Patient Participation

Survey of patient participation groups in the United Kingdom

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It is over 10 years since Dr Peter Pritchard started the first successful patient participation group at Berinsfield. Since then patient participation has emerged as a new dimension in health care, and the time is now ripe for a review of what has been achieved so far. Before reporting the results of a survey of patient participation groups, however, it is important to set the scene.

The essence of patient participation is that the receivers (potential or actual) and providers of health care work together in a spirit of mutual understanding to improve all aspects of the health care "system" in its broadest sense, particularly at the community level. This approach is obviously in radical contradistinction to the traditional health care model. Firstly, it challenges the adequacy—and appropriateness—of a profession always assuming that it knows what is best for the community it serves. Secondly, it recognises the very positive contribution that can and should be made to a community's health care by all those who live in it.

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This basic change of approach may easily be dismissed by those who wish to do so as an undesirable and unnecessary aberration, conjured up in the minds of "Hampstead trendies" who are anxious to jump on the bandwagon of consumerism. The survey which follows will, I hope, prove otherwise. Patient participation is in fact very much in the highly respectable tradition of "whole person medicine," the basic beliefs of which are that it is important to recognise and respect the patient as a thinking, feeling, and unique person, who needs to be listened to and encouraged to decide things for himself or herself. Patient participation is, quite simply, counselling writ large.

Patients liaison group

It is easy for those who are involved to wax lyrical about the value and achievements of patient participation. What has occurred over these past 10 years, however, is not inconsiderable, and points the way to a new and fruitful relationship between receivers and providers of health care. The recent initiative of the Royal College of General Practitioners in setting up a patients liaison group, in which lay members will make up at least half, to act as a "think tank" for the college is a most promising development. The lay contribution to many aspects of health care—for instance, all aspects of patient care, health education, practice organisation, and medical education—will be explored. The patients liaison group will report to the college council, which, it is hoped, will listen attentively and act positively. It will require a mammoth effort of broad mindedness, perspicacity, and humility on the part of the council, but if we are patient I believe that they will come up trumps. The college recognises, however, that patient participation is most realistic and most relevant at a local level, and its faculties are being encouraged to take up the challenge to experiment in their own areas. The college could play a vital part in coordinating and evaluating such exercises.

Patient participation groups will, of course, remain the "sharp end" of patient involvement, as it is at the level of the practice that the lay public interact most with the health care system. (This has always been a problem for community health councils, whose members are one vital step removed from the scene of the action.) Patient groups will be looked to more and more as a vital source of information for both the college's new patients' group and the faculties, and the National Association for Patient Participation should be able to act as an intermediary, along with other patient organisations.

So far only one university department of general practice has started a patient participation group. Let us hope that the college's initiative will encourage more to follow suit and to explore the educational potential of patient participation at all levels. Curtis[1] described the contribution of patient feedback in vocational training—again, a worth while new dimension for course organisers, trainers, and trainees to consider.

Survey

I circulated a questionnaire last year to the 37 groups known to be operating at the end of 1981. Replies were received from 36 (97%). Information was sought concerning each group's history, the practice, how the group works, its activities, its funding, particular problems, and achievements. A guarantee of confidentiality was given, so that in the description that follows individual groups are not identified unless the information is already common knowledge.

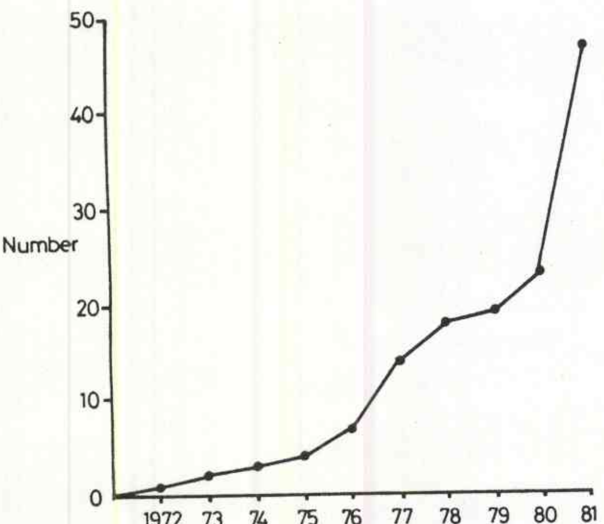

FIG 1—Total number of patient participation groups established in the United Kingdom 1972-81. Some no longer exist.

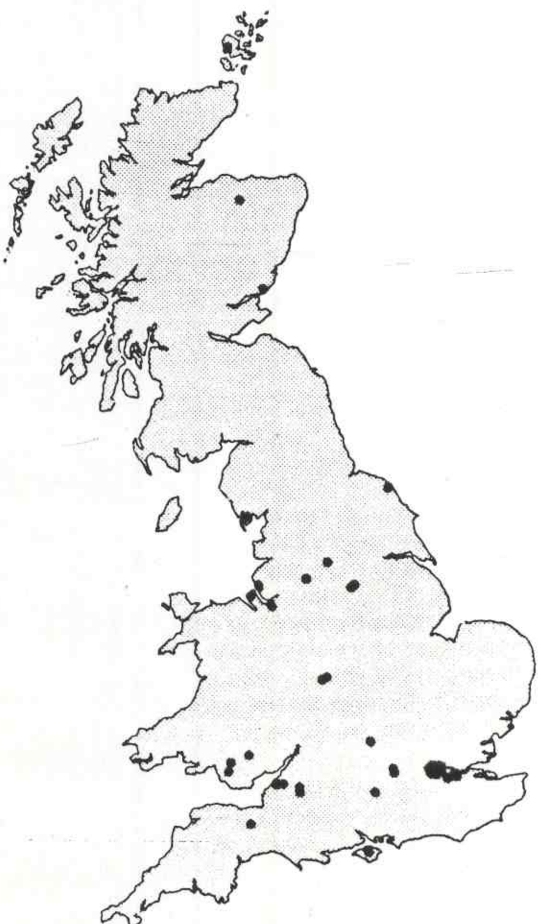

FIG 2—Location of 38 patient participation groups at the end of 1981.

HISTORY

The rate at which groups have started up is increasing.

Rate at which groups have started up

Year	No	Practice
1972	1	Berinsfield, Oxford
1973	1	Aberdare, S Wales
1974	1	Bristol
1975	2	Glyncorrwg, S Wales; Taunton
1976	3	Isle of Wight; Limes Grove, London; West Kirby, Wirral
1977	2	Gallion's Reach, Thamesmead; Kentish Town, London
1978	4	Birley Moor, Sheffield; Buchanan Road, Sheffield; Egton, N Yorks; Lee Bank, Birmingham
1979	3	Basingstoke; Birchfield, Birmingham; Princes Park, Liverpool
1980	6	Darbishire House, Manchester; Kilburn, London; Royal Crescent, Bath; Runcorn, Cheshire; Stromness, Orkney; Walthamstow, London
1981	13	Abergwynfi, S Wales; Carnoustie, Angus; Craven Park, London; Dartford, Kent; Fairfield Park, Bath; Highfield, Cumbria; Keith, Aberdeenshire; Kings Cliffe, Peterborough; Lakeside, Thamesmead; Maghull, Merseyside; Pill, Avon; Todmorden, Lancs; Woodley, Reading

Five or six other groups that operated for a while but have since ceased to do so were not included in this study, though it would be of great interest to know why they were not able to survive.

In most groups (75%) the idea came from one of the doctors. Patients have been the instigators of only three, and the remaining six were suggested by the practice manager or administrator 2; an attached social worker 1; a member of a community health council 1; "doctors and patients simultaneously" 1; and a doctor, minister, and social worker together 1.

PRACTICE

All but three of the 36 groups are associated with group practices of two to 10 partners, and all but 10 are based in health centres. Fourteen of the practices are in urban residential areas, 10 in industrial, nine in "town and country," and three are completely rural. Nineteen of the practices cater for a very largely working class population and three for a predominantly middle class one. The remaining 14 are described as "mixed."

HOW PATIENT PARTICIPATION GROUPS WORK

There is, fortunately, no "standard pattern" of how a patient participation group works. This makes it difficult, however, to describe and classify them.

Membership—One criterion that distinguishes groups is the position of patients of the practice in relation to the group that is supposed to be representing their interests. The commonest is the group that is, in effect, an association to which all patients of the practice or health centre automatically belong. The committee of such a group is simply the executive body within the group. A few groups *are* the committees, which usually aim at representing the interests of the whole practice (patients $\pm$ staff), health centre, or, in the case of one Scottish group, the local community. Patients in these practices do not automatically belong to the group but are usually encouraged to attend and participate in its activities. (To confuse matters, a "patients' committee" may belong to either of the above categories. The titles adopted by different groups are given in the 1982 directory, available from Mrs Joan Mant, Hazelbank, Peaslake, Guildford, Surrey GU5 9RJ.)

I have no evidence whether or not "belonging" to the group makes any difference to the interest patients take in its affairs. Theoretically it might help to increase patients' identification with their group's aims and activities if they feel that they are members of it.

Representation—Over 70% of the groups pride themselves on being "democratic." The committee and officers, if such exist, are elected annually by the patients. What in fact happens is that the patients who attend the annual general meeting—from 0·1 to 2·0% of the practice list—formally vote in the new committee. I have not heard of the need for a poll at any of these. Far from there being competition among candidates, it is often hard to find patients who are willing to join the committee or hold office.

In contrast to the elected committee is that composed of representatives who have been invited to help to run the group. Eight groups operate in this fashion, and those on their committees (or equivalent) have been asked to represent health centre or surgery users, local organisations (Women's Royal Voluntary Service, Women's Institute, St John Ambulance, etc), different communities served by the practice, or practice staff members, or all of these. There seems to be no evidence that the "democratic" system works any better than its counterpart, or vice versa. Six groups prefer to dispense with a formal committee altogether, though they usually have a convenor and secretary. One such group, when asked whether there was a committee, replied "No in principle; yes in practice."

Of the 30 groups with committees, all but three invariably have a patient in the chair. In those three one has a doctor and in the other two the office rotates between patients and staff—"whoever seems the best person for the job." Doctors oversee the executive activities of two of the groups without committee. Committee size varies from four to 25, and seems to bear no relation to practice size. Committees tend to meet monthly, though three meet every other month, four quarterly, and one meets three times a year.

The time commitment of secretaries, chairmen, and ordinary committee members varies enormously—from half an hour to 15 hours a month. The doctors concerned give between nil and six hours a month, though this may be more in the initial stages. In some groups—generally of the "democratic" kind—doctors are not invited to attend committee meetings. One such group is rethinking this policy after three years because "we are now feeling that perhaps we haven't connected very well with the staff and doctors on substantial issues about practice and health policy."

ACTIVITIES

Groups vary greatly in the extent of their activities and the relative priority they give to each. One group covers all seven categories, one group covers six, eight groups cover five, 11 groups cover four, eight groups cover three, four groups cover two, and three groups cover only one. The number of activities bears only a slight relation to the age of the group.

Activity	*No of groups*
Voice and interaction	32
Health education	30
Community and practice support	24
Special interest and self help groups	17
Fact finding	11
Providing information	17
Fund raising	9

Voice and interaction

For most groups this is the essence of patient participation—the direct communication between patients and their doctors outside the consulting room, a mutual listening process. Of the 36 groups surveyed, 29 provide specific opportunities for patients to express their thoughts and feelings about the service

offered and to make suggestions as to how things might be improved. Such contributions appear to be welcomed by most doctors concerned with patient participation groups, though four groups feel that insufficient notice is taken of patients' opinions or requests.

There is a degree of frustration in almost half the groups at the reluctance of patients to come forward with their comments or suggestions. "They are too content!" was how one respondent put it. Two groups operate a "sit in" service in the waiting room; committee members take it in turn to chat and discuss the service provided with patients waiting to see their doctor. Despite this, however, constructive comments or criticism were seldom forthcoming.

The results of patients having a say in the running of their practices include the appointment of women partners; changes in surgery hours; changes in telephone answering machine messages; improvements in waiting areas; improvements in the call-in system; better health centre facilities for disabled patients; interpreters for foreign patients. Several groups have lobbied successfully for improvements in local health and community services, directing their requests to departments and organisations outside the practices. Such action has resulted in an improved chiropody service; the prevention of a planned cut back in the local ambulance service; speeding up plans for a health centre; better parking facilities at the health centre; improvements in visiting arrangements in the children's ward of the local hospital.

Over 85% of patient participation groups provide opportunities for patients to discuss health and other relevant matters with their doctors and practice teams. Emphasis was placed on how such interaction helps to break down the traditional barriers. Twelve groups have regular "brains trusts," or the like, at which the doctors are quizzed on matters relating to health, the practice, and the National Health Service by patients who attend.

Twenty groups have set up systems to handle grievances informally. These vary from contacting a person or giving a number to telephone to a form to fill in, which is designed to ensure strict confidentiality. An example of the last is the "speak up" system devised by the Isle of Wight group. Several groups have difficulties in getting patients to complain at all; but it is interesting that five of these apparently lack a system designed to make it easier for patients to voice their feelings. That grumbles are common among patients is well known, even in the best run practices; few of these misgivings ever see the light of day, however, either because patients do not consider them

serious enough to "make a fuss about" or because they fear repercussions.

There is a smattering of evidence from this survey that the patients of those practices with complaints systems that are designed to be sensitive, discreet, and confidential, thus preventing "exposure," are more willing to express their grievances. Only three groups reported difficulty in handling grievances. Details were not forthcoming, but it seems that one group feels that "the practice tends to see (grievances) as minor."

Health education

A patient participation group provides an extremely convenient forum for health education. Not surprisingly, therefore, all but seven groups put on programmes of regular meetings, discussions, and debates covering a wide range of topics. The most popular seem to be those about cancer, women's ailments, prevention of heart disease, when to call the doctor, where to have a baby, and alternative medicine. In most cases a local consultant is invited to give a talk or participate in a discussion or debate. The groups' own doctors also take an active part in many of these meetings.

Attendance at these sessions is seen as a problem, however, by 70% of groups. Often it is only a tiny minority of the patients on the practice list who put in an appearance, and this usually includes a steady band of regulars. This probably reflects the enthusiasm shown by the general public as a whole for evening meetings of any kind. It has been shown that a much better turnout may be achieved if personal invitations are sent to patients from their doctors to come to health education sessions of particular relevance to them. Such an approach by the Bristol group resulted in attendance rates of over 20% of men aged 35 to 55 to talks on the prevention of heart disease and of over 23% of women (same ages) to talks on breast and cervical cancer. Sending such invitations was obviously more laborious, and money had to be found to pay the postage (see "funding" below). The response and feedback was so enthusiastic, however, that more sessions were planned.

Several years ago the Aberdare group obtained funding from the area health authority to make videotapes of some of its health education talks. It was realised that a large proportion of the practice was not interested in attending meetings nor in reading reports of them in the local press. The answer, therefore, was to take the films to the patients, and several showings in various venues have taken place. One or two groups have put

on first aid classes, and the West Kirby group is proud of the classes it has started in cardiopulmonary resuscitation, which now train about 30 people a week. The Birchfield group has produced two superbly illustrated booklets on "Health in the over 60s" (which won an award from a local charity in this field) and on the prevention of home accidents. Booklets or pamphlets provided by two other groups contain a variety of medical information for patients; another two groups are arranging medical book lending services for their patients. Three groups organise health centre open days, which allows patients to see a bit of what goes on behind the counter.

Community and practice support

This comes under two headings: the use of patients as volunteers and social activities.

Volunteers—Twelve groups operate community care services of varying complexity to meet some of the needs of fellow patients in difficulties. Fetching prescriptions, evening and night sitting, and transport are among the commonest tasks. Crèche facilities at surgeries and clinics and even clinic helpers are provided by some groups. One practice runs a weekly lunch club for its elderly patients who live alone; another has an enthusiastic circle of volunteers who knit for newborn babies and send flowers to those in hospital and hampers and presents to a few patients at Christmas. Yet another has found patients to act as interpreters. Voluntary work of this sort appeals to many patients. One respondent said it was her way of saying "thank you" to the practice for the help she had received herself. Nevertheless, half the groups that run volunteer schemes have difficulty at times in recruiting, though only three reported that too much demand is made on their volunteers. All the schemes are coordinated by patients, and in only one group was this job reckoned to be arduous. (Practice based community care schemes are not the invention of groups. Several have been operating successfully for years, set up in practices by doctors who realised their potential but who have not joined the patient participation "movement.") One Scottish group is unique in having community care as its only interest and activity. It hopes to coordinate all the local helping organisations, both statutory and voluntary, acting as a bridge between them.

Social activities—A selection of these are organised by 12 groups—coffee mornings, outings, wine and cheese evenings, etc—and many are linked with fund raising. Some, however, are intended to help solely in breaking down barriers and

towards building up community spirit and friendship among those whose lives lack these.

Special interest and self help groups

Sixteen groups have arranged a selection of group activities that appeal to certain patients—to help them slim, keep fit, give up smoking (the three most popular), cope with their condition (diabetes, old age, stroke, hypertension, back pain, alcoholism, bereavement, depression, hay fever, and cystitis have all been catered for), cope with their young children, or learn yoga. The popularity of such groups varies, and sometimes they fizzle out. I do not know how effective these groups are.

Fact finding

At least four groups have produced and circulated questionnaires, designed either to find out what patients think of the practice system, particularly appointments, or what their opinions are about their doctors' approach to looking after them. The responses from two such inquiries led to improvements in the appointments system and the system for requesting home visits, and to a realisation by the doctors that their patients would appreciate more information about what was wrong with them and their treatment than had been forthcoming during consultations.

Ten groups have carried out surveys into practice or health centre facilities and facilities in the practice area either to identify deficiencies or to produce guidebooks. Suggestion boxes have generally been disappointing and highly inefficient for collecting useful information. One group has examined the practice accounts "in order to make recommendations."

Providing information

Various publications are provided by several groups. Health education material has already been mentioned. West Kirby, Kentish Town, Walthamstow, Dartford, and Keith groups have all produced guides to their practices or health centres. Limes Grove, Birchfield, Fairfield Park, and Todmorden produce magazines or newsletters. The Bristol group has put together detailed handbooks on local accommodation for the elderly and on local day facilities and concessions, both of which are sold for 50p to patients and the general public. Several groups pin

the minutes of their committee meetings, and also those of the local community health council, on the practice notice board. Information about patients' rights is also displayed. The Isle of Wight and Bristol groups have annual "fixture cards" that list all meetings and give information about the groups and the services they offer.

Fund raising

Six groups have been successful in raising money to buy medical equipment; one group alone has bought peak flow meters (for asthmatic patients), home blood pressure kits, an enuresis (bed wetting) alarm, and a physiotherapy ultrasonic machine costing £500. Other groups have bought toys, plants, and pictures for the waiting room.

Survey

FUNDING

Funding is an important—and for 44% of groups a daunting—aspect of running a patient participation group. Annual budgets seem to range between £50 and £150, though four groups spent well over this in 1981, one over £850. Large spending of this sort is usually accounted for by special projects, such as publishing booklets. With few exceptions groups attempt to raise as much as they can from the patients by arranging social functions, raffles, sponsored activities, and so on. One group does very well each year from a cake and biscuit stall at the local May Day fair. Roughly half the groups are helped out financially by their doctors, who donate between a quarter to a half of the budget. Sometimes this is only as a "starter"; more often it is a regular contribution. Financial help is frequently sought from outside organisations, either statutory or otherwise, usually for help with particular projects. Because this is an area of considerable practical interest to many groups, it will be dealt with in some detail.

Before their demise area health authorities made money available to three groups: £10 for leaflets, Berinsfield; £300 for making health education films, Aberdare; £700 to produce and publish a "centre users" guide, Kentish Town. One district management team allocated £10 to help a group to start operating, and a local social services department in London provided £50 for the same purpose. Local charities, firms, and other organis-

ations have also helped: a total of £250 was granted over two years by three local charities to enable the Bristol group to publish their booklets; £270 was contributed by local charities to support the work of one community care group; £25 and £40 have been received by two other groups from local firms and organisations. £300 was given by the King's Fund in London to finance the Bristol group's 1981 health education programme, their application to the local area health authority having been turned down. Several groups have received fees from press, radio, and television. Drug companies are understood to have made small contributions to some budgets.

PROBLEMS

A list of the problems that groups commonly have (from my experience) was included in the questionnaire. Groups were asked to indicate those which applied to them and to mention others that they had found particularly difficult. Of the several that have already been mentioned, getting patients to participate is by far the commonest. Only one group denied any problem whatever in this area.

Failure to attract a reasonable number of patients to meetings bothers most groups. Apart from the general apathy shown by most patients, the two biggest difficulties appear to be the cost of communicating effectively with all the patients and the lack of freedom to publicise the group's activities. Effective publicity costs money in design, printing, or postage; it also encroaches on professional ethics. Any attempt to advertise meetings or other group activities outside the walls of the practice premises, it is feared, will bring down the wrath of local practitioners, the BMA, and even the General Medical Council on the heads of the doctors concerned. The position has, in fact, been clarified to a degree by the central ethical committee of the BMA, who have agreed that to advertise bona fide health education meetings in public places cannot be construed as being other than in the public's interest. Matters of domestic importance to the practice only are to be kept for patients' eyes and ears only, however.

Five groups reported adverse reactions to their publicising activities, and two of these had studiously avoided advertising any activities outside the practice. On the other hand, 17 groups regularly put up posters in chemist shops, libraries, and other suitable public places, and some even have their activities regularly reported on the radio without apparently incurring anybody's wrath.

Groups are fairly content about the degree of involvement of

the doctors in group affairs, but less so about practice staff: 38% of groups obviously have great difficulty in getting staff to take any interest or play any part in their activities, though open hostility was not reported. One group tried to win over its staff by inviting them to judge a children's painting competition, meeting and chatting with them beforehand armed with glasses of sherry. The ploy worked quite well.

A few other difficulties were mentioned on the questionnaires:

"When new doctors come into the practice we have to start from the beginning to educate them in patient participation."

"The (committee) tend to represent an articulate, radical, middle class minority and so cannot have the authority and power which would accrue if they were truly representative of the whole body of patients."

". . . but now support from patients is negligible and support comes from a handful of patients mostly advanced in years, and some have physical disability to a lesser or greater degree."

"Finding times when a 'cross-section' of people can meet together. Pensioners prefer daylight hours; young people prefer evenings."

"Red tape—problems associated with operating an NHS health centre—consultation with administrator and staff committee invariably produces objections to most suggestions put forward."

"Diversity—far from apathy, we find that there are several strong areas of interest on the committee, resulting in only partial support for any one project. Thus it is difficult to get adequate commitment to make a project work."

"We have one committee member who is very critical and very persistent, getting us a bad name with the staff and making it difficult to work as a team."

"The ethics which prevent doctors from giving names and addresses is a great handicap (to effective communication)."

ACHIEVEMENTS

People often ask "What has actually been achieved having patient participation in your practice?" Groups were asked how they would respond to this question. Their replies fell into four broad categories: services provided or initiated by the group; contributions made to health care; contributions made to the practice organisation; improvements in the relationship and mutual understanding between the patients and the practice.

Services

These ranged from providing equipment, for example, through various activities such as self help groups, lunch clubs, and socials, to services such as transport, community care, pamphlets and guides, and crèches.

"An evening of music and poetry and a sponsored marathon runner (a patient) raised £540, and already a glucometer and audiometer have been purchased and put to good use."

"Crèche-minding at well baby clinics is now considered by the doctors to be an essential part of the surgery set up."

"Bringing the patients together enabling them to help one another."

"Citizens' advice service—very successful—on a voluntary basis."

"The constant care group (sitting service) is a considerable achievement."

"Collecting useful information about facilities in the locality for elderly, disabled, etc."

Health care

Several groups are proud of their health education programmes and booklets and the way they have been able to share in the effort to promote preventive care. The West Kirby sessions in cardiopulmonary resuscitation have already been mentioned. (It has been shown conclusively in the United States that training a large proportion of the general public to be capable of reviving those who have collapsed with heart attacks has a greater impact on mortality than the provision of intensive care units and is a great deal less costly.) A group in the north of England had arranged for one of their doctors to talk on health topics at the local school. The successful outcome of lobbying for chiropody and ambulance improvements by a group in South Wales has been mentioned.

Practice organisation

The most impressive array of achievements is in practice organisation.

"We were instrumental in getting the first lady doctor partner here; we now have three."

"More cheerful waiting room and toys being allowed. Improved notices and a clearer recorded message for phone." (This from a patient initiated group.)

"Often quite simple things—for example, patients can't hear reception call their names because of poor acoustics, so we lobbied for a tannoy."

"Initially, when community was small, group was able to give support to doctor in obtaining suitable accommodation to provide an effective service to an ever growing community."

"Patients complaining are invited to 'sit in' with receptionists to see the other side of the coin. (One patient said that after three hours of this he now knew how Custer must have felt.)"

"The management group does influence the workers' group, and has been instrumental in formulating policy for the practice —for example, how new workers are appointed. It is controlled by patients."

"We have provided, and will continue to provide, accommodation for medical students who are attached to the practice for study."

"Sharing problems concerning the structure of the health centre and appointment system and changing the time of drug collections."

"Enabling patients to make better use of the health centre— going to a different doctor, when to ring up, etc."

Perhaps the most impressive achievement of all was the way in which one group set about mending what seemed to be an irreparable rift among the partners. A meeting was requested by the group to which all the doctors came. Confidence was expressed by the group in each of the doctors, whose different personalities and approaches were considered entirely complementary. They were all asked to resolve their dispute in the interests of the practice, and this they did.

Mutual understanding

Many groups believe that setting up their group has led to definite improvements in mutual understanding and rapport between patients and practices.

"Being able to communicate with the doctors."

"The informal atmosphere at meetings enables patients to voice fears, concerns, etc. Doctor/patient barriers are beginning to be broken down."

"Helping staff and doctors to become a bit more aware of patients' attitudes to the health centre and its services."

"Slowly establishing idea of other uses for health centre than purely medical activities."

"Agreement by doctors that a group can start and to sending some sort of questionnaire."

"Attending the children's clinic is becoming a social event. The health centre is becoming part of the community."

"We are already aware of the changing attitudes of many of our patients—they are talking more freely and asking questions about themselves." (This from a doctor with an eight month old group.)

"People spoken to do seem to be highly delighted that somebody is taking an interest in their opinions and desires outside the privacy of the consulting room."

"I'm sure the group helped our first trainee to be accepted."

"It is perhaps an achievement that we as a group are beginning to argue strongly against fairly set views—for example, on the need for a crèche, more privacy when speaking to the receptionists, and not accepting that change is not required, is difficult, receptionists can't cope, health board won't approve, etc."

"The committee sees its significant achievement as creating a forum in which a new and genuine dialogue is taking place between practice staff and patients."

"(The realisation that) a small group of patients can influence doctors and staff to the benefit of the practice as a whole."

I am indebted to all the people who took time to complete the questionnaire, often at considerable length and in considerable detail. I would be glad to hear of new groups and in due course learn how they are faring.

Information on setting up and running a patient participation group may be obtained from Mrs Joan Mant, chairwoman of the National Association for Patient Participation, Hazelbank, Peaslake, Guildford, Surrey GU5 9RJ; tel 0306-730405.

Reference

[1] Curtis P, *et al.* Patient participation in a medical education environment. *J Fam Practice* 1981;**13**:247-53.

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