

Patient participation in general practice: who participates?

MARTYN AGASS

ANGELA COULTER

DAVID MANT

ALICE FULLER

SUMMARY. A postal survey of 4066 men and women aged between 16 and 64 years was carried out in a general practice in Oxfordshire which had a patient participation group, established in 1972. The aim of the survey was to ascertain the knowledge and use of the group among adults aged 16–64 years. The adjusted response rate was 73%. Despite the length of the group's existence only 45% of these patients were aware of it and only 7% had ever attended a meeting. Awareness of the group and sometime attendance were significantly less in men, patients aged between 16 and 29 years, those in social classes 4 and 5, single people and those who smoked. Patients who consulted more than four times per year were more likely to be aware of the group than less frequent consulters. The possible reasons for the unrepresentative nature of the patients attending the group are discussed, together with implications for practice policies and development. Various strategies for making the group more representative are proposed, including advertising within the practice and elsewhere, and the formation of special interest groups for patients with defined medical and social needs, in the hope that this will make the concept of patient participation more relevant.

Introduction

THE concept of patient participation groups in general practice became reality when two practices, at Aberdare¹ and Berinsfield,² established them in 1972. These developments followed a wave of consumerism which saw the formation of the Consumer's Association. In 1963 the Patients Association was established which sought to represent the interests of disaffected hospital patients. There had also long been disquiet at the lack of accountability of general practitioners and several studies of patients' attitudes and level of satisfaction with their care were published at the time.^{3–5} These broad trends continued with the introduction of community health councils in 1974 following a reorganization of the health service. The slow growth of individual patient participation groups culminated in the formation of the National Association for Patient Participation Groups in 1978 and there are now estimated to be 131 practices with organized patient representation (Mant J, personal communication). In recent years consumerism has evolved further to embrace the concepts of health promotion

and individual responsibility for health; among its achievements have been the formation of a number of self-help groups at both local and national levels.

The Berinsfield practice lies 10 miles south of Oxford and is unusual in that it serves two distinct populations. Half the patients (3200) live in Berinsfield itself which was largely developed by the local authority in the 1960s; this population consists mainly of social classes 3 and 4 in contrast to the predominance of higher social classes in the practice population living in the 10 villages found within a four mile radius of Berinsfield.

Patient participation groups differ widely in their aims and structure; some involve patients in planning of services while others concentrate on fund raising or act as centres for the coordination of social and welfare needs. The patient participation group at Berinsfield was established shortly after the practice had moved to a new health centre, and its aim was to involve patients in this change and give them the opportunity to participate in the planning and introduction of new services.^{6,7} Until recently, the group met three times each year. The existence of the group is advertised in the practice's booklet for new patients and by a notice in the waiting area in the health centre. In addition, organizations in each of the villages, including for example, parish councils, schools, playgroups, women's institutes and groups for the elderly, are invited to send a representative, who must be a practice patient, to each meeting. The representative may bring a friend. Attendance at the meetings has varied over the years from 15 to 60 patients. All the doctors attend and both practice-based and attached staff are invited too; there is a lay chairman. At each meeting the representatives are invited to raise any questions, complaints or views from members of their group; these may be discussed generally or answered more specifically by one of the doctors or another member of the primary health care team. Later, the doctors and staff raise matters related to the practice, perhaps introducing new members of staff, or describing changes in practice organization or in local health service policy. Sometimes short talks are given on an aspect of health education. Minutes are written and are displayed in the health centre waiting room and are also sent to each of the representatives who in turn, report back to their village groups.

Several descriptive research studies have been published^{8,9} but there has been little evaluation of the effectiveness of patient participation groups. The extent to which patient participation groups reflect the profile and needs of the practice population is unclear. It may be that the group provides a forum for the higher social classes in which to articulate their needs; the views of those patients in social classes 3 and 4 who may be less likely to attend meetings may therefore go unacknowledged though their needs may be greater.^{10,11}

This study, conducted in 1986, aimed to ascertain the knowledge and use of our patient participation group in adults aged 16–64 years.

Method

A postal questionnaire was sent to each patient aged between 16 and 64 years registered at the Berinsfield health centre. Although the questionnaire had not been formally piloted many of the questions had been used in previous surveys undertaken by one of us (A C). The questionnaire asked about age; sex,

M Agass, MRCP, MRCP, general practitioner, Berinsfield Health Centre, Oxford; A Coulter, MSc, primary care research officer, Unit of Clinical Epidemiology, University of Oxford; D Mant, MRCP, MFCM, lecturer in general practice; A Fuller, BSc, research officer, Department of Public Health and Primary Care, University of Oxford.
Submitted: 25 July 1990; accepted: 23 October 1990.

occupation, age at completion of full time education, marital status (single, married or living as married) and smoking habit, and for the number of consultations at the health centre in the past year. Social class was then coded according to the Office of Population Censuses and Surveys classification, using own last occupation, or partner's occupation if living as married and never employed. The questionnaire then asked all respondents if they had heard of the patient participation group and whether they had attended one of its meetings. Patients who had not heard of the group were asked if they would like further information about it.

The initial sample size was 4066; 170 questionnaires were returned marked 'gone away' and 172 patients had been deleted from the practice list at the time of the third mailing and were assumed to have gone away. This gave an eligible sample of 3724, of whom 2737 (73%) had returned questionnaires at the completion of a third mailing. Of these 2737 patients, 201 did not answer the questions relating to the patient participation group and have therefore been excluded from this analysis.

The confidence intervals given are based on the standard error of a proportion. The statistical significance of the difference between two proportions was assessed by the chi-squared test. The significance of linear trend was assessed by the chi-squared statistic for trend (with one degree of freedom). The adjusted odds ratios were produced by generalized linear interactive modelling using the stratification reported in Table 1.

Results

Table 1 shows the proportion of patients who reported attending or being aware of the patient participation group. The existence of the group was known to 41.5% of the 2536 patients

and 3.1% of patients who had attended a meeting. Both awareness of the group and attendance was related to age (P trend < 0.001); only three patients under 30 years of age had ever attended a meeting. Fifty four per cent of women had either heard of or attended the group compared with 35.8% of men (P <0.001). Only 1.1% of men had attended a meeting compared with 5.1% of women (P <0.001). Patients who were married, or living as married, were also more likely to report awareness of the group (52.9%) than single people (29.1%; P <0.001) but the difference in attendance between these groups was not statistically significant (3.5% compared with 2.3%).

Awareness of and attendance at the patient participation group were related to social status, as measured by occupational class and by educational attainment. While 58.9% of patients from classes 1 and 2 were aware of the group, awareness fell to 33.6% in social classes 4 and 5 (P trend <0.001). Similarly 5.7% of patients from social classes 1 and 2 had at some time attended a meeting compared with 2.2% from social class 3M and 1.0% from social classes 4 and 5 (P trend <0.05). Patients who had completed full-time education by the age of 16 years were significantly less likely to have attended a meeting than those finishing at an older age (2.0% compared with 5.2%; P <0.001). The proportion of patients who said that they were not aware of the existence of the patient participation group but were interested in hearing more about it was fairly similar in all sub-groups (from 7.9% to 10.9%).

After adjustment for demographic factors, the likelihood of attendance was compared according to smoking habit and recent consultation rate at the health centre (Table 2). Awareness of the patient participation group was greater for non-smokers (47.1%) compared with smokers (40.4%), although the adjusted odds ratio was not significantly increased. More non-smokers

Table 1. Percentage of patients who were aware, had attended or who were interested in the Berinsfield patient participation group (PPG) by demographic characteristics.

| | Total no. of patients | Percentage of patients | | | |
|---|-----------------------|------------------------------------|--------------------------------|---------------------------------|----------------------------------|
| | | Aware and had attended PPG (95%CI) | Aware but had not attended PPG | Not aware but interested in PPG | Not aware, not interested in PPG |
| <i>Age (years)</i> | | | | | |
| 16-29 | 879 | 0.3 (0.0-0.7) | 27.1 | 10.5 | 62.1 |
| 30-49 | 1065 | 4.7 (3.4-6.0) | 49.3 | 8.9 | 37.1 |
| 50-64 | 592 | 4.4 (2.7-6.1) | 51.2 | 7.9 | 36.5 |
| <i>Sex</i> | | | | | |
| Male | 1234 | 1.1 (0.5-1.7) | 34.7 | 8.8 | 55.4 |
| Female | 1302 | 5.1 (3.9-6.3) | 48.9 | 9.6 | 36.4 |
| <i>Age at completion of full time education (years)</i> | | | | | |
| ≤16 | 1651 | 2.0 (1.3-2.7) | 39.5 | 8.4 | 50.1 |
| 17-18 | 451 | 6.4 (4.1-8.7) | 47.0 | 10.9 | 35.7 |
| 19+ | 434 | 3.9 (2.1-5.7) | 46.6 | 10.8 | 38.7 |
| <i>Social class^a</i> | | | | | |
| 1 and 2 | 795 | 5.7 (4.1-7.3) | 53.2 | 9.6 | 31.6 |
| 3N | 276 | 2.2 (0.5-3.9) | 38.4 | 9.4 | 50.0 |
| 3M | 668 | 2.2 (1.1-3.3) | 42.6 | 8.5 | 46.7 |
| 4 and 5 | 488 | 1.0 (0.1-1.9) | 32.6 | 10.0 | 56.4 |
| Unclassified | 309 | 2.6 - | 30.4 | 8.4 | 58.6 |
| <i>Marital status^b</i> | | | | | |
| Single | 824 | 2.3 (1.3-3.3) | 26.8 | 9.6 | 61.3 |
| Married | 1712 | 3.5 (2.6-4.4) | 49.4 | 9.1 | 38.0 |

^aOPCS classification. ^bMarried includes living as married. CI = confidence intervals.

Table 2. Attendance at and awareness of patient participation group (PPG) according to smoking habit and consultation rate.

| | Total no of patients | Attended PPG | | Aware of PPG ^a | |
|---|----------------------|---------------|---|---------------------------|---|
| | | % of patients | Adjusted ^b odds ratio (95% CI) | % of patients | Adjusted ^b odds ratio (95% CI) |
| <i>Smoking habit</i> | | | | | |
| Smokers | 735 | 1.5 | 1.0 | 40.4 | 1.0 |
| Non-smokers | 1801 | 3.8 | 2.0 (1.1–4.0) | 47.1 | 1.1 (0.9–1.4) |
| <i>Number of consultations in past year</i> | | | | | |
| ≤1 | 798 | 1.4 | 1.0 | 30.7 | 1.0 |
| 2–3 | 794 | 2.9 | 1.8 (0.9–3.8) | 42.3 | 1.6 (1.3–2.0) |
| 4+ | 944 | 4.8 | 2.4 (1.2–4.8) | 59.7 | 3.1 (2.5–3.8) |

^aIncludes those who attended. ^bAdjusted for demographic factors shown in Table 1. CI = confidence intervals.

had attended a meeting (3.8% compared with 1.5%) and this was reflected in a significantly increased odds ratio of 2.0. Patients who had consulted at the health centre more than four times in the previous year were more likely to have heard of the patient participation group and to have attended it and the adjusted odds ratio was significantly increased for both attendance (2.4) and for awareness (3.1).

Discussion

Although these findings are not necessarily applicable to the patient participation group movement as a whole, encompassing as it does so many diverse activities, they are nevertheless important. The patient participation group movement has been in existence for almost two decades. Its establishment and subsequent evolution represented a significant philosophical change for the medical profession, giving patients the opportunity to voice their criticisms of primary care and to play a larger part in the development of individual practices and local health care. After initial optimism about the advantages to both patients and doctors of an effective patient participation group,⁶ the movement has failed to live up to its initial promise. Doubts about the degree to which group members are representative of patients as a whole have been voiced¹² and the establishment of new groups has been disappointingly slow. Indeed this has been compounded by the relatively high rate of group disbandment, quoted at 25% in one study,¹³ where it was attributed to lack of interest by patients, particularly those from social classes 3 and 4, and to inadequate organizational input by the doctors.

At Berinsfield less than half (45.1%) of patients aged 16–64 years were aware of the group's existence and this proportion is similar to other studies;¹⁴ it is possible that this figure may have been higher if patients over 65 years of age had been included in the study. Despite the length of time the group had been in existence, and advertising within the health centre and in the practice leaflet only 7% of the surveyed patients had attended a meeting. A large proportion of attenders were members of other local organizations. Awareness and interest in the group tended to be greatest in older women and those patients in social classes 1 and 2. This anomaly may, at its worst, encourage the development of inappropriate health care strategies and perpetuate inequalities of health within the practice population.

So how can the membership of our group be altered to reflect more precisely the practice population as a whole? One possibility would be to allow the group to continue in its present form, while striving to increase attendance at meetings, so making it more representative. This was accomplished in one area by the creation of a 'patients' liaison worker' whose brief was to gather patients' ideas and expectations and to inform them about the

patient participation group.¹⁵ Alternatively, members of an existing patient participation group might have an information desk in the waiting room or act as an 'area representative' for defined neighbourhoods.

In essence, these strategies mean greater advertising of the group, both within the health centre to new and existing patients and also to those who consult less frequently.¹⁶ External advertising is probably a more powerful vehicle in this respect and has been facilitated by the General Medical Council's acceptance of the Monopolies and Mergers Commission's recommendation on the matter.

Another more radical strategy would be to shed the passive acceptance of the group's present structure and to encourage actively participation from those whose health needs are greatest. It has been demonstrated that with rigorous monitoring and organization, and the commitment of the whole primary care team, the uptake of preventive health care by deprived patients can be improved.¹⁷ This approach could perhaps be extended to the field of patient participation.

Others have suggested the formation of special interest groups within the practice aimed at patients with defined medical and social needs.¹⁸ This would encourage attendance from a broader social spectrum and lay the foundations for true participation. Indeed representatives from these smaller 'special interest groups' may in turn be motivated to participate in a more general patient participation group discussing broader issues relating to patient care and practice administration.

One of the greatest challenges facing medicine today is the practical application of our existing knowledge about the aetiology of modern pandemics such as ischaemic heart disease. This requires evolutionary change in the way doctors, health professionals and politicians think and act and in the health beliefs of our patients. If we are to be truly effective in promoting health, then it is essential that we involve patients fully in our plans; genuinely representative patient participation could be one of the most powerful means of accomplishing this task.

References

1. Wilson A. Experience of patient participation at Aberdare. In: Pritchard P (ed). *Patient participation in general practice. Occasional paper 17*. London: Royal College of General Practitioners, 1981.
2. Pritchard PMM. Patient participation in primary health care: a discussion paper. In: Pritchard P (ed). *Patient participation in general practice. Occasional paper 17*. London: Royal College of General Practitioners, 1981.
3. Cartwright A. *Patients and their doctors: a study of general practice*. London: Routledge and Kegan Paul, 1967.

4. Varlaam A, Dragoumis M, Jeffreys M. Patients' opinions of their doctors — a comparative study of patients in a central London borough registered with single-handed and partnership practices in 1969. *J R Coll Gen Pract* 1972; **22**: 811-816.
5. Sidel VW, Jeffreys M, Mansfield PJ. General practice in the London borough of Camden. Report of an enquiry in 1968. *J R Coll Gen Pract* 1972; **22**: Suppl 3.
6. Pritchard PMM. Community participation in primary health care. *Br Med J* 1975; **3**: 583-584.
7. Burgess J. Berinsfield community participation group. *Br Med J* 1981; **282**: 1593-1594.
8. Pritchard PMM. Patient participation in primary health care — a discussion paper. *Health Trends* 1979; **2**: 92-96.
9. Pritchard PMM. Involving the patient — participation in primary health care. *Oxford Medical School Gazette* 1982; **32**: 26-28.
10. Department of Health and Social Security. *Inequalities in health. Report of a research working group*. Black D (Chmn). London: DHSS, 1980.
11. Whitehead M. *The health divide: inequalities in health in the 1980s*. London: Health Education Council, 1987.
12. Sand PW. *Patient participation groups: an analysis of consumer participation in general practice*. MSc thesis, University of Surrey, 1978.
13. Mann RG. Why patient participation groups stop functioning: general practitioners' viewpoint. *Br Med J* 1985; **290**: 209-211.
14. Hutton A, Robins S. What the patient wants from patient participation. *J R Coll Gen Pract* 1985; **35**: 133-135.
15. Policy Studies Institute. *Promoting health through participation. Research report 659*. London: PSI, 1987.
16. Petrie J. Publicising patient participation groups. *Br Med J* 1986; **293**: 369-370.
17. Marsh GN, Channing DM. Narrowing the health gap between a deprived and an endowed community. *Br Med J* 1988; **296**: 173-176.
18. Hart JT. *A new kind of doctor*. London: Merlin Press, 1988.

Acknowledgements

We thank the patients and staff of the health centre, Berinsfield, and the staff and resources of the Oxford Community Health Project and the University of Oxford Department of Public Health and Primary Care. The study was supported by a grant from the Scientific Foundation Board of the Royal College of General Practitioners. David Mant and Alice Fuller are supported by the Imperial Cancer Research Fund.

Address for correspondence

Dr M Agass, The Health Centre, Berinsfield, Wallingford, Oxfordshire OX10 7NE.

RCGP

Scholarships
and
Awards



INTERNATIONAL TRAVEL SCHOLARSHIPS AND THE KATHARINA VON KUENSSBERG AWARD

The Royal College of General Practitioners invites applications for international scholarships to enable general practitioners from this country to travel overseas to study aspects of health care relevant to this country's needs or to help other countries develop their own systems of primary care.

The scholarships are also available to doctors from overseas who wish to visit this country to study an aspect of health care relevant to their own country's needs.

The College also makes available from time to time the Katharina Von Kuenssberg Award for international exchange or study.

The value of each scholarship will not normally exceed £1000.

This year the College would especially welcome applications from doctors to attend the 13th World Conference of WONCA (World Association of Family Doctors) which takes place in Vancouver, Canada, on 9-14 May 1992.

If you would like further details or an application form please contact: The Clerk to the International Committee, Royal College of General Practitioners, 14 Princes Gate, Hyde Park, London SW7 1PU. Telephone: 071-581 3232.

The closing date for applications is Friday 30 August 1991.

RCGP

Clinical
and Research
Division



RESEARCH TRAINING FELLOWSHIPS IN GENERAL PRACTICE

A number of research training fellowships are now available to young principals who are members of the RCGP. Applications are invited for these research training fellowships which will allow doctors to undertake research in general practice for a period of up to two years. The fellowships are designed to allow young principals to pursue an original line of enquiry, learning about research methods and design relevant to general practice, preferably proceeding to a higher degree. Applicants will be expected to have a formal link with a university department of general practice, RCGP research unit or department of postgraduate medicine.

Remuneration will allow a doctor to spend up to four sessions per week for a maximum of two years on a research project but flexibility will be allowed in terms of allocation of time for individual research work.

Applications should include a summary of the proposed research and details of the relationship with the supporting academic unit, together with confirmation of the arrangement from the head of the academic unit involved.

Application forms and further details can be obtained from Jenny Singleton, Clinical and Research Division, Royal College of General Practitioners, 14 Princes Gate, London SW7 1PU, to whom applications and curriculum vitae should be submitted by 31 July 1991.



MRCGP EXAMINATION — 1991/92

The dates for the next two examinations for membership of the College are as follows:

October/December 1991

Written papers: Tuesday 29 October 1991 at Centres in London, Manchester, Edinburgh, Newcastle, Cardiff, Belfast, Dublin, Liverpool, Ripon, Birmingham, Bristol and Sennelager.

Oral examinations: In Edinburgh on Monday 9 and Tuesday 10 December and in London from Wednesday 11 to Saturday 14 December inclusive.

The closing date for the receipt of applications is Friday 6 September 1991.

May/July 1992

Written papers: Wednesday 6 May 1992.

Oral examinations: In Edinburgh from Monday 22 to Wednesday 24 June and in London from Thursday 25 June to Saturday 4 July inclusive.

The closing date for the receipt of applications is Friday 21 February 1992.

Further details about the examination and an application form can be obtained from the Examination Department, the Royal College of General Practitioners, 14 Princes Gate, London SW7 1PU. Telephone: 071-581 3232.