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## PRACTICE OBSERVED

PRACTICE RESEARCH

### Why patient participation groups stop functioning: general practitioners' viewpoint

RICHARD G MANN

**Abstract**

Out of the 67 patient participation groups that were known to the National Association for Patient Participation as having been established by the end of 1983, 17 (25%) are not functioning. The general practitioners concerned with these non-functioning groups were interviewed to identify problems that they had in keeping the group going and to seek possible explanations for the problems. Fourteen of the groups had stopped functioning in part owing to lack of interest by patients. Groups become non-functioning often in the first year of starting up, and this may be because of the nature of the practice population that they seek to represent.

**Introduction**

The first patient participation groups were established about 1973 in new health centres in Aberdeen, south Wales, Berrinsfield, Oxon, and Bristol. Since then 67 groups have been started. There are approximately 9000 practices in Britain, and so these groups represent roughly one in 135 practices. Growth in the number of groups starting up has been slow and some groups have stopped functioning.

This study aimed at describing the development of the patient participation group movement, with special reference to groups that have stopped functioning, and determining why.

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some have stopped functioning by relating their experience to that of matched groups that are functioning. These questions have not been investigated previously, and the fact that there are non-functioning groups has been referred to only once.<sup>1</sup>

**Definitions**

A "functioning group" is one where the committee holds regular meetings regardless of how often the group meets and so the group's activities continue to be organised. The purpose or function of the group—to provide feedback between doctors and their patients outside the consulting room—is maintained.

A "non-functioning group" normally means one where meetings have been suspended and the committee disbanded. (Four groups, however, although committee meetings have been suspended and thus the group's basic function has stopped, there is a chance that the same committee will try to reorganise the group because there are no apparent differences in the experience of these four and other "non-functioning" groups they are included in this category.)

Though a group may no longer function in a practice, the concept of patient participation and notions of starting a new group usually linger, both legacies of a previous group.

**Method**

A brief questionnaire was mailed to each general practitioner whose name was listed beside the 54 groups in the 1983 *Directory of Patient Participation Groups* (National Association for Patient Participation). This identified groups that had stopped functioning since being listed. Those that had stopped functioning before the directory was compiled were omitted to me by the association. Forty-four (81%) questionnaires were returned. Follow-up was made to clarify the status and lifespan of every group known to the association up to the end of 1983 was established.

Other patient participation groups identified were eligible for inclusion in a survey by interview, which was designed to outline similarities

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through all the immediate problems. For instance, in one group "the terrible problems of the new health centre have been overcome, hence little work for the group." In such cases groups should generate a new initiative rather than disband, particularly when, in this case, they have worked over seven years to become integrated into the health centre. Some functional groups have successfully negotiated such problems.

The committee is a vital component of any group and six doctors recorded problems in this area. One committee "lacked the necessary motivation," possibly because those who participated, unlike "middle class and union members," were "united to committee work." Another "lacked a clear leader and task, which led to disension." As happened in another group, this may have caused meetings to be disruptive, which "didn't provide any long-term motivation." One group was distracted early on when it failed to elect officers, and another group failed to elect a new committee at the last meeting.

Other problems included overdependence on a doctor or patient (four groups), the doctor attempting to withdraw his support in the interests of group autonomy, and a group collapsing "after three years due to a committee which left all the work to the secretary who (through illness) couldn't continue." And a cautious note unfolded: "a group was started because of a move to a new health centre, which was located in the grounds of a small district hospital, so it failed to define any useful improvement in health centre facilities or to justify its existence."

**WHEN DO GROUPS BECOME NON-FUNCTIONING?**

"Groups become non-functioning most often within one year and between four and five years after they are started. General practitioners were asked, "Do you think there is a problem period in the life of groups?" Most said yes, but only those with non-functioning groups offered an explanation. In the first year "the novelty fades like anything new." For groups that folded at the later stage general practitioners said that "after a time groups tend to stagnate, finding it hard to recruit new people," or alternatively they can go "full circle" and actually "run out of things to do." By contrast, some doctors with groups that were functioning chose not to identify a particular problem period beyond being, for example, that "you've got to keep working at any group."

**ARE CERTAIN GROUPS PRONE TO NON-FUNCTIONING?**

The problems encountered by the 13 functioning and the 13 non-functioning groups were similar: lack of patient interest, seven and five groups respectively; committee breakdowns, one and four; combinations of the above, one and three; other problems, four and one. Certain underlying differences emerged, however. Average attendance at open meetings during the life of groups that stopped functioning was 14.8 people, whereas the functioning groups averaged 36 people. This difference was statistically significant. Of the functioning groups, five had an average of 0-15 participants at open meetings and eight groups that were functioning chose not to identify a particular problem period beyond being, for example, that "you've got to keep working at any group."

Development of patient participation groups from 1972 to end of 1983

	1972	1973	1974	1975	1976	1977	1978	1979	1980	1981	1982	1983
Total No. of groups formed	1	2	3	6	9	13	23	30	37	47	53	67
No. of ceasing groups	1	1	2	3	9	13	23	30	35	40	43	60
No. of new groups	1	1	1	3	3	4	10	7	7	10	6	14
No. of non-functioning groups*	0	0	0	0	0	0	0	2	5	3	7	17

\*A total of 17 by the end of 1983.

Since each group is tailored to the local needs of the patients in the practice whom it seeks to represent groups inevitably show a range of interests. Some similarities emerged, however, from the 26 groups that I studied. Over half of the groups were associated with health centres (n=22) and with teaching practices (n=15). Roughly half of each type of group were formed solely because the idea of patient participation appealed, and 85% (n=11) of each type were initiated by a general practitioner.

**WHY GROUPS BECOME NON-FUNCTIONING**

General practitioners who were associated with 14 of the 17 non-functioning groups stated that in part the demise of the group was due to lack of patient interest. One doctor described "an element of sheer apathy." When groups start up interest is usually strong and a committee of active patients is formed. Subsequently, interest lapses and, unless this is halted, even the active patients disappear.

Several doctors suggested what the cause of the lack of interest in their groups was. One thought that in his inner city practice, which was made up of a mobile population with a large ethnic component, there was "no natural community a group could represent." Another thought that because the patients were predominantly working class they were "not used to taking control of their lives" in the way that membership of a patient participation group requires and so did not participate. In another practice a large proportion of the patients were young married couples with children, who have little time to spare for a group. Rather than blame the patients, however, another doctor blamed the group, believing "patient numbers were low due to a failure of planning—we lacked the necessary organisation."

What may happen, though, is that groups maintain sufficient interest for many years and then reach a stage when they have talked

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### Discussion

The experience of patient participation groups that have stopped functioning has not been reported before. It is hoped that by reporting these findings there may be a better understanding of the practice as an institution and the reasons why it continues. It is unrealistic to hope that every practice might incorporate a patient participation group. Many groups have stopped functioning, and there is evidence that however well organised they are the practice setting is crucial to their survival.

Though groups stop functioning for many reasons, lack of patient interest was thought to be the fundamental problem. Unless patients participate in sufficient numbers groups are not representative "of the practice population." They also depend on a few enthusiastic people and thus are vulnerable when these people are unavailable or lose their motivation. Wood also saw lack of interest as the major barrier to the growth of the patient participation movement.<sup>1</sup> She believes, however, that until all efforts are made to advance the existence of groups, within the awkward guidelines of the BMA's Central Ethical Committee, this cannot be interpreted as signifying a lack of need.

Perhaps before trying to start a group the organisers should

### ONE HUNDRED YEARS AGO

As I forboded in my last letter, Dr. Sandwich has been obliged to resign his appointment of Subdirector of the Egyptian Sanitary Service. Pressure was brought to bear upon him from high quarters, as obstacles were thrown in the way of every administrative action which he undertook, so that he found it useless to retain his post. He will remain in Cairo, and continue his private practice. He has been succeeded by Surgeon-Major H. R. Greene, who has had considerable experience in sanitary administration in India and elsewhere. He came from Wady Halfa to take his new appointment. Surgeon-Major Greene has a good knowledge of written Arabic, which he will find invaluable in the difficult post on which he has just entered. No real changes in the personnel of the service have yet been made, but there will probably be some before very long. It is indeed reported that Ismail Pasha Yussef is discontented with his new post of Director of the Service, and intends to leave as soon as the can. Will he succeed him in mere matter of conjecture, but it is at least certain that any English director were alone, but such a simple and inexpensive method of written Arabic cannot be hoped for under the present control. A commission is shortly to sit on the subject of drainage of Cairo. The difficult problem of what to do with the ancient and almost sacred "habib" will be the primary subject of consideration. The habib is a deep canal, dry in summer, which carries Nile water across the elevated part of Cairo during the inundation. It receives the drainage of the houses it passes in its course, and is, consequently, little better than an open, almost curriental, sewer. Its yearly cutting, at the rising of the Nile, is the subject of a popular festival, at which, for many centuries, a virgin victim used to be sacrificed. It has been proposed, on one hand, to cover it in, and, on the other, to keep it permanently dry, and divert it into a road. The former plan would be too expensive, and would interfere with national prejudice. As regards the general question of removal of sewage, there is no doubt that no system of drainage will be successful, and that the system of dry removal is the only one suitable to the peculiar conditions of Cairo. The commission organizes with the Department of Public Works, of which Colonel Moncreff is head. Dr. Chaflay Bey and Mr. Hooker represent the Sanitary Service, a third member is a civil engineer, and a fourth the Subgovernor of Cairo. To the committee itself we can not expect, but the question arises, "Will anything be done in the sequence of it?" Surgeon-Major Greene has a scheme for providing all the provincial noxious with a double system of removal of sewage, the dry part being carried away to sewer farms, the wet being allowed, as now, to sink into the ground, or run off into canals and pools. It is to be hoped that this may be found for carrying out, and other reforms. Unfortunately, the surplus 110,000, which stood over from a previous year, and was to have been applied to reforms during this year, has been lost to the Sanitary Service, through not having been appropriated before the close of last year. This is another illustration of the hazardous way in which Egypt is at present ruled. The new Victoria Hospital, supported by the communities of the four Protestant nations—England, Germany, Switzerland, and the United States—is completed, but has not yet been formally opened. It is nursed by the Kaiserwerth Protestant Sisterhood, which institution refuses to allow any but Protestants to be members of committee of the hospital; it takes in charge, by inadvertence, several Roman Catholics were appointed on the committee of the Victoria Hospital, and only recently did it become known that their appointment was against the rules. Although their retaining was not insisted on, much ill-felling was aroused by the knowledge of the intolerant regulation. An amateur musical and operatic performance was about to be given at the time, and the proceeds were to have been devoted to the Victoria Hospital; but, on account of this unfortunate misunderstanding, they were diverted to the native hospital. The performance was very successful, and it is expected that more than £500 will be handed over the Kas-el-din Hospital. Mr. Milton, the resident medical officer, recently performed operations at this hospital. The operation was done under full antiseptic precautions, and appeared to be wholly successful. The patient rallied, and was doing well for two or three days, when she unexpectedly died. *Posi* worms, all the parts involved by the wound were found to be doing well, but a nest of lumbered worms was found in another part of the peritoneal cavity, which had set up peritonitis, from which, presumably, the patient died. No aperture was found through which the worms might have perforated the bowel. Dr. Farquharson, M.P., has been visiting Egypt for the last three or four weeks. He will reach England in time for the opening of Parliament. He will have much to tell the government of the sanitary requirements of his country. (*British Medical Journal* 1885; 401.)

Dr. Norman Moore, who has already discussed, with great skill, the question of the true cause of death of several historical characters, has communicated to the *Athenaeum* of January 18th an opinion on the alleged death, by slow poisoning, of Queen Catherine of Aragon. Contemporary historians believe that that pious and unfortunate princess really died by foul means, but Dr. Moore points out that the embalmer of her corpse made the following note: "He had found all the internal organs as healthy and normal as possible, with the exception of the heart, which was quite black and hard, and he took it out, but he did not change colour, but he cut it open, and the inside was the same. Moreover, a black round body" that of disease might write, if called upon to describe an actual specimen. Though there is evidence, even now, amongst the inexperienced to call anything in a sick man or in a corpse "black" that is darker than usual, it must be admitted that the "black round body" is very suggestive, and the symptoms of the royal patient also support Dr. Moore's theory, that she died of melanotic sarcoma. It has been suggested in a later number of the same periodical that Dr. Moore may have been perfectly correct as to his surmise of the existence of melanotic sarcoma, but that the patient's death was, at least, hastened by ill-use. (*British Medical Journal* 1885; 393.)

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## Lifestyle assessment: applying microcomputers in family practice

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**Abstract**

A randomised trial of assessment by computer was conducted with 180 patients in a family practice clinic. Histories of alcohol, tobacco, and drug use were obtained by computer (n=80), interview (n=80), or self-completed questionnaire (n=80). The results of previous research suggest that some patients may provide more accurate information about "sensitive" problems to a computer. No significant differences, however, in levels of consumption or problems were reported for the three methods of assessment. Patients gave differential ratings about the method of assessment, with the computer rated as more interesting but also more mechanical, cold, and impersonal. Although the interview was initially preferred by most, patients who completed the assessment by computer showed a significant bias (65% (13% to 43%) in their preference for the computer after the assessment. The results of our study indicate that patients' acceptance of computers in family practice may be favourably influenced by direct experience with a microcomputer.

**Introduction**

Computers offer considerable potential for helping the busy family practitioner. "The availability of low cost but powerful microcomputers has been accompanied by a proliferation of software packages for virtually every aspect of office administration and patient care." Despite this promise there are snags with respect to performance of equipment, costs of installing it and acceptance by staff.<sup>1</sup> Both doctors and patients have had misgivings about the use of computers in general practice.<sup>2-4</sup>

"We examined the application of microcomputers to the assessment of lifestyle with patients who visited their family doctor. Our main objective was to evaluate the acceptance by patients of assessment by computer. Also, encouraged by suggestions that some patients may provide more accurate information about "sensitive" problems to a computer,<sup>5,6</sup> our second objective was to determine whether patients would tell more about their use of alcohol, tobacco, and drugs to a computer than in an interview or on a self-completed questionnaire.

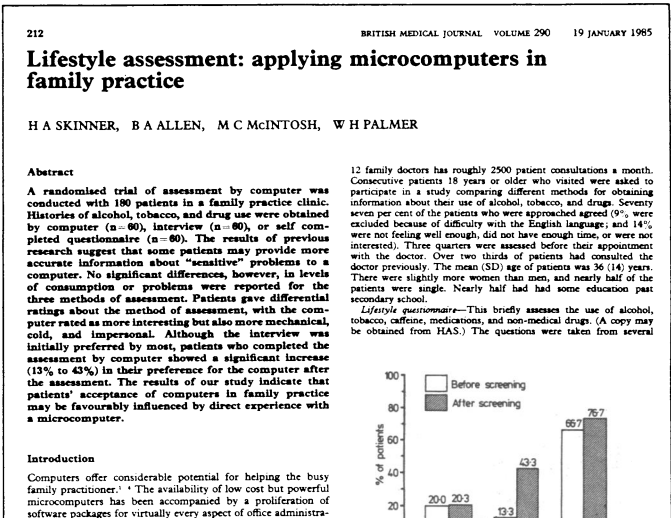
**Methods**

Our sample was 180 outpatients at the Family Practice Service affiliated with Toronto General Hospital. This group practice with

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12 family doctors in 290 patient consultations a month. Consecutive patients 18 years or older who visited were asked to participate in a study comparing different methods for obtaining information about their use of alcohol, tobacco, and drugs. Seventy seven per cent of the patients who were approached agreed (9% were excluded because of difficulty with the English language; and 14% were not feeling well enough, did not have enough time, or were not interested). These quarters were assessed before their appointment with the doctor. Over two thirds of patients had consulted the doctor previously. The mean (SD) age of patients was 56 (14) years. There were slightly more women than men, and nearly half of the patients were single. Nearly half had had some education past secondary school.

**Family questionnaire.**—This briefly assesses the use of alcohol, tobacco, caffeine, medications, and non-medical drugs. (A copy may be obtained from HAS.) The questions were taken from several sources, including our previous study,<sup>7</sup> the Health of Canadians survey,<sup>8</sup> and two screening instruments (MAST<sup>9</sup> and CAGE)<sup>10</sup> that are often used to detect drinking problems.<sup>11-14</sup> It took roughly 10 minutes to administer.

**Rating of the method of assessment.**—Patients ranked their preference for the three methods (interview by computer, self-completed questionnaire, face to face interview) both before and after they completed the lifestyle questionnaire. Also, their perception of the assessment preferences was measured using a 16 item semantic differential scale on a five point scale. The specific adjective pairs were drawn from the three factors of evaluation (pleasant-pleasant, potency (easy-hard), activity (easy-hard)).

Patients were randomly assigned to one of three methods, which were administered in private rooms at the clinic. Three patients out of 63 who were assigned refused to participate in the assessment by computer, and two patients of 62 assigned withdrew from the study during the face to face interview. All patients assigned to the assessment by questionnaire completed the assessment. The final groups were balanced in size: computer 60, interview 60, questionnaire 60.

The face to face interview was conducted by specially trained research assistants who asked questions from the lifestyle questionnaire in a straightforward manner without excessive probing or supportive counselling. Patients were given instructions for answering the lifestyle questionnaire and completed it privately. The computer interview was conducted using the IBM Personal Computer. After a brief introduction to the microcomputer patients answered three sample questions at the keyboard to familiarise themselves with the

