

## Systematic review of involving patients in the planning and development of health care

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### Abstract

**Objective** To examine the effects of involving patients in the planning and development of health care.

**Data sources** Published and grey literature.

**Study selection** Systematic search for worldwide reports written in English between January 1966 and October 2000.

**Data extraction** Qualitative review of papers describing the effects of involving patients in the planning and development of health care.

**Results** Of 42 papers identified, 31 (74%) were case studies. Papers often described changes to services that were attributed to involving patients, including attempts to make services more accessible and producing information leaflets for patients. Changes in the attitudes of organisations to involving patients and positive responses from patients who took part in initiatives were also reported.

**Conclusions** Evidence supports the notion that involving patients has contributed to changes in the provision of services across a range of different settings. An evidence base for the effects on use of services, quality of care, satisfaction, or health of patients does not exist.

### Introduction

Over the past 20 years, governments throughout western Europe and North America have encouraged patients to contribute to the planning and development of health services. In England and Wales the involvement of patients is central to current efforts to improve the quality of health care.<sup>1</sup> Underlying these changes is the belief that involving patients leads to more accessible and acceptable services and improves the health and quality of life of patients.<sup>2,3</sup> This view is endorsed by government policy, which states that involving patients leads to “more responsive services and better outcomes of care.”<sup>4</sup>

Several authoritative guides to different ways to involve patients in the planning and development of services have been published,<sup>5,6</sup> but engaging patients is not an easy task, and no consensus on which methods are most effective under different circumstances exists.<sup>4</sup> We therefore carried out a literature review to examine the effects of involving patients and the circumstances in which these take place.

### Methods

We identified papers for possible inclusion by combining searches of electronic databases, hand searches of reference lists of papers, contact with experts in the field and groups of patients belonging to the national Patients Forum, and a purposive hand search of grey literature held at the King's Fund and Department of Health libraries (for details see [bmj.com](http://bmj.com)).

### Criteria for selection

We included papers that described the involvement of patients, defined as “the active participation in the planning, monitoring, and development of health services of patients, patient representatives, and wider public as potential patients.”<sup>6</sup> Excluded papers described patient involvement in other activities such as research, community development, health promotion, self management and self help, and the role of doctors and patients in determining individual treatment choices. We also excluded papers that described the measurement of patient satisfaction or patient preferences without describing how this information was used to help development of the service.

### Qualitative analysis

When reading articles for inclusion in the review each reviewer (DR, CM, or MJC) completed an annotation form. This allowed the reviewer to describe the nature of the evidence contained in the paper (quantitative research, qualitative research, review of previous literature, case study, expert opinion), the context of involvement (geographical setting, nature of the service, and patient group), the method used (for example, survey, patient representation at meetings), and finally whether or not outcomes of involvement were reported.

### Results

We found 337 studies about involving patients in the planning and development of health care. Of these, we accepted 42 papers (12%) that described the effects of 40 initiatives involving patients (for study details see [bmj.com](http://bmj.com)). Of these, 31 were case reports, five were the results of surveys, three examined records of meetings, and three described the findings of action research.

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Four reports clearly described the use of qualitative research methods. We did not find any reports that used comparative or experimental research methods. Papers described a range of different models of involvement applied in a range of settings in hospitals and the community. The different effects of involving patients and the nature of the evidence to support these findings are summarised in the table. We were unable to identify any reports that investigated the effects of involving patients on the health, quality of life, or satisfaction of those using services.

#### Effects on users involved

Several papers commented that patients who participated in initiatives welcomed the opportunity to be involved and that their self esteem improved as a result of their contribution. The findings of surveys and interviews with patients are in support. We also identified reports in which patients described dissatisfaction with the process. Several studies commented that staff involved in initiatives found the experience rewarding, but others describe difficult relationships between patients and staff.

#### Changes to services

Among the most frequently reported effects of involving patients was the production of new or improved sources of information for patients. Other changes included efforts to make services more accessible through simplifying appointment procedures, extending opening times, improving transport to treatment units, and improving access for people with disabilities.

Several reports describe new services being commissioned as a result of the requests of patients, including advocacy, initiatives aimed at improving opportunities for employment, complementary medicine, crisis services, and fertility treatments. Two reports describe how involving patients led to proposals to close hospitals being modified or abandoned.

#### Other effects of patients being involved

Eight reports state that initiatives had a more general effect on organisational attitudes to involving patients. These included comments that staff attitudes to involving patients became more favourable and that the culture of organisations changed in a way that made them more open to involving patients. Some projects resulted in further initiatives aimed at strengthening the involvement of patients. Concerns were also expressed by researchers who found evidence that involving patients was used to legitimise decisions that would have been made whether or not patients supported them. One report concluded that the

#### What is already known on this topic

Involving patients in planning and delivering health services is recommended as a means of improving the quality of services

Methods for engaging with patients have been considered in depth, but the effects of involving patients are less clear

#### What this study adds

Few studies have explored the effects of involving patients

Involving patients has contributed to changes in service provision, but the effects of these on quality of care have not been reported

decision making process was slower because patients were involved.

#### Overall impact of involvement

Attempts to gauge the overall impact of involving patients have been made by conducting surveys of participants and retrospectively examining records of meetings. A survey of the leaders of public involvement initiatives of Health Systems Agencies in the United States in 1980 asked respondents to judge the effects of involving patients. Of the 154 (76%) who replied, 75% (116) said that involving patients had improved the quality of health services and 46% (71) that it had led to improvements in people's health. Of 63 patient participation groups in primary care settings surveyed in Britain in the mid-1980s, 32 (52%) were able to provide details of at least one change that groups had initiated.

Facilitated meetings between workers in primary care and patients with diabetes in 17 primary care centres in Stockholm in the mid-1980s generated 196 plans for improving patient care. Eighteen months later the extent to which plans had been implemented was evaluated: 70% (137) of plans had been implemented. A retrospective examination of records from meetings of five mental health forums in Kent, United Kingdom, identified 57 concerns raised by groups over a two year period. Of these, 22 (39%) resulted in a response from providers of services that was judged acceptable.

#### Discussion

Patients have contributed to the planning and development of services across a range of settings, but the effects of this process on the quality and effectiveness of services is unknown. This absence of evidence should not be mistaken for an absence of effect. Healthcare providers may be increasingly required to demonstrate that they involve patients in the planning process, but they will also continue to be accountable for the decisions they make. A better evidence base may be necessary to persuade providers to place greater emphasis on patients' views when making decisions about services.

We thank members of a steering group that oversaw the project, groups from the Patients Forum and others who responded to our request for grey literature, and staff at the Department of

Nature of evidence supporting effects of involvement of patients in planning and delivering health care

Effect	Quantitative research (observational or experimental studies)	Qualitative research	Case studies
Positive effects on patients who participate	×	✓	✓
Negative effects on patients who participate	×	✓	✓
Changes to information given to patients	×	×	✓
Changes to existing services	×	✓	✓
Development of new services	×	✓	✓
Increased use of services	×	×	×
Increased satisfaction among patients	×	×	×
Improved health or quality of life for patients	×	×	×

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Contributors: see [bmj.com](http://bmj.com)

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Competing interests: None declared.

1 NHS Executive. *The NHS plan: a plan for investment, a plan for reform*. London: Department of Health, 2000.

2 Beresford P, Croft S. *Citizen involvement: a practical guide for change*. Basingstoke: Macmillan, 1993.

3 Barker J, Bullen M, de Ville J. *Reference manual for public involvement*. Bromley, West Kent, Lambeth, Southwark, and Lewisham Health Authorities, 1997.

4 NHS Executive. *Patient and public involvement in the new NHS*. Leeds: Department of Health, 1999.

5 McIver S. *Obtaining the views of users of health services*. London: King's Fund, 1991.

6 Kelson M. *User involvement: A guide to developing effective user involvement strategies in the NHS*. London: College of Health, 1997.

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## Involving users in the delivery and evaluation of mental health services: systematic review

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### Abstract

**Objectives** To identify evidence from comparative studies on the effects of involving users in the delivery and evaluation of mental health services.

**Data sources** English language articles published between January 1966 and October 2001 found by searching electronic databases.

**Study selection** Systematic review of randomised controlled trials and other comparative studies of involving users in the delivery or evaluation of mental health services.

**Data extraction** Patterns of delivery of services by employees who were current or former users of services and professional employees and the effects on trainees, research, or clients of mental health services.

**Results** Five randomised controlled trials and seven other comparative studies were identified. Half of the studies considered involving users in managing cases. Involving users as employees of mental health services led to clients having greater satisfaction with personal circumstances and less hospitalisation. Providers of services who had been trained by users had more positive attitudes toward users. Clients reported being less satisfied with services when interviewed by users.

**Conclusions** Users can be involved as employees, trainers, or researchers without detrimental effect. Involving users with severe mental disorders in the delivery and evaluation of services is feasible.

### Introduction

The Department of Health in the United Kingdom is committed to involving patients in the NHS; it is establishing the Commission for Patient and Public Involvement in Health. Users and carers have been involved in delivering and evaluating mental health services, but the effects of this involvement have not been rigorously assessed.<sup>1-3</sup>

We sought evidence on involving users and the outcomes of involvement on clients (those receiving services).

### Methods

We searched Medline, Embase, CINAHL, PsycINFO, HealthSTAR, Cochrane Controlled Trials Register, Web of Science, HMIC, and BIDS for references in English between January 1966 and October 2001 (see [bmj.com](http://bmj.com)).

We wrote to experts and organisations who had an interest in involving healthcare users asking whether they were aware of additional studies. We searched the references in all papers for additional studies, whether we included them or not. We searched collections by hand in the Health Sciences Library of the University of Leeds.

### Inclusion and exclusion criteria

We included evaluations of the impact of research on services if users had an active role in the design or in collecting data. We also included studies about users who delivered services by training mental health professionals.

We included studies about delivery involving users in partnership with others if services were integrated by health professionals and users working together in a team; cross-consultation; or recruitment, training, supervision, or payment of users by healthcare providers.

### Exclusion criteria

We excluded studies if they dealt with only

- Learning disabilities
- Involvement in decisions about a user's own treatment
- Providing information to users
- User satisfaction surveys that were researched by the provider (which do not require users' partnership)
- General health services not specifically aimed at mentally ill people
- Forensic services
- Services for mentally ill people which are not health related, such as housing or vocational rehabilitation
- Services with no contact with professionals or which could not be run by professionals which operate outside the mental health system—for example, self help groups



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