

Effective Health Care

Bulletin on the effectiveness
of health service interventions
for decision makers

This bulletin focuses on
the communication,
information giving and
sharing of decisions
between health
professionals and
people with cancer.



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Informing, communicating and sharing decisions with people who have cancer

- Current NHS policy emphasises the need for good communication between health professionals and patients.
- The most common complaints made by people with cancer are about poor communication and inadequate information.
- Patients cannot express informed preferences about their care, choose to be involved in decision-making, or indeed choose not to participate, unless they are given sufficient and appropriate information.
- Health professionals need to know how best to elicit patients' need and readiness for information as well as their desire for involvement in decision-making.
- Health professionals are likely to need training and support if patients' information needs are to be met. Key issues include: placing a higher priority on patient information; understanding patients' needs and preferences; and helping patients to access and understand relevant and appropriate information.

A. Background

There is widespread agreement that people should be informed about health care options and involved in decisions about their own care. In England and Wales, The National Institute for Clinical Excellence (NICE) is intent on achieving a patient focus in its work and *The NHS Plan* emphasises the need for patients to have more say in their own care and more influence over the way in which the NHS works.¹ Similarly, *The NHS Cancer Plan* for England and Wales emphasises the need for good communication between health professionals and patients, both for delivering high quality care and for empowering people to be involved in decisions about their own care.²

If the goals of current NHS policy are to be achieved then many issues will need to be addressed. A number of possible barriers relating to the effective involvement of patients in decisions about their own care have been identified.^{3,4} These include uncertainty about patients' desire for participation, the types of information needed and problems with accessing suitable patient materials. Eliciting the preferences of patients and involving them in decisions about their care requires that health professionals have excellent communication skills and that good quality information is readily available to patients when it is needed. Adequate resources will have to be made available, as there are costs associated with developing, providing, using and dealing with the consequences of initiatives to support patient participation.⁵

This bulletin focuses on the communication, information giving and sharing of decisions between health professionals and people with cancer. It does not address issues of communication with the general public, those undergoing cancer screening or patients suspected of having cancer. The bulletin draws upon evidence from systematic reviews produced by the Cochrane

Consumers and Communication Group, other systematic reviews and from guidance produced by the National Cancer Guidance Steering Group, (see appendix for Methods).

A.1 Patient-centred care

Patient-centred care has been defined in a number of different ways and there is currently little consensus about the exact meaning of the term.⁶ However, it is usually taken to mean: the use of active listening skills by professionals; encouraging patients to express their agendas; attempting to understand patients' points of view and expectations; and working with patients in the management of their illness.⁷ Improving communication, meeting patients' information needs and sharing decisions can be seen as components of patient-centred care.

B. Communicating with patients

In 1993 the General Medical Council (GMC) recognised the need to teach communication skills as part of the British undergraduate medical education. Despite such training, the most common complaints made by cancer patients are about poor communication and inadequate information.^{8,9} These complaints are not surprising given the findings from a survey of all consultant non-surgical oncologists working in the UK.¹⁰ Eighty-three per cent of the 476 consultants contacted responded; almost half considered that they had not received sufficient training in communication skills. These clinicians had stress factor scores for dealing with patients' suffering which were significantly higher than those who felt sufficiently trained (29% vs 21%, $p < 0.0001$). Clinicians' ability to communicate with patients was not directly assessed. This finding suggests that training may have a role to play in managing stress. Generic

communication skills training is advocated for health professionals as part of *The NHS Plan*.¹ It is likely that training programmes will include instruction in identifying and meeting the information needs of patients, along with facilitation of patient involvement in decision-making, where this is desired.

A recent systematic review evaluated communication training programmes for nurses.¹¹ Of the 14 studies included, eight were based in an oncology setting (two randomised controlled trials (RCTs), one controlled trial and five pre-post test). Only one study measured effects on patients; this (RCT) found reduced levels of anxiety but no improvement in health professionals' empathy skills (the only professional outcome measured). The other RCT and the controlled trial found improvements in health professionals' attitudes. The five pre-post test studies reported mixed results. The findings of this review should be treated with some caution. It is unclear whether all relevant studies were identified and the quality of the included studies was not assessed.

An overview of five studies evaluating training programmes specifically for health professionals dealing with people with cancer found positive changes in communication skills in some participants.¹² Those who reported more negative attitudes at the beginning of the training programme appeared to benefit most. The programmes were based around the acquisition of specific skills and/or strategies for dealing with specific situations.

A large UK-based RCT is in progress in which approximately 180 oncologists have been randomised to receive training based on the Cancer Research Campaign Psychosocial Oncology Group Communication Skills Training Model.¹³⁻¹⁴ The training includes exercises and activities for skills development, knowledge acquisition and personal awareness of how these impact on both physician and patient. Each participant defines his or her own

learning needs. Doctor outcomes include empathy and psychosocial support, checking patients' understanding of information, and identification of patients' cues. Patient-related outcomes include participation during consultations, satisfaction with communication, recall of information and willingness to disclose psychosocial concerns. The results of this trial are due to be reported later this year.¹⁴ An ongoing systematic review aims to assess the effects of interventions to promote patient-centred care within clinical consultations.¹⁵ Preliminary findings suggest that the types of training methods used and the communication skills taught differ widely. The full results of this review will be published later this year.

Box 1 Criteria for producing 'good' quality patient information

Duman & Farrell ²¹	CHiQ ²⁴	Entwistle & O'Donnell ²³
informs about condition and available treatments and options	accessibility – appropriate format	clear statement of aims
comprehensive, unbiased information about outcomes	accuracy	relevant
outlines uncertainties and gaps in knowledge	appropriateness	accurate
caters for people from a diverse range of backgrounds	availability	accessible, comprehensible
regularly reviewed and updated	continuity – information is presented with other resources	acceptable
integrated into a planned shared decision making programme	currency – being up-to-date	gives further sources of information
simple and easily understood language and design	legibility – clear presentation	reliability of information
	originality (not duplicating other sources)	
	patient involvement	
	readability	
	reliability	

C. Informing patients

A recent survey of over 2000 people currently receiving treatment for cancer in one of 34 hospital out patient departments in the UK found that 87% of people preferred to be given as much information about their illness as possible (both good and bad).¹⁶ Information is required for different purposes: understanding the presenting symptoms and/or disease; learning about available services; and participating in decisions about treatment options.¹⁷ Information can be provided in a variety of ways. Patients cannot express informed preferences about their care, choose to be involved in shared decision-making, or indeed choose not to participate, unless they are given sufficient and appropriate information. Findings from recent focus groups carried out with cancer patients suggest that people report experiencing a dearth of information although a great deal is theoretically available.¹⁸

In addition, current information materials often omit relevant data, fail to give a balanced view of the effectiveness of different treatments, ignore uncertainties and rarely promote a participative

approach to decision-making.¹⁷ Improving the quality of information available to patients is a key component of UK health policy. Both *The NHS Cancer Plan* and *The Cancer Information Strategy* discuss communication and the provision of good quality information materials.^{2,19} To oversee the development, content and availability of cancer information, a new Cancer Information Advisory Group is being set up.

In the meantime there are instruments available to help judge the quality of written information about treatment options²⁰ and also to assist in the production of good quality information materials.²¹⁻²³ See box for criteria for producing 'good' quality patient information.

Current sources of evidence-based cancer information include *The Cancer Library* which is available via *The Cochrane Library*. *The Cancer Library* provides a regularly updated collection of summaries of Cochrane systematic reviews written specifically for consumers. A Cancer Database is also being developed by Macmillan Cancer Relief and The Centre for Health Information Quality (CHiQ) which will be a source of reference to information materials about cancer and its management.²⁴ The database is to

be piloted in four information services during Spring 2001, then following an evaluation it will be available via the NHS Direct on-line website <http://www.nhsdirect.nhs.uk>. The National Electronic Library for Health will also include information for patients and the public (<http://www.nelh.nhs.uk>).

C.1 Tailored information

An overview of 44 articles addressing the information, education and communication needs of people with cancer published between 1990 and 1997 emphasised the importance of tailoring information to meet patients' educational background, cultural orientation, and general level of comprehension.²⁵ A recent Scottish RCT has also shown that patients with cancer prefer information based on their own medical records rather than general information.²⁶

The Teamwork Project aims to help people with cancer work in partnership with health professionals with the aid of a Personal Information File.¹⁸ The file is in two main parts. One contains general information about cancer, tests, diagnosis, treatment and care and relevant information can be added at any time; the second is a personal health diary where a record is kept of health and health

care including personal test results and details of medication prescribed. The file is currently being evaluated in several NHS Trusts.

Other personalised information includes recordings or summaries of consultations between people with cancer and their doctors. A recent systematic review of eight RCTs has evaluated the effects of recordings or summaries of consultations given to people with cancer.²⁷ There was considerable variation between the studies in terms of interventions, participants and outcomes. Interventions ranged from giving audiotapes to people at the end of the consultation to making a written summary of the key points discussed during the consultation. Participants differed in terms of type of cancer, length of time since diagnosis, and whether they received 'good news' or 'bad news' during their consultation. Outcomes included uses and opinions of the recordings or summaries, information recall, experience of health care, and health and well-being.

Across the seven studies which provided data, between 83% and 96% of participants receiving tapes or letters reported that they had found them useful. Four out of seven studies also reported better recall in the groups which received personalised recordings or summaries than in the control groups. Of the six studies that assessed anxiety and/or depression, none reported statistically significant differences between the intervention and control groups. However, one study found mixed results among participants in the intervention group; psychological morbidity increased at follow-up in those with a poor prognosis compared with those with a better prognosis.

Although the quality of the trials was poor, overall the evidence suggests that providing a record of the consultation can increase both the amount of information recalled and satisfaction with the information given. There is some evidence to suggest that recordings might encourage

participation in subsequent consultations and no clear evidence that they affect psychological health (either positively or negatively). Health professionals might want to consider giving either written summaries or audio-tapes of consultations to patients who have expressed a preference for this type of information.

Health professionals are likely to need support if patients' information needs are to be met. The learning needs of clinicians in fulfilling the information needs of patients include: placing a higher priority on patient information; understanding the patient's needs; understanding the emotional aspects of learning; helping patients to understand, learning from the patient and knowing about information sources.²⁸ Another issue to be addressed is who should be routinely providing patient information?¹⁸ Ensuring that such needs and issues are addressed in both undergraduate and continuing education will help in achieving the goals of current government policy.

As well as the challenges to health professionals in meeting peoples' information needs, organisational challenges have also been recognised and recommendations made.²⁸ These include: treating patients' information needs as a core activity; ensuring adequate funding, space and time devoted to patient information; producing, implementing and reviewing guidelines on patient information and auditing methods of working.²⁸

D. Involving patients in decision-making

The shared decision-making model is increasingly being advocated as a way of promoting clinical effectiveness and more appropriate and efficient use of resources.³ A partnership between professionals and patients in which both

contribute to decisions about treatment or care is encouraged. This differs from the informed choice model where the emphasis is on the patient to make the decision and from the more traditional model where the health professional makes the decision.²⁹⁻³²

People are likely to vary in the extent to which they want to participate in decision-making as well as in which decisions. Health professionals will need the necessary skills to elicit preferences for involvement along with other communication skills.³³ Other necessary conditions are likely to include partnership, explicit discussion, an informed patient, and complete arrangements for follow-up.³⁴

D.1 Decision aids

One way to support patient involvement in treatment decision-making is through the use of decision aids. Decision aids can help people make specific and deliberative choices by providing information on the options and outcomes relevant to their health status.³⁵ Decision aids may also include other information about the disease or condition, probabilities of different outcomes for the individual, and the opinions and experiences of others. These aids include decision boards, interactive videodiscs, computer programmes, audiotapes, and printed material.

The effectiveness of decision aids has been assessed in three reviews,³⁶⁻³⁸ one of which has been produced by The Cochrane Consumers and Communication Group.^{35, 38} All three reviews included studies which were available up to and including 1998. The search strategy used in The Cochrane review has been re-run and the same inclusion criteria applied, with the addition that participants had to have a cancer diagnosis.

Four RCTs examining the use of decision aids with cancer patients were identified (Table 1). Three included women with breast cancer³⁹⁻⁴² and one included men with prostate cancer.⁴³

Table 1 RCTs of decision aids for cancer patients

Author, year, country, randomisation, follow-up	Population	Intervention	Results	Comments
<p>Davison 1997⁴³ Canada Randomisation procedure: Block Length of follow-up: 5-6 weeks</p>	<p>Population: Men (n=60) newly diagnosed with prostate cancer Decision: which treatment to undergo</p>	<p>G1. 'Empowerment' (n=30) list of questions & a pack of information (based on their needs and wants) to assist with decision-making G2. Control (n=30) given information package and told it might be useful to read</p>	<p>Assumed role in decision making: significantly higher proportion of men in G1 reported that they assumed a more active role in decision-making than in G2 ($\chi^2=11.32$, $P<0.001$) % assuming an active role G1=56.7%, G2=16.7% % assuming a collaborative role G1=33.3%, G2=50.0% % assuming a passive role G1=10.0%, G2=33.3% Anxiety: no sig. differences Depression: no sig. differences</p>	<p>85% of participants read all written information Most men reported the question list was useful</p>
<p>Goel 1998^{40,41} USA Randomisation procedure: Cluster randomised using surgeons in blocks of 8 (randomly generated numbers) Length of follow-up: 6 months</p>	<p>Population: Surgeons: general surgeons practising in community hospitals Patients: women with newly diagnosed stage I/II breast Decision: whether to undergo a mastectomy or breast conserving therapy</p>	<p>G1. Decision aid (n=86) tape and workbook which included explicit presentation of probabilities, photographs and graphics (based on published guidelines and research where possible). Also included a values clarification exercise G2. Control (n=50) pamphlet containing identical information content but had no numbers, photographs, graphics, or values clarification exercise</p>	<p>Anxiety: no sig. differences Knowledge: scores were similar across the groups. The mean knowledge score in G1 was 14.7 (SD=2.0) and 14.4 (SD=2.2) in G2 ($P=0.433$) Decisional conflict post-intervention: Overall mean decisional conflict scores: 1.98 (SD 0.52) in G1 (n=78) and 2.08 (SD 0.46) in G2 (n=45). The differences were not statistically significant but there was a trend for lower decisional conflict in the decision aid group Decisional regret at 6 months follow-up: no sig. differences between groups</p>	<p>Comparisons were corrected for cluster randomisation Participants in G1 reported being in favour of the decision aid More than 85% wanted to take part in decision-making cost = greater than \$2,500 (Canadian)</p>
<p>Maslin 1998⁴² UK Randomisation procedure: Not stated Length of follow-up: 9 months</p>	<p>Population: Women (n=100) from a specialist breast cancer unit who had just had a diagnosis of breast cancer confirmed Decision: whether to undergo radiotherapy, chemotherapy or surgery</p>	<p>G1. Interactive video disk (IVD) (n=51) which provides information about cancer and treatment choices, exploring issues of uncertainty and variations in practice. Based on research evidence and intended for use as a shared decision-making programme G2. Standard care (n=49). Usual care consisting of standard information and care from a multidisciplinary team</p>	<p>Acceptability of IVD 82% found IVD to be just about the right length 96% found it to be interesting or very interesting 92% found it to be easy or very easy to understand 72% felt they had a much clearer idea about breast cancer 67% were glad they had used it 28% found it helpful but would not necessarily use it again 94% found it beneficial 92% would recommend to someone who had breast cancer 54% stated it had been interesting but had not influenced their decision 30% felt it had definitely influenced their decision Anxiety and depression: significant fall in anxiety at 9 months ($p<0.001$). No real change in depression scores in either group Health status: a slight fall in anxiety, which was not significant. The mental health score suggested a significant improvement within the IVD group, median score rising from 60 at onset to 68 ($p=0.02$) Treatment decision: no statistically sig. difference between the groups Nine months after diagnosis 12.5% of the women said that the IVD had changed their choice of surgical treatment. Of these 14.2% said the IVD had changed their choice of adjuvant therapy Across both study groups 21% of women said the doctor made the decision, 15% said the decision was shared between the patient and doctor, and 44% said the decision was shared between the patient, clinical nurse specialist and the doctor</p>	<p>Unclear whether some of the results presented are based on between or within group comparisons Disk was positively evaluated by those who used it</p>
<p>Street 1995³⁹ USA Randomisation procedure: not stated Length of follow-up: not stated</p>	<p>Population: Women (n=60) with stage I/II breast cancer Decision: whether to opt for a mastectomy or breast-conserving therapy</p>	<p>G1. Interactive, multimedia programme (n=30) 'Options for treating breast cancer' Information about the disease, treatment options and experiences of other women using text, graphics, audio narration, music and video clips. At several points patients are prompted to ask questions, express concerns and offer options when they see their physician. Takes 30-45 minutes to complete G2. Brochure (n=30) 'Care of patients with early breast cancer' containing similar information (apart from experiences of other women) to the multimedia programme but in a written form</p>	<p>Knowledge: women in G1. (mean 75.5%, SD=13.64) tended to learn more than those in G2. (mean 71.4%, SD=15.17%) ($F=3.30$, $P=0.07$) Optimism about future: no sig. differences between the groups Treatment decision Number of women who chose breast conservation: Group 1. 76% (23/30) Group 2. 58% (17/30)</p>	<p>In some cases data were not presented in terms of differences between the two groups</p>

In breast cancer patients making major treatment decisions, little evidence was found that: video disk presentations were better than usual care;⁴² interactive multimedia better than written information;³⁹ or a tape and workbook better than a pamphlet.^{40, 41} A very small (non-significant) difference was found toward there being less decisional conflict (agreement/disagreement about being certain, informed, clear about values and supported in decision making) in the tape and workbook group.^{40, 41} The costs of developing and evaluating the tape and workbook were estimated to be more than \$250,000 (Canadian).^{40, 41}

In contrast, there was some evidence that decision aids were helpful for men with prostate cancer in reducing anxiety and influencing decision-making about treatment.⁴³ Men exposed to an 'empowerment' intervention (an information and question pack based on their needs and wants) assumed a significantly more active role in decision-making and had lower anxiety levels than men who were given just an information pack.⁴³ Overall support was also found for decision aids in the Cochrane review where patients with a variety of different diagnoses were included.³⁵⁻³⁸ Improved knowledge, increased participation and decreased decisional conflict were reported.³⁸

Although questions around the use of decision aids remain, including the type of aid to use, the choice of appropriate outcomes to measure and their effect on communication between patients and professionals,³¹ they can provide a useful way of displaying and providing information about treatment options.

D.2 Barriers to implementation

The feasibility of implementing shared decision-making programmes, one of which concerned surgical treatment choice for breast cancer, has been tested in three fee-for-service hospitals in the USA.⁴⁴ Although clinicians judged the programme to

be clear, accurate, informative and appropriate, referral to the programme was low. During the first three months 15% (4 out of 27) of eligible patients with breast cancer were referred to the programme. Time pressures were the main barrier to implementation. It is likely that similar barriers would exist in the UK.

E. Recommendations

- If the goals of current NHS policy are to be achieved then the information needs of patients must be addressed. Initiatives like *The Cancer Information Strategy*¹⁹ should take into account differences in peoples' preferences for information and involvement in decisions about their treatment and care.
- Health professionals need to know how best to elicit patients' needs and readiness for information as well as their desire for involvement in decision-making. Appropriate communication skills training addressing such issues should be considered. Whilst the GMC recognises the need to teach communication skills at undergraduate level, it should be extended and included in all higher training. Key issues include: placing a higher priority on patient information; understanding patients' needs and helping people to access and understand relevant and appropriate information. Any programmes offered should be appropriately evaluated and measure patient outcomes as well as professional skills.
- Personalised or tailored information is an option. Recordings or summaries of key consultations may benefit adults with cancer, without causing additional anxiety. Health professionals could consider giving either written summaries or audio-tapes of consultations to people who have expressed a preference for them. However,

the effects of such interventions will need to be carefully monitored as the evidence for their effectiveness is limited.

- People with cancer should be given the opportunity for involvement in decisions about their treatment and care. However, individual preferences for different levels of involvement need to be respected. Health professionals could consider the use of appropriate decision aids, although evidence about the likely effects in people with cancer is limited and further evaluation is recommended.
- Time pressures are likely to be a barrier to implementing initiatives like shared decision-making programmes. Adequate resources will have to be made available to support the costs associated with developing, providing and using interventions to support patient participation.

Appendix – research methods

Systematic reviews were identified via the following electronic databases:

CINAHL 1982-08/2000
The Cochrane Library CD-ROM 2000 Issue 3
Database of Abstracts of Reviews of Effectiveness (DARE) – 08/2000
DH-Data 1983-08/2000
ERIC 1980-08/2000
EMBASE 1966-08/2000
HELMIS 1984-08/2000
HTA Database all – 08/2000
King's Fund Database 1979-08/2000
MEDLINE 1966-08/2000
PsycLit 1980-08/2000
Science Citation Index 1981-08/2000
Social Science Citation Index 1981-08/2000

and by contact with experts in the field. Individual search strategies for each database are available from NHSCR. Two reviewers assessed each individual review for inclusion, one reviewer extracted the data and assessed the quality.

Details of the methods for each of the Cochrane systematic reviews^{27, 35} are available on *The Cochrane*

Library. Details of the methods followed in the *National Cancer Guidance* documents are available from the documents produced for each cancer site.^{9,12}

Update searches for the review of decision aids

The set of searches is based on the strategy used in The Cochrane review.³⁵ It updates the searches from 1998 to 2000, and restricts the results to decision aids which relate to cancer patient care. The databases searched were:

CancerLit 01/98-06/00
CINAHL 02/98-07/00
EMBASE 03/98-9/00
MEDLINE 04/98-10/00
PsycLit 03/98-06/00

Authors of primary studies were also contacted for further identification of relevant studies.

Two reviewers assessed each study for inclusion, one reviewer extracted the data and assessed quality, and another checked it. Any disagreements were resolved by consensus.

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