

Effectiveness of strategies for informing, educating, and involving patients

Evidence that strategies to strengthen patient engagement are effective is substantial, argue **Angela Coulter** and **Jo Ellins**, but any strategy to reduce health inequalities must promote health literacy

Policy makers increasingly believe that encouraging patients to play a more active role in their health care could improve quality, efficiency, and health outcomes. But critics have dismissed talk about patient engagement and patient centred care as political correctness—a misplaced concern with the “touchy feely” aspects of health care, with no scientific basis and little relevance to the quest for excellence in clinical care. Who is right? To what extent is the planned shift towards greater patient engagement supported by robust research evidence?

Engaging patients

Patient focused quality interventions recognise and try to support patients in actively securing appropriate, effective, safe, and responsive health care. Initiatives may aim to engage patients in their own or their family’s individual clinical care, or they may try to involve the public in improving the responsiveness of health services. This article focuses on the first of these two initiatives (box 1).

Box 1 | Patient focused quality interventions

To improve health literacy

- Provision of printed leaflets and health information packages
- Provision of computer based and internet health information
- Targeted approaches to tackle low levels of health literacy in disadvantaged groups
- Targeted mass media campaigns

To improve clinical decision making

- Patient decision aids
- Training for clinicians in communication skills
- Coaching and question prompts for patients

To improve self care

- Self management education
- Self monitoring and self administered treatment
- Self help groups and peer support
- Patient access to personal medical information
- Patient centred telecare

To improve patient safety

- Information to help choose safe providers
- Patient involvement in infection control
- Encouraging adherence to treatment regimens
- Checking records and care processes
- Patient reporting of adverse drug events

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Methods

As part of a wider research initiative to collate and synthesise research on performance, quality, and cost effectiveness in health care, we searched the literature for evidence on patient focused quality interventions. We systematically searched electronic databases including Medline, Embase, CINAHL, DH-DATA, PsycINFO, Association for Management Education and Development, British Nursing Index, Cochrane Library, Database of Abstracts of Reviews of Effects, King’s Fund, National Electronic Library for Health, National Health Service Research Register, World Health Organization, and Agency for Healthcare Research and Quality. We also searched specialist websites including those of patient organisations, and we did a reference scan for key papers. We aimed to collate existing evidence on the impact of the initiatives in box 1, particularly that derived from well conducted systematic reviews. All the research we identified can be found at the Health Foundation’s quest for quality and improved performance database (www.health.org.uk/qquip) and a full report of the findings can be downloaded free from the Picker Institute’s website.¹

How should we measure impact?

Choosing appropriate criteria to evaluate patient focused interventions is difficult. Studies have used various outcome measures, and the lack of standardisation hampers comparison of results. Relevant outcomes include impact on patients’ knowledge and understanding of their condition; impact on their experience of illness and treatment; impact on use of services and costs; and impact on health behaviour and health status (box 2). We identified 129 systematic reviews plus many other studies, which covered all four topics in box 1 and all outcomes in box 2.

The table summarises the findings of the systematic reviews. While the results of some reviews were negative (no difference between intervention and control or worse outcome with the intervention) or mixed (positive for some outcome measures and negative for others), most were positive (beneficial effect) for the outcomes selected for our overview.

Improving health literacy

Health literacy is fundamental to patient engagement. If people cannot obtain, process, and understand basic

health information, they will not be able to look after themselves well or make good decisions on health. Health literacy is not just about ensuring that patients can read and understand health information, it is also about empowerment. Patients with low health literacy have poorer health status, higher rates of hospital admission, are less likely to adhere to prescribed treatments and self care plans, experience more drug and treatment errors, and make less use of preventive services.² Achieving greater health literacy in the population is integral to improving the health of disadvantaged populations and to tackling health inequalities.

Evidence from reviews suggests that well designed written information (such as leaflets) can be a useful adjunct to professional consultation and advice and can improve health knowledge and recall, especially if information is personalised. For example, providing information and educational support to cancer patients improved their understanding of their condition and prognosis, leading to reduced anxiety and improved symptom management.³ As another example, preoperative information improved surgical patients' knowledge and sense of empowerment.⁴ Leaflets on their own have little effect, but combined oral and written information can improve patients' experience and, in some cases, reduce use of health service resources.

Other resources, such as websites, can also improve knowledge, and studies of such resources have shown high user satisfaction and beneficial effects on self efficacy and health behaviour. An initiative in the United States that provided computer based support for disadvantaged populations found that they benefited more from this type of intervention than did other groups, perhaps because they have more to gain from health information.⁵ Evidence suggests that interventions designed to mitigate the effects of low literacy can improve knowledge and health behaviour, but few studies have shown an impact on reducing inequalities in health status.⁶

Summarised findings of systematic reviews on effectiveness of strategies to inform, educate, and involve patients in their treatment

Topic	Total number of reviews found	Effects on patients' knowledge	Effects on patients' experience	Effects on use of health services	Effects on health behaviour and health status
Improving health literacy	25	Reported in 13 reviews: 10 positive, 2 mixed, 1 negative	Reported in 16 reviews: 10 positive, 5 mixed, 1 negative	Reported in 14 reviews: 9 positive, 3 mixed, 2 negative	Reported in 13 reviews: 4 positive, 6 mixed, 3 negative
Improving clinical decision making	22	Reported in 10 reviews: 8 positive, 2 mixed	Reported in 19 reviews: 12 positive, 6 mixed, 1 negative	Reported in 10 reviews: 6 positive, 4 mixed	Reported in 8 reviews: 2 positive, 1 mixed, 5 negative
Improving self care and self management of chronic disease	67	Reported in 19 reviews: all positive	Reported in 40 reviews: 24 positive, 11 mixed, 5 negative	Reported in 25 reviews: 14 positive, 9 mixed, 2 negative	Reported in 50 reviews: 39 positive, 15 mixed, 6 negative
Improving patient safety	18	Reported in 4 reviews: all positive	Reported in 1 review: positive	Reported in 3 reviews: 2 positive, 1 negative	Reported in 17 reviews: 8 positive, 9 mixed

Box 2 | Examples of outcomes of interest

Patients' knowledge

- Knowledge of condition and long term complications
- Self care knowledge
- Knowledge of treatment options and likely outcomes
- Comprehension of information
- Recall of information

Patients' experience

- Patients' satisfaction
- Doctor-patient communication
- Quality of life
- Psychological wellbeing
- Self efficacy
- Involvement and empowerment of patients

Use of services and costs

- Hospital admission rates
- Emergency admission rates
- Length of hospital stay
- Number of visits to general practitioners
- Cost effectiveness
- Cost to patients
- Days lost from work or school

Health behaviour and health status

- Health related lifestyles
- Self care activities
- Treatment adherence
- Severity of disease or symptoms
- Physical functioning
- Mental functioning
- Clinical indicators

Targeted mass media campaigns have been used to inform patients and the public, often to promote specific health behaviours or patterns of service use—for example, to increase uptake of screening or to reduce inappropriate use of certain drugs, procedures, or services. Well organised campaigns can have a beneficial effect on behaviour, but it is hard to disentangle the effects on patients from those on professionals, as mass media campaigns can reach and potentially influence both groups.^{7 8}

The Institute of Medicine's review helped promote health literacy,² but large gaps remain in our knowledge about how it can be improved. More research is needed in this area, especially the impact of interventions on literacy related disparities.

Improving clinical decision making

Many options are often available for treating a problem and the difference between the benefit to harm ratios of each may be uncertain or small. Treatment choice should then be guided by the patient's preferences. Patients may need help to understand the treatment options and outcome probabilities, and the clinician must communicate risk effectively and elicit and respect patients' preferences. This type of partnership approach is known variously as shared or informed decision making, evidence based patient choice, or concordance.

To facilitate shared decision making, patient decision aids have been developed for a wide variety of conditions and treatments. An inventory of such aids is available from the University of Ottawa's Health Research Institute (<http://decisionaid.ohri.ca/cochinvent.php>). Decision aids have been tested in several randomised controlled trials, and we found 10 systematic reviews evaluating their effectiveness. The reviews show that such aids improve patients' knowledge and understanding of their condition and of the treatment options and outcome probabilities; they also improve agreement between patients' preferences and subsequent treatment decisions.⁹

Decision aids can be cost effective, especially if coupled with face to face counselling. For example, a large randomised trial of decision support for patients with menorrhagia, which included a video of the treatment options and outcomes, an accompanying booklet, and a structured interview with a nurse to help patients express their preferences, resulted in reduced hysterectomy rates and lower mean overall service costs—\$1566 (£794; €1178) in the intervention group compared with \$2751 in the control group (mean difference \$1184; 95% confidence interval \$684 to \$2110).¹⁰

Educational interventions designed to increase participation of patients in treatment decisions have also been shown to be effective. Coaching and question prompts for patients and training in communication skills for health professionals can improve patients' knowledge and information recall and help to increase participation in decision making.

Despite evidence of benefit, widespread implementation of innovations to improve decision making and promote greater patient involvement has yet to occur. Barriers include lack of awareness, knowledge and skills, concerns about time and resource pressures, and fear that patient involvement could undermine clinician-patient relationships.¹¹

Self care and self management in chronic diseases

Self care includes staying fit and maintaining good physical and mental health, as well as the day to day management of long term conditions such as diabetes. The way that care is delivered, as well as the delivery of specific educational programmes, can affect people's ability to undertake preventive and self care activities. We identified 67 systematic reviews on how best to support self care.

Approaches that provide information only are mostly unsuccessful, but educational and self help programmes that are actively supported by clinicians improve health outcomes for patients with depression, eating disorders, asthma, diabetes, and hypertension. A review that looked at group based educational programmes for patients with type 2 diabetes found that they improved blood pressure, fasting blood glucose concentrations, glycated haemoglobin, patients' knowledge of their condition, and quality of life.¹² Short self

management courses run by voluntary groups seem to improve knowledge, coping behaviour, adherence, self efficacy, and cost effectiveness, but the effects may diminish over time.¹³ Educational programmes involving health professionals seem to be more effective for disadvantaged populations.¹⁴ Interactive computer based support systems also have positive effects on a range of outcomes, including knowledge (standardised mean difference 0.46, 0.22 to 0.69), social support (0.35, 0.18 to 0.52), and clinical outcomes (0.18, 0.01 to 0.35), but it is not clear whether they are more cost effective than face to face delivery.¹⁵

Patient held records can enhance patients' knowledge and sense of control.¹⁶ Self monitoring of blood pressure, blood glucose, and oral anticoagulation, as well as remote telemonitoring, can be both effective and cost effective.¹⁷ Research into home based telecare is still in its infancy. Studies so far indicate potential benefits in terms of social support, quality of life, use and cost of health services, and, in some cases, physiological outcomes.¹⁸

Despite the large number of studies carried out to evaluate self care interventions, the evidence base still has large gaps. Long term outcomes, cost effectiveness, the comparative effectiveness of different self care support strategies, and which components of complex interventions provide the greatest benefit have not been adequately evaluated.

Improving patient safety

The part that patients can play in improving the safety of their care has been recognised only recently, and research into this matter is still in its early stages. Ways in which patients can have an effect include making informed choices about providers, helping to reach an accurate diagnosis, contributing to safe use of medications, participating in infection control initiatives, checking the accuracy of medical records, observing and checking care processes, identifying and reporting treatment complications and adverse events, and practising effective self management and treatment monitoring. Most research has focused on safer use of medicines through improved adherence and encouraging patients to participate in infection control initiatives such as hand washing.

Various strategies for improving adherence to treatment have been evaluated. The most effective involve simplifying dosing regimens.¹⁹ The results of other interventions—such as patient education, information, and counselling—are less conclusive. Evidence suggests that encouraging patients to ask health workers if they have washed their hands can improve hygiene if the provision of hand washing facilities is also improved.²⁰

Partnerships with patients to reduce errors and improve safety can only be successful if patient involvement is valued and supported. Problems of health literacy must also be tackled for patients to understand and act upon information about safety and risk.

SUMMARY POINTS

A substantial evidence base exists for building strategies to strengthen patient engagement

Any strategy to reduce health inequalities must promote health literacy and engagement

Patients could help select treatments, manage long term conditions, and increase safety of drug use and infection control

Interventions can improve patients' knowledge and experience, use of health services, health behaviour, and health status

Conclusions

Synthesising the results of evaluations of such a diverse range of interventions is an ambitious task. Some people might say it is too ambitious to be done reliably, but policy overviews such as this—which are designed to inform planning at a system level—are inevitably “broad brush.” Nevertheless, this overview is no substitute for careful reading of the original reviews, and we hope that the newly established Health Foundation’s quest for quality and improved performance database will help readers to access these.

The systematic reviews we identified varied in how they described the interventions studied, the outcomes measured, and whether outcomes were presented qualitatively or quantitatively. Some provided no clear descriptions of the interventions or the study context. Patients’ demographic and clinical characteristics were sometimes missing or poorly reported; the length of follow-up was often relatively short, so the longer term effectiveness of many of the interventions is unknown; and few studies evaluated the cost effectiveness of interventions or considered their potential opportunity costs.

Nevertheless, we believe there is a substantial evidence base, albeit imperfect, on which to build strategies to strengthen patient engagement. Most reviews reported improvements in important outcomes, and several promising avenues to pursue have been identified.

Because health literacy is central to enhancing involvement of patients in their care, all strategies to strengthen patient engagement should aim to improve health literacy. Many people will have difficulty taking advantage of these new opportunities if the problem of health literacy is not dealt with. This could widen health inequalities, or even create new ones.

Thus, patients’ knowledge and understanding can be improved, at least at the individual level. Patients with acute and chronic health problems benefit when they are involved in their care, both at home and in clinical settings, and evidence suggests that this can lead to better use of resources. Shared decision making and self management are mutually supportive approaches, which should be given equal importance and implemented consistently.

Health information materials, decision aids, self management action plans, and other “technologies” of patient engagement are most effective when they supplement or augment, rather than replace, interactions between patients and professionals. As patients take on new health roles, ongoing support from health professionals may become even more important. Health professionals must be given the opportunity to develop their competencies in patient centred care—particularly their communication skills. Clinicians must also be given the resources needed to work collaboratively with their patients, to help

them access and understand health information, and to offer support in making choices to those who need it.

Contributors and sources: AC has more than 20 years’ experience of health services research in the UK. She is currently chief executive of the Picker Institute, an independent research and development institute specialising in measuring patients’ experience of health care. She is a member of the *BMJ*’s editorial board. At the time of carrying out the research JE was policy and public affairs manager at the Picker Institute, but she has recently moved to the NHS Centre for Involvement at Warwick University. Both authors conducted the literature searches, data selection, and analysis and wrote the manuscript. AC is guarantor.

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