

## Research papers

# User involvement in clinical governance

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### ABSTRACT

**Aims** This study aimed to identify how different trusts in England were utilising lay involvement through their clinical governance committees.

**Method** It considered the perspectives of both the trust and the lay members. Twenty-three clinical governance chairs and lay participants returned a questionnaire.

**Results** This study found that the lay participants were far from representative of the local popula-

tion in terms of socio-demographics and special interests, and highlighted deficiencies in their recruitment and training.

**Conclusions** The conclusions point to successful approaches that could be applied by trusts.

**Keywords:** clinical governance committee, primary care trust, user involvement

## Background

In 1974 the government created community health councils (CHCs) in order to formalise the process of lay participation in the design of the health service. This movement to encourage patients' views on the delivery of healthcare continued throughout global healthcare, with the World Health Organization (WHO) and the United Nations Children's Fund (UNICEF) making the joint Alma Ata declaration in 1978 that, 'people have the right and duty to participate individually and collectively in the planning and implementation of their health care'. At the same time in the UK the National Association for Patient Participation was developing into an organisation that today works with over two hundred affiliated patient participation groups, representing more than a million patients.

More recently there has been a fresh government-led impetus to include the views of the consumers of healthcare in its provision. The 1997 White Paper *The New NHS: modern, dependable* called for a 'rebuilding of public confidence in the NHS, accountable to patients, open to the public and shaped by their views'.<sup>1</sup> Further insistence on the importance of patient participation came in the documents, *Developing a Strategy for Public Participation in the NHS* and *Patient and Public Involvement in the New NHS*.<sup>2,3</sup> However, until recently with initiatives such as the *Public Engagement Toolkit* little detail

was included about how this influence was to be harnessed.<sup>4</sup>

Chapter ten of *The NHS Plan* promises a 'patient prospectus' to be published by NHS organisations in which the views received from patients will be recorded and acted upon.<sup>5</sup> However, patient participation is to be more than reactionary, it is also to be harnessed as a way of shaping service delivery. Linked to this issue, is an awareness from the British Medical Association (BMA) that only when staff appreciate the needs of patients will they be able to alter the service to meet those needs.<sup>6</sup> The question therefore turns to how to utilise the views of patients in the delivery of healthcare.

User involvement is permeating many areas of healthcare, including the National Institute for Clinical Excellence (NICE), Commission for Health Improvement/Clinical Standards Board investigation teams and clinical governance committees. The BMA recognises that, 'one of the main aims of clinical governance is greater openness and accountability in healthcare provision. The active participation and partnership of clinicians and patients is key to the new NHS'.<sup>6</sup> However, both patients and staff must understand what patients are able to contribute, as a lack of awareness of the valuable role of the lay participants can lead to their being viewed as tokenistic. Far from being tokenistic, the utilisation of lay participants is to be an example of democracy as their role involves influencing the healthcare provision for the local population that they represent.

## Methods

A literature search identified commonly valued aspects of lay recruitment and involvement including lay participants' membership of special interest groups, their recruitment and the availability of support and training.<sup>7,8</sup> These aspects were then addressed in two questionnaires:

- the questionnaire for the chairs addressed issues such as how many lay members were on their committee, how they were recruited, the lay members' contribution and any difficulties and benefits encountered
- the questionnaire for the lay members considered whether they were a member of a special interest group, whether they received or desired any training and about their experience of being on the committee. It also collected socio-demographic information.

The questionnaires contained both partially closed and open questions and were mailed twice to 111 trusts/primary care groups (PCGs) in the northwest of England. The closing date for the questionnaires was May 2002. The results were analysed and text coded into common themes. The reliability of the coding of textual data was encouraged through responses being shaped by specific, neutral open question prompts. It was further enhanced by providing quotes rather than headings and through the bracketing out of presuppositions.

## Results

The headings below relate to general information about respondents and the questions posed to either the clinical governance chairs or the lay members, whilst the text boxes exemplify the written comments relating to these questions.

### Initial information

Twenty-three clinical governance chairs and 23 lay members returned questionnaires. Table 1 shows the use of lay representation on the clinical governance committees of those chairs who responded. This is expanded on in Box 1.

### The socio-demographics of lay members

The socio-demographic characteristics of lay members are summarised in Table 2.

**Table 1** Numbers of lay members on the clinical governance committees of those chairs who responded

Number of lay members on clinical governance committee	Frequency
0	6
1	5
2	7
3	4
4	0
5	1

### Box 1 Comments relating to trusts' user involvement

Clinical governance committee chairs:

'My trust recognises the need to involve people at all levels.'

'It is a matter of shame to me that my trust has not yet invited a lay member to participate. It is something our trust is particularly bad at across the board and something I have repeatedly flagged and will continue to do so in the future.'

**Table 2** The self-declared socio-demographics of lay members

Demographic	Result
Ethnicity	All 'white: UK'
Age	All over 36, 83% over 46 years
Gender	60% female
Disability	4% registered disabled
Education	83% degree or postgraduate level

### Box 2 Comments relating to representativeness

Clinical governance committee chairs:

'Some is better than none.'

'Lay members are not representative.'

'Our clinical governance subcommittee consists almost solely of doctors.'

## Lay members: do you belong to a special interest group?

Figure 1 shows that 26% of lay participants were members of a special interest group. These included The Joint Epilepsy Council, Action for ME, Learning Disability and Teaching, Diabetes UK and Age Concern.

A related aspect to the membership of special interest groups is that 35% of lay members described themselves as a health professional.

### Box 3 Comment relating to special interest groups

Nurse 'lay' member:

'Although lay participation has a role, it should not overshadow the views of the clinicians or management. Some lay representation is too slanted to special interest groups.'

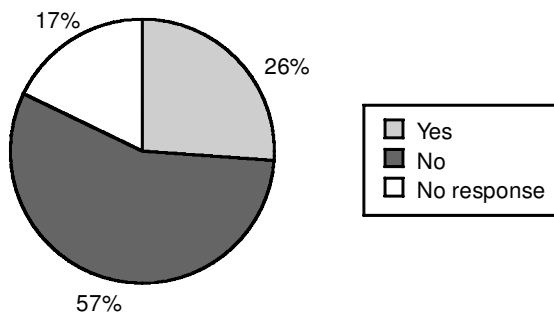


Figure 1 A pie chart to illustrate whether the lay members belong to special interest groups

## Chairs: how were lay members recruited?

An analysis of the answers to this question is shown in Figure 2.

The majority of lay members were approached directly, often by the chief executive, the medical director or the director of quality. The 'other' category included recruitment through the CHC, from non-executive members and from voluntary groups within the trust. One trust, the Royal Liverpool Children's NHS Trust recruited through advertising.

Thirty-nine percent of clinical governance chairs noted that they recruited lay members after they had drawn up a candidate specification.

These specifications included the desire that the lay representative would have a 'searching and challenging nature', 'good communication skills', be 'pragmatic rather than judgemental' and 'have the ability

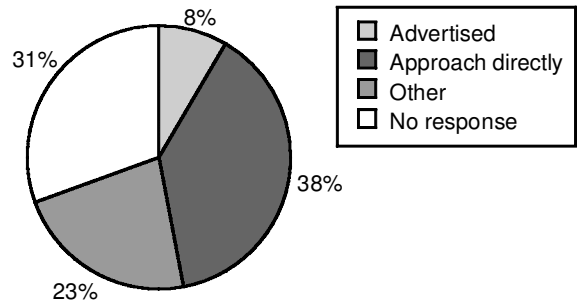


Figure 2 A pie chart to show clinical governance chairs' responses regarding their recruitment method for lay members

to represent service users'. Others merely asked that the lay member had some experience of the service offered by the trust.

Over half (54%) of the chairs who responded noted that they did not experience any difficulty recruiting.

## Lay members: did you receive training on joining the clinical governance group?

Seventy percent of lay participants did not receive any form of training upon joining the clinical governance committee.

Training received included meeting each of the key players, reading guidelines for corporate and clinical governance, attending workshops, attending conferences, including a nationally run one by the CHC, visiting the primary care and acute trust structures and watching a video on clinical governance.

### Box 4 Comments relating to training

Lay member:

'This is a new PCT and full training programmes are in the pipeline. I did have a detailed discussion with professional staff members.'

'It is not easy to be an equal partner until your own knowledge and experience increases regarding the issues under discussion.'

Clinical governance chair:

'They need a fair amount of support and induction to understand the organisation and concepts of clinical governance.'

## Lay members: would you have valued some/more training?

Thirty-nine percent of lay members said they would like more training, 22% gave no response.

### Box 5 Comments relating to assistance needed

Lay members:

‘I have some good background knowledge of clinical governance but more knowledge in order to feel comfortable challenging clinicians would be very useful.’

‘An NHS decoder for medical conditions, treatments, working group acronyms etc . . . [would have been useful].’

‘As an educated person I cope well by using my own experience. However, further training re the hospital’s infrastructure might have helped.’

‘I think our role has evolved with time. Having a point of contact for help or to share concerns has made a difference. We have the clinical governance co-ordinator and director of nursing to speak to as a first point of contact.’

The respondents also made a variety of additional comments which are exemplified in Box 6.

## Discussion

Before discussing the main findings, limitations of this study must be acknowledged. The low response rate impinges upon the validity of the reported results. This response rate is in spite of mailing the questionnaires twice, via the clinical governance chairs and the chief executive’s office. It was not possible to assess how representative those responses received from clinical governance chairs/lay members were of all clinical governance chairs/lay members. Additionally, whilst 54% of the chairs noted that they did not experience any difficulty recruiting, the value of this result is affected by the fact that different chairs used different methods of recruiting.

Nevertheless, there are clear themes to be drawn from the results.

- There is evidence that the typical lay member is white, over 46 years and educated to degree level. It is extremely unlikely that they have been recruited through advertisement, with few having candidate specifications decided upon in advance of appointment. It is worth noting that this is not

an approach advocated in equal opportunities legislation, and it is rarely used in other areas of recruitment. The appointment of someone nominated by existing healthcare committee members is less likely to lead to a diversification of the views already represented within the committee.

- To facilitate a broad section of the local community being represented, the post of lay participant should be advertised locally. This approach was undertaken by the Royal Liverpool Children’s Trust who advertised in the Liverpool Echo, receiving 12 applicants, two of whom were successful. They drew up a skills profile which included an interest in local child health issues, having a searching and challenging nature and good communication skills and being pragmatic. Existing patient groups may provide valuable input as to what they feel should be identified in the ideal candidate. Some of these criteria are hinted at by Charlotte Williamson, the Chairwoman of Consumers in Ethics in Research, when she notes:<sup>7</sup>

‘Representativeness comes from the ability of the patients who are members of a working group to explain patients’ views and interests through argu-

### Box 6 Additional comments

Lay member:

‘Some . . . perceive clinical governance to be the preserve of the clinical professional team and are negative about their quality standards being questioned.’

‘Usually the decisions appear to have been reached and the group is there to rubber stamp documents presented to us.’

‘It has taken time and persistence. Health professionals were wary of me at first, but seem to appreciate my contribution now.’

‘I am the lay chair and feel a lay member’s contribution can be encouraged by a lay chair so that the meeting is not dominated by clinicians.’

‘After a year as a lay rep on a local healthcare group I am afraid that I am feeling quite discouraged. There is little real commitment to patient and public involvement despite lip service and it’s an uphill struggle. I consult patients, bring in feedback, and find it blocked so that change doesn’t happen. The two lay reps on our board receive half the remuneration of everyone else. It is hard not to feel that patient–public involvement is at the very bottom of any list of priorities.’

ment and audience. What is expected of doctors who are members of the working group should apply to every member of the working group.'

- Several of the trusts that decided upon candidate specifications identified communication skills as being desirable. To ensure lay participants are able to communicate and comprehend the issues being discussed, many clinical governance committees have utilised the expertise of health practitioners. This will indeed give these candidates a head start in terms of orientation to healthcare issues and vocabulary. Furthermore, they are members of the community and potential patients. However, their value is lessened by their familiarity with the medical model and the presence of a bias in favour of healthcare professionals on clinical governance committees. Thus they would be less able to bring a fresh perspective to issues discussed. An answer to this problem may be available through providing training in terminology and, where appropriate, committee procedure, as illustrated by Van Wersch and Eccles.<sup>8</sup> This training must also include an exercise demonstrating to all members the valuable contribution lay members are able to make. It is also worth noting that communication skills are not solely the preserve of professionals.
- There is evidence that the lay members are representative of specific groups, whether this be a health profession (35%) and/or a special interest group (26%).
- Linked to this issue is the concern that lay participants are not able to give a broad view of the patient experience, rather that they represent 'one agenda' groups who act to further the interest of that group. Healthcare members of the clinical governance group are also prone to this behaviour and it is for the chair of the committee, be they clinical or lay, to ensure that neither a medical member nor a lay member is allowed to talk in their own self-interest but that they talk in the interest of patients generally.
- The role of the chair is to steer a delicate path between utilising the experiences of one member that are likely to be common to many and identifying those issues that are uniquely the benefit to an individual or small number at the expense of the majority. This concern is likely to be lessened by increasing the number and diversity of lay representatives. Just as healthcare professionals are diverse in their opinion and area of expertise, so are lay participants. By having only one or two lay members, the valuable experiences of many sections of the population will remain unheard and therefore unrepresented. It is clearly impossible to state that there is one patient opinion on any area of clinical governance. The

diversity of contribution by lay members has already been noted in some of the comments made by the clinical governance chairs. A number of ways of increasing their contribution have been hinted at, these have included using appropriate language, providing induction and training and giving them the confidence to be frank and open. It is also important to determine the balance between lay participants and healthcare professionals on clinical governance committees. Williamson suggests that, in working groups, maintaining an equal balance through equal number demonstrates that lay participants are held in equal esteem.<sup>7</sup>

## Conclusions

It is clear that trusts/PCGs are starting to address user involvement through their clinical governance committees, and it is encouraging that their contribution is considered significant by the clinical governance committee chairs and that the lay members themselves feel valued. Nevertheless, there is a great diversity of experience and support for lay members, this article has identified areas of good practice which can be shared. This includes the drawing up of candidate specifications before advertising for lay members, training and clear chairmanship, and an increased number of lay members. It is evident that trusts need to identify ways to hear the voice of those currently unrepresented through lay participation.

The lay members are clearly extremely keen, given their attendance and contribution. Nevertheless, they are not representative of the population served by the trust; the question therefore turns to whether they are given the resources and support to gather and then represent the views of this population.

The public will not accept a corporate approach to healthcare, instead they demand carer and patient involvement in service design. This patient-up, in contrast to trust-down, approach also has staff support as illustrated by the Government's NHS staff survey.<sup>9</sup>

This article has highlighted how trusts can make the most of lay participants through clinical governance. Their appointment needs to be open to scrutiny and their value increased through appropriate training and good chairmanship. Their views have to be made more representative by using resources to consult the community, by increasing their numbers and by having their opinions valued and most importantly acted upon. The ability of lay members to be representative of their community is a function of the number of lay representatives on the clinical

governance committee and the ability of these individuals to demonstrate the views of others. However, clinical governance committees are only one area where patient involvement can be seen, there are many more opportunities opening up to lay participation including patient forums, citizens' surveys and public consultation meetings.

At a local level, trusts are starting to develop patient involvement strategies. It is only through such initiatives being developed and progress being made in the way patient participation is used as a resource rather than a token that the National Health Service will truly start to meet the nation's health demands.

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