What the patient wants from patient participation

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SUMMARY. In a general practice with an existing patient participation group, a survey of patients was undertaken to ascertain knowledge of and interest in the group. It was hoped that this might avoid the failure that had befallen other groups of this type. Analysis of the questionnaire provided useful information: there was interest in the group, with a potential attendance of almost three-quarters of the respondents. There was a clear lack of knowledge about the functions of the group, but the evidence was that if the desired activities were to be arranged and publicized they would be well attended.

Introduction

THE first successful patient participation group was formed in 1972 in Berinsfield, Oxford,[1] with the general objective of allowing the views of patients to be heard directly by general practitioners so that objectives and priorities for the practice can be identified. A survey published in 1982[2] reported 37 active patient participation groups, and there are now more than 60. As more groups have formed, an increasing proportion have floundered — some in their first year and some after three or more successful years. A failure rate of 25 per cent for such groups has been reported;[3] while there may be no common problem, it suggests a need for a market research exercise. One purpose of the present study is to determine what patients want and expect from such groups.

The Collingham Health Centre Users Group was formed early in 1982 with many of the aims and activities described by other groups.[2,4] It is organized by a chairperson and committee, and membership is open to all patients. Possible enhancements to the services already provided by the health centre staff included patient involvement in planning health services; transport facilities for patients; delivery of prescribed drugs and talks on health-related topics. Within a year these and many other functions were being undertaken by the group.

Some of the services were clearly successful, others less so. The crèche provided every Tuesday afternoon by a team of volunteers was infrequently used, whereas the screening clinics initiated by the group and organized with the assistance of the practice computer were invariably fully booked. The attendance at meetings, talks and discussions was apparently declining. Many groups have found that some topics attract larger numbers than others. The Aberdare group have reported attendances varying from over 100 people for a talk on 'Bleeding in women' to only eight for a talk on 'Medicine in the USA'.[5]

It was hoped that the survey described in this paper would help our own group to develop in the right direction, protecting it from failure owing to the provision of unwanted and unused facilities. By confirming the need for and interest in the group, enthusiasm could be regenerated among organizers, and fresh aims could be identified. Ideas for new groups to pursue may be identified in advance by the administration of a questionnaire to the potential members.

Method

A questionnaire on patient participation was designed to be administered to patients of the Collingham practice. The aims of the questionnaire were to:

1. Assess the general state of awareness of the Collingham Health Centre Users Group and its function;
2. Ascertain attitudes towards patient participation;
3. Inform those completing the questionnaire about the existence of the group and stimulate interest in its functions;
4. Provide feedback on the value of functions already carried out or planned for the future;
5. Assess potential interest and attendance if the group could develop in the required directions.

A pilot questionnaire was designed in sections with these aims in mind and was administered to patients in the practice waiting area. Initially, patients were asked to

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hand in the forms to the investigator, who asked what problems they had found in completing the questionnaire. Using a word processor, questions could be clarified and rephrased almost instantaneously, and the stocks of questionnaires were continuously updated and improved. When the questionnaire was thought to be as efficient as possible, the final version was printed and, after a two-week interval, was administered in the same way to all willing patients in the waiting room during selected surgeries and clinics.

This method of distributing a questionnaire yielded a large sample quickly and cheaply, but there were some problems — the principle one being that patients who were called to the doctor while completing their questionnaire naturally abandoned this task, leaving half-finished forms in the collection tray.

It was noticed that administering the questionnaires in the waiting room created an unusually relaxed and social atmosphere — diverting patients from their usual preoccupations. The sample became heavily weighted with high attendance groups, despite attempts to even things out in the later stages of data collection. It was particularly hard to find young males or people who had attended meetings of the group. All questionnaire responses were anonymous.

Results

The final questionnaire was developed after 60 patients had completed and commented on earlier drafts. The final version was completed by 154 patients: 14 of the questionnaires were too incomplete for inclusion; other questionnaires were only partially completed, such that the final analyses involved sample sizes varying from 128 to 140.

Figure 1 shows the questions and the answers from respondents. Since patients were not randomly selected, it was thought inappropriate to carry out a detailed statistical analysis; the results are therefore a simple description of the overall responses.

Potential attendance at meetings was encouraging. Only 40 patients were certain that they would not attend a future meeting. However, the questionnaire design was such that two further questions were avoided by answering 'maybe' instead of 'no', so these figures could be over-optimistic. One possible attender requested that meetings be occasionally held during the afternoon, rather than always in the evening.

As expected, attendance at meetings substantially increased awareness of the group's functions, but even regular attenders were unaware that the group carries out nine of the functions listed and is considering another two. Only marriage guidance counselling has not been carried

Question 1

Sex		*Age*	
Male	63	Under 20 years	9
Female	89	20–39 years	50
No response	2	40–59 years	44
		60 years or over	37

Question 2

Have you previously heard of the Collingham Health Centre Users Group?

Yes	67
No	73

Question 3

a) *How many of the group's meetings, functions, etc, have you attended?*

All/Most/A few/One	9
None	131

b) *About how many times do you come to the health centre each year for treatment?*

0–3 times	57
4–6 times	40
7–12 times	24
More than 12 times	17

Question 4

Shown below are some ideas about patient participation groups or their members. Please show whether you agree or disagree with each one by drawing a circle around your answer.

		Agree	Disagree
a)	Those who get involved in such groups are interfering busybodies	15	125
b)	Such groups are a great help to relatives of the sick	126	5
c)	User groups provide another 'political platform' for people who talk too much	26	96
d)	Patient groups could raise money for extra equipment	126	10
e)	Doctors should not involve patients in their decisions	31	99
f)	Patients and health visitors should unite to insist on better health facilities	124	10
g)	Some people will 'take advantage' of groups who offer help	90	40
h)	The care I receive is good enough already	123	12

Question 5

Shown below are 12 ways in which a patient participation group could improve medical care. The items are followed by two rows of boxes. In row 1 please tick six of the boxes to show the six most useful things listed which a patient participation group could help with. In row 2 please tick the boxes of any items which you know our group at Collingham has already helped with. If you do not know of anything the group has done please cross out row 2.

		Think activity desirable	Think activity already exists	Actually exists
c)	Providing transport for those who cannot reach health facilities	108	24	Yes
e)	Visiting and helping the sick, elderly and disabled	105	5	Yes
l)	Collecting prescribed drugs for people without transport	98	41	Yes
b)	Raising money for extra medical equipment	91	19	Yes
j)	Organizing clinics for the early detection of illness	87	14	Yes
h)	Organizing groups for patients with similar illnesses, to exchange ideas and give support	57	6	Considered
k)	Arranging first aid classes for interested patients	52	0	Considered
a)	Arranging talks and discussions about health matters	50	16	Yes
f)	Providing a child-minding service during surgery times	47	15	No longer
i)	Campaigning for better health service provision	46	3	Yes
d)	Organizing a marriage guidance counselling service	20	1	No
g)	Organizing social events where patients and staff can get to know one another	13	9	Yes

Question 6

Do you think you will ever attend a meeting of the Collingham Health Centre Users Group?

No	40
Maybe	72
Yes	22

If your answer to question 6 was No, Please indicate why.

Not interested	10
No spare time	14
No transport	5
None of these	10
All of these	1

Figure 1. *Questionnaire on patient participation with number of responses shown.*

out or considered by the group and this is clearly not thought by the majority of patients to be a suitable function for a patient group to take on.

The results suggest a low level of awareness about the group and its functions. The functions known about most widely were the provision of transport and the delivery of prescribed drugs. Even those respondents who had not heard of the group knew about these functions. This is understandable since these functions organized by the Health Centre Users Group are actually carried out by village-based 'divisions' which may not be identified with the Users Group by those who take advantage of the facility.

A brief comparison of functions desired by different groups of patients showed a discrepancy between the views of those who attend meetings and the rest of the patient population. However, the group of 'Meeting attenders' was represented by only nine people.

Discussion

It is clear that the patient group at Collingham could reassess its functions in line with the responses elicited. The social events and health talks provided at present seem to appeal to a minority of patients, but, if the fund-raising elements of the events were stressed, their popularity would perhaps increase. The crèche is not desired by patients — not even women in the relevant age group supported the facility.

The questionnaire neglected to ask patients whether they belonged to the group, and in retrospect this would have yielded an interesting response. It is likely that some form of 'joining' would increase awareness and attendance. A membership card bearing details of the services provided and coming events would ensure that people knew what was happening and that they were eligible to attend, but distribution would be confounded by the ethics of advertising.

A change of name might increase interest in the patient participation movement as a whole. The term 'patient' has implications of 'sick person' and may put off those who pride themselves on never needing the doctor. The Collingham group has now adopted the name 'Village Care' to overcome this.

Awareness of the group can only be increased by some form of publicity, which may raise ethical problems. Even in a rural practice such as Collingham, the waiting room is the only place in which advertising of any description may be hung indiscriminately, which leaves us with the difficulty of how to involve the infrequently attending, fit section of the population. Although the closest neighbouring practice is seven miles away, there is no monopoly on patients. Anything which could be construed as advertising may be seen as canvassing for patients and risks infringing the ethical code. In urban areas this problem is intensified by the closer proximity of practices and the additional transport facilities which may enable patients to choose more conveniently between one practice and another. After informal discussions with our neighbouring practices, we felt able to advertise the patients' group activities in the parish magazine, which only circulates within the core of the practice area and also in the village shops.

This leaves us with the question how to advertise the activities of the group in the remaining 20 villages covered by the practice. The only conclusion we reached which does not seem to risk the charge of canvassing is to use volunteers to distribute letters to every patient registered within the practice in these villages. The use of a computer to personalize the letters could be considered, and this may stimulate interest still further.

All advertising is produced by the patients' group itself after consultation with the doctors. The only other stricture which is applied is that the doctors' names should not be entered as individuals on any of the literature. Thus we feel that after consultation with the neighbouring practices, advertising can be used in a careful and controlled way to stimulate interest in patient participation groups. It is an inevitable dilemma, however, that the success of general practice patient groups is dependent upon the time served question of advertising ethics.

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