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

Mike J Crawford, Deborah Rutter, Catherine Manley, Timothy Weaver, Kamaldeep Bhui, Naomi Fulop, Peter Tyrer

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. 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. This view is endorsed by government policy, which states that involving patients leads to “more responsive services and better outcomes of care.”

Several authoritative guides to different ways to involve patients in the planning and development of services have been published. Involving patients is becoming less discretionary and more compulsory for the providers of services, but engaging patients is not an easy task, and no consensus on which methods are most effective under different circumstances exists. 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. Electronic databases searched comprised medical literature (Medline from 1966, Embase from 1988, PsychINFO from 1967), nursing literature (CINHAL from 1982), healthcare management literature (HMIC and HELMIS from 1983), and grey literature (EAGLE from 1980). We used medical subject headings and free text searches related to “user involvement”—combinations of “client,” “consumer,” “patient,” “user,” and “empowerment,” “involvement,” “participation,” “representation,” for those related to planning and delivering health services—combinations of “health,” “health care,” “health services,” “service,” “welfare” and “delivery,” “development,” “organisational delivery,” “organisational change,” “organisational development,” “planning,” “provision.” Searches were restricted to papers published in English between January 1966 and October 2000.

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. We included all papers that described the effects of involving patients in the planning and development of health care. 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.

Two researchers (DR and CM) independently examined titles and abstracts of papers to decide if the
full text articles should be obtained. Where there was
disagreement, this was resolved through consultation
with a third reviewer (MJC). Full text articles were then
examined and additional papers excluded if a more
detailed examination showed that papers did not fit the
study’s aims.

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 litera-
ture, case study, expert opinion), the context of involve-
ment (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. Classifying papers in this way allowed us to
develop a series of categories represented by keywords
that were entered onto a bibliographic database and
subsequently used to search for papers illustrating par-
ticular themes. An initial examination of findings
showed that most papers that presented outcomes of
involvement were case reports from workers involved
in projects. Our approach to data analysis was
therefore restricted to a narrative account of outcomes
of involving patients and the nature of the evidence
used to support these claims. Because no system for
rating the quality of information in case reports exists,
we could not assign quality ratings to the papers we
included.

Results
We found 337 studies about involving patients in the
planning and development of health care. Of these, we
excluded 294 (87%) because they did not describe the
effects of involvement.

Accepted studies included 42 papers (12%) that
described the effects of 40 initiative involving patients
(table 1). 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.
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 table 2. 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 partici-
pated in initiatives welcomed the opportunity to be
involved and that their self esteem improved as a result
of their contributions.8-14 The findings of surveys and
interviews with patients are in support.15 16 We also
identified reports in which patients described dissatis-
faction with the process.17 18 Several studies com-
mented that staff involved in initiatives found the
experience rewarding,19 20 but others describe difficult
relationships between patients and staff.21

Changes to services
Among the most frequently reported effects of involv-
ing patients was the production of new or improved
sources of information for patients.8 22-30 Other changes
included efforts to make services more accessible
through simplifying appointment procedures,26 30-32
extending opening times,24 29 30 31 improving transport to
treatment units,25 26 and improving access for people
with disabilities.8 26

Several reports describe new services being
commissioned as a result of the requests of patients,
including advocacy,24 27 initiatives aimed at improving
opportunities for employment,25 24 complementary
medicine,25 crisis services,26 and fertility treatments.27
Two reports describe how involving patients led to
proposals to close hospitals being modified or
abandoned.21 24

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 involv-
ing patients became more favourable,8 16 19 35 and that
the culture of organisations changed in a way that
made them more open to involving patients.27 37 Some
projects resulted in further initiatives aimed at
strengthening the involvement of patients.26 37
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.10 38-40 One report concluded
that the decision making process was slower because
patients were involved.26

Overall impact of involvement
Attempts to gauge the overall impact of involving
patients have been made by conducting surveys of par-
ticipants 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.41 42 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.25

Facilitated meetings between workers in primary
care and patients with diabetes in 17 primary care cen-
tres 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.24 25 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.15 Of these, 22 (39%) resulted
in a response from providers of services that
was judged acceptable.

Discussion
A review of more than 300 papers on involving
patients in the planning and development of health
care found that few described the effects of this
Table 1 Reports providing details of the effects of involving patients in planning and delivering health care

<table>
<thead>
<tr>
<th>Study</th>
<th>Nature of evidence</th>
<th>Form of involvement</th>
<th>Nature of service</th>
<th>Location</th>
<th>Reported outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carlson and Rosenqvist29</td>
<td>Retrospective review of records</td>
<td>Consultation meetings with 34 patients</td>
<td>Diabetes management in primary care</td>
<td>Sweden</td>
<td>Changes to organisation of care and information for patients.</td>
</tr>
<tr>
<td>Milkov25</td>
<td>Retrospective review of records</td>
<td>Five patient forums</td>
<td>Mental health</td>
<td>UK</td>
<td>Unspecified changes to organisation and delivery of services.</td>
</tr>
<tr>
<td>Nell24</td>
<td>Retrospective review of records</td>
<td>Patient representation at 12 planning meetings</td>
<td>Primary care</td>
<td>USA</td>
<td>Broad range of suggestions for changes to services.</td>
</tr>
<tr>
<td>Pilgrim and Waldron24</td>
<td>Action research</td>
<td>Patient group with 14 members</td>
<td>Mental health</td>
<td>UK</td>
<td>Extension of content mental health team-hour: advocate found: service information for users published.</td>
</tr>
<tr>
<td>Sheppard9</td>
<td>Action research qualitative methods</td>
<td>Meetings with patients at five general practitioners' practices</td>
<td>Primary care</td>
<td>UK</td>
<td>User involvement appaciated by patients and providers.</td>
</tr>
<tr>
<td>Taylor14</td>
<td>Action research</td>
<td>Range of consultation projects across all sectors and stakeholders</td>
<td>Learning disability</td>
<td>UK</td>
<td>Implementation of revised patient information; patients' input into substantial overhaul of services.</td>
</tr>
<tr>
<td>Bow17</td>
<td>Telephone survey of 31 managers; case studies</td>
<td>Patient forums</td>
<td>Mental health</td>
<td>UK</td>
<td>Patient dissatisfaction.</td>
</tr>
<tr>
<td>Checkoway et al31, Checkoway35</td>
<td>Survey of 154 service providers</td>
<td>Patient representation at meetings</td>
<td>General health</td>
<td>USA</td>
<td>Increased confidence of users who participate; changes to services provided.</td>
</tr>
<tr>
<td>Hendess5</td>
<td>Survey of service providers</td>
<td>London based patient groups and forums</td>
<td>Broad range</td>
<td>UK</td>
<td>Changes in policy, quality and methods of service delivery.</td>
</tr>
<tr>
<td>NHSE32</td>
<td>Survey of service providers</td>
<td>Mixed involvement initiatives</td>
<td>Range of settings</td>
<td>UK</td>
<td>Simplified procedures, provision of new services.</td>
</tr>
<tr>
<td>Richardson and Bray37</td>
<td>Postal survey</td>
<td>60 patient participation groups</td>
<td>Primary care</td>
<td>UK</td>
<td>Reorganisation of waiting rooms; development of new clinics; changes to operating times.</td>
</tr>
<tr>
<td>Todd et al14</td>
<td>Interviews, qualitative analysis</td>
<td>Patient and carer representation on planning boards</td>
<td>Learning disability services</td>
<td>UK</td>
<td>User and carer dissatisfaction.</td>
</tr>
<tr>
<td>Akkinni and Farrah33</td>
<td>Case study</td>
<td>Audit involving interviews with 32 service users</td>
<td>Community paediatric</td>
<td>UK</td>
<td>Changes to dissemination of information.</td>
</tr>
<tr>
<td>Barnes13</td>
<td>Case studies</td>
<td>Three user groups</td>
<td>Mental health</td>
<td>UK</td>
<td>Improved service outcomes.</td>
</tr>
<tr>
<td>Barnes31</td>
<td>Case study</td>
<td>User committee</td>
<td>Community care for physically disabled</td>
<td>UK</td>
<td>No changes implemented.</td>
</tr>
<tr>
<td>Berger et al15</td>
<td>Case study</td>
<td>Consumer committee</td>
<td>HIV clinic</td>
<td>Australia</td>
<td>Patient friendly services and support; improved self esteem of patients.</td>
</tr>
<tr>
<td>Broderski33</td>
<td>Case study</td>
<td>Survey of 140 people by CHC</td>
<td>General health</td>
<td>UK</td>
<td>Reversal of plan to close hospital.</td>
</tr>
<tr>
<td>Dixon et al33</td>
<td>Case study</td>
<td>Two patients employed as consumer advocates in assisted outreach team</td>
<td>Mental health</td>
<td>USA</td>
<td>Improved engagement with patients and staff awareness, but problems with boundaries.</td>
</tr>
<tr>
<td>Elisabeth14</td>
<td>Case studies</td>
<td>Three citizens' juries</td>
<td>General health</td>
<td>UK</td>
<td>Increase in participants' self confidence and interest in local democracy.</td>
</tr>
<tr>
<td>Gummer and Furey35</td>
<td>Case study</td>
<td>Staff-patient forum: patients represent six groups</td>
<td>Mental health</td>
<td>UK</td>
<td>Improved design of new services; plan for advocacy; improved information, training and recruitment; culture shift; increased user self esteem.</td>
</tr>
<tr>
<td>Harris35</td>
<td>Case study</td>
<td>Patient forum</td>
<td>Mental health</td>
<td>UK</td>
<td>Promoted further user involvement.</td>
</tr>
<tr>
<td>Harrison and Mott37</td>
<td>Case studies</td>
<td>Health panels: run by CHC</td>
<td>General health</td>
<td>UK</td>
<td>Little evidence of changes to services.</td>
</tr>
<tr>
<td>Heagthrop11</td>
<td>Case studies</td>
<td>Range of initiatives including campaign by CHC</td>
<td>Broad range</td>
<td>UK</td>
<td>Reversal of plan to close hospital.</td>
</tr>
<tr>
<td>Kirk et al37</td>
<td>Case studies</td>
<td>Range of initiatives including interviews with service users</td>
<td>Primary care</td>
<td>UK</td>
<td>Supported existing plans for expansion of services.</td>
</tr>
<tr>
<td>Lord et al14</td>
<td>Case study with qualitative methods</td>
<td>Stakeholder meetings including service users</td>
<td>Mental health</td>
<td>Canada</td>
<td>Shift in service delivery toward individualised care; broader based ownership and control.</td>
</tr>
<tr>
<td>Mikes35</td>
<td>Case studies</td>
<td>Survey of 120 patients and three focus groups</td>
<td>Medical outpatients</td>
<td>UK</td>
<td>Development of information and shared care record book.</td>
</tr>
<tr>
<td>NHS Executive25</td>
<td>Case studies</td>
<td>Mixed methods (surveys, meetings)</td>
<td>General health</td>
<td>UK</td>
<td>Impact on strategies unclear; some service improvements; better communication with local residents.</td>
</tr>
<tr>
<td>Papert17</td>
<td>Case study</td>
<td>Service users panel</td>
<td>Medical outpatients</td>
<td>UK</td>
<td>Patient information and appointment cards restored; disability benefits improved.</td>
</tr>
<tr>
<td>Pearson et al35</td>
<td>Case study</td>
<td>Health and welfare council</td>
<td>General health care</td>
<td>USA</td>
<td>Pressure from service users speeded up changes to organisation of blood banks.</td>
</tr>
<tr>
<td>Post25</td>
<td>Case study</td>
<td>User focused monitoring</td>
<td>Neurological disorder</td>
<td>UK</td>
<td>Patients and staff found user involvement rewarding.</td>
</tr>
<tr>
<td>Shearman14</td>
<td>Case study</td>
<td>Survey of discharged patients</td>
<td>General hospital care</td>
<td>Australia</td>
<td>Development of information booklet.</td>
</tr>
<tr>
<td>Silva11</td>
<td>Case study</td>
<td>Client group to plan respite facility</td>
<td>Mental health</td>
<td>USA</td>
<td>CLients directed service design; became volunteer staff; reduced dependency on CHCs.</td>
</tr>
<tr>
<td>Smith35</td>
<td>Case study</td>
<td>Ex-ante representation at meetings, survey of current clients</td>
<td>Mental health</td>
<td>USA</td>
<td>Promotion of rehabilitation through enhanced self worth, self reliance.</td>
</tr>
<tr>
<td>Summers and McKee31,37</td>
<td>Case study</td>
<td>Mixed: focus groups, consultation, interviews, patient survey, and CHC</td>
<td>Maternity services</td>
<td>UK</td>
<td>Strategy reflects call for more lay workers; better accountability; staff interest in user views stimulated.</td>
</tr>
<tr>
<td>Summers and McKee31,37</td>
<td>Case study</td>
<td>Mixed: focus groups, user forum, survey of voluntary organisations, and CHC</td>
<td>Mental health</td>
<td>UK</td>
<td>Improved self esteem for users; staff interest in user views stimulated.</td>
</tr>
<tr>
<td>Tahnie14</td>
<td>Case study</td>
<td>Consumer board overseeing service providers</td>
<td>Mental health</td>
<td>USA</td>
<td>Training for staff on patient needs.</td>
</tr>
<tr>
<td>Wilkins14</td>
<td>Case study</td>
<td>Patient and staff interviews; survey</td>
<td>Outpatient services</td>
<td>UK</td>
<td>Waiting times, notes retrieval, patient information, and feedback to patients improved.</td>
</tr>
<tr>
<td>Wintor and Barnes,15 Barnes and White,37 and Barnes and Winsdon</td>
<td>Case study with qualitative methods</td>
<td>Survey, citizen advocacy, meetings</td>
<td>Community health and social care</td>
<td>UK</td>
<td>Improved access to services; enhanced self esteem of users who participated; service provider became more open to user involvement.</td>
</tr>
<tr>
<td>Woods25</td>
<td>Case study</td>
<td>Questionnaire survey</td>
<td>Surgical inpatient</td>
<td>UK</td>
<td>Revised admissions and discharge procedures and information; improved auxiliary services; complementary medicine; liaison group established.</td>
</tr>
<tr>
<td>Young14</td>
<td>Case study</td>
<td>Lay board of directors controlling a primary care clinic</td>
<td>Primary care</td>
<td>Canada</td>
<td>Dissatisfaction among service providers.</td>
</tr>
</tbody>
</table>

CHC = Community Health Council.

* A form of quality assessment by service users. † Two separate case studies in one report.
process. Those that have done so are generally case studies where project administrators running projects have commented on what the project achieved. Although these reports support the view that involving patients has contributed to changes to services, the effects of involvement on accessibility and acceptability of services or impact on the satisfaction, health, or quality of life of patients has not been examined.

We found some of the most informative material for this review in grey literature. While we made considerable effort to locate grey literature, the methods we used would not have identified all reports on this subject, especially those from outside the United Kingdom. Another potential problem in interpreting the results is that publication bias may favour the publication of reports from initiatives that were judged to be successful.

Several factors may account for our central finding, the limited amount of information about the effects of involving patients. The aims of involving patients have always been broader than just improving the quality of health care. Involving patients has been viewed by many as a democratic or ethical requirement: because patients pay for services they have a right to influence how they are managed. An alternative view is that involving patients is not intended to devolve power to patients but to legitimise the decisions of policy makers and administrators. It is argued that through consulting with users of health services, support for decisions that would otherwise be unpopular can be obtained. Such aims imply that establishing mechanisms for involving patients should be seen as an end in itself rather than as a means of improving the quality of services. However, initiatives that fall short of bringing about changes to services are not in keeping with the aims of current policy or patients.

The effects of involving patients are likely to be complex, affecting different aspects of services in different ways. The views of patients are among many factors that influence change in health services, and providers of health care remain the final arbiter of how much weight is attached to patients’ views. Separating out change specifically attributable to the participation of patients is a difficult task. Despite these problems, possible effects, amenable to formal evaluation, of involving patients have been discussed, including extent of use of the service, satisfaction, and quality of life. Patients’ involvement is not without its costs, and including outcome measures in future evaluations of involving patients could enable comparisons of different approaches and evaluation of the effects of suggestions made by patients.

**Table 2** Nature of evidence supporting effects of involvement of patients in planning and delivering health care

<table>
<thead>
<tr>
<th>Effect</th>
<th>Quantitative research (observational or experimental studies)</th>
<th>Qualitative research</th>
<th>Case studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive effects on patients who participate</td>
<td>×</td>
<td>×</td>
<td>×</td>
</tr>
<tr>
<td>Negative effects on patients who participate</td>
<td>×</td>
<td>×</td>
<td>×</td>
</tr>
<tr>
<td>Changes to information given to patients</td>
<td>×</td>
<td>×</td>
<td>×</td>
</tr>
<tr>
<td>Changes to existing services</td>
<td>×</td>
<td>×</td>
<td>×</td>
</tr>
<tr>
<td>Development of new services</td>
<td>×</td>
<td>×</td>
<td>×</td>
</tr>
<tr>
<td>Increased use of services</td>
<td>×</td>
<td>×</td>
<td>×</td>
</tr>
<tr>
<td>Increased satisfaction among patients</td>
<td>×</td>
<td>×</td>
<td>×</td>
</tr>
<tr>
<td>Improved health or quality of life for patients</td>
<td>×</td>
<td>×</td>
<td>×</td>
</tr>
</tbody>
</table>

**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

**Conclusions**

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 are 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 Health, Kings Fund, and Imperial College for their help in identifying grey literature.

Contributors: MC, TW, KB, NF, and PT conceived the study, MC, DR, and CM collected and analysed data. MC, DR, CM, TW, KB, NF, and PT contributed to analysing data, interpreting the results, and writing the paper. MC is the guarantor.

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