

The Cancer Information Maze

Report investigating information access for people with cancer

Developed by the Association of the British Pharmaceutical Industry in partnership
with CancerBACUP and Ask About Medicines - October 2005



cancerBACUP
helping people live with cancer



Executive Summary

People with cancer are today faced with treatment decisions to a greater extent than almost any other patients. The government is moving towards full involvement for people with cancer in the decision-making process, but for this to happen, they need to be empowered to understand and make the choices that will lead to the best possible outcome for their individual circumstances and condition. Some observers have suggested that information will become the healthcare currency of the future, with those denied access to appropriate information not obtaining access to the best healthcare.

At every stage of the cancer treatment pathway the availability of information is vital for patients to be involved with all aspects of their care. Information helps people, particularly those with a chronic or long-term condition, to gain a sense of control. It helps with treatment compliance and self-management and leads towards a more adult relationship between patients and health professionals, and away from the traditional paternalistic approach. Recent cancer patient surveys have found, however, that information and communication issues continue to be a common cause of complaints from people with cancer, despite there being probably more information available to them than most other patient groups.

The provision of high quality information for people with cancer is a clear and growing need because, although some patients are satisfied with the information that they receive, large numbers are still being denied this basic requirement. In some cases this is because information is not available in a form and at a level that makes it accessible for them, while in other cases it is too difficult to navigate through the maze of information to find material appropriate for their needs.

Increased patient involvement in decision making during all aspects of cancer care relies on appropriate information. Healthcare providers need to assist patients in improving their levels of understanding by providing them with high quality, consistent and easily accessible information, appropriate to individual patient needs and wishes. Power questions, personalised information prescriptions, and greater involvement of specialist nurses as both information providers and guides to services are all initiatives which may help to achieve patient empowerment.

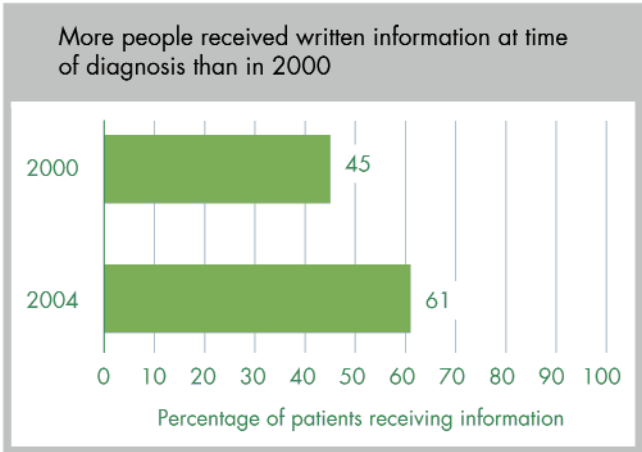
Introduction

The effective provision of information is vital for successful interactions between healthcare professionals and patients – with effects ranging from the psychological benefits of understanding what is happening, to empowering them to make better decisions. This applies to both oral communication with healthcare professionals and printed or audio/visual material. Empowerment can be defined as having the rights, capabilities, resources and opportunities to make strategic choices and decisions. Empowerment enables patients to make joint decisions on their care and obtain information on the nature of their condition and its treatment, a key component of the patient journey. This is particularly true for people diagnosed with cancer, where the rapid pace of development and the range of treatment options available means that patients and carers are repeatedly faced with highly complex decisions about their care.

The Satisfaction Gap

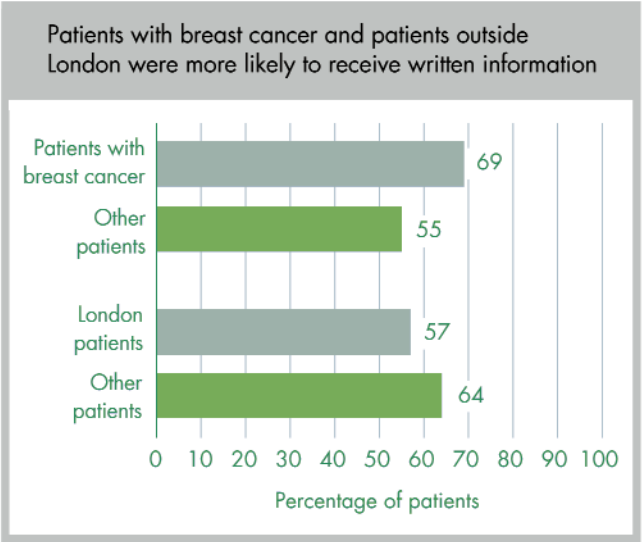
People with cancer are faced with treatment decisions to a greater extent than almost all other patients, and levels of involvement are increasing as the Government drives to “[put] the patient at the centre of cancer care”¹. This has included a greater emphasis on communication. However, despite this, a recent Healthcare Commission report has found that cancer patients across England are now less satisfied with their experience of care than they were in 2000². In 2000, a Department of Health national survey of patients with six major cancer types from across all NHS trusts in England found that 89% of cancer patients were generally satisfied with the extent to which they were involved in their care; in 2004, this had fallen to 85%.

The NHS National Cancer Patient Survey in 2000 reported that there were considerable gaps in the provision of written communication. A new survey by the National Audit Office (NAO) in 2004³ found things changing; more information about the diagnosis of cancer was communicated more effectively and with greater sensitivity than in 2000 (see figure below).



Information and communication issues continued to be a common cause of patient complaints. Shockingly, the survey found that while people who received printed information about their diagnosis generally found it to be understandable and helpful, 4 in 10 cancer patients still do not receive any written information at all.

The voluntary sector produces much useful information related to diagnosis, cancer types, treatment options and support services. The situation varies: some cancers – notably those with high profile charity status such as breast cancer – have better levels of information provision than others. An information deficit was also found across London, with those living outside the capital far more likely to have access to written information (see figure below).



One reason for this may be the lack of accessible information for ethnic minority patients, especially when English is not a first language. It is recognised that such patients have particular problems with communication issues around diagnosis.

Satisfaction with the consultation at the point of diagnosis was found to have improved, yet 1 in 7 patients still did not feel that they understood completely what was wrong with them. Notably, the NAO found that only around 10% of cancer patients were given a record of what was discussed at their consultation, despite this being recently recommended by the National Institute for Clinical Excellence⁴. This is a particular area for concern because it can be difficult for people to take in information at this emotional time.

The survey found that communication with physicians and nurses in the secondary care setting remained generally good. Only a very small proportion of patients had difficulty understanding their doctor's explanations of their condition, tests or treatment (2%). However, a third of patients found the information 'fairly easy', rather than 'very easy' to understand. Patients understood the answers to the questions they asked more often in 2004 than in 2000, but 15% still felt they had not received clear replies to their questions³.

In health care generally, people feel they need more help to understand the possible side effects of treatments. Patients' understanding of the side effects of cancer treatment has improved significantly since 2000, but in 2004 one-quarter reported that they had less than a full understanding of side effects, or that the issue was not discussed with them. Men with prostate cancer were almost twice as likely to remain uninformed about side effects, which in the case of prostate cancer can be considerable³. In general, breast cancer patients in this survey declared themselves the most satisfied with the information they were given.

Most cancer patients in 2004 felt that they have a good understanding of how well their treatment was progressing (80%). Again, patients with prostate cancer were significantly less well informed than other cancer patients; they were twice as likely to have unmet information needs. Patients over 80 years of age were less likely to have their questions answered satisfactorily after the first consultation³. They were likely to be less well informed about side effects, despite being particularly vulnerable, partly because they are more likely to have pre-existing health conditions that can complicate treatment.

On completion of their treatment pathway, most patients in the 2004 survey reported that they felt well informed about what to expect after they left hospital, and 96% were given a contact to use should problems arise following discharge. Information gaps were identified, in relation to continuing healthcare needs and community support. Forty per cent were not given information about relevant support groups (no improvement since 2000)³.

One in five patients in 2004 still received no written information about what would happen next, although this was an improvement on 2000. Where provided, this information was almost universally satisfactory³, highlighting the need to improve the distribution of such material.

The survey identified a failure to consider patients' home circumstances before discharge. Patients also lacked information on the financial concerns that can arise from being out of work for long periods of time or no longer able to work. Seventy-seven per cent received no advice on disability-related benefits or other financial issues, despite 48% saying that they would have liked some³.

What Cancer Patients Want

For many people, a diagnosis of cancer invokes a sense of uncertainty and fear. More and more people are surviving cancer, although it remains, in many cases, a terminal illness and can suggest a future which some patients do not care to dwell on. Clear, comprehensive information can do much to alleviate patients' fears and can help them to regain control of their lives. However, the level of information that people prefer and the extent to which they want to be involved in treatment choices both vary.

A minority of patients may wish to know little about their prognosis and/or treatment choices, as a personal coping strategy⁵. Some older people in particular may choose not to know their prognosis in detail and because of traditional attitudes may find involvement in decision making difficult⁶. Nevertheless, research has shown that many clinicians underestimate patients' desire for information and that they are often unaware of patients' preferences and their desire to participate in decisions about their care

In 2001, a study of over 2000 patients under investigation for cancer showed that 87% wanted all possible information, both good and bad news; 94% wanted to know what all the possible treatments were and 97% wanted to know what all the possible side effects of treatment were⁷. This study showed convincingly that the vast majority of patients with cancer want a great deal of specific information concerning their illness and treatment. According to the authors, "failure to disclose information out of a belief that significant numbers of patients prefer not to know is untenable".

Treatment decisions for cancer treatments tend to be based on a trade-off between benefit and toxicity. A 2004 evaluation of 23 studies found that clinicians often make decisions for their patients, yet the match between patient and clinician decision making is poor as individuals vary hugely in their response. Some patients will accept chemotherapy for a survival benefit of 1 week, while others would not choose chemotherapy even for a survival benefit of 24 months⁸. This raises the issue of how information about risks and benefits is communicated to people with cancer and the importance of giving them choice to make informed decisions.

It takes a skilled professional to navigate this minefield. These skills will be more and more in demand, since it is clear that attitudes are changing and the move away from a clinician-centred consultation to shared decision making (see below) is the model for the future.

<p>Clinician choice Clinician decides, patient consents</p>	<p>Shared decision-making Information shared, both decide together</p>
<p>Clinician as agent Clinician elicits patient's views, then makes decision</p>	<p>Consumer choice Clinician informs, patient makes decision</p>

Models of clinical decision-making²

According to Joanne Rule, Chief Executive at leading cancer information charity, CancerBACUP, in the future information itself will be the new healthcare currency. In Ms Rule's opinion, access to the best healthcare will depend not just on how much money a person has but how much information they have – and this brings us to a whole new debate about equality.

“Healthcare that can deliver this cultural shift will be the most patient responsive,” she says. “Professionalism may need to be redefined to enable patients to become less deferential and more informed. But it is only in this way that professionals will ‘be with’ patients as they find their way together through complex, perhaps contradictory scenarios”.

Defining Information Needs

The Picker Institute and CancerBACUP have highlighted the information that patients are likely to require before making any decisions on their treatment. This includes detailed consideration of treatment options linked to outcomes data, a thorough understanding of how their treatment will be administered (tablet, injection or drip) and whether they will receive it at home or in hospital, a detailed knowledge of side effects and the likely impact of all this on their quality of life. They are looking for information that is robust and regularly updated. In particular, patients have requested information on whether they have to accept the treatment offered, and what will happen if they don't. Patients usually want to know how quickly they will find out if the treatment has been successful, and what will happen when it has been completed. In general they feel that they should be able to ask questions relating to their specific circumstance, be told how to find further information, and have time to make a fully informed decision.

The aspects of treatment likely to provoke the most questions include its effectiveness in treating the particular type and stage of cancer, how it works, when treatment should be started, how long it will last and how many treatment courses will be needed. A treatment schedule can empower patients to know what to expect and when, so they can plan their lives around their treatment with full understanding of the consequences.

Patients also need more practical information in order to make a fully informed choice. This might include information about the quality of service and treatment options provided by individual cancer centres, hospitals and clinicians, accessibility and waiting times for these services, access to the results of clinical trials and hospital-acquired infection rates. The impact treatment may have on daily living is also a key consideration. Will they still be able to work? go on holiday? drink? exercise? socialise fully? Questions about the impact of treatment on caring for children, planning a family, and sexual relationships may need addressing.

Once treatment is started, patients need to know what to do if they experience side effects – if, when and how they can manage side effects themselves and when to involve the nurse or doctor. Concerns about stopping or delaying treatment should be addressed. In recent years there has also been a move towards providing information about the use of complementary therapies, because many

patients find them an additional support. In 2004, NICE recommended that high quality information about complementary therapies and services, including diet, should be made available⁴. However, the NAO survey which coincided with the publication of the NICE report found that, at this time, only half of all patients who had tried such approaches had received information about them from their hospital³.

How Information Helps

Information helps by providing patients, particularly those with a chronic or long-term condition, with a sense of control. It helps with treatment compliance and self-management because patients can weigh up pros and cons of different options, make decisions and know what to expect. It leads towards a more adult relationship between patients and health professionals and away from the traditional paternalistic approach that so many patients find stifling, resulting in a greater satisfaction with care. Appropriate information can also help to promote health: research has found that patients who are dissatisfied with the information they received are more likely to be depressed than satisfied ones⁹.

Barriers

With so many examples of good information practice, why are so many patients with cancer still under-informed?

As in other disease conditions, many patients find it difficult to get the best from their interactions with healthcare professionals because they are unprepared and unequipped with the questions that would help elicit the information they need¹⁰.

In cancer particularly, research has found that lack of understanding of medical terms and knowledge about the human body and disease processes can be a real barrier to successful communication.

Cancer is a complex and varied condition and subtle aspects of prognosis and treatment options can be hard to communicate. Research shows that patients have a poor understanding of even basic medical terms and phrases normally used in cancer consultations, despite feeling confident when asked that they did understand them fairly well¹¹. Only half the patients taking part in this survey, for

example, knew that when a doctor tells you “the tumour is progressing” this is not good news. Furthermore, patients’ knowledge of the structure and function of their body varies. The same survey showed that one in ten patients could not correctly identify the lungs, while over half could not locate the liver¹¹. Patients’ own assessment of their understanding of the information given them appears unreliable in many cases, and this is often tested as their treatment course continues.

Levels of functional literacy and numeracy – defined in the government report *A Fresh Start* as: “the ability to read, write and speak in English and to use mathematics at a level necessary to function at work and in society in general” – are often overlooked¹². Over 7 million adults in England (around 1 in 5 of the population) are estimated to have difficulties with literacy and numeracy¹³. Of these, around 1 million have a first language other than English.

A more recent report defined the problem in a different way, more in line with the structure of our current educational system. In this report¹³, a total of 5.2 million adults in England were described as lacking in basic literacy (i.e. were at Entry level 3 or below according to the National Standards for Numeracy and Literacy), while 17.8 million adults (56%) of the overall population between the ages of 16 and 65 years of age had literacy skills at Level 1 or below (for explanation see box below).

Levels of literacy attainment in England¹³

	Adult literacy attainment	Percentage of 16–65yr olds (n)
Entry level 1 or below	Can read short texts with repeated language patterns on familiar topics; read signs and symbols and produce limited writing – very short sentences only	3% (1.1 million)
Entry level 2	Can read short straightforward texts on familiar topics and obtain information from familiar sources (e.g. a leaflet, short letter, Yellow Pages). Shows some awareness of audience when writing (e.g. short informal letter or note)	2% (0.6 million)
Entry level 3	Reads more accurately and independently and obtains information from every-day sources (e.g. popular newspapers). Is able to communicate in writing, information and opinions with some adaptation to the intended audience (e.g. short formal letter, note or form)	11% (3.5 million)
All entry level 3 or below		16% (5.2 million)
Level 1	Reads texts of varying lengths on a variety of topics and obtains information from different sources (reports, text books, work manuals). Written communication demonstrates an ability to express ideas and opinions clearly using length, format and style appropriate to audience and purpose (formal letter, memo, brief report etc)	40% (12.6 million)
Level 2 or above	Reads from texts of various complexity accurately and independently (complex books, text books, reports, training manuals). Writes to communicate information, ideas and opinions clearly and effectively using length, format and style appropriate to purpose, content and audience (such as a complex letter, essay, report).	44% (14.1 million)
TOTAL		100% (31.9 million)

This educational and skills challenge also has an impact on the provision of effective healthcare. A report by the National Consumer Council (NCC) in 2004⁴ defined the term 'health literacy' as "the capacity of an individual to obtain, interpret and understand basic health information and services in ways which are health-enhancing". The report called upon the NHS to take action to address the persistent gaps in health literacy, especially among the socially disadvantaged.

'Health literacy' as defined in the NCC report means more than just being able to transmit information. It is about developing the skills to acquire and read health information and successfully apply it to one's own situation. The government report Tackling Health Inequalities¹⁵ found that poor educational attainment was a key factor in the cycle of health inequalities. Supporting people with low literacy skills remained a considerable challenge for healthcare professionals. This was compounded by many people either underestimating their need for help or hiding it due to a perceived stigma associated with asking for help¹².

Ed Mayo, NCC Chief Executive commented: "Building health literacy isn't only about changing the mindset of a population trapped by their respect for and deference to health professionals. It also means a more user-focused approach from the NHS – making information available in plain language, when and how patients want it."

Patients from black and minority ethnic groups often experience particular problems with understanding information about their care, particularly when English is not their first language. The National Cancer Patient Survey in 2000 revealed that most ethnic minority patients, especially South Asian patients, were less likely to understand information about their diagnosis and treatment options, to their obvious disadvantage³. A large range of non-English written, audio and visual aids are to be found in some urban hospitals, but the provision of such information is still a problem for most hospitals.

A report developed by CancerBACUP entitled Beyond the Barriers: First national review of cancer information and support projects for black and ethnic minority groups (BME) describes the factors preventing BME communities from accessing cancer services and information such as language and social taboos. For instance, women from some cultures may conceal symptoms of breast, cervical and ovarian cancers because in their communities it is taboo to talk about sexual organs, reporting problems to a doctor only when it is too late for them to be given a potentially life-saving treatment¹⁶.

Clearly, for some patients, access to information in a form that they can understand remains a challenge. The Department of Health is very clear on the issue of informed consent, stating in their guide for consent to treatment in 2001: “If the patient is not offered as much information as they reasonably need to make their decision, and in a form they can understand, their consent is not valid”¹. However, in the same year it was also recognised that: “there is...often a yawning gap between good intentions and the reality of day to day practice...a change of culture is required to ensure that patients become informed partners in their own care”¹⁷.

Over-simplistic and over-optimistic information that glosses over risks and controversies also fails to inform patients appropriately. A paternalistic attitude can result in patients having unrealistic expectations about their treatment and can ultimately increase their chances of experiencing dissatisfaction, anger and resentment¹⁸. Information should be open, balanced, accurate and tailored to each individual’s needs if communication barriers are to be overcome¹⁹.

Some patients also cite information overload as a problem. With so much information available via the internet there is a perception that patients are turning detective in the hope of finding the ‘magic cure’ that has evaded their specialist. However, this does not reflect reality for most people. The most frequent enquiries received by CancerBACUP are to help people make sense of what has happened during the official consultation – for example, information leaflets and clarification, as well as for emotional support. People who use a website before telephoning CancerBACUP do ask more complex questions than those people who did not first visit an internet site.

Ten most frequent subjects of helpline enquiry.

Emotional support	31.4%
Request for publications / booklist	21.1%
Primary site specific information	15.8%
Clarification of medical information received	13.9%
Chemotherapy	13.6%
Prognosis	7.2%
Radiotherapy	6.8%
Symptom control	6.2%
Diet and nutrition	5.9%
Surgery	5.9%

(Source CancerBACUP: Statistics from April 2004 – March 2005)

Health websites are hugely popular – of the 15–25% of adults in the UK estimated to access the internet regularly, more than half use it to find information on health-related issues. However, such websites can mislead as well as inform, either because people don't understand them or because sites are themselves flawed – sometimes intentionally biased, or through a lack of vigorous quality control. Access to the quality controlled information available to healthcare professionals through peer-review publishing of professional journals and societies is often barred to patients, residing in members-only sections or only available at a price.

Information sources giving conflicting opinions can be a source of much stress, yet little in the cancer arena is clear-cut. What is important is clear guidance for patients on the finding and interpretation of credible sources of information, such as the Ask About Medicines Health and Medicines Information Guide and Directory. However, public concern about the culture of the health service and changes in public policy are leading to improvements in public sector provision, such as the NICE guidelines on supportive and palliative care²⁰.

Cancer Culture

Living with cancer can expose patients and their families to a wide range of new and confusing experiences. At the same time they are often faced with an urgent need for decisions about tests and treatment options and fears for their future and for those who depend on them. Patients, when questioned about this time, talk about a need for respect, sensitivity, trust in those who will be supporting them through this journey (emotional as well as physical support) and also, overwhelmingly, a need for co-ordination of available services³. Underpinning all this is the need for consistent and clear information.

Where do patients seek reliable and free information on their conditions? A recent non cancer specific MORI poll²¹ found that patients consider their doctor to be the most useful source of information about medicines. Nearly 70% found doctors more useful than any other source, ahead of pharmacists, in-pack drug information leaflets, nurses, the internet, friends and family, NHS Direct or the media. Nevertheless, most patients polled felt that a range of different types of information from a range of sources was desirable.

Internet use by patients at all stages of cancer care is now widespread, from early investigations to follow-up after treatment²². Patients use the internet to find second opinions, seek support and experiential information from other patients, interpret symptoms, seek information about tests and treatments, help interpret consultations, identify questions for doctors, make anonymous private inquiries, and raise awareness²³. Although the quality of internet information varies widely, patients may use the internet to develop expertise in their cancer which will better equip them to ask questions elsewhere.

The variability in the quality of cancer information in the public domain and people's strong need to be informed about their condition are some of the reasons why the Government has set out a strategy to make information sharing an integral part of NHS healthcare. The NICE guidelines on supportive and palliative care for patients with cancer, published in March 2004⁴, recommend that cancer patients and their carers should have easy access to a range of high quality information about cancer and cancer services. It states that materials should be free and patients should be offered appropriate help to understand the information in the context of their own circumstances.

Faced with the rapid pace of breakthrough in cancer therapy, patients are faced with ever more complex treatment decisions, particularly when it comes to decisions about participation in clinical trials. Patients given this option require clear information, enough time to consider the options and on-going psychological support.

The Importance of Informed Patients

The provision of quality information empowers patients and enables them to make informed and effective choices about their care. Information exchange is at the core of the relationship between the patient and the healthcare professional. Full and open information about cancer and its treatment, tailored to the patient's individual requirements, is essential in building trust within that relationship¹⁹. Informed patients can accept guidance from their healthcare professional and retain their autonomy and sense of self-determination. This builds confidence that their choice of treatment is the most appropriate one for them.

The provision of patient information may improve a number of outcomes for cancer patients. Evidence from studies evaluating the effectiveness of patient

information in its various forms (ranging from written information, patient care records and patient educational programmes, to audiotapes, audiovisual aids and interactive media) has shown that these had positive effects above and beyond that of usual care provision²⁴. Patients were found to have a better knowledge and understanding of their cancer and its treatment, and to be better able to recall this information. They were also better equipped to manage their symptoms. Their levels of satisfaction with their care and their level of healthcare use also improved. Patients were more positive and less depressed.

Treatment compliance is likely to be enhanced by appropriate education. People who are involved with healthcare decisions and understand their treatment take a greater degree of ownership and responsibility for their care²⁴.

This is likely to be of particular importance with the recent emergence of new forms of oral-based therapies that place a greater emphasis on patients managing their own treatment. While these new formulations are often favoured by people with cancer mainly because they are more convenient and treatment can be carried out in the comfort of their own home, patients self-administering oral chemotherapy don't receive the same amount of teaching and monitoring as those attending clinics for intravenous delivery. Thus, as the popularity of these forms of chemotherapy continues to grow, patient education will be vital to ensure patient safety, optimal dosing and compliance^{25,26}.

The Way Forward

Angela Coulter argues that information should have a purpose: to support patient involvement in treatment and help them move towards making decisions in their care²⁷. As part of a vision to involve people in their treatment decisions, Better information, better choices, better health²⁸ outlines the Government's strategy to improve access to the kind of high quality information patients need to help make choices. It is based on the principle that patients should have access to quality information, tailored to their individual requirements and delivered in the way they want. They should receive as much support as they need to fully access and understand it. The aim is no less than to make communication and information provision central to healthcare in the NHS.

Tailored information takes into account diversity in ethnicity, culture, religion, language, gender, age, ability, socio-economic status and literacy levels. A universal translation and interpreting service is now available on NHS Direct to

help overcome language barriers and CancerBACUP have introduced an oral helpline service called Cancer in Your Language which links the caller to an interpreter and a specialist cancer information nurse. Consistent, UK wide, accredited information will also become available through a range of media including interactive digital TV, telephone helplines, Internet and printed directories²⁸.

Future initiatives in working with local healthcare providers will explore ways to enhance community support to take better account of local needs.

The Patients Association have suggested using hospital-based PALS (Patient Advice and Liaison Services) as central conduits making them the hospital's central information point. PALS also take material into the wards including information provided by the voluntary sector which increases its reach²⁹. Cancer charities would like to see cancer specific information services in hospitals where there is a cancer centre or cancer unit.

Truly individualised patient information requires dialogue with healthcare professionals. Better communication on both sides of the patient–professional relationship is required if people are to achieve shared healthcare decisions. Yet despite recommendations that a proportion of the consultation period should be set aside to specifically discuss and assess the patient's information needs, time is generally short.

Training professionals in the essential skills of listening to and empathising with patients can make a significant difference to health outcomes^{30,31,32}. Patients themselves often need to be empowered to become active users of healthcare information. Initiatives such as the Ask About Medicines questions and the Department of Health's 'power questions' initiative aim to do this by offering sets of model questions designed to help patients get the information they need from consultations within the limited time available. The Ask About Medicines questions are promoted in the annual Ask About Medicines Week, while the Department of Health has proposed making power questions available on appointment letters, prescriptions and other printed material²⁸.

Information prescriptions

Another practical way that has been suggested to overcome time constraints while supporting the aim of information provision is the concept of the ‘information prescription’. The information prescription, provided by the healthcare professional at the time of consultation, is an individualised way to ‘signpost’ patients to appropriate sources of further information and support. The prescription would be given following discussions about the patient’s concerns, fears and information needs surrounding their diagnosis and treatment. Information prescriptions have the potential to become a useful focal point for a number of NHS activities²⁸.

The information prescription could help to resolve a dilemma that has been discussed by the Department of Health Coalition for Cancer Information³³, namely how do we make information-giving an integral part of care? How do we decide whose responsibility it is to offer information at a particular time?

Information provision for cancer patients should not be confined to official consultation times alone. Cancer is a multidisciplinary concern and different professionals play a role at different times in the patient journey. The specialist cancer nurse often plays a central role in facilitating communication and the flow of information across the healthcare team (of which the patient is the key member). They provide expert advice, support and advocacy for the patient throughout their cancer journey and so may be ideally placed to coordinate their information needs during that journey. It is essential that patients can find effective help and advice when problems or concerns arise between scheduled appointments, and contact with nurse specialists is one important way that information can be provided, including perhaps through information prescriptions.

People with cancer require different information at different stages in their journey to help them navigate the many aspects of their condition including:

- Identifying potential symptoms or having them detected in routine screening
- diagnostic tests
- diagnosis
- medicines
- other treatment options (e.g. surgery)
- clinical trials

- experimental treatments
- side effects
- managing symptoms of cancer (e.g. pain control)
- living with cancer
- communication with and reactions of friends and family
- employment, financial issues
- self help
- end of active treatment and recovery or move from active to palliative care
- terminal care.

Nurse specialists could make a significant contribution to the organisation and development of cancer services, and they are likely to be pivotal in innovating and coordinating the provision of patient information from the cancer centre. Associated bodies, such as the valuable CancerBACUP and Macmillan nurses (who take care into the patient's home), are also key players in providing cancer patients with the support they need and deserve.

Conclusions

The provision of high-quality information for cancer patients is a clear and growing need. Although some patients are satisfied with the information that they receive, large numbers are still being denied this basic requirement. The current choice agenda is focused on “which hospital” or at most “which doctor”. However, the real choice in the NHS – the kind of choice that will drive up standards and improve patient experiences – will be about the what and the how of healthcare, not just the when and the where.

The Bristol Inquiry placed partnership between patient and healthcare professional at the centre of an evolving process of trust by which the exchange and provision of information is at the core of an open and honest relationship between healthcare professionals and patients¹⁹.

A successful move towards increased patient involvement in decision making during all aspects of their care relies on this need for appropriate information being fulfilled.

Healthcare providers need help to assist patients in improving their understanding, by providing them with easily accessible information, appropriate to individual

patient needs and wishes. Power questions, personalised information prescriptions and greater involvement of specialist nurses as information providers and guides to services are all initiatives which may help to achieve patient empowerment. Improved information standards in some areas, such as breast cancer, have already shown that patient organisations and the pharmaceutical industry can support empowerment in patients by helping them gain a greater knowledge and feeling of involvement. However, there is no substitute for a good and open relationship between cancer patients and their healthcare professionals.

The Association of the British Pharmaceutical Industry (www.abpi.org.uk) is the trade association for about a hundred companies in the UK that produce and research prescription medicines. As part of its role, it has worked with Datapharm to provide an online resource www.medicines.org.uk to help patients access information on medicines.

CancerBACUP (www.cancerbacup.org.uk) is the only national charity that specialises in providing information on all types of cancer. All CancerBACUP services are free to cancer patients, their relatives and friends. CancerBACUP runs a freephone information service that is available on 0808 800 1234 (Mon-Fri, 9am-8pm).

Ask About Medicines (www.askaboutmedicines.org) is an independent campaign to increase people's involvement in decisions about their medicines use. The aim of the campaign is to contribute to people's ability to control their own health and healthcare through better understanding of what medicines do and how to make the most appropriate use of them.



cancerBACUP
helping people live with cancer



References

1. Department of Health. Reference guide to consent for examination or treatment. March 2001
2. Picker Institute. Is the NHS getting better or worse? An in-depth look at the views of nearly a million patients between 1998 and 2004. 2005
3. Department of Health. Tackling cancer: improving the patient journey. Report by the Controller and Auditor General. 2005
4. NICE. Supportive and palliative care for people with cancer: Part A and Part B. Department of Health. March 2004
5. Leydon GM et al. Cancer patients' information needs and information seeking behaviour: in depth interview study. *BMJ* 2000;320:909-913
6. Chouliara Z et al. Perceptions of older people with cancer of information, decision making and treatment: a systematic review of selected literature. *Ann Oncol* 2004 Nov;15(11):1596-602
7. Jenkins V, Fallowfield L, Saul J. Information needs of patients with cancer: results from a large study in UK cancer centres. *Br J Cancer* 2001;84(1):48-51
8. Jansen SJ, Otten W, Stiggelbout AM. Review of determinants of patients' preferences for adjuvant therapy in cancer. *J Clin Oncol* 2004;22(15):3181-90
9. Jones R et al. Cross-sectional survey of patients' satisfaction with information about cancer. *BMJ* 1999;319:1247
10. Meredith P, Emberton M, Wood C. New directions in information for patients. *BMJ* 1995;311:4-5
11. Chapman K et al. Lay understanding of terms used in cancer consultations. *Psychooncology* 2003 Sep;12(6):557-66
12. Department for Education and Skills. Report of Working Group chaired by Sir Claus Moser. Improving literacy and numeracy: a fresh start. 1999
13. Department for Education and Skills. The Skills for Life Survey: a national needs and impact survey of literacy, numeracy and ICT skills. DfES Research Brief RB490, 2003
14. National Consumer Council. Health literacy: being able to make the most of health. PD 38/04. June 2005
15. Department of Health and Treasury. Cross cutting government review. Tackling health inequalities. 2002
16. Beyond the Barriers: providing cancer information and support for black and minority ethnic communities. CancerBACUP 2004
17. Bates T. The ethics of consent to surgical treatment. *Br J Surg* 2001;88:1283-84
18. Fallowfield L, Jenkins V. Communicating sad, bad, and difficult news in medicine. *Lancet* 2004;363:1556.
19. Kennedy et al. The report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995. The Bristol Royal Infirmary Enquiry. 2001
20. National Institute of Clinical Excellence. Guidelines on supportive and palliative care for patients with cancer, published in March 2004
21. MORI. Research sponsored by Medicines Partnership: Medicines and the British 2003, The Public and Prescribed Medicines. 2004
22. Rule J. Consumer information, communicating best practice to patients, press and politicians. Presentation at the First International Conference on Cancer on the Internet. New York, USA, June 19-20, 2003
23. Ziebland S et al. How the internet affects patients' experience of cancer: a qualitative study. *BMJ* 2004;328:564
24. McPherson CJ. Effective methods of giving information in cancer: a systematic literature review of randomized controlled trials. *J Public Health Med* 2001 Sep;23(3):227-34
25. Hartigan K. Patient education; the cornerstone of successful oral chemotherapy treatment. *Clin J Oncol Nursing* 2003;7(6s):21-4
26. Deery P, Faithfull S. Developing a patient pathway to deliver a new oral chemotherapy. *Prof Nurse* 2003
27. Coulter A et al. Sharing decisions with patients: is the information good enough? *BMJ* 1999;318:318-22
28. Department of Health. Better information, better choices, better health: putting information at the centre of health. 2004
29. The Patients Association. Report into the provision of information literature by patient groups. 2005
30. Jenkins V, Fallowfield L. Can communication skills training alter physicians' beliefs and behavior in clinics? *J Clin Oncol* 2002 Feb 1;20(3):765-9
31. Fallowfield L et al. Efficacy of a Cancer Research UK communication skills training model for oncologists: a randomised controlled trial. *Lancet* 2002 Feb 23;359(9307):650-6
32. Fallowfield L, Jenkins V, Farewell V, Solis-Trapala I. Enduring impact of communication skills training: results of a 12-month follow-up. *Br J Cancer* 2003;89(8):1445-9
33. Department of Health Departmental Report for 2004. ISBN: 010162042X