

FOREWORD

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I wish also to thank all those members of Patient Participation Groups and colleagues who have contributed many ideas.

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The aim of this paper is primarily to help general practitioners who are thinking of starting a group, but it is hoped that others will read it too.

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PATIENT PARTICIPATION IN GENERAL PRACTICE

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Patient participation in general practice

P. M. M. Pritchard, MA, FRCGP

■ INTRODUCTION

Patient participation, in common with much that is new in general practice, got off to a slow start. Now, 10 years after the formation of the first patient participation group (PPG), there are still only about 50 groups known to be operating in the United Kingdom, but the number doubled in 1981 and is increasing exponentially (*Figure 1*).

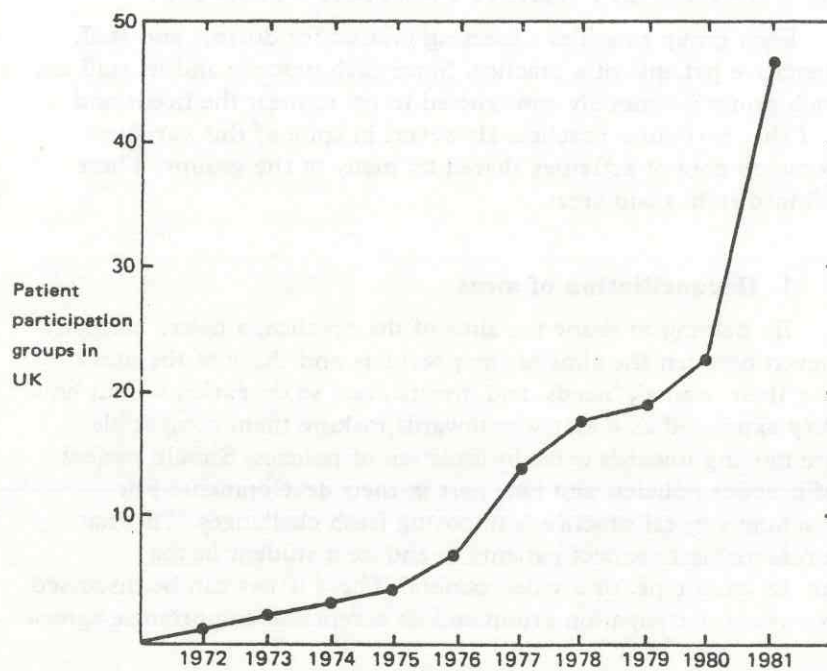


Figure 1 The growth of patient participation groups in the United Kingdom. Reproduced with kind permission of Dr. T. Paine and the Editor, *Oxford Medical School Gazette*.

The idea has been well supported by the Royal College of General Practitioners and their sponsorship of a day conference in January 1980 was probably the turning point in achieving professional acceptance. The proceedings of this conference, and other papers, were published as

Occasional Paper 17 (Pritchard, 1981), and in the introduction, Dr John Horder, then President of the College, wrote:

It reflects poorly on medical care, as we provide it, that patient participation should need promotion. It betrays a world divided into consumers and providers, when the alternative is for the consumer to be the first provider: a world in which the providers plant a protective hedge around their garden, when no hedge is needed; a world where expertise flowers, a special language is talked, and trained people enjoy special privileges and feel different; the weeds in the hedge are misunderstanding and mistrust.

The aim of this chapter is not so much to promote patient participation, as to describe what it does, its snags and benefits, and how to go about setting up a group.

■ WHAT DOES PATIENT PARTICIPATION DO?

Each group provides a meeting ground for doctors and staff, with representative patients of a practice. Since each practice and its staff are different, each group is uniquely constructed to try to meet the needs and aspirations of that particular practice. However, in spite of this variation, there is a common core of activities shared by many of the groups. These activities fall into eight main areas:

1. Reconciliation of aims

By helping to shape the aims of the practice, a better harmony can be achieved between the aims of the providers and those of the users. Doctors have their 'wants', 'needs' and 'musts', and so do patients—but how often are they expressed as a first step towards making them compatible? Practices are moving towards overt formulation of policies. Should patients be aware of practice policies, and take part in their development? For instance, teaching general practice is imposing fresh challenges. To what extent is it reasonable to expect patients to endure a student in the consultation, an audiotape, or a video camera? These issues can be discussed openly in a patient participation group and an acceptable compromise agreed.

2. Feedback for planning and evaluation

An architect designing a house would expect to be guided by the client at the planning stage, and also to hear how the plans worked out in practice. His aims would be to correct any faults in the plans and to save himself making the same error twice. As a bonus he would have a satisfied customer, who felt involved in the final outcome. Similarly, general practitioners running primary care services need help from patients both at the planning and evaluation stages in order to achieve maximum effectiveness.

3. Under-served groups in the community

The 'iceberg' of unreported illness in the community is well known (Hannay, 1979). Similarly, groups like the elderly, single parents and poorer people have more difficulty in making their needs known. Some patient participation groups help to call attention to unmet local need, and often meet the need themselves. Some have developed extensive community care services where these have been lacking.

4. Linking health care with other community networks

People receive care from a wide range of agencies in the community, besides doctors and nurses. Staff find it difficult to be aware of all the possible helping agencies. Members of patient participation groups often belong to other organizations, and can use these links to improve the co-ordination and effectiveness of care.

5. A forum for complaints

A survey of patients by the National Consumer Council has shown that 5 per cent of those who attended their doctor in the past year had grounds for dissatisfaction—yet none of them complained to the doctor or through the formal complaints procedure. This reluctance to complain can harm the doctor-patient relationship, whereas a more open sharing of grumbles may improve the service and lead to less frustration and anger against doctors. Patients rarely want to punish the doctor; they hope that by complaining, other patients will be saved the unpleasant experience they had. Similarly, the general practitioner also has a chance to grumble, which he is otherwise officially denied! Complaints play a very small part in the work of patient participation groups, but they are considered to be a useful safety valve. A more positive approach is the norm, whereby more desirable behaviour can be praised, and so reinforced.

6. Helping to develop preventive programmes

Traditionally, general practitioners have provided care on request. Some patients may resent being summoned for screening, though immunization reminders are generally accepted. The general practitioner cannot easily define the limits of acceptable behaviour, but with patients' help the mandate can be re-negotiated. Patients can also give practical help in the wording of questionnaires and in the heavy clerical and administrative work generated by preventive programmes, subject of course to the need for confidentiality, which is considered later.

7. Health promotion

The National Health Service is mostly orientated towards disease and its treatment, rather than to prevention and health promotion. Promotion of a healthy lifestyle—though emphasized by the World Health Organization as an essential ingredient of primary health care—does not receive the attention it deserves.

Much can be achieved locally with health education and self-help groups. Recent experience has shown that health education must be in tune with people's health beliefs and appreciation of risk (King, 1981), and that self-help groups are more effective if they are community based rather than professionally sponsored (Danaher, 1982). This suggests that a community or individual based approach to health promotion is preferable to a 'lecturing' or mass media style of education, and patient participation groups who have adopted this approach have found that many people are prepared to contribute their energies and skills for an objective which they can see as relevant for them. It is a move towards returning the responsibility for health to the patient, and so increasing patient autonomy, which should provide a crumb of comfort to medicine's most trenchant critic—Ivan Illich (1982).

8. Influencing other organizations

Compared with the powerful voices of hospital and health authority staff, general practice speaks only in a whisper. As a result, it loses its share of resources and local services such as general practitioner hospitals, peripheral consultant clinics, ambulance depots and chiropody. It has been found that a patient participation group can speak with great authority about local services, and its voice is often heeded where the general practitioner's pleas have been ignored. Thus the strength of such groups lies in their firm base in the community, where they have most power to influence authority.

■ EVALUATION

So far, nearly all the groups have felt that they were useful, and few have failed. However, such evaluation has necessarily been subjective, as described by Wood and Metcalfe (1980), who claim that patient participation groups increase the effectiveness of the practice, improve doctor-patient relationships and extend the role of the general practitioner. Unfortunately, although several descriptive research studies have been undertaken (Pritchard, 1981), good evaluative studies are so far lacking. Thus at present there is no methodology and outcome measures are still to be chosen. These might be: better doctor-patient relationships, the level of complaints, patient satisfaction or effectiveness of care, but until this new venture is able to attract the level of funding which this type of research needs we will have to rely on subjective views.

■ BENEFITS

Many potential benefits of patient participation groups were implicit in the description of the functions of such groups, but there are other, more specific benefits, which should be noted by those considering setting up a group.

1. The counselling style extended

General practitioners are now taught to listen to their patients in the consultation, to encourage them to find solutions to their problems, and to help them choose and implement those solutions. What applies at an individual level between doctor and patient applies equally to a group of patients meeting doctors and staff to discuss practice problems. Or, looked at another way, it is an extension of the counselling style into the field of practice management. By increasing the sense of partnership between user and provider, the distinction becomes blurred in that the users help with provision of care and services. Doctors work *with* patients, rather than doing things *to* patients, and so foster patient's autonomy and sense of responsibility. What was seen as the doctor's practice becomes *the patients'* practice, providing for *their* health. An adult-to-adult relationship replaces the less fashionable parent-child relationship.

2. Adapting to change

Society is in a state of rapid change, so that systems designed for previous social patterns may not be able to cope with today's world. The difficulties of providing care in inner cities is an example. If general practice is to change to meet society's needs, it must be sensitive to those needs, and be helped to adapt to change. This is an important role for the patient participation group—as a listening post in the community and supporting general practitioners and staff in making the appropriate changes.

General practitioners can feel very isolated from the community they serve, particularly if they live outside the practice area. The patient participation group can help to identify community needs for the doctor, and so increase his job satisfaction.

3. Open medicine

Professions have come under criticism for the way they have excluded the public from their sources of information. Medical information, of variable quality, is now freely available to the public, so that the days of professional exclusiveness are numbered. A patient participation group can help doctors and staff come to terms with 'open medicine'.

■ DIFFICULTIES

Inevitably there are some difficulties encountered in setting up patient participation groups but none are insuperable given determination and good will.

1. Doctors' attitudes

General practitioners are not alone in their resistance to change. When threatened by change, some reason must be found to stave off the threat. A survey of the attitudes of general practitioner trainers to patient participation (Wood and Metcalfe, 1980) concluded that patient participation groups would:

- increase friction between doctors and patients,
- decrease the effectiveness of the practice,
- limit the role of the general practitioner,
- prove unnecessary, and a current fad.

None of these trainers had their own patient group. When the same questions were asked of doctors and patients who had such a group, the answers were diametrically opposite!

2. Colleagues' attitudes

General practitioners are reluctant to introduce changes to which their neighbouring colleagues might object, and indeed some have objected strongly to anything which might smack of advertising or currying favour with patients. Perhaps the real anxiety is not that they will lose patients but that one day patient participation may become a normal part of general practice, as recommended by the World Health Organization (Kaprio, 1979) and that one day they will have to accept it, whether they wish to or not. There is no doubt that the anxiety is real, and conscientious doctors do not want to upset their colleagues.

3. Advertising

The Central Ethical Committee of the British Medical Association has produced guidelines about advertising, which distinguish clearly between community-based activities such as health education lectures open to all the community which may be freely advertised, and matters domestic to the practice which can be advertised only to patients of the practice.

The limitation on publicity makes the work of patient participation groups much more difficult. If, however, neighbouring practices are in agreement, the limitation may be relaxed. As more practices start such groups, this is likely to become a non-issue, particularly as the General Medical Council is

unlikely to take a serious view of doctors and patients trying to form links with the aim of improving services!

4. Confidentiality

Sensitive handling of information will ensure that confidentiality does not become an issue. For example, names of patients with a particular diagnosis should not be given to a self-help group without the patient's consent. Similarly, lay people should not have access to an age-sex register for mailing purposes, unless they are bound to secrecy, as the practice staff already are.

5. Patient hostility—patient power

'Patient power' is a catch-phrase beloved of journalists (*Journal of the Royal College of General Practitioners*, 1974) which conjures up an image of patients dominating doctors. Doctors who do not have experience of a patient group develop nightmarish fantasies of the practice being taken over by their most aggressive and difficult patients, who will make their life a misery with complaints and interference. This is a false picture. In the real world, patients are very grateful to doctors who allow them to become involved, and are keenly aware of the limits to which this freedom to communicate can be pushed, and the small amount of time which doctors can be expected to devote to participation. General practitioners have plenty of power to spare, and when they work in partnership with their patients, the power of the whole greatly exceeds that of the sum of the parts.

6. Practical difficulties

Once the attitudinal barrier has been surmounted, doctors are faced with the very real practical difficulties of getting a group going and these will be dealt with in the following section which offers guidelines.

■ STARTING A GROUP

There are two main types of group, 'open' and 'nominated'. Open groups are formed from open meetings which any patient may attend. Nominated groups are formed from representatives of other community groups and associations. The type of group chosen affects the manner in which it is formed: but in some cases it is the other way round—when an attempt to form an open group fails, a nominated group is formed. Much discussion has taken place about which type is more representative or effective. What matters is that the group should be formed, should survive, and should do effective work in developing patient care services.

Anyone thinking of starting a group in the United Kingdom would do well to write to the Central Information Service for General Medical Practice, or the National Association for Patient Participation, (*see* end of chapter for addresses). They will give the address of a 'link person' of a group which is either close geographically or has similar practice circumstances and philosophy. Their group may be visited, or their advice sought.

Open groups

There are five methods of starting an open group.

1. Postal questionnaire or circular. All adult patients or families in the practice may be asked for their suggestions about improving the way the practice runs, and be invited to an open meeting at which there will be a general discussion, and the election of a committee. This is an expensive method in terms of postage, stationery and labour, and may produce a disappointingly small response from contented—or apathetic—patients. It is, however, seen to be democratic, and it does inform all patients about the group.

It is perhaps easier to carry out a questionnaire survey once the group is going and in a position to help with addressing and delivering letters. The BMA Ethical Committee's advice should be heeded and leaflets cannot be left about in public places such as chemists and the village hall unless all the neighbouring general practitioners have agreed. It is quite a good idea to telephone them first.

2. Handouts to patients. Reception staff can hand out leaflets to all patients attending the surgery or health centre for any purpose, over a period of 1–2 months, with an invitation to attend a meeting. This is a cheaper and easier method, and is biased towards those receiving medical care. It can be very effective if the receptionists deal with it, and the leaflet is persuasively worded.

3. Start activities first. A popular method is to hold health education lectures for the whole community, which can be widely advertised on notice boards, and through local press and radio. Once established a committee of attenders can be elected to take over the running of the health education programme. From this committee, the patients of the practice concerned can be identified and asked to form the nucleus of a patient participation group. To this nucleus may be added nominees of groups of practice patients, for instance, attenders at child health, antenatal, hypertension or diabetic clinics.

4. Focus on one project. Sometimes chance plays a hand, with a group of patients coming forward suggesting that they raise money to buy equipment for the practice, or run a voluntary car service, or such-like. From this

beginning, a group of motivated patients can arise, which can then be encouraged to widen its aims to become a more representative group.

5. *Enlist the help of the Community Health Council (CHC).* A CHC (the statutory consumer body in the NHS) usually operates at district level on behalf of a population of about 250,000. In this population there are likely to be about 100 general practitioners, in 25–30 practices. The CHCs are usually interested in patient groups and can be very helpful. If a neighbouring practice is hostile to the starting of a group, the CHC can act as an intermediary. It can also get projects such as transport schemes going.

Nominated groups

There are two ways of starting such a group.

1. *Involve all known community agencies.* In some areas, people are reluctant to come to meetings, and get involved in yet another community agency. The nominated group may be the answer, and has worked well in very diverse circumstances—from rural to deprived inner city practices. Some people argue that it is less democratic and less open, but these objections are not insuperable. What counts is that the group should engage people's interest and use their knowledge and energy to help the service to function effectively. At this stage flexibility and variety must be the keynote.

To form a nominated group the first step is to discover all the organizations which exist in the community served by the practice. These may be community associations, older people's clubs, youth clubs, parish councils, women's institutes, townswomen's guilds, parochial church councils, political associations, young wives' groups, single parent groups, tenants' associations and so on. Health visitors, social and community workers, sub-postmasters, councillors and any other people active in the community can help to collect the names of the organizations and their secretaries. The next step is to write to them all setting out the aims of the patient group, and asking them to attend a meeting, or send a nominee. The meeting must be at least 2 months ahead, and a reminder can be sent 1 week beforehand. They can also be asked to suggest any organizations not yet known to the practice. It is helpful if the nominee can bring a friend (for company, help with transport, etc.). Both should be patients of the practice if possible, but the choice of nominee is left entirely to the nominating organization.

In this way, the patient group can tap a number of existing community networks, and so become known to a larger population than are likely to attend a patient group meeting. These linkages increase the information base of the group, and may increase the power base too. Research has shown that most group members attend as citizens rather than as patients, so it is natural that people who attend them will already be active in the community in some way, and research confirms this too. Personal experience is that the people

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- Wood J. and Metcalfe D. (1980). Professional attitudes to patient participation groups: an exploratory study. *Journal of the Royal College of General Practitioners* **30**, 538-41.

Further Reading

- The following articles describe the work of specific patient participation groups:
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