

○ Evidence on the effectiveness of strategies to improve patients' experience of cancer care

CANCER REFORM STRATEGY  
PATIENT EXPERIENCE WORKING GROUP

ANGELA COULTER

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## Executive summary

This paper provides an overview of the evidence base for key recommendations made by the Patient Experience Working Group.

- *Providing information at key points along the care pathway.*  
Information for cancer patients or those at risk of cancer can be very beneficial, especially if it is personalised to the individual and offered at appropriate stages in a care pathway. Few studies have examined the cost-effectiveness of providing information to cancer patients, but since it can enhance patients' knowledge and ability to cope it would appear to be a worthwhile investment.
- *Offering patients a choice of treatment and care packages.*  
Shared decision-making about treatment options is important, but not widely practised in clinical care. Patient decision aids have been shown to increase patients' knowledge, involvement in decision-making and preventive behaviour, and they lead to more appropriate use of tests and treatments. In some circumstances they have also been shown to improve cost-effectiveness by reducing use of unnecessary or unwanted interventions.
- *Providing support for self-care and self-management*  
Well-planned education and support can help patients cope with the effects of their illness, increasing their sense of self-efficacy and encouraging the adoption of healthier lifestyles. In some cases this has led to a reduction in consultation and admission rates with resultant cost savings. Self-management education appears to work best when it is fully integrated into clinical care and when patients' learning is supported and reinforced by health professionals.
- *Obtaining systematic feedback from patients by means of surveys*  
An association has been found between poor quality experience and worse health outcomes, so reviewing and improving patients' experience should be a priority. Surveys of patients' experience can help staff view their services from the patient's perspective and they have been shown to act as a stimulus for quality improvements, especially when the results are made available to the public.
- *Involving service users in decisions about reconfiguration and service development*  
Public involvement in service development can lead to improvements in quality and responsiveness. More intensive efforts to secure lay involvement in determining priorities are more effective than traditional consultation methods, but they are fairly costly to organise.

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# 1 Introduction

The Patient Experience Working Group has made a number of recommendations for improving patients' experience of cancer care, including the following:

- Providing information at key points along the care pathway
- Offering patients a choice of treatment and care packages
- Providing support for self-care and self-management
- Obtaining systematic feedback from patients by means of surveys
- Involving service users in decisions about reconfiguration and service development.

It is important that policy development builds on a clear understanding of the relevant evidence base and gives careful consideration to the likely impact of any innovations. This report aims to assist this process by providing a brief overview of research findings of relevance to each of the recommendations listed above. In doing so it draws on an extensive literature review that was carried out by the Picker Institute, funded by the Health Foundation and published in August 2006.<sup>1</sup> For the purposes of this report, we have selected studies that are of particular relevance to patients with cancer to illustrate the likely effects of the various interventions.

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## 2 Methods

Studies were identified by means of systematic searches of electronic databases including Medline, Embase, CINAHL, DH-DATA, PsycINFO, AMED, British Nursing Index, Cochrane Library, DARE, King's Fund, National Electronic Library for Health, NHS Research Register, WHO, AHRQ, specialist websites including those of patient organisations, and a reference scan of key papers. The aim was to gather existing evidence on the impact of initiatives designed to improve patients' experience, in particular that derived from well-conducted systematic reviews. Where no systematic reviews were identified the material was supplemented by other well-conducted studies. The database can be found at [www.health.org.uk/qquip](http://www.health.org.uk/qquip) and a full report of the findings is available at [http://www.pickereurope.org/Filestore/Publications/QEI\\_Review\\_AB.pdf](http://www.pickereurope.org/Filestore/Publications/QEI_Review_AB.pdf).

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## 3 Providing information at key points along the care pathway

The delivery of high quality and appropriately targeted health information is central to the provision of modern healthcare. Patients need such information in order to:

- understand what is wrong
- gain a realistic idea of prognosis
- make the most of consultations
- understand the processes and likely outcomes of possible tests and treatments
- assist in self-care
- learn about available services and sources of help
- provide reassurance and help to cope
- help others understand
- legitimise seeking help and their concerns
- learn how to prevent further illness
- identify further information and self-help groups
- identify the 'best' health care providers.<sup>2</sup>

Patients' information needs are highly diverse. They are shaped by demographic characteristics including age, gender and socio-economic status, as well as the patient's particular circumstances, beliefs, preferences and styles of coping.<sup>3</sup> There are also important differences due to individuals' skills and abilities, with particular needs arising from low literacy, auditory/visual impairment and minority languages. The type of information that is sought by an individual patient is likely to change during the course of their illness. In the initial stages following diagnosis, there is a preference for practical information to support care decisions, including information on treatment options and their likely outcomes. More in-depth and specific information needs emerge later, when the patient's focus often turns to issues of self-care and long term prognosis.

Research points to the importance of tailoring information to patients' needs and characteristics. In comparison to general information, personalised materials tend to produce better health and service-related outcomes and are more highly valued by patients themselves. Computer-based systems are one means by which a tailored approach to consumer health information provision may be achieved, ideally using the patient's medical record as a prompt to deliver the right information at the right time. Written health information (leaflets, booklets) can be helpful to reinforce oral communication in medical consultations, as can material in other formats, including audiotape and videotape. Mass media communications can be used to reach groups unobtainable by other means and, if carefully targeted, can have a beneficial effect. Strategies for reducing inequalities by targeting information to people with low levels of health literacy have not been well studied, but there is some evidence of potential benefit.

### **Box 1: Information about cancer prevention and treatment**

*Sowden and Arblaster (2000)* conducted a Cochrane systematic review of mass media interventions for preventing the uptake of smoking in young people.<sup>4</sup> Six studies met the inclusion criteria, all using a controlled trial design. Two of the studies concluded that mass media was effective in influencing smoking behaviour. Both campaigns described in these studies had a solid theoretical basis, used formative research in designing campaign messages, and were relatively intensive over longer periods of time.

*McPherson and colleagues (2001)* conducted a systematic review to determine the most effective methods for delivering information to cancer patients.<sup>5</sup> This covered a variety of information types, including audiotapes, audiovisual aids, interactive media, information leaflets, telephone helplines, patient care records and educational programmes. The evidence indicated that the interventions had positive effects on a number of patient outcomes, such as knowledge and recall, symptom management, satisfaction, preferences, healthcare utilisation and emotional wellbeing. Two important findings from the review are that: a) cancer patients are a heterogeneous population whose information needs differ according to their preferences and coping styles; and b) tailoring information to the patient increases the relevance and enhances recall of the information provided.

*Black and colleagues (2002)* conducted a systematic review of the literature on the effectiveness of community-based strategies to increase women's participation in cervical cancer screening.<sup>6</sup> Nineteen studies were included in the review; mass media campaigns were most commonly evaluated, either alone or in combination with other interventions. Seventeen of the 19 studies measured outcomes in terms of smear rates and, of these, 12 reported statistically significant improvements compared to controls (although in some studies the actual difference was small). Of the four studies of mass media campaigns alone, the only one that was effective targeted a definite sub-population with tailored material. All five studies that combined mass media campaigns with other interventions were effective at increasing smear rates or early cancer detection.

*Eysenbach (2003)* conducted a systematic review of literature on cancer patients' use of the internet and its impact on health outcomes.<sup>7</sup> Twenty four surveys were identified, which included responses from a total of 8,679 patients with cancer. These covered four types of internet use: communication (email), community (virtual support groups), content (health information) and e-commerce. From the available evidence, the effect of electronic support groups is unclear, although recent studies suggest they can increase perceived social support and decrease loneliness. Internet information has positive effects on self-efficacy and task behaviour, empowers patients to make health-related decisions and improves confidence in the doctor-patient encounter. However, patients reported feeling overwhelmed by the sheer volume of internet output and confused by conflicting medical information about cancer treatments.

*Gaston and Mitchell (2005)* carried out a systematic review of studies evaluating approaches to providing information to patients with advanced cancer.<sup>8</sup> They concluded that consultation tapes have a small but significant effect on patients' knowledge and satisfaction. Summary letters can also be effective, but patients tend to prefer the audiotape format. There is some evidence that written information can decrease levels of anxiety. Take home materials can also be shared with friends and family, thereby increasing levels of practical and emotional support. The added effect of videotape information is uncertain.

*Jones and colleagues (2006)* compared various different approaches to delivering information to cancer patients.<sup>9</sup> They were particularly interested in the impact of information on psychological well being. Four hundred patients were recruited, and were randomised into eight groups defined by binary factors (personalised versus general information; patient interactively selecting information versus automatic production; and receive versus not receive anxiety management advice). The quantity of information that was automatically produced was much higher than the amount that patients chose for themselves. Participants who received automatically produced booklets were more likely to find the information useful and more satisfied with what they had received, but some found the booklets overwhelming. More of the patients who received personalised materials felt these told them something new and of relevance to their situation. They were also more likely to show the information to others and to say that it helped them in discussions about their illness and treatment. There was no significant difference between the three groups in relation to changes in anxiety or depression.

The research indicates that many patients want more information than they currently receive and that health professionals tend to overestimate the amount of information they supply. Leaflets on their own have not been shown to improve health behaviour or health status, but written information used as an adjunct to professional consultation and advice has been shown to improve patients' health knowledge and outcomes, particularly when it is personalised to the individual.

Alternative format resources, such as websites, can also improve knowledge and studies have demonstrated high user satisfaction and beneficial effects on self-efficacy and health behaviour. The internet is a valuable source of health information, but the quality and reliability of health websites is variable. Harm arising from unreliable websites may be under-reported. Although the digital divide remains a problem, there is some evidence of greater health benefit for disadvantaged groups when access barriers are overcome, for example by providing free computers. Initiatives designed to specifically target low literacy groups have had mixed results, with some studies showing beneficial effects on knowledge and behaviour, but there have been relatively few attempts to test the effect of these initiatives on reducing health inequalities.

Targeted mass media campaigns have been shown to increase awareness, but the effects may be short-lived. There is some evidence of impact on utilisation of services, e.g. uptake of cervical cancer screening, but little evidence of beneficial effect on health behaviour apart from smoking, where studies have shown that the mass media may be effective in reducing smoking rates among young people.

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## 4 Offering patients a choice of treatment and care packages

Failures in communication of information about illness and treatment are the most frequent source of patient dissatisfaction. The traditional model of decision-making assumed that doctors and patients shared the same goals, that only the doctor was sufficiently informed and experienced to decide what should be done, and that patient involvement should be confined to giving or withholding consent to treatment. However, this paternalistic approach now seems seriously outdated. Many, if not most, patients nowadays expect to be given information about their condition and the treatment options, and they want clinicians to take account of their preferences. Some expect to go further: to be actively engaged in the decision-making process, or even to take the decisions themselves. This type of partnership or patient-led approach is known as *shared decision-making*.

Shared decision-making has been defined as “*a process in which patients are involved as active partners with the clinician in clarifying acceptable medical options and in choosing a preferred course of clinical care*”.<sup>10</sup> When choosing a treatment or preventive procedure the aim is to select options that increase the likelihood of desired health outcomes and minimise the chance of undesired consequences. In modern clinical practice there are often multiple options for treating a problem and these decisions are sometimes ‘close calls’, i.e. the benefit/harm ratios are uncertain or marginal.<sup>11</sup> In these circumstances the best choice depends on how an individual patient values the potential benefits and harms of the alternatives. In shared decision-making the intention is that both the process of decision-making and the outcome – the treatment decision – will be shared.

Most patients expect to be given information about their condition and the treatment options and they want clinicians to take account of their preferences. Some expect to be actively engaged in the decision-making process, or even to take decisions themselves. The desire for participation has been found to vary with age, educational status and disease severity, but these factors explain only part of the variance. An age-related trend has been found in a number of studies – younger and better educated people are more likely to want to play an active role,<sup>12-14</sup> but despite the association between age and decision-making preferences, age on its own is not a reliable predictor of a patient’s preferred role.<sup>15</sup> Older people are particularly likely to suffer from the presumption that they are incapable of taking decisions or unwilling to face choices about their medical care. Care of patients at the end of life is a case in point. National guidance requires that do-not-resuscitate orders should not be applied without first discussing the issue with patients and/or their relatives, yet there is evidence that this does not happen in two thirds of cases.<sup>16</sup>

People’s preferences may vary according to the stage in the course of a disease episode and the severity of their condition. Surveys of healthy populations tend to elicit much more positive responses about involvement in decision-making than surveys of people with life threatening conditions. For example, an Australian population survey found that more than 90% preferred an active role in decisions about diagnostic tests or treatments,<sup>17</sup> whereas a British study of the decision-making role preferences of cancer patients found that 48% of those with breast cancer and only 22% of those with colorectal cancer wanted to be involved.<sup>18</sup>

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Patients cannot express informed preferences unless they are given sufficient and appropriate information, including detailed explanations about their condition and the likely outcomes with and without treatment. In other words, they need decision support. Patient decision aids are standardised evidence-based tools intended to facilitate the process of making informed values-based choices about disease management and treatment options, prevention or screening. They are designed to supplement rather than to replace patient-practitioner interaction. The content is usually based on reviews of clinical research and studies of patients' information needs. They use a variety of media to present the information in an accessible form to patients including leaflets, audiotapes, workbooks, decision boards, computer programmes, interactive videos, web sites, structured interviews, and group presentations. They do not set out to be didactic or prescriptive. Instead they aim to help patients clarify their values and preferences and weigh up the potential benefits and harms of alternative courses of action.

Most decision aids incorporate three key elements: information provision and risk communication, values clarification, and guidance or coaching in deliberation and communication. There are more than 500 decision aids listed on the Cochrane register ([www.ohri.ca/decisionaid](http://www.ohri.ca/decisionaid)) covering a wide range of conditions and treatment options, including cancer treatments.

### **Box 2: Patient decision aids for cancer screening and treatment**

*Jepson and colleagues (2001)* reviewed six controlled trials of decision aids focusing on informed choice in antenatal and prostate specific antigen (PSA) screening.<sup>19</sup> Uptake in the intervention groups was significantly higher than control for HIV testing, the same for Down's syndrome screening, and lower for cystic fibrosis screening. In the two trials of prostate screening the effects were inconsistent. The authors concluded that there was insufficient evidence to determine whether the provision of information about potential benefits and harms of screening affected uptake.

*Whelan and colleagues (2001)* carried out a systematic review to describe and evaluate the use of decision aids for cancer patients.<sup>20</sup> They identified 61 unique studies, including 18 randomised controlled trials, five non-randomised trials and various other study designs. More decision aids had been developed for patients with breast and prostate cancer than for other types of cancer. Decision aids increased patients' knowledge and involvement in decision-making. Anxiety and depression scores were not increased. Among men making decisions about prostate cancer screening, significantly fewer decided to proceed with screening after receiving a decision aid.

*Edwards and colleagues (2003)* looked at studies that assessed the effects of different types of individualised risk communication (i.e. information that is personalised to specific risk groups instead of presenting figures for the population as a whole) for patients who are deciding whether to participate in screening.<sup>21</sup> They identified 13 randomised controlled trials, ten of which addressed breast screening. Individualised information was associated with an increased uptake of screening. However the two studies that provided the most detailed risk estimates were the only ones to show a reduction in uptake of tests.

*Briss and colleagues (2004)* looked for studies that evaluated interventions to improve decision-making about cancer screening.<sup>22</sup> They reviewed 15 studies looking at the use of small media, counselling, group education, provider-oriented strategies, or combinations of these, to promote informed decision-making. The interventions helped to improve patients' knowledge and

promoted greater accuracy of risk perceptions, but few studies looked at whether they resulted in an appropriate level of participation in decision-making or whether decisions were consistent with patients' preferences or values.

*O'Connor and colleagues (2003)* organised an extensive systematic review of randomised controlled trials of decision aids for the Cochrane Collaboration.<sup>23</sup> They identified 34 trials published up to the end of 2002 that looked at decision aids aimed at helping patients to make treatment or screening decisions. In comparison to usual care, decision aids were found to increase patient involvement in decision-making by 30% (95% CI 10-50%), knowledge scores increased by 19 points out of 100 (13-24), the proportion of patients with realistic perceptions of the chances of benefits and harms improved by 40% (10-90), decisional conflict scores reduced by nine points out of 100 (6-12), the proportion of patients who remained undecided reduced by 57% (30-70), and agreement between patients' values and the treatments chosen increased. These improvements were achieved without harmful effects on satisfaction or anxiety levels. The review reported screening and treatment uptake rates in 16 trials, of which seven focused on decisions about major elective surgery. Six of the seven trials demonstrated 21-44% reductions in use of more invasive surgical options, without adverse effects on health outcomes.

These authors also found that more detailed decision aids performed better than simpler ones in respect of knowledge increases, realistic perceptions of likely benefits and harms of treatments and agreement between values and choice. Few of the trials published to date have included measures of cost-effectiveness, but among the three British trials that did include economic measures, decision aids were found to be cost-effective in one and would have been cost-neutral in two others if less expensive delivery methods (e.g. the internet) had been used.

The evidence suggests that shared decision-making is beneficial but not widely practised.<sup>24</sup> Doctors often fail to explore patients' values and preferences and risk communication is often poorly expressed by doctors and not well understood by patients. Communication skills training should be the main mechanism by which clinicians learn about and gain competencies in the principles and practice of shared decision-making, but it is rarely included explicitly in medical curricula.<sup>25</sup>

Decision aids for patients improve knowledge and information recall and lead to increased involvement in the decision-making process. Patients using decision aids experience less decisional conflict with no evidence of increase in levels of anxiety. Decision aids have also been shown to have an impact on health services utilisation, leading in some cases to reduced cost.<sup>26</sup>

In spite of policy commitments and evidence of benefit, initiatives to promote shared decision-making, better risk communication and fully informed decision-making have not been widely implemented. Well planned strategies are required which should include training for clinicians and the provision of high quality evidence-based decision aids for patients. One example of how this can be done is the UK urology informed decision-making project which is promoting shared decision-making for patients with prostate cancer using DVDs and booklets, personal decision forms and systematic training for urologists and specialist nurses.<sup>27</sup> The plan is to roll this out to all urology departments in the UK by April 2008 and to ensure that the methodology is transferable to other conditions.

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## 5 Providing support for self-care and self-management

At its most basic, self-care refers to the practices undertaken by individuals towards maintaining health and managing illness. A more comprehensive definition of self-care is offered by the UK Department of Health, as:

*“the actions individuals and carers take for themselves, their children, their families and others to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital”.*<sup>28</sup>

A range of interventions have been developed and implemented to improve patient self-care, with self-management education being the most common and well known. The principles of self-care have been delineated in a number of theoretical models, mostly developed within the fields of psychology and behavioural science. Of these, it is Bandura’s self-efficacy theory that is most widely referred to.<sup>29</sup> Self-efficacy refers to an individual’s belief in their capabilities to successfully learn and perform a specific behaviour. A strong sense of self-efficacy leads to a feeling of control, and willingness to take on and persist with new and difficult tasks. When applied to health, this theory suggests that patients are empowered and motivated to manage their health problems when they feel confident in their ability to achieve this goal. On this view, interventions for improving self-care should focus on confidence building, and equipping patients with the tools (knowledge and skills) to set personal goals and develop effective strategies for achieving them.

The cornerstone of government’s efforts to promote self-care is the Expert Patient Programme (EPP), launched in England and Wales in September 2001. Pilot courses began in 26 PCTs in April 2002, but by the end of the pilot phase (April 2004) almost 300 PCTs had implemented courses or were officially committed to the programme. By 2008, it is anticipated that the EPP will have been mainstreamed across the NHS. The EPP is based on the chronic disease self-management programme (CDSMP) developed by Kate Lorig and colleagues at the Patient Education Research Center at Stanford University, California. The CDSMP is a generic, lay led, community-based self-management course run over six weekly (two and a half hour) sessions. The programme aims to build patients’ skills, resources and confidence towards better managing their long term condition; the subjects covered in the courses include:<sup>30</sup>

- cognitive skills
  - relaxation and fatigue symptom management
  - anger, fear and frustration management
  - the role of healthy eating and exercise
  - communication skills
  - managing medication
  - managing depression
  - planning for the future and making an action plan
  - problem solving
  - making informed treatment decisions
  - working in partnership with the health professional team.
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Although it has been claimed that these self-management courses improve health outcomes, the current evidence for their effect on health status is mixed.<sup>31</sup> The effects may be greatest when the learning is reinforced by health professionals. Other strategies for supporting patients in caring for themselves include the use of self-monitoring equipment, self-treatment using over-the-counter medicines, self-help groups, patient-held records and patient access to personal medical information, and patient-centred telecare. Most studies of self-care or self-management have focused on chronic conditions such as asthma, diabetes or arthritis, but we identified a number of systematic reviews that included cancer patients or those at risk of cancer.

### **Box 3: Supporting self-care for cancer patients or those at risk of cancer**

*de Ridder and Schreurs (2001)* identified 35 controlled studies of interventions aiming to help chronically ill patients cope with their condition<sup>32</sup>. The studies were of the following chronic conditions: AIDS, asthma, cancer, cardiovascular disease, chronic pain, diabetes and rheumatoid arthritis. In all of the studies, a cognitive behavioural approach was adopted. While both problem-focused (e.g. self-management, lifestyle skills) and emotion-focused (e.g. relaxation, distraction) coping strategies were represented, interventions of the former kind prevailed. Generic and disease specific outcomes measures were used to evaluate effects on coping. Irrespective of the particular outcome measure used, the studies produced positive findings. However, small study sizes limit the conclusions that can be drawn from this. In some cases, the mediating role of coping on patient outcomes was evaluated by assessing the impact of the intervention on coping, and the impact of coping on the desired endpoint. Strong associations were observed in both sets of relationships. Due to variations across the studies, and the multi-component nature of many of the interventions evaluated, it was not possible to determine which coping strategies or components lead to the greatest improvements.

*Lancaster and Stead (2002)* examined the effectiveness of different forms of self-help materials for smoking cessation.<sup>33</sup> They were specifically interested in the impact of structured self-help materials rather than basic smoking cessation information. Sixty trials were identified; 33 compared materials to no intervention or standard materials and the remainder compared tailored or targeted materials or compared other variations of programmes. The content and format of the materials differed substantially, with the American Lung Association *Freedom from smoking in 20 days* manual the most commonly-used approach. A pooled analysis of eleven trials comparing self-help to no intervention produced an effect that just reached statistical significance. The studies found no benefit for adding self-help materials to face-to-face advice or nicotine replacement therapy. The evidence showed that tailored materials were more effective than standard literature, and the largest effect sizes were for trials that compared tailored materials to no intervention.

*Rehse and Pukrop (2003)* conducted a meta-analysis of 37 controlled studies of psychosocial interventions in adult cancer patients<sup>34</sup>. Specifically, they analysed the effects of such interventions on patients' quality of life. The interventions evaluated were classified under one of the following four headings: i) patient education programmes primarily providing medical or procedural information; ii) professionally guided support groups of cancer patients providing mutual help; iii) coping skills training, utilising techniques including biofeedback, behaviour modification and reinforcement schedules; and iv) psychotherapeutic interventions including psychotherapy and counselling. The overall effect size was 0.31, indicating a positive but moderate impact on quality of life. Effect sizes were greater for patient education; male only samples; interventions of longer duration (at least twelve weeks); where QoL measurements were

based on patient self-reports; where QoL referred to functional rather than emotional adjustment; and in studies that had higher than average methodological quality scores. A multivariate analysis found that, when all other variables were controlled for, duration of intervention was the only predictor of improved outcomes that remained significant. There were no significant differences between the effect sizes for social support, coping skills training and psychotherapy.

*Murray and colleagues (2004)* conducted a Cochrane systematic review to assess the effects of interactive health communication applications (ICHAs) for people with chronic disease<sup>35</sup>. ICHAs were described as 'computer-based, usually web-based, packages for patients that combine health information with at least one of social support, decision support, or behaviour change support'. Twenty four RCTs met their inclusion criteria which examined the following conditions: AIDS/HIV (2 studies); Alzheimer's/memory loss (2); asthma (6); cancer (3); diabetes (6); eating disorders (1); encopresis (1); obesity (2); and urinary incontinence (1). Primary outcome measures included knowledge, social support, self-efficacy, emotional outcomes, and behavioural and clinical outcomes. ICHAs were found to improve knowledge, social support, health behaviours and clinical outcomes. There was insufficient data to determine impact on emotional outcomes or cost-effectiveness. Results indicated probable positive effects on self-efficacy, but more data is needed to clarify this.

*Campbell and colleagues (2004)* systematically reviewed the evidence on peer support programmes for cancer patients<sup>36</sup>. Twenty one studies, involving 17 different programmes, met their inclusion criteria. While high participant satisfaction was consistently reported, many studies had low response rates and did not elicit feedback from non-respondents or drop-outs. Telephone and internet support groups offer anonymity to patients, and were reported to be of particular benefit to patients with less common forms of cancer, to homebound patients, to geographically distant patients and to those desiring privacy. Patients reported benefiting from the provision and exchange of information that support programmes offered, and the non-randomised studies found that patients had a better understanding of their cancer experience and were more informed as a result of their involvement in these programmes. There were three randomised trials (all of group-based peer support programmes), none of which found that peer support groups led to significant improvements in quality of life. In all three studies, peer group support had a marginally negative effect on certain outcomes including mental health, physical functioning, negative affect, general health, depression and anxiety, life satisfaction, self competency and social competency. One study, involving patients with Hodgkin's Disease, reported a decrease in activity level among peer support group participants.

Self-care interventions vary considerably in their objectives, content, method of delivery, duration and target population. There are significant limitations to the evidence base and in particular there has been insufficient evaluation of long-term outcomes, cost-effectiveness, comparative effectiveness of different self-care strategies, and of which components of complex interventions provide greatest benefit.

Nevertheless, self-management education for people with chronic conditions has been associated with improvements in knowledge, coping behaviour, adherence to treatment recommendations, self-efficacy, and symptom management. There is also some evidence of a reduction in health service utilisation and cost, and enhanced quality of life. While self-management education leads to short term improvements in health behaviour and dimensions of health status, these effects tend to diminish over time. By contrast, quality of life effects are more likely to be sustained beyond the intervention period.

Participation in self-help and support groups has not been shown to have any major effects on health behaviour or status, but many participants report benefits from sharing information, experiences and practical solutions. Support groups can benefit carers by improving their confidence, coping ability, family functioning and reducing the burden of care.

Patient-held records are generally found to be useful by patients and increase their sense of control. Recording consultations improves understanding and the uptake and recall of information, but neither of these interventions has been associated with improved clinical or behavioural outcomes.

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## 6 Obtaining feedback from patients by means of surveys

Patient feedback surveys are increasingly seen as a key component of healthcare quality monitoring and improvement.<sup>37</sup> In recent years there has been a trend away from global satisfaction measures towards more detailed measurement of patients' experience. In the UK, USA, Canada, Australia, Denmark, Norway, and many other European countries, findings from such surveys are now widely available.

A number of different rationales have been posited for organising patient feedback surveys. The following reasons are most frequently cited:

- To help healthcare staff understand the patient perspective
- To stimulate competition between providers in relation to quality benchmarks
- To monitor patients' experience against explicit standards
- To describe and explain variations in the experience of different patient sub-groups
- To motivate providers to make quality improvements
- To identify 'the best' providers and produce rankings
- To inform patients when choosing a provider.

The main way in which patients' views on healthcare performance have traditionally been sought is through the measurement of patient satisfaction. Satisfaction is not usually recorded routinely in healthcare, so specially designed surveys have to be organised to seek the views of representative samples of patients or members of the public. Satisfaction is an ill-defined concept which has been measured in many different ways.<sup>38-42</sup> Generally recognised as multi-dimensional in nature, there is no consensus on which domains should be included or which are most important. Patient satisfaction is sometimes treated as an outcome measure, i.e. satisfaction with health status following treatment, and sometimes as a process measure, i.e. satisfaction with the way in which care was delivered.

Satisfaction ratings reflect three variables: the personal preferences of the patient, the patient's expectations, and the realities of the care received.<sup>40;43;44</sup> Public attitudes are influenced by many factors, including the media, commercial pressures and by patients' interaction with health professionals. Expectations may also be influenced by cultural norms and by health status. Disentangling the effect of expectations, experience and satisfaction can be problematic when patient or public views are used to measure trends in performance. Studies have found systematic differences between the views of the public (healthy people/potential patients) and the views of current users of health services.<sup>45</sup> Patients' age and reported health status are associated with ratings of healthcare, and sex and socio-economic status can also make a difference to patients' evaluations, although the impact of these variables on hospital rankings is small.<sup>46</sup> Patients may be further differentiated in terms of disease severity, chronic versus acute illness, and so on and all these factors may influence their responses.<sup>47</sup> Expectations and concerns are also likely to be affected by the user's experience of health care and their knowledge of, or dependency on healthcare providers.

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Because of these problems, there has been a recent shift towards measuring patients' experience instead of asking them to rate their satisfaction with care.<sup>37</sup> Following qualitative research (interviews and focus groups) to find out what patients think are the most important features of their healthcare, fixed-response questionnaires have been developed focusing on specific dimensions of patients' experience.<sup>48</sup> Instead of asking patients to tick boxes indicating how satisfied they were using general evaluation categories (e.g. excellent, very good, good, fair, poor), they are asked to report in detail about their recent experiences with a particular hospital, primary care organisation, or clinician. This type of survey asks respondents to say whether or not certain processes or events occurred during a particular visit, a specific episode of care, or over a specified period. These questions are intended to elicit reports on what occurred (experience), rather than the patient's evaluation of what occurred (satisfaction). In each case, the resulting data represent the perception of the patient, but the response task is different in the two cases. The first asks "what was your experience?" the second asks "how would you evaluate that experience?"

Questionnaires that use these report-style questions are seen as being more useful for helping providers to determine what action to take to address quality problems. Knowing that, say, 15% of patients rated their care as "fair" or "poor" doesn't give a manager or clinician a clear view of what they need to do to improve procedures and processes in their hospital. On the other hand, knowing more precise details of what went wrong, for example, the proportion of patients who said they had to wait more than 15 minutes for the call button to be answered, and monitoring trends over time in these indicators, can be more actionable. Focusing on the details of patients' experience should help to pinpoint the problems more precisely.

#### **Box 4: Impact of patient feedback surveys on the quality of care in organisations**

*Draper and colleagues (2001)* described the establishment and impact of surveys that measured patient satisfaction with healthcare in Victoria, Australia.<sup>49</sup> Regular patient surveys have been carried out in acute hospitals in Victoria since the early 1990s. Six months after the first survey, the Department of Human Services in Victoria sought feedback from individual hospitals on the extent to which the survey results had been used as a basis for implementing changes. Generally, hospitals had focused on one of three areas for quality improvement: food services, physical environment or information provision and communication (particularly at discharge and around medications). However, the study found that most hospitals had not instigated action on the basis of survey results. Respondents highlighted the difficulties of pinpointing the wards/sections where problems were arising as a barrier against making system changes. The authors make various suggestions for helping hospitals to examine the implications of their survey results and act upon them.

*Hildenhovi and colleagues (2002)* implemented a patient survey in a Finnish university hospital's outpatients departments between 1997 and 1999.<sup>50</sup> The survey enabled the detection of strengths of the service and long-term trends from the patient's perspective. Patient evaluations improved year by year, despite the fact that the questionnaire focused on issues that were rated poorest by patients. The worst ratings related to information provision and adherence to appointment times. The authors concluded that the survey instrument can be used to generate information to stimulate quality improvements.

*Crawford and colleagues (2003)* conducted a systematic review of user involvement strategies, which included evidence on the impact of patient surveys.<sup>51</sup> This evidence is difficult to interpret, as surveys have often been used as one component in mixed-method initiatives. Nonetheless,

studies show that surveys can contribute to improved service delivery and quality of care. For example, national surveys of patients with coronary heart disease led to new services (rapid access clinics) and improvements in pain control and patient information.<sup>52</sup> Another survey, of surgical inpatients, led to revised admissions and discharge procedures/information, improved ancillary services and the establishment of a liaison group.<sup>53</sup>

*Gillies and colleagues (2003)* carried out an interview study with 1,104 physician organisations across the USA to compare various quality of care indicators between California and the rest of the US and explain the differences.<sup>54</sup> Physician organisations in California were more likely to have external incentives to improve quality and more likely to use recommended care management processes for treating patients with chronic diseases. Among other external incentives that may provide an incentive to adopt higher quality standards, physician organisations in California had a higher rate of public reporting of patient satisfaction results than those elsewhere.

*Sweeney and colleagues (2005)* evaluated the impact of the Patients Accelerating Change (PAC) project in England, which aims to facilitate health care providers' use of patient survey data to improve the quality of care.<sup>55</sup> They conducted interviews with 28 individuals in nine acute NHS trusts, and concluded that the PAC project had led to positive outcomes, including improved communication and information; patients feeling valued and listened to; and improved processes and procedures (e.g. discharge processes and pain management). It had also helped to focus attention on patient and public involvement within the provider organisations. Negative effects included pressures on staff time and some resistance to change on the part of other staff not involved in the project.

*Leddy and Wolosin (2005)* analysed patients' ratings of satisfaction with pain control obtained from surveys carried out in 240 hospitals across the USA involving more than 3,000,000 patients.<sup>56</sup> The average score for all patients treated before the implementation of Joint Commission standards on pain control, which included a requirement for regular measurement and recording of patients' experience of pain, showed a small but significant improvement after implementation. Although satisfaction with pain control varied within a relatively narrow range in the two and a half years before the institution of the standards, it subsequently showed an overall upward trend. The authors concluded that clinicians should continue to obtain regular feedback on patients' satisfaction with pain control.

*Davies and Cleary (2005)* interviewed clinical and administrative staff in hospitals in Minnesota to obtain information about the use of patient survey data in quality improvement.<sup>57</sup> Interviewees described a number of quality improvement initiatives that had been stimulated by survey results, including improvements in waiting times and access arrangements, better patient information and education, improved pain control and training front of house staff in customer relations. However, they identified more examples of barriers to change than success. Organisational barriers included lack of supporting values for patient-centred care, competing priorities, and lack of an effective quality improvement infrastructure. Professional barriers included clinicians and staff not being used to focusing on patient interaction as a quality issue, individuals not necessarily having been selected, trained or supported to provide patient-centred care, and scepticism, defensiveness or resistance to change following feedback. Data-related barriers included lack of expertise with survey data, lack of timely and specific results, uncertainty over the effective interventions or time frames for improvement, and consequent risk of perceived low cost-effectiveness of data collection. Factors that appeared to have promoted data use included board-led strategies to change culture and create quality improvement forums, leadership from senior physicians and managers, and the persistence of quality improvement staff over several years in demonstrating changes in other areas.

*Coulter (2006)* examined trends in patients' experience as measured in 19 English national patient surveys carried out between 1998 to 2005.<sup>58</sup> Improvements were observed in those areas that have been the subject of coordinated action, e.g. hospital waiting times, cancer care, coronary heart disease and mental health. Most patients reported positive experiences of primary care, but many wanted more information, especially about their medicines. In secondary care, many patients wanted more involvement in treatment decisions, more help with pain relief, and better support for self-care. Although most patients said they were treated with dignity and respect by NHS staff, there were signs that care is still often delivered in a paternalistic manner, with many patients given little opportunity to express their preferences or influence decisions about their care. Transitions between different health care providers, and between hospital and home, were not as well-coordinated as they should be. Many patients wanted more help with recovery and rehabilitation, including financial and employment advice and information about relevant support services. Nevertheless, the patient survey results suggest the quality of NHS care is improving, albeit slowly.

Well-designed patient surveys appear to give a reliable picture of the quality of care in healthcare organisations. There is an association between poor quality experience and worse health outcomes and poor results on patient care surveys are associated with a higher rate of malpractice lawsuits.

Few studies have looked specifically at the impact of patient feedback on the quality of cancer care, but in general the evidence suggests that patient surveys can be used to stimulate quality improvements. Two national surveys carried out in 2000 and 2004 of patients receiving cancer treatment in hospitals in England found significant improvements between the two time periods. Patient feedback surveys are most effective if the results are publicly available and if healthcare providers use them as part of a broader quality improvement strategy.

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## 7 Involving service users in decisions about service development and reconfiguration

There is increasing recognition that a high quality health service is one which is both organised around and responsive to the needs of the people who use it. To this end, patients and the public must have genuine opportunities for involvement in decisions about their own care and the way that services are delivered. There is substantial overlap between public involvement and other lay participation strategies, which can be confused rather than clarified by the definitions and concepts that are available. In the UK, the term patient and public involvement (PPI) is often used as shorthand to describe the processes by which members of the public can shape service development. However, a useful distinction between these types of involvement can and should be made, with patient involvement describing “the involvement of individual patients, together with health professionals, in making decisions about their own care”.<sup>59</sup> Public involvement differs from this both its methods and objectives. By involving the public in *strategic* decision-making, improvements at an organisational level are hoped for.<sup>51</sup> Public involvement is also different from community development, insofar as the latter (at least in its ideal form) focuses on enabling communities to themselves define and resolve problems in their local areas rather than engaging them in dialogue within organisational structures.<sup>60</sup>

Unsurprisingly, the notion of having a say in how health services are planned, developed and delivered is popular among the general public. Particularly as users of health service, lay individuals often feel that they can make valuable and unique contributions to decisions about service provision. In a recent British survey, the overwhelming majority of respondents were generally supportive of the overall concept, as well as indicating an interest in getting personally involved in decisions about local GP and hospital services.<sup>61</sup> It found that:

- 90% of the public agree that local people ought to have a say in how local health services are run
- 74% would like to have a say in how their GP surgery is run
- 74% would like to have a say in how their local hospital is run.

While people like the idea of sharing decisions about local services in theory, they appear to be less keen on getting involved when actual opportunities arise. Indeed, many public involvement initiatives have reported difficulties recruiting or retaining sufficient numbers. This does not necessarily reflect public apathy, and could be equally attributable to the ineffectiveness of organisation’s recruitment strategies. Nonetheless, there is an apparent disparity between interest in the principle and practice of shaping service development among the general public.

### **Box 5: Effects of public involvement on service development and quality**

*Crawford and colleagues (2003)* updated and extended an earlier systematic review<sup>62</sup> on the effects of involving patients in the planning and development of health care.<sup>51</sup> They identified papers which described a wide range of involvement methods, often within the same study; these included patient forums and participation groups, citizen’s juries, public meetings and user

representation at meetings. These show that user involvement can positively contribute to changes in services: for example, by making services more accessible through simplification of appointment procedures, longer opening hours, improvements in transport and targeting access problems for people with disabilities. There is also evidence that involvement can lead to new services being commissioned and the production of new or improved sources of patient information. In most studies, users welcomed the opportunity for involvement and benefited from improved self-confidence. However, there were also some negative findings, including concerns that user involvement was employed to 'rubber stamp' decisions that had already been taken. Decision-making may also be slowed down when service users are involved and studies document many examples where such involvement has not resulted in changes to the organisation and delivery of services. The authors note that the evidence-base for the benefits of user involvement is not strong, and that studies have tended to focus on qualitative process evaluation or surveys of service users and/or providers. Consequently, impact on service use, patient satisfaction, health or quality of life is not known. The literature review indicated that some staff felt resentment towards patients in being given a voice to shape service development, when they themselves had none.

*Simces and colleagues (2003)* were commissioned by Health Canada to review evidence for the link between public involvement/citizen engagement and quality health care.<sup>63</sup> They identified studies which explored PI/CE across various areas including planning and development of healthcare; healthcare governance; and community development/collaborative practices. Such studies claim a range of benefits in relation to health care or health outcomes. However, in practice they provide limited empirical evidence to demonstrate that public involvement contributes to better quality healthcare and few studies undertook any systematic evaluation of public involvement using specific criteria or outcome measures.

*Carr (2004)* collected literature on user participation in social care services.<sup>64</sup> Although there is much interest in this issue, there is a paucity of research monitoring and evaluating the outcomes of service user involvement. The author outlines the problems of measuring cultural and organisational change, and its sustainability. Studies have indicated the benefits of user involvement for those personally involved, including increased social contact, knowledge and skills, opportunities for learning and self-esteem. However, it is not clear whether it has an impact at a collective level – for example, in the instigation of change or improvement of services. The review found that much attention has been given by service providers to the process of user consultation, but not to the aims and outcomes of that consultation.

*Farrell (2004)* reported the findings of twelve projects to improve patient and public involvement in health care, five of which specifically examined user involvement in the development and/or evaluation of services.<sup>65</sup> These projects were evaluated using stakeholder surveys or interviews, or a combination of these methods. The studies provide some evidence that user involvement can have a number of beneficial outcomes: for example, increases in people's confidence, understanding and skills; influence on policies, plans and services; and sharing of learning, resources and expertise across local health economies. Potential barriers to user involvement include a differences of opinion about what constitutes an appropriate level of involvement; a perception among the public that health service managers do not welcome their involvement; a failure to create working partnerships with the voluntary and community sector; and insufficient efforts to raise awareness of user involvement or publicise specific opportunities.

*McIver (1998)* reported on an evaluation of six citizen's juries set up as NHS pilot schemes between 1996 and 1997.<sup>66</sup> This sought to: assess the extent to which citizens juries was effective in enabling local people to contribute to debates about local health services; to assess the benefits and drawbacks of citizens juries; and to consider citizens juries in the context of other public

involvement methods. Through the citizens juries, people were able to formulate practical recommendations about courses of action and these recommendations did have some influence of decision made by health authorities. Other benefits included: allowing health authorities access to a wider range of views than they were used to; facilitating the development of informed public views, which were felt by health authorities to be particularly useful; increased knowledgeability among participants about the NHS; and providing members of the public with a route into further participation in NHS practices. The drawbacks of this approach were: the time and effort needed to plan the jury; the associated costs (approximately £16,000 plus staff time); and that only a small number of people could participate who may not be representative of the broader local community. The authors notes that citizens jury pilots addressed many of the shortcomings of other public involvement methods because: they were clear about the role the public would play; they had built-in mechanisms to ensure views would have an influence on services; they addressed practical issues (e.g. physical access, transport, information) that contribute to good public involvement.

*Stevenson and colleagues (2004)* outlined the findings of research, commissioned by the Scottish Executive Development Department, into the use of People's Juries and People's Panels in Social Inclusion Partnerships to assess how useful these approaches are for increasing community involvement and input into local decision-making.<sup>67</sup> They concluded that these methods had limited impact on specific plans or strategies in Social Improvement Partnership areas. In some cases, juries and panels were integrated into wider structures and systems but in others they were viewed as 'stand-alone' initiatives. Both methods are resource intensive, and there is clear evidence that effectiveness was restricted as insufficient time and resources were devoted to them. Additionally, they are likely to be more effective when addressing a specific topic or issue, when linked to existing planning or budgetary cycles and when their recommendations fall within the responsibility of a single organisation.

*Pickard and colleagues (2002)* investigated the involvement of users in clinical governance activities within Primary Care Groups (PCGs) and Trusts (PCTs).<sup>68</sup> They collected data from key stakeholders in 12 PCGs or PCTs, using semi-structured interviews. Despite an organisational commitment to lay involvement in clinical governance, in practice little is being done. Lay members of PCG/PCT boards rated the influence on decision-making as low, and the authors question whether public viewpoints can realistically shape professional viewpoints. Lay board members were also relatively 'safe', as they were largely drawn from the professional strata.

The evidence base for public involvement is relatively weak and none of the studies we identified looked specifically at its impact on the quality of cancer care. There are many published accounts of public involvement initiatives, but few provide data on benefits or costs, and almost none has involved a formal assessment of outcomes. In part, this is likely to reflect the difficulties of evaluating public involvement projects, and the lack of an agreed framework for such evaluation. While more evaluations are required, these should be informed by a much needed debate on how outcomes should be defined and measured. Importantly, the aims of public involvement, against which initiatives will be measured, need to be understood both from the perspective of participants as well as those of managers and/or professionals.

Where the existing literature is most instructive is in identifying a number of factors which promote or hinder public involvement. These include lack of clarity about aims and objectives; resource limitations and organisational constraints; professional or managerial resistance; problematic relationships between stakeholders; and concerns about representativeness. Acknowledging these barriers and developing clear strategies to overcome them would be a useful

starting point for future projects, and should guide the development of more effective strategies for devolved governance in the health sector.



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## 8 Conclusions

The evidence suggests that providing information to cancer patients or those at risk of cancer can be very beneficial, especially if it is personalised to the individual and offered at appropriate stages in a care pathway. Written, audio, video and computer-based information materials can improve patients' knowledge and understanding of their condition and the treatment options. When used as part of a well-planned educational campaign, information has been shown to reduce risk factors such as smoking and increase uptake of cancer screening. Few studies have examined the cost-effectiveness of providing information to cancer patients, but, since it can enhance patients' knowledge and ability to cope, it would appear to be a worthwhile investment.

Patient decision aids have been shown to increase patients' knowledge, involvement in decision-making and preventive behaviour, and they lead to more appropriate use of tests and treatments. In some circumstances they have also been shown to improve cost-effectiveness by reducing use of unnecessary interventions. Well-designed evidence-based decision aids could bring considerable benefits to NHS cancer patients. The urology informed decision-making project for prostate cancer patients is an important initiative that should be extended to other cancer specialties.

Support for self-care should be a very important priority now that patients are living longer with cancer as opposed to dying from it. There are many ways in which such support can be provided, including educational programmes, telephone and internet support groups, professional and peer support. Well planned education and support can help patients cope with the effects of their illness, increasing their sense of self-efficacy and encouraging the adoption of healthier lifestyles. In some cases this has led to a reduction in consultation and admission rates with resultant cost savings. Self-management education appears to work best when it is fully integrated into clinical care and when patients' learning is supported and reinforced by health professionals at every opportunity.

An association has been found between poor quality experience and worse health outcomes, so reviewing and improving patients' experience should be on the agenda of the boards of all healthcare organisations. Surveys of patients' experience can help staff view their services from the patient's perspective and they have been shown to act as a stimulus for quality improvements, especially when the results are made available to the public.

Public involvement in service development can lead to improvements in quality and responsiveness, but it is important to avoid mere tokenism when trying to engage people in this way. More intensive efforts to secure lay involvement in determining priorities, for example citizen's juries, are more effective than traditional consultation methods but they are fairly costly to organise. While there are benefits to be gained from involving lay people at all levels of policy and practice, the evidence points to greater effectiveness from directly involving patients in their own care and by providing personalised information and support.

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**Picker Institute Europe**

King's Mead House

Oxpens Road

Oxford OX1 1RX

Tel: +44 (0)1865 208100

Fax: +44 (0)1865 208101

Email: [info@pickereurope.ac.uk](mailto:info@pickereurope.ac.uk)

Website: [www.pickereurope.org](http://www.pickereurope.org)

Charity Registration no: 1081688



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