Whose interests do lay people represent? Towards an understanding of the role of lay people as members of committees

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Abstract

Increasingly, lay people are appointed as members to health service committees. The term 'lay' is used loosely and the reasons for involving lay people are seldom clearly defined. This paper argues that the different roles that lay people play need to be explicitly defined in order for their contributions to be realized. Although lay members of health service committees are generally assumed to be working for patients' interests, our observations lead us to think that some lay people tend to support professionals' or managers' interests rather than patients' interests as patients would define them. We suggest that lay people fall into three broad categories: supporters of dominant (professional) interests, supporters of challenging (managerial) interests and supporters of repressed (patient) interests. These alignments should be taken into account in appointments to health service bodies. Further research is needed on the alignments and roles of lay members.

Introduction

Politicians, health-care professionals, managers, patients and the public all have an interest in influencing the planning and delivery of health-care and regulating its professions. Public policy emerges from the shifts in power between these stakeholders. Perhaps professional power reached its peak in British health-care with the creation of the NHS in 1948. The decision to have a separate structure for the NHS, managed by appointed rather than elected boards, meant that the medical profession was freed from lay control for the first time.¹ Up till then doctors who worked in hospitals had been 'managed' by

local authorities or, if they worked in voluntary hospitals, by the lay board of governors. Since this peak in 1948 there has been an increase in the power of managers and in lay representation. These generally followed crises in public confidence in the medical profession's ability to safeguard patients. For example, in the 1970s the scandals about long stay hospitals led to the creation of community health councils as local watchdogs in 1974. In the 1990s the case of the Bristol cardiac surgeons that came to the General Medical Council led to a public outcry and concern about whether the professions could be trusted to regulate themselves. Now professional regulatory bodies are increasingly

involving lay people in order not to lose the 'privilege' of self-regulation.²

In addition, there are a number of reasons why professionals, managers and the government want to involve lay people.

- To demonstrate openness in decision-making.
- To confer legitimacy on professional and management decisions, such as around 'rationing' services.
- To ensure probity and provide oversight.³
- To safeguard the public interest by bringing in the views of people who have neither professional self-interest nor commercial links to the health-care industry.
- To contribute a user perspective or 'patient voice' to professional discussions.⁴
- To bring additional skills to the committee, for example, legal, financial or media.⁵

In addition, there may also be a desire to promote patient and citizen participation in the health service. Participation, that is the process by which those who are affected by decisions contribute towards reaching those decisions,⁶ is not our primary concern here. Lay members on NHS committees are invited to join them or appointed to them by Government or by local decision-makers. In this way the terms of participation through lay membership is controlled and limited.

Many national and local NHS committees now have at least one lay member. At national level lay people are involved in government advisory committees, statutory bodies, patient liaison groups of the medical royal colleges and professional regulatory bodies. At local level, lay people have been members of the boards of hospitals ever since they were founded.⁷ Today, they are appointed as chairs and non-executive directors of health authorities, trusts and primary care groups. Lay people are also members of maternity services liaison committees, research ethics committees and audit committees. They are conveners and chairs of review panels for NHS complaints. As members of community health councils (CHCs) and voluntary organisations they are involved in monitoring and planning services.

Yet there is little empirical research on their role and no thought-out strategy about how lay people will be recruited, what skills they need or how they should be held accountable. This paper draws on information used by government and appointing bodies and on the experiences of the authors' own involvement in the health service user movement and in NHS committees. It attempts to distinguish between the different sorts of people who may be appointed to health service bodies as 'lay' people, and so to put forward a model for understanding lay involvement, that can provide the basis for further research. We describe lay attitudes which have developed as a result of socialisation as they relate to the three main interest groups within health-care: consumers (patients, past patients, potential patients, carers and user/patient/consumer groups); corporate rationalizers (executive managers, civil servants, public health doctors); and health professionals, especially doctors in clinical practice.⁸

What is a lay person?

Though it is frequently used, there have been few attempts to define and clarify lay participation.⁹ According to Collin's dictionary a 'lay' person is 'non-professional or non-specialist or an amateur' and this is largely the definition adopted in the health service.

So lay people are defined, not by the positive attributes that they might have, but by who they are not and what they do not have. Lay people are those who have not gone through the training or socialisation into the particular profession under discussion (such as medicine, nursing, chiropractic) which we refer to as the index profession. Therefore, lay people are assumed to have retained the 'ordinary' norms and values of the society. In contrast, health professionals acquire new norms, assumptions, values and ways of behaving during their training and early professional practice.¹⁰

These professional assumptions and values can be traced through reading professional journals and listening to professionals talk. What lay people's norms, values and perspec-

tives might be supposed to be is less clear, even though their putative value as members of health service groups lies in the differences between their perspectives and those of professionals or managers.

Five main negative implications of this definition of 'lay' follow. Firstly, it does not distinguish between 'real' lay people and members of health professions other than the index profession. Nurses are appointed by the Privy Council as lay persons on the General Medical Council and a doctor as a lay person on the General Chiropractic Council. Such people may have important contributions to make, but it is stretching sense to give them lay places on committees.

Secondly, it may blunt recognition of the demographic and cultural differences between groups and individuals. The term 'health professional' covers a wide range of ability, knowledge and socio-economic attributes; the term 'lay' covers an even wider range.

Thirdly, the definition fails to recognize the range of different skills and experiences that lay people can bring to a committee: financial skills, managerial skills, experience of specific sorts of health-care, etc. Even among lay people, who are appointed as health-care consumers because of their experiences as patients or their links with Community Health Councils (CHCs) or user groups, there are important differences which we discuss later.

Fourthly, the definition can seem to imply that as lay people become more knowledgeable and develop more understanding of the professions, health services and clinical issues, they lose their amateur status and, thus, their value. Like the wise fool of mythology lay people's innocence and naiveté are considered useful by professionals, managers and health service commentators. Knowledgeable individuals are considered unrepresentative of other lay people. In particular, activist members of voluntary lay groups are liable to be regarded as unrepresentative (atypical) and, therefore, unable to represent (voice) the views of their peers. There is little understanding that activists are found in all groups, political, professional, trades union,

environmental, etc. and tend to become leaders. So they are the individuals who are most likely to be elected or appointed to positions in which they are expected to argue for the interests and values of their peers. The effectiveness of such 'representatives', depends on their understanding of their peers' views, values and interests and how they marshal the evidence and present their arguments.

Such activists tend to come from high level occupations and social groups.¹² To that extent, some of their perceptions may be different from those of their peers. That would of course be true for any socio-economic or other subset of people who otherwise were peers. That is why it is desirable to conduct surveys of properly drawn samples of the views of wider populations on specific issues. It is also desirable to widen the recruitment of people from groups that may be overlooked or are hard to reach.¹³ But single lay people who are not members of an organized group can speak only for themselves.

Sometimes professionals or managers appoint a patient or a carer, who is currently using or has recently used services, as the legitimate representative of other users. Thus, some maternity services liaison committees have recruited women who have recently had babies.¹⁴ But a new mother is unlikely to be able to contribute a wider user perspective or to have the background knowledge to explore the ramifications of health service planning decisions, the complex politics of maternity care or the technical arguments about the evidence base for guidelines and policies. She may be inhibited from expressing views that might antagonize professionals if she is likely to have another baby at the same unit. But, by giving her membership, people from CHCs and user groups can be sidelined as not truly 'representative'. They can be seen as partisan and different from other users because of their expertise or links to other consumers. So their informed views can be discounted when desired.¹¹

Fifthly, lay people can be excluded from committees that are seen as scientific or technical. Political scientists recognize that such exclusion is a way of limiting debate in the

interests of powerful interest.¹⁵ However, lay people are still excluded from a few bastions, such as the European Medicines Evaluation Agency or the Pharmacovigilance Committee of the Committee on Safety of Medicines. User groups believe that lay membership is important.¹⁶ This exclusion is especially important since, as the National Consumer Council has noted, links between professionals and pharmaceutical companies mean that it is virtually impossible to appoint professional members to the Committee who do not have links with the industry or, on some level, a conflict of interest.¹⁷ Pharmaceutical companies are major funders of medical research.

Thus, the negative definition of 'lay' can lead to the exclusion of lay people from groups or committees to which they could contribute. Some of this exclusion arises from an assumption among those involved in health-care that a common objective – the welfare of patients – is paramount for all concerned. The belief that everyone is working for the 'best interests' of patients can be used to hide or confuse the genuine differences in interests between patients and health professionals or managers that can emerge. Significantly, the first health-care regulatory body that recognized consumer interest and made appointments through general advertising was the Hearing Aid Council, set up by the Department of Trade and Industry as part of consumer protection legislation, rather than the Department of Health or the Privy Council.

Lack of clarity about the purpose of involving lay people and the 'qualifications' they need, also means that when lay people are appointed to committees, their contributions can be devalued by other members. There is wide evidence of the difficulties that individual lay members on professional committees face and the tactics that can be used to reduce the effectiveness of their contribution.¹⁸ Difficulties are often attributed to lack of training or resources for both the professional and the lay members. Instead it is a fundamental problem that relates to uncertainties in lay people's role or purpose, method of selection, accountability and terms of reference.

Models of lay involvement

Rather than accepting negative definitions of 'lay', we need to move towards the recognition that lay people can offer different positive contributions. Apart from any ancillary skills in finance or communications, lay members vary in how they identify and respond to health-care issues. Although there has been some research into the influence and effectiveness of lay members of health service governance bodies^{19,20} there has been none into their knowledge of or alignment with the interests and values of the various stakeholders in health-care. The same is true for the lay members of most other health service committees. It is our hypothesis, based on our observation of lay people on CHCs, health authorities, trusts and diverse other NHS committees, that individual lay members' contributions tend to cluster predominantly in support of the interests of one or other of the three major sets of interests and interest-holders in health-care. These are the dominant interests of doctors and other health-care professionals; the challenging interests of executive managers; and the repressed interests of patients.⁸ All three interest groups have some interests in common or that overlap amongst all three or between any two; and some that are different among all three or between any two. Identifying each group's interests in any specific issue or situation can, therefore, be difficult, especially as within each major interest group there are subgroups and ambiguities of interests.⁸ It is more difficult in that lay members' alignments with one or other interest group are not necessarily evident to themselves.²¹ Moreover, positions taken can shift from issue to issue; so individuals can seem to belong to more than one category at a time. This partly reflects the complexities of how stakeholders' positions can shift between issues and for the same issue. It partly also reflects members' imperfect knowledge of how the different stakeholders define their own interests and values at any one time. Health professionals and managers also change their definitions of their own interests as

well as their peers' interests from issue to issue and over time. In the long run, these shifts enable consensus to emerge or to be negotiated between the stakeholders.²² Nevertheless, some regularities in alignments are discernible when lay members' contributions and positions on a variety of issues are observed closely.

I Supporters of dominant interests

Most lay people with little experience of health-care support dominant interest-holders' definitions and practices. That support is, as it were, the default position for lay people. It requires no special knowledge of health professionals' or managers' or patients' perceptions, values or views. It requires no special analysis of how each group sees or would see its interests when they conflict or might conflict with those of the other groups. It requires no special skill in marshalling evidence or argument.

Most, probably almost all, lay members of health service bodies belonged to this category 30 years ago. Indeed, there were no other precedents or models of socialisation. Radical patient groups had only just started in this country.²² Health service administrators were still administrators not managers beginning to challenge doctors.²³ So the identification and articulation of patients' interests different from those of health professionals had only just begun. Lay members of governance bodies tended to defer to doctors' views.²⁴ In the 'scandals' that have hit the headlines, the lay members of governance bodies have supported dominant interests by failing to be critical of the care provided or in not probing into suspect situations. At Normansfield hospital for people with severe learning disabilities, Hospital management committee members were criticised in the late 1970s for [allowing] themselves to be confused [and] stopped in their tracks, by the use of terms such as 'clinical responsibility'.²⁵ At Bristol Royal Infirmary 20 years later, the non-executive directors knew of the allegations of high mortality rates for some paediatric cardiac surgery but asked no questions.²⁶ So the assumption that lay people will always uphold

the norms and values of the society to which they belong cannot be sustained. Professional interests are dominant because most people support them.⁸

As well as an initial tendency to support dominant interests, such lay people are perhaps more easily flattered than the other two types into further support for dominant interests, simply by being appointed to groups containing high status professionals. There is always a risk that lay people will be co-opted to support professionals, but it is a particularly high risk for this group of lay members.

Today, lay members on health service bodies and committees who uncritically support health professionals' interests are probably scarcer than they used to be. But they can appear on some community health councils, research ethics committees and maternity liaison committees.²⁷ As well as participating in trusts and authorities, they can be involved in patient participation groups in general practice.²⁸

II Supporters of challenging interests

Some lay members of health service bodies come from backgrounds in business, finance, management, health economics or policy analysis. They tend to support executive managers' (corporate rationalizers') interests.²⁹ Those interests lie mainly in the rational and cost effective use of resources and in controlling doctors' performance and expenditure. These lay members tend to be somewhat unsympathetic to patients as well as to doctors. They do not seek to understand the perceptions, views or interests of either – typically they read neither consumer nor health professional journals. But their views on issues not directly related to resources tend to be unpredictable and drawn from their personal experiences of health care. As they are often middle class men, those experiences are likely to have been favourable.³⁰ They seldom recognize that there is a body of knowledge and opinion about the experiences, perceptions and views of patients that can outweigh their personal preferences and anecdotes.

In the 1980s the Conservative government appointed people from industrial or financial backgrounds to health authorities and trusts in large numbers.³¹ Some continue to be appointed to boards and committees. Thus their particular type of lay contribution is well established.

III Supporters of repressed interests

Some lay people develop an acute sense of patients' disadvantage in health-care, of the repression of their interests.³² They may have had a personal or vicarious unsatisfactory experience of health-care, perhaps one that threatened their safety or their concept of themselves as a person. Some have felt an 'awakening' comparable to that which some women feel when they realize that women like themselves are disadvantaged in a society where masculine interests are dominant. They may then have started or joined self-help or activist patient/consumer groups, channelling their anger into constructive work to identify and promote patients' interests. Or they may have backgrounds in medical sociology, community health council or consumer organization work, certain kinds of health service research or feminism.

Appointed to health service bodies in very small numbers in the past, they are now being appointed more freely, as people 'who represent the interests of NHS users and carers and the local community'.³³ Their views are formed through close attention to patient/consumer groups and their journals; through familiarity with research into patients' views; and through abstraction from their own and other patients' experiences. As they, too, have become more prominent in the health service, they have achieved positions from which they can influence the appointment of other lay people who support patients' interests. So their particular type of lay contribution is likely to increase.

Selecting lay members

Clarification is urgently needed about the appointment procedures, terms of reference and accountability of lay members. These arrange-

ments affect who is appointed, whose interests they support and what they contribute. Given the existence of these three types of lay members, two questions arise: How can each type be identified during selection or appointment? Which type is appropriate for which health service body?

Of course, there are variations in ability and experience within all three types. There can also be indistinct boundaries between them. In interviews, people tend to recognize and wish to appoint people like themselves; so the composition of the recommending or appointing groups is important in determining the appointments made.

To some extent the types can be identified by looking at their CVs and at interview performances.

Type I lay people, who predominantly support dominant interests, tend to belong to provider lay groups like Hospital Friends or to charities or voluntary organisations dominated by health professionals or drug companies.³⁴ They usually do not belong to radical patient/consumer groups or to community groups. They may come from professions similar to medicine such as law or teaching. In an interview, they will seldom be well informed about controversial issues in health-care or, if they are, will take the dominant interest-holders' position.

Type II lay people, who predominantly support challenging interests, will be strongly indicated by their backgrounds; often in management, the private sector or academics. In interviews they may make references to resources and express reservations about giving information and choice to patients. People who give greater weight to equity than to individual patient choice also tend to support corporate rationalizers.

Type III lay people, who predominantly support repressed interests, tend to be members of radical patient or consumer or disability or ethnic minority groups; are perhaps members of professions ancillary to medicine; and will side with patients' interests in controversial issues.

Within this type, differences in personal and social experiences subtend three subtypes:

patients and carers; user or consumer groups, and consumerists or patient advocates.³⁵ Patients and carers are important, but they are not able to represent (voice) other patients' points of view because they seldom know what they are. Consumer groups, such as community, advocacy and self-help groups, are committed to identifying and articulating the interests of patients and other users. Patient advocates are those users whose knowledge of patients' interests and concerns is wider and more abstract than that of any single user or patient group.¹¹ Their perspectives are usually organized around general principles of information and choice, support and advocacy, safety and redress.

Within type III, there are, therefore, wide variations. It will be important to monitor the numbers and proportions of appointments of lay people from minority ethnic communities, disadvantaged groups and patient or user groups themselves. Voluntary organisations can have very different philosophies and views that affect how they will respond to particular issues. For example, within organisations representing people with mental health problems there are wide differences: some represent patients who see themselves as 'survivors' of the mental health system, while others predominantly represent parents and carers.³⁴ In addition, representatives from 'single issue' user groups may be concerned with promoting the specific issues that affect people with a particular condition or in particular circumstances, rather than general issues concerning all users. All these points have to be taken into account when making appointments, just as parallel points should be taken into account when appointing health professionals.³⁶ The question of which lay people should be appointed to which health service bodies is intensely political. Now that interests in health-care are well differentiated, whether type I members have any place is questionable; the professional members of the group or committee can speak for dominant interests. After excluding type I lay people, much must depend on the purposes of the body. Governance bodies with executive managers as directors need some type II lay non-executive directors to monitor

the executives' actions and hold them to account. But they will also need type III non-executive directors to identify and champion patients' interests. Bodies with a high proportion of health professionals as members and little or no managerial input will need type III members. Yet health professionals feel ambivalence towards those who speak for repressed interests; they can fear as well as respect them. Much depends on the personal qualities and communication skills of both the professional and the lay members, as well as on their ideological alignments.

Conclusions

Those making appointments to health service committees take care to ensure that the relevant professions and specialists are represented. It is now time to identify the different interests that lay people can represent. The interests of the public as citizens, as patients, and as carers may conflict with each other, as well as with the interests of health professionals and managers. There is need for clarity of purpose here. There is also need for a positive definition of 'lay' so that variations within the umbrella term 'lay' can be recognized and respected within committees once the appointments are made. In particular, the expertise, experiential and theoretical, that characterize type III members must be acknowledged. As the only category of lay people who can consistently speak for patients' interests when they conflict with the interests of professionals or managers, as well as when they coincide, their contribution is crucial to the health service, as well as forming part of the complex matrix from which politicians must draw out the public interest.

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