doctors. So don't be too downcast if only 10 or 20 people turn up to hear more about it. Lots of successful groups have started very modestly. If you have opted for a meeting to promote the scheme (some practices start an activity first, such as a community care scheme, and develop a PPG from there), your presentation and selling skills will again be

needed. Try to give everyone who comes a chance to feel involved from the word go. Breaking the meeting up into groups of six or eight, to discuss among themselves what you have just told them (there's no need to move into separate rooms), will get people thinking and enthusiastic. Something that appeals to a lot of people is to feel that they are being given an opportunity to contribute to a worthwhile experiment; there's also a strong tendency to want to make an experiment work. Before the meeting breaks up, you will need to ask for volunteers for the steering committee. Most groups have about 12 patients on their committees, but this may be too many to aim for at the start. Too much arm twisting is usually self defeating in the end, so start small and build up. If you have already found one or two patients who are willing to act as a committee nucleus, it will make things that much easier. The numbers who volunteer will to a large extent determine the range of activities of the group. Avoid being over ambitious; people, including you, will be put off by the number of jobs they have to do. There is, however, an advantage in having a selection of PPG activities. If any prove unsuccessful, the group has other eggs in its basket.

There is often some doubt as to how closely concerned the doctor(s) should be in the operation of a PPG once it has commenced activities. My own experience may be relevant. I announced that, having come up with the idea, I now thought it was over to the patients as far as the running of the group was concerned. I felt it was wrong for a doctor to be influencing a scheme set up to give the patients a voice of their own. It wasn't long before the steering committee began to resent my apparent distance from the group, and the lesson I learnt was that you cannot have one sided participation. The compromise, which seems to have worked, was for me, or one of my partners, to attend committee meetings by invitation, and as many of the group's evening meetings as possible. Visible support from doctors goes a long way to maintain PPG morale.

The first year or 18 months of a PPG's life is usually straightforward. Trouble making patients on the committee are seldom a problem; but if they are, their fellow members usually sort them out and they go away without a receptive audience. (I don't mean by this that groups should avoid all criticism of the way the practice is run. Constructive criticism, and coming up with alternative solutions to problems, is part of their *raison d'être*.) Once the novelty has worn off to some extent, and the founding members start to feel they have done their bit, a period of doldrums and doubt can overtake a group. New blood is needed, and everyone wonders where it is going to come from. This is a time to inject some extra special effort again, and it may also be worth while at this stage to carry out a pretty honest review of the group's achievements and likely potential; and if everyone agrees it is right to continue, to organise another big publicity drive. Once a group is over this phase of post-honeymoon blues, momentum tends to be maintained. One of the assets of the National Association for Patient Participation is the opportunity it provides for PPGs in different regions of Britain to meet each other and share experiences. It is a great boost to a struggling group's morale to hear that other people have had similar problems, and have found ways of solving them. One of the commonest frustrations is the unwillingness of patients to participate. You have to recognise that it is a minority interest—probably attracting the same proportion of people in a community who might want to attend evening classes. So to achieve a satisfactory response to any meeting, say, one has to make the subject sound relevant to the audience in question, and this again is where skills in communication and "selling" are so valuable.

Setting up a PPG is challenging and exciting, and not without certain risks. One of the refreshing things about PPGs is the lack of standardisation; every practice, and every group, must do its own thing. I have merely suggested a framework, and I am sure no one will feel bound to stick to it. Have a go... and good luck!