

# Partners or partisans? Patient participation at Marylebone health centre

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**SUMMARY.** *This paper outlines some of the issues which arose for patients and professionals involved in patient participation projects at the Marylebone health centre in London. It describes the projects undertaken and focuses on the practical implications of working with rather than for patients. Dilemmas surrounding patient participation are discussed, including the ways volunteers are rewarded, how doctors and patients can share knowledge, how participation is affected by professional boundaries, and why a regular group meeting may not necessarily be the best way to involve patients in decision making. The successes of patient participation are also highlighted.*

**Keywords:** *patient participation; patient participation groups.*

## Introduction

**P**ARTICIPATION is one of the developing tenets of primary health care, and yet it raises difficult issues for professionals and patients alike. During a discussion at the Marylebone health centre, a patient summarized the dilemma: 'What needs to be made clearer is the patient's role as a patient and his/her role as a participator in the running of the centre.' We talk of patient empowerment and patient participation, but what does this really mean in the context of a general practice in the centre of London?

Doctors' traditional position of authority has been challenged over recent years. The new focus on consumerism emphasizes the role of patients as purchasers of a service and doctors as sellers, reversing the old pattern where doctors gave directions and patients followed instructions.<sup>1</sup> The patient is now more informed about health issues, and the competence gap between patient and physician has narrowed.<sup>1</sup> The nature of general practice is therefore changing, and there is increasing emphasis on working with patients rather than working for them. Patients are being encouraged to participate in the clinical decisions made and the services provided. As the power relationship between doctor and patient changes, health care is seen increasingly as a contract between doctor and patient in which both sides are equally powerful.<sup>1</sup>

The National Association for Patient Participation was established in 1978 to foster patient participation and to provide a link between groups. In general, the role of such groups has included planning, dealing with patients' complaints, providing health education, organizing voluntary care and feeding back information on patients' needs to health care providers.<sup>2</sup>

General practitioners have varying reasons for encouraging participation. Some see it as a way of providing help to their patients and emphasize health education and voluntary activities. They see patients as 'an enormous resource'.<sup>2</sup> Some are keen to encourage self care, and point to doctors' limitations in curing or

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preventing illness, while others are concerned to create a mechanism for consumer feedback about their practice. Other perspectives range from a concern about their relationship with patients to a commitment to much wider political ideals.<sup>2</sup>

## Marylebone health centre

The Marylebone health centre is based on a holistic, primary health care model which emphasizes the need to empower patients and enable them to take more control of their health and well being. Complementary therapies are provided alongside general practice and in-house counselling is available. Patients can also be referred to a christian counselling service. Patients are encouraged to participate in health education and community activities and to provide ideas and feedback on health centre services and management. The general practice is supported by the family health services authority in the usual way. The 'extra' services were funded initially by a five year grant from the Wates Foundation, and are now supported by a charity, the Marylebone Centre Trust, donations from patients and various fundraising activities.

Patients can attend various classes including self care, stress management, massage, meditation and yoga. Alongside the team of doctors, complementary therapists, a social worker and administrative staff, a health educator is employed part-time to run the education and community programmes and to promote patient participation.

## Patterns of patient participation

### *Users group*

When the health centre was established in 1987, patients were invited to join a users group. The aims of the group were:

- To promote dialogue about current provision of primary health care and to encourage suggestions for improvement.
- To plan and run jointly a health education and self care programme with the aim of improving patients' health and increasing their responsibility for maintaining their own health.
- To develop a voluntary, mutual self help scheme.

The invitation to patients to attend the introductory meeting of the users group stated that 'the name users groups has been chosen rather than patient participation group to emphasize health and partnership.'

The users group, which met every eight weeks, consisted of eight patients, the social worker, health educator, one general practitioner and a representative from the church. The group made recommendations about how the new health centre should be run, including how long appointments should be and when surgeries should be held. The education programme was largely driven by the education officer, but the group was asked for its ideas and opinions. Classes included yoga, meditation, reminiscence groups, exercise groups, and a general health discussion group.

### *Volunteers*

During the next two years, a successful volunteer scheme was established. Patients were encouraged to provide practical help to other patients, to support the health centre administratively, and to run some of the self help groups, courses and social events.

Volunteers offered a range of services including letter writing, escorting/transporting patients, shopping, childminding, sitting with frail adults and reading. Potential volunteers were asked to complete an application form and to provide two referees. These references were taken up and the 'volunteer was interviewed before being accepted.<sup>3</sup> This scheme continues to be a useful resource, and a database of volunteers is now held on the practice computer system for access during consultations.

A separate group of volunteers became 'befrienders', offering emotional support to isolated, usually elderly, patients referred by the practitioners. The volunteers themselves were supported with monthly meetings facilitated by the centre's social worker and a health researcher who was registered with the practice.

Other patients volunteered to help with the practice newsletter and to undertake administrative tasks such as typing, correspondence and filing. One patient initiated and taught a movement to music class (subsequently funded by the Adult Education Institute), others started a crèche one afternoon a week. All of these activities are still taking place.

### *Ideas group*

After two years, key issues about the day to day running of the centre had been resolved and there seemed to be little left for the 'users group to discuss. Staff and patients' energy and enthusiasm in the group dwindled. At the same time, evaluation of the education programme showed that most of the 385 participants came from outside the practice — only 1% were registered at the health centre. More energy was needed to develop programmes specifically for patients at the practice. Thus, the users group was disbanded and an 'ideas group' formed. This would continue the work of the users group, but its main function would be to plan and promote a patient education programme.

The ideas group was introduced at an evening meeting to which all patients were invited. Most of the users group chose to continue their involvement, but new faces also appeared. About 25 patients attended the introductory meeting, and eight of them opted to meet regularly as the ideas group. The group was chaired by the health educator. It was decided that no doctor should attend meetings unless invited, since it was felt that patients could speak more freely if doctors were not present.

Feedback from the ideas group was channelled into a management group, which consisted of two patients from the ideas group, the practice director (a general practitioner), practice manager and health educator. A separate fundraising group, with the same members of staff but two different patients (members of the ideas group), also met regularly. This group concentrated on bring and buy sales, car boot sales and on recruiting 'friends of Marylebone' who each paid £15 a year. A total of £9000 was raised in the first year which has been repeated in subsequent years.

Following an initial burst of energy, the ideas group had a similar experience to the users group and other patient participation groups.<sup>2</sup> Once a patient education programme had been established and means for more effective patient feedback (a suggestions box) provided, there were not enough issues to keep the group discussions going every six weeks. As one member of the group said, 'There's nothing to get our teeth into any more.'

As services increased, the practice was under pressure to raise funds, and discussion of fundraising activities began to take over the meetings. This was frustrating for patients who had joined the group out of an interest in health, and wanted to be involved in policy making. However, staff felt that it was difficult to involve the group in decisions on policy issues which might require medical knowledge.

The decisions the group did make were small but useful. For example, they decided where the patient suggestions box should

be sited, and ways in which information about classes and activities could be more widely disseminated. But there was a feeling — not unique to Marylebone<sup>2</sup> — that the doctors were not interested in the group and its views. Minutes of meetings were distributed to staff, but one patient commented, 'I don't think they know we exist.' Others in the group excused the doctors: 'They were so busy, no more could be expected from them.' The groups' comments that they felt they were not being heard were greeted with bewilderment by the doctors, who felt that the group had not suggested much, and when it had, its ideas had been acted upon, exemplified by the practice director's comment, 'When have I ever said "no"?' In a national survey on patient participation, few staff said they had ever refused to do something they had been asked to do.<sup>2</sup>

The health educator who was running the programme became a go-between for patients and staff. The patients could say things to the health educator that they felt unable to say to the doctors. While this enabled them to say more, it also meant that they felt they were not always 'heard' and did not receive information direct from source. There was a tendency on both sides to doubt the feelings being relayed by the go-between (the member of staff coordinating the befrienders group had a similar experience).

The ideas group has now been dissolved, by mutual consent. It has been replaced by evening meetings twice a year to which all staff and patients are invited. The meetings provide an opportunity for staff and patients to get to know each other socially, and provide a forum for direct discussion between professionals and patients. A fundraising group continues to meet and a steering group to implement the patient's charter has been established. Patient representation at staff meetings is also under discussion.

### **Working towards solutions**

In many instances, staff and patients at the Marylebone health centre had different expectations of patient participation. Staff were concerned about confidentiality and the patient-professional boundary, volunteers were sometimes unclear about their role and patients were disappointed that they had not been involved in 'real' decision making. In the end, only a handful of patients had participated. Was it really worth the effort? How could these difficulties be resolved and more patients be encouraged to participate?

### *Is volunteering a gift or a contract?*

The schemes which have succeeded most at the health centre are those which provide patients with clearly defined tasks and regular support. For example, the befrienders group, which meets once a month, has increased in size and continues to provide an important service for isolated patients.

Professionals and patients frequently have different criteria for success. For patients, these criteria usually depend upon why they became involved in the first place. Professionals comment that patients who volunteer have particular needs which are met through volunteering. But many patients maintain that they volunteered because they wanted to give something back to the health centre, having benefited from its services themselves. Others want to be 'part of the team' and are interested in being involved in the 'different' model of health care Marylebone health centre offers.

Some volunteers are professionals in their own right, and offer their professional services free to the health centre. If the service offered is turned down, the volunteer can feel rejected and unvalued, particularly if he or she feels that it is a service which the health centre should be offering.

Do these volunteers give their services expecting no recompense, or do they give their skills and time expecting something

in return, in other words, is there a hidden contract? As Webber and colleagues point out, 'Schemes must provide for reciprocity: those who help must get something out of the scheme, and those who receive must have something to give in return.'<sup>3</sup>

#### *Feedback and professional involvement*

Volunteers must feel that the doctors value their opinions and judgement. Feedback mechanisms are important. For example, doctors referred patients for befriending, but sometimes appeared uninterested in any feedback. Befrienders felt nervous about going in to the doctor to report information about the person they had befriended. The befrienders had to fit in with the professional's agendas. To redress the power balance, one of the general practitioners now attends the befrienders meeting at regular intervals.

The involvement of professionals is important. To patients, doctors are still the kingpins in general practice, and patients need direct contact with them to feel that they are participating. It does not seem to be enough to have an intermediary member of staff as go-between. Despite the fact that the ideas group had decided not to have a doctor at the meetings, in retrospect the group would have felt more powerful if a doctor had been there. Equally, if patients are to organize fundraising events, it is important that professionals from the practice attend, join in, and thank and congratulate the volunteers involved.

In an attempt to clarify the role of volunteers at the health centre, anyone — patient or non-patient — who volunteers at Marylebone health centre is now given a brief job description. This is negotiated with the volunteer and describes the task they are expected to complete and what they can expect from the health centre in return. One member of staff is allocated as a support/supervisor for each volunteer. A full-time patient liaison officer, who is not registered with the practice, has also been employed to coordinate and support the volunteers.

#### *Professional boundaries and confidentiality*

Working alongside patients as volunteers raises issues of professional boundaries for the staff involved, particularly the clinicians. It was confusing for doctors if volunteers asked them about their own medication or treatment when they met in reception; doctors felt that such discussions should be dealt with in the consulting room. Volunteers were sometimes hurt by this attitude and such situations are also difficult for doctors.

Issues of confidentiality, particularly with befrienders, have also caused concern. The patients who are befriended are not referred to by name at the monthly meetings. Patients are not allowed to deal with the patient filing system or patient correspondence.

#### *Professionalization: who has the final say?*

Perhaps the biggest issue for professionals is how to involve patients in decisions which require 'medical knowledge'. For example, can patients be involved in decisions about budgeting or allocation of resources? Who should decide which complementary therapies are made available? As Adams points out, professionalization is a problem, 'not because professional judgement and skills should be undervalued, but knowledge must be shared and made available, not used to have undue influence over others. Professionals have one kind of knowledge and ability and citizens have another — both are valid and should be utilized.'<sup>4</sup>

There may be an inherent reluctance on the doctors' part to take patient participation groups seriously: 'It was not so much that doctors actively hindered the progress of the group, but they did not do so very much to help it along.'<sup>2</sup> It is important that the group should be proactive and reactive — as well as commenting

on suggestions made by professionals, the group must be encouraged to make suggestions of its own, and these suggestions should be considered seriously by staff.

Professionals must be wary of creating expectations which are unrealistic. They may feel that creating an environment in which issues can be raised and discussed is an achievement in itself and that the process is as important as the end result. But this is not necessarily the perception of the patients involved.

One of the biggest challenges to patient participation is how to bring doctors and patients together in a 'neutral' setting where both groups feel equal and can discuss their needs and visions without becoming defensive.

#### *A group is not necessarily the answer*

A patient participation group may work well in the early stages of establishing a health centre. But as the number of issues to discuss decreases, it is difficult to sustain interest particularly when the group feels peripheral and uninvolved in major decision making. An established group taps into the same few people time and again and those outside the group may feel excluded: it is difficult to introduce new voices.

The newly introduced twice-yearly meetings at Marylebone health centre should enable more patients to participate. Patients are invited to come and meet staff informally, out of office hours. The meetings provide an opportunity to build relationships, to discuss both staff and patients' expectations, to encourage each other and consider suggestions for change, and to make key decisions. They also provide a regular opportunity for review.

Nevertheless, it is important not to under-rate what has been achieved despite the difficulties encountered. Attitudes and values are difficult to measure, but they have inevitably been altered by the practice's commitment to patient participation.

#### *New models for evaluation*

If patients are to participate in planning and implementing services, they should also be involved in evaluating them. A patients' satisfaction study, undertaken by the Marylebone Centre Trust, has tried to allow patients to participate in evaluating the health centre. Unstructured interviews with patients set the agenda for a questionnaire which was circulated throughout the patient population. The results of this study will be reported elsewhere.

#### **Conclusion**

As Brownlea points out, 'Participation may be seen as a way of broadening the range of inputs to a decision, but in fact may represent a kind of tokenism. The input is received, but very quickly discarded as of little or no consequence. The motions have been gone through. The democratic ideal has been observed, but there is little power behind the participants' input.'<sup>5</sup> The expected difference that participation is supposed to achieve might well vary between those drawn into the system to participate and those already in the system and who have the ultimate decision-making power. Rather than influencing a decision, participation may provide a platform for the acceptance of a decision made elsewhere in the system. As such, participation may validate or legitimate the *status quo* rather than promote change.<sup>5</sup>

There are clearly many lessons to be learnt from the Marylebone health centre experience. Patients are most able to participate when there are clearly defined roles for them to undertake and when they have a specific member of staff to whom they are responsible and with whom they can work. Beyond this specific voluntary activity, patients and staff must meet regularly to negotiate the role that patients are to have. The hopes and expectations of both parties must be discussed and taken into account.

Opportunities to take stock and assess progress together must also be created.

Participation is ultimately about moving away from a 'them and us' mentality towards a partnership which, as reported in a National Association for Patient Participation newsletter, can be of mutual benefit to all parties.

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### Useful address

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