

## Professional attitudes to patient participation groups: an exploratory study

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**SUMMARY.** An exploratory study of the development of patient participation groups in general practice and general practitioners' attitudes towards them suggests that many general practitioners may not yet be aware of this innovation and may at first react negatively to the idea. This response stems in part from misconceptions about the origins and functions of these groups, a failure to see their relevance to professional objectives, and a fear that they will threaten general practitioners' autonomy and status. In contrast, general practitioners who have formed groups believe they have an important contribution to make to their developing role and have been encouraged by their experience so far. Therefore, at present, patient participation groups should neither be rejected out of hand, nor welcomed as a panacea.

### Introduction

**T**O be effective the primary health care team must respond and adapt to the constantly changing needs of the community it serves. However, social pressures to conform with one's professional neighbours, combined with deficiencies in training and present conditions of practice tend to prevent this happening. Conservative attitudes and a reluctance to modify established ways of working are, unfortunately, all too commonplace.

As a result, there is an ever present risk of a rift developing between the type of service provided by the primary health care team and the needs of the community. Some of the current concern about the state of

primary care in inner cities (Royal Commission on the NHS, 1979) and the growth of critical attitudes towards general practice (Cartwright and Anderson, 1979) may be viewed as symptoms of this danger. Such a situation cannot be in the interest of the community or professional health workers. Ways must be found to bridge the present gap and to avoid future gaps developing.

The experimental development of patient participation groups in general practice can be seen as an attempt to do just this: to devise new methods of communication and to create new working relationships within the practice. Since 1972 more than 20 general practitioners have formed such groups—two out of three of them in the last three years. In 1978 a National Association of Patient Participation Groups was formed to encourage the setting up of further groups and the exchange of ideas and information. The second annual conference of this association, held in Oxford in 1979, provided the stimulus for a small, exploratory study of the development of these groups and general practitioners' attitudes towards them.

Previously published information about patient participation groups in general practice was limited to reports of the activities of individual groups and discussions by doctors who had formed them (Paine, 1974; Pritchard, 1975, 1979; Wilson, 1977; Dakin and Milligan, 1980), two research studies which concentrated on the activities of four pioneering groups (Sand, 1978; Shaw, 1978) and press articles.

### Aims

The main aim of the study was to compare the attitudes of general practitioners in whose practices groups were operating with the attitudes of general practitioners who had no experience of them. The study was also designed to obtain background information about the origins of the groups, their aims and activities, and the general practitioners who had been involved.

## Method

Two samples of general practitioners were selected: one of general practitioners in whose practices groups were known to be operating and one of general practitioners who, according to available records, did not have any first-hand experience of them.

The first sample was selected from the 15 practices listed by the National Association of Patient Participation Groups (1980). In each of these groups, the intention was to interview either the general practitioner who had been most closely involved in the birth of the group or who was most involved in the group's activities at the time of the study. In the event, general practitioners from 10 of the listed practices took part in the study. In two of the other practices the appropriate general practitioner was unavailable during the two-week fieldwork period. In the other three practices, general practitioners were either not involved in the groups or unwilling to participate. In four of the practices where no general practitioner was interviewed, background information about the groups was collected from a layman who held a key position.

The sample of general practitioners who did not have any experience of groups was limited to general practitioners in the North-Western Region for cost reasons. It was also limited to trainers on the grounds that they would be more likely than their colleagues to be abreast of innovations in general practice. Fifteen trainers were randomly selected from the list of trainers in the region and, very encouragingly, all of them took part in the study.

Telephone interviews were conducted with all participating general practitioners by experienced social scientists on a number of wide-ranging topics. Not all the participants, however, discussed all of the topics. In view of the exploratory nature of the study and the varying age and experience of the groups, it was felt more important to elicit full statements of opinion on points which seemed significant to participants rather than keep to formal questions and answers. As a result, answers emerged with varying degrees of comprehensiveness and clarity.

All interviews were conducted in the spring of 1979 and tape-recorded for subsequent analysis. On average, each interview lasted an hour.

## Results

### *Group origins*

All the general practitioners in the study emphasized that the urge to form a patient participation group had come from inside rather than outside the practice team: the groups were a result of a professional initiative and not a response to any spontaneous demand from their patients.

The decision to form a group had often resulted from three distinct influences: the general practitioners' deep-

seated personal and professional beliefs, their attitudes towards groups, and local circumstances.

The beliefs which had led them to form groups were many and varied. They included: the belief that general practitioners should be accountable to their patients and a sense of guilt that they were not; the belief that, with the rise of the consumer movement, a professional initiative might pre-empt a less palatable alternative; the belief that if general practitioners are to play an effective preventive role, they will have to involve the public; and the belief that it is impossible to develop or manage a responsive and relevant health service without the participation of the public.

In responding to these beliefs and deciding to form groups in their practices, none of the general practitioners appeared to have considered seriously whether there were more effective or efficient ways of achieving their goals. The idea of forming a group seemed to appeal instantly to general practitioners who had had good experiences of training and self-help groups and who were already convinced that they were effective educational and problem-solving tools.

While their belief in the need to form a group in their practice had often developed over a considerable period of time, the decision to put belief into practice had often coincided with changes in the practice or a growing realization of problems in the community. Some general practitioners had started a group when they were considering introducing new preventive services and some when they were moving to a health centre or a new practice. Others had formed groups when they became aware of gaps in community services, the lack of play spaces in the area, and the 'Fort Knox image' of the practice created by a 'dragon receptionist'.

### *Group aims and activities*

Reflecting the varied reasons for starting groups and the different practice circumstances, the groups, individually and collectively, had a blurred, diversified role. However, an examination of the stated aims of all the groups suggested that collectively they were attempting to fulfil five major roles:

1. To act as a planning tool by providing the practice team with feedback about patients' needs, concerns, and interests.
2. To act as a safety-valve by dealing with patients' grumbles and complaints about the practice.
3. To act as a tool for health education.
4. To act as a support for the practice by organizing voluntary care in the community.
5. To act as the eyes and ears of the practice neighbourhood by feeding back information about their needs to other parts of the health service.

In pursuit of these aims, the groups had become involved in an extensive range of activities which varied enormously in number and type (Table 1).

**Table 1.** A selective list of group activities.

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Providing transport to the surgery/hospital
Collecting prescriptions
Crèche for surgery
Waiting room exhibition of old photographs
Assistance with a tetanus prophylaxis campaign
Modifying the appointments system
Campaigning for improved health centre facilities
Groups for alcoholics
Slimming clubs
Coffee mornings for young mothers
Lunch clubs for the elderly
Social clubs for the mentally ill
Christmas carol service
English classes for immigrants
An area caretaker
Street wardens
Practice open days/social evenings
Monthly newsletter
Children's party
Children's painting competition
Pre-retirement classes
Making health education films
Keep-fit classes
Jogging groups
Survey of the needs of the elderly
Submitting evidence to the Royal Commission on the NHS
Local radio broadcasts
Designing health games
Organizing petitions for improved health services
A booklet on 'Hints on Keeping Well'

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### *General practitioners' attitudes*

The general practitioners who had formed patient participation groups did not conform to any stereotype in terms of their personal or background characteristics. Beneath their superficial background differences, they seemed to share very similar ideas about health and attitudes to general practice.

On the whole, they adhered to the view that there was more to health than the absence of illness, disability, and stress, and more to general practice than ameliorating these conditions. They were aware of the importance of social and economic influences on health and conscious of the limitations of modern medicine. They therefore placed a strong emphasis on prevention, on 'demystifying medicine', and on increasing the public's understanding of health.

Closely related to this view of health was the belief that general practitioners should act as counsellors or educators as well as technical experts. Far from being disillusioned about general practice, these general practitioners were convinced that it was possible for them to practise high quality medicine and gave every impression of gaining much satisfaction from their work. Typically, they saw their patients as capable friends.

The idea of patient participation slotted naturally into this framework of belief. It is therefore possible that other general practitioners with similar views may find the idea of patient participation groups appealing.

### *General practitioners' views on groups*

These general practitioners claimed that their experience of patient participation groups had not dramatically changed their beliefs about their potential value. On the contrary, their limited experience had confirmed their feeling that such groups could help increase their understanding of their patients, make the practice more responsive to patients' needs, and enable them to do things they would not otherwise have been able to do. Some had also noted that far from unleashing a flood of complaints, the number of grumbles had diminished as the groups developed.

At the time of the study, nearly all the general practitioners interviewed seemed satisfied that their groups were working reasonably or very well, allowing for their tender age. This is not to say, however, that they had not encountered difficulties. Quite a number had found it difficult to inform patients about the formation of the groups, to ensure that different categories of patients were represented, to deal with complaints diplomatically, and to cope with changes in group membership. Some had also been disappointed by the small numbers who were prepared to take an active part and others had become frustrated by, or resigned to, the slow pace at which the groups evolved.

Despite these setbacks, these general practitioners remained convinced that patient participation groups were a help rather than a hindrance in their work and were no threat to their autonomy or status. None were thinking of winding them up.

### *Trainers' views on groups*

The development of patient participation groups was not common knowledge among the trainers interviewed. Ten out of 15 trainers had never heard of them and those who had had no clear idea of what they were or did. Some initially confused them with self-help, therapy, and health education groups, such as the British Diabetic Association and the Epilepsy Association.

Confronted by this low level of awareness, the interviewers went on to explore the trainers' off-the-cuff reactions to the development of such groups. On the whole, their first reactions were negative. They wrongly imagined that the initiative had come from patients or patient bodies such as community health councils, or that groups had emerged in response to patient dissatisfaction. Many also guessed that such groups would probably have developed in large health centres in inner city areas where they imagined doctor/patient relationships were poor. Inconsistently, some of these trainers felt that such groups would operate only in practices with super-human, energetic doctors with Balint-training and more 'patience for patients' than they had themselves. Only such doctors, they felt, would be able and willing to take on the challenge such groups would present. As a result of these beliefs, many were quick to jump to the conclusion that such groups would rep-

resent yet another form of 'interference' and would inevitably lead to further lay invasion of their professional decision-making territory, further loss of autonomy, and conflict.

While the idea of patient participation had very little immediate appeal to these trainers, nearly all agreed that patients had a right to participate and have a say in practice decisions. Exactly what they meant by this, however, remained unclear. The two trainers who were against the idea of patient participation in principle were nearing retirement.

With the exception of these two trainers, all the trainers recognized, on reflection, that both they and their patients could benefit in some way from this innovation. Such groups could provide a means of increasing their patients' understanding of their workload and the difficulties of providing care, and this in turn would help improve doctor/patient communication. Many trainers also realized that such groups could provide an additional source of feedback from patients about practice organization. Few, however, were convinced of the need for this, as they were satisfied with the feedback they already obtained from individual patients. From their patients' point of view, many trainers felt these groups could provide a useful channel for trivial complaints and for health education.

While nearly all trainers appreciated that both they and their patients could benefit from patient participant groups, most were put off by the prospect of actually developing one. They were particularly daunted by the hostility that such groups might evoke from other doctors and ancillary workers and their own lack of the necessary social skills. Many were also doubtful whether patients in general would be interested. Some suspected that only atypical patients, such as 'That's Life' freaks', 'moaners', 'hypochondriacs', 'committee types', and 'bored housewives' would be attracted to join. Lack of time, money, and suitable premises were advanced as further disincentives to forming a group.

Asked as a summing up whether or not the idea of a patient participation group could be of any interest in their practice, 10 of the 15 trainers replied that they thought it very unlikely at present. Moreover, only two of the five trainers who thought the idea could be of interest were sufficiently keen to request further information or to volunteer 'to give it a go'.

## Conclusions

The findings of this study indicate that general practitioners who have formed patient participation groups are likely to regard this innovation in a very different way from many of their colleagues. Those who have formed such groups on their own initiative do not feel threatened by them and have found them a help rather than a hindrance. They are confident that they can work and make an important contribution to general practice. So far, groups have tried to play a variety of roles and

have been involved in an extensive range of activities.

General practitioners with little knowledge of patient participation groups are likely to harbour mistaken ideas about their origins and functions and to dismiss them as irrelevant and unnecessary in their practice. They are also likely to be sceptical that such groups can work and to fear that they will lead to further loss of their autonomy and status.

The idea of patient participation in general practice is therefore an emotive one which holds both great promise and great risk for general practitioners. As the first attempts are made to put this complex idea into practice, it seems necessary to guard against rejecting them out of hand or welcoming them as a panacea. Further experiment, accompanied by non-partisan observation of their operation, is needed before any real assessment can be made of exactly what these groups can and cannot achieve.

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## Review body for doctors, dentists and pharmacists?

In a written Commons reply on April 17, Dr Gerard Vaughan (Minister for Health) said: "Discussions are still continuing about the possibility of establishing a review body procedure for retail pharmacists. I am not yet in a position to say when a decision will be announced."

## Reference

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