

Lay perspectives: advantages for health research

Vikki A Entwistle, Mary J Renfrew, Steven Yearley, John Forrester, Tara Lamont

Although involvement of the consumer is increasingly being advocated in health related research, it is not welcome universally. Furthermore, the underlying rationale is rarely made explicit. Policy makers, health care professionals, and researchers need to be clear about the benefits and ways of including lay perspectives and the criteria for evaluating these. Examples of lay involvement in setting research agendas,¹⁻⁴ methodological debate,⁵ and specific projects^{4 6 7} are accumulating, but little clear evidence about the benefits and costs of different ways of incorporating lay input into health services research is available.

We outline two basic reasons for incorporating lay perspectives into research and discuss some common objections. A framework is offered to help clarify the dimensions of lay involvement in health research. We use the term "lay" to mean people who are neither health care professionals nor health services researchers, but who may have specialised knowledge related to health. This includes patients, the general public, and consumer advocates.

The origins of lay involvement

The current interest in incorporating lay perspectives into health services research reflects broad social and political trends and developments in health care that have involved some breaching of the boundaries between medical professionals and others. The assumptions that the "experts"—doctors and biomedical researchers—are the best judges of what research is needed and should be exempt from democratic accountability are questioned. In addition, theoretical and empirical work on the philosophy and sociology of science has shown that the culture and values of those involved can influence research and the knowledge derived from it.⁸ The relevance of much research that has been driven by narrow professional and academic interests is increasingly being questioned.^{9 10}

Given this context, there is naturally an increasing interest in incorporating lay perspectives in research. This is not confined to the identification and solution of local problems and empowerment of disadvantaged



Summary points

Including lay people in health services research has been mandated politically and could improve the quality and impact of research

Patients and other lay people often have insights and expertise that complement those of health care professionals and researchers

Input from lay people may influence the setting of research priorities; the identification of problems; the design and execution of projects; and the interpretation, dissemination, and implementation of research findings

There are many potential lay contributors and ways of identifying their views and incorporating these into decisions; the appropriateness of particular combinations will vary in different contexts

Incorporation of lay perspectives into research and the methods used to achieve this must be evaluated rigorously

community groups, which cannot be done without lay involvement.^{11 12} Lay involvement is also advocated in more traditional empirical research that describes and analyses patterns of ill health, the causes and consequences of health problems, and the effectiveness of health care. We concentrate here on the last type of research, in which the potential benefits of lay involvement may be less obvious.

Why incorporate lay perspectives into research?

Including lay people in research may be seen, firstly, as politically mandated and, secondly, as a way of improving the quality of research. Although both these reasons include an element of moral imperative, each suggests a different approach and different criteria for evaluating input from lay people.

Politically mandated lay involvement

Research decisions are political as well as academic because different projects are likely to benefit different people. Prevailing notions of democracy suggest that the public, as the "owners" of publicly funded research, should have a say in what is done and how. They also suggest that research funds should be allocated by means that pay attention to the views of all those with legitimate interests. In the current climate, lay involvement may also be seen as politically expedient because it can serve to legitimise decisions.

When lay involvement is seen primarily as a political imperative, it becomes a goal in its own right. The processes of decision making become the focus of attention,

NHS Centre for Reviews and Dissemination, University of York, York YO1 5DD
Vikki A Entwistle, research fellow

Centre for Reproduction, Growth and Development, University of Leeds, Leeds LS2 9JT

Mary J Renfrew, professor, midwifery studies

Department of Sociology, University of York
Steven Yearley, professor

John Forrester, research fellow

Health Studies, Audit Commission, London SW1P 2PN

Tara Lamont, project manager

Correspondence to: Dr Entwistle
vae1@york.ac.uk

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and concern for the quality of the resulting decisions (and hence research) may become secondary.

Improving the quality of research

The argument that greater attention to lay perspectives may improve the quality of research is based on the premise that lay views often differ from those of health professionals and researchers—that they have legitimacy and can sometimes add value. Students of the sociology of science are familiar with a case in which government scientists calculated safe limits for chemical exposure to agrochemicals on the basis of laboratory tests. The scientists were oblivious to what farm workers knew about the practicalities of spraying in the wind and rain, with flaws in their protective clothing and a cocktail of other chemicals in use; their calculations were therefore inadequate.¹³

Patients may also have important insights that researchers may overlook—insights into things that cause problems for patients, or the types of technology and outcomes that patients value or are concerned about. Diverse lay perspectives on the impact of health care interventions, for example, may enhance understandings in assessing health technology.¹⁴

Examples of the contributions lay people make to research include raising funds, identifying important questions and relevant outcomes, drawing up priorities for research topics, appraising protocols, recruiting and preparing information for participants, undertaking research, and interpreting research findings.^{4-7 15 16} Lay involvement in generating knowledge may increase the perceived relevance and acceptance of findings.^{4 17} It may also encourage consumer groups to disseminate research. The inclusion of lay perspectives may therefore lead to research findings being more fully implemented.

Objections to lay involvement

Objections to incorporating lay perspectives in research are often raised. These include claims that lay participants are rarely typical, that lay interests can be adequately represented by others, that lay perspectives will not improve decision making in research, and that lay people may be biased or partial.

Lay people who get involved are rarely typical

If lay people are to be involved as a way of legitimising politically a decision or project, individuals who are democratically elected or are recognised as being typical or representative may be required. However, if lay input is intended to improve the relevance and quality of research, people with specific expertise, insight gained from experience, or the ability to present a range of relevant lay views will be more appropriate. Statistical or electoral representativeness is not the only criterion by which the appropriateness of lay (or other) contributors should be judged.

Lay interests can be adequately represented by others

Health professionals often assume that they understand fully their patients' points of view and concerns, and that additional efforts to identify these are unnecessary. However, studies show this may not be the case,^{18 19} and many health professionals have a poor understanding of their patients' views.²⁰

Health professionals who are briefed explicitly to represent patients' interests may sometimes be able to do so. For example, a group who had prolonged contact with patients with end stage renal disease were able to identify the sort of information that people newly diagnosed with this condition require.²¹ However, the assumption that health professionals generally can identify patients' concerns and views across a range of issues is invalid. In addition, health professionals may have conflicts of interests that limit their ability to argue from lay perspectives.

Lay perspectives will not enhance research decision making

There is also a view that lay people who do not have much formal medical knowledge and are not familiar with scientific methods or current research evidence will not be able to add anything to research decisions. In research teams, however, everyone brings different skills and expertise, and lay people may provide valuable additional insights. Although lay participants, like others, may need adequate briefing and explanation of technical language, this does not render their contribution worthless.

Lay input will be biased or partial

Another objection is that the vested interests of patients may lead them to act in partial and non-scientific ways. For example, patients who believe that a new treatment is better than an existing one may be unwilling to support randomised controlled trials that compare the two. This objection can be countered on two fronts. Firstly, some patients might be more willing to contribute if they understood better the rationale underlying some types of research—for example, uncertainty about the effectiveness of unevaluated treatments. Secondly, patients are not the only people with vested interests—clinicians too are often reluctant to support trials because of their individual beliefs in the superiority of one treatment.^{22 23} Lay perspectives may provide an important counterbalance to other interests that have tended to dominate research.²⁴

An outline framework

The issues and practicalities of incorporating lay perspectives may vary according to the health topic being investigated, the stages of research being considered, and the types of lay input sought. We offer a basic framework to help clarify thinking about lay input from a researcher's perspective. The framework has three focuses that reflect important questions that are interlinked in practice, but separated here for clarity. Firstly, what is the aim of lay input, and at what stage(s) of research is it needed? The value of lay input and the appropriateness of different contributors may vary considerably according to the stage of research (box). Secondly, who can best contribute lay perspectives? Thirdly, which approaches will best identify, express, and use relevant lay views? Within each dimension, we suggest relevant variables (see box). Our lists are not, however, intended to be definitive.

Some strengths and weaknesses of individuals and groups

The potential contributors have different strengths and weaknesses. For example, people with experience of a specific disease as patients are likely to be more valuable than organisations with generic health interests to project teams considering which outcomes are important for studies of treatment effectiveness.

The variability of consumer organisations warrants particular mention. Not all are run by and for the people they represent, and some, such as professional groups, may have narrow views and vested interests. For some health conditions there are several consumer groups with conflicting views. This need not invalidate lay involvement, but it does suggest that contributors should be selected carefully and that several lay contributors may be needed.

Good practice

Identifying lay views and integrating these into decisions may be quite distinct processes. Lay people may thus be given a voice without necessarily being involved in decision making. The merits and practicalities of different approaches to incorporating lay views are beyond the scope of this paper, but suggestions about good practice have been made elsewhere.^{25 26}

Discussion

The incorporation of lay perspectives into health research may be politically desirable and in some circumstances may enhance the quality of the work done. Questions do need to be asked, however, about the advantages, disadvantages, and resource implications of lay involvement in different circumstances, and further debate is required about how it should be evaluated.

Groups who are planning to include lay perspectives in research should consider what they are trying to achieve. We have proposed a framework to encourage clearer thinking about the types of research decisions to which lay perspectives might contribute, the appropriateness of different lay contributors, and approaches to obtaining lay input. It is unlikely that there will prove to be one single "best" approach, but some combinations of types of lay people and ways of identifying and incorporating their views seem better than others in contributing to particular stages of research.

The willingness of lay groups and individuals to contribute on the terms set by policy makers, health professionals, or researchers needs to be considered. Although some groups explicitly seek representation on key research committees, others may see these requests for help from the establishment as a drain on their limited resources. It may be particularly important to provide potential contributors with explanations and evidence of how their efforts can benefit them or future recipients of health care and remunerate them for their input and expenses.

Lay participation may need to be facilitated, for example by technical briefing and skills training for lay people, and by training health professionals and researchers to enhance their ability to understand lay perspectives and to work effectively with lay people in different situations.

Outline framework for lay input into health research

Stages of the research process

- Broad setting of priorities (including decisions of funding agencies about the populations, health conditions, interventions, and problems to which research funds will be allocated).
- Specific research projects:
 - Identifying problems and formulating questions
 - Design of projects (including decisions about study design and outcome measures)
 - Project execution (including recruitment, data collection and analysis)
 - Interpretation of findings and development of recommendations
 - Dissemination of findings and implementation of any recommendations (including decisions by researchers, referees, and editors that influence how and where findings are communicated).

Possible contributors of lay perspectives

- Patients and former patients
- Carers (whose interests sometimes conflict with those of patients)
- Potential users of specific health services (for example, older people and pregnant women)
- General public as potential patients, citizens, or taxpayers
- Community leaders
- Individuals or organisations who serve or represent lay people (consumer advocates, self help groups, consumer health information services, community health councils, etc)
- Organisations with generic health interests:
 - Organisations with specific interests, for instance associations that focus on specific diseases
 - Health professionals, or social scientists who have studied lay views

Ways of identifying and using lay input

- By reading—both lay publications and studies of people's views
- Various forms of consultation (surveys, focus groups, Delphi studies, open meetings, etc)
- Citizen juries, lay consensus conferences
- Integration of lay people in the assessment of research proposals and reports
- Inclusion of lay people on committees and working groups

Although the primary aim of health care should be to benefit its recipients, and health services research should ultimately serve to improve health care, patients and other lay people are not the only ones with legitimate views and important insights to contribute. Many of the issues raised here also apply to those health professionals who have often been precluded from research activities, just as lay people have been.

Inevitably, attempts to reflect lay views in research will result in negative and positive experiences. Debate and practice should become better informed if people can evaluate previous attempts to incorporate lay perspectives. It is therefore important that experiences from diverse settings are documented and made available for others to learn from.

- 1 MacIwain C. AIDS activists say basic research is underfunded. *Nature* 1993;363:388.
- 2 Marshall E. The politics of breast cancer. *Science* 1993;259:616-7.
- 3 Tighe RJ, Biersdorff KK. Setting agendas for relevant research: a participatory approach. *Can J Rehab* 1993;7:127-32.
- 4 Oliver SR. How can health service users contribute to the NHS research and development programme? *BMJ* 1995;310:1318-20.
- 5 Nowak R. AIDS researchers, activists, fight crisis in clinical trials. *Science* 1995;269:1666-7.
- 6 Bell RW, Damrosch SP, Lenz ER. The polio survivor as expert: implications for nursing rehabilitation research. *Rehab Nurs* 1994;19:198-202.
- 7 Renfrew M, McCandlish R. With women: new steps in research in midwifery. In: Roberts H, ed. *Women's health matters*. London: Routledge, 1992:81-98.
- 8 Yearley S. Understanding science from the perspective of the sociology of scientific knowledge: an overview. *Public Understanding of Science* 1994;3:245-58.
- 9 Bastian H. *The power of sharing knowledge*. Oxford: UK Cochrane Centre, 1995.

- 10 Barnes B. *About science*. Oxford: Blackwell, 1985.
- 11 Cornwall A, Jewkes R. What is participatory research? *Soc Sci Med* 1995;41:1667-76.
- 12 Flynn BC, Wiles DW, Rider MS. Empowering communities: action research through healthy cities. *Health Ed Q* 1994;21:395-405.
- 13 Irwin A. *Citizen science: a study of people, expertise and sustainable development*. London: Routledge, 1995;111-5.
- 14 Ong BN. The lay perspective in health technology assessment. *Int J Technol Assess Health Care* 1996;12:511-7.
- 15 Chalmers I. What do I want from health research and researchers when I am a patient? *BMJ* 1995;310:1315-8.
- 16 Goodare H, ed. *Fighting spirit: the stories of the women in the Bristol breast cancer survey*. London: Scarlet Press, 1996.
- 17 Goodare H, Smith R. The rights of patients in research: patients must come first in research. *BMJ* 1995;310:1277-8.
- 18 Dolan JG, Bordley DR, Miller H. Diagnostic strategies in the management of acute upper gastrointestinal bleeding: patient and physician preferences. *J Gen Intern Med* 1993;8:525-9.
- 19 Hares T, Spencer J, Gallagher M, Bradshaw C, Webb I. Diabetes care: who are the experts? *Q Health Care* 1992;1:219-24.
- 20 Coulter A, Peto V, Doll H. Patients' preferences and general practitioners' decisions in the treatment of menstrual disorders. *Family Pract* 1994;11:67-74.
- 21 Groome PA, Hutchinson TA, Tousignant P. Content of a decision analysis for treatment choice in end stage renal disease: who should be consulted? *Br J Gen Pract* 1994;14:91-7.
- 22 Alderson P. Equipose as a means of managing uncertainty: personal, communal and proxy. *J Med Ethics* 1996;22:135-9.
- 23 Lumley J, Bastian H. Competing or complementary? Ethical considerations and the quality of randomized trials. *Int J Technol Assess Health Care* 1996;12:247-63.
- 24 Chalmers I. The perinatal research agenda: whose priorities? *Birth* 1991;18:137-45.
- 25 Hamilton-Gurney B. *Public participation in health care. Involving the public in health care decision making: a critical review of the issues and methods*. Cambridge: East Anglian Regional Health Authority, 1994.
- 26 Local Management Government Board. *Community participation in local agenda 21*. Luton: Local Government Management Board, 1994. (Local agenda 21 round table guidance.) (Accepted 21 July 1997)

Continuing medical education

Learning and change: implications for continuing medical education

Robert D Fox, Nancy L Bennett

This is the third in a series of seven articles looking at international trends and forces in doctors' continuing professional development

Medical education, particularly continuing medical education (CME), has been greatly influenced by studies of adult learning. The observation that it is not teaching but learning that leads doctors to change their practice has resulted in a shift in perspective: rather than education being regarded as instruction, it is regarded as facilitation of learning. This paradigm shift has been based on research into how and why doctors change their practice and into the role of learning in that process.

The direction of continuing medical education in North America and elsewhere has changed in response to the new perspective that has emerged from contemporary studies of learning and change. The nature of this new perspective is evident from a comparison of the common elements of CME in the 1980s with the approach that is now being used. Traditionally a CME programme was an educational event that applied appropriate resources and methods to fulfill set instructional objectives. Such programmes were often considered to be good if the information was valuable, the lecturer skilful, and the setting comfortable. Too often, however, there was little or no actual effect on medical practice, even though all three conditions were met.

The critical difference in the 1990s is that it has increasingly been accepted that CME programmes are based—or should be—on the principle of teaching and education as a means of facilitating learning. This new approach has been adopted in response to studies on how and why doctors change their performance in clinical practice and the role of learning in that process. This article describes some of these models and sets out the key principles that have emerged for continuing medical education in the past decade.

Understanding change in clinical performance

Understanding and managing change is an essential part of professional practice. Just as doctors wish to

Summary points

The purpose of continuing medical education is to facilitate change in clinical practice

CME should be based on the natural processes learners use to change

Three interconnected systems are used in making changes: self directed curriculums, small group interaction, and organisational learning

CME must construct systems to complement and support the learning of practice based learning

intervene in illness to change the health status of patients, the aim of CME is to intervene in those aspects of medical practice that can be improved. CME is a systematic attempt to facilitate change in doctors' practice.

Differences observed over time in patients' health and in doctors' performance and their knowledge and skills are the types of changes that have been the focus of research on CME. Change in one of these areas may or may not lead to changes in another. For example, a change in the ability to perform a clinical procedure does not always result in that procedure being incorporated into clinical practice. Furthermore, a change in clinical performance does not automatically lead to a change in patients' outcomes.

These distinctions have challenged planners of continuing medical education to identify their objectives more clearly. What has emerged is an emphasis on doctors' performance as the target of strategies to facilitate learning and change. This focus calls for needs and outcomes that are described in terms of the performance of doctors rather than their competence or the health status of their patients.

Research Center for Continuing Professional and Higher Education, University of Oklahoma, Norman, OK 73037-0003, USA

Robert D Fox, professor

Department of Continuing Education, Harvard Medical School, PO Box 825, Boston, MA 02115, USA

Nancy L Bennett

Correspondence to: Professor Fox rfox@ou.edu

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