

A second opinion, because there's no second chance

→ Marc Beishon

Patients want the option of consulting a second doctor, and the evidence shows that, for a minority of them, treatment decisions have altered significantly as a result. But could granting every patient the legal right to a second opinion tie up precious resources as each one 'shops around' in search of the opinion they want to hear?

“I wish we had checked there was nothing else we could have done” – it's one of the common regrets of the relatives of people who have died from cancer, and a reminder that worries about treatment can extend beyond the patient to possibly many years of soul searching by those left behind. Access to second opinions about diagnosis and treatment can provide vital reassurance for patients and their families at a time when they feel most vulnerable, and reassurance is a common reason for asking for referrals to other specialists, or for people seeking information independently, particularly on the Internet.

“I see three types of patients looking for second opinions on treatment,” says Fatima Cardoso, a medical oncologist at the Jules Bordet Institute in Brussels. “There are those who are happy with their doctor and just want to be

reassured they are having the best care. Some say they don't want their oncologist to know, just confirmation that he or she is correct. Then there is a group who are unhappy with the relationship with their doctor, and the third group are people looking for new treatments and trials, normally referred on by their oncologist. We see all these types of patient and do a lot of second opinions – I wouldn't say one reason is more common than another.”

The reasons why patients seek second opinions in cancer, and in medicine generally, raise many issues, some of which have not been well researched. Clearly, the opportunities for patients to research medicine in the Internet age is of primary interest. It is increasingly changing the face of the traditional doctor–patient relationship, with healthcare becoming more 'consumer led', although many patients remain reluctant to 'distrust'

their specialist, while there are still a minority of 'paternalistic' doctors who do not encourage second opinions.

Then there is the question of whether a healthcare system or society should grant legal or just moral rights to obtaining second opinions. In turn, there are questions about cost and structure – should a second opinion system be formalised for some or all complex conditions, and would there be a net cost, or would there be savings thanks to better treatment? And could there be enough capacity to carry out more formal second opinions?

A good place to start to answer these questions is to look at what data there are on where second opinions have made a difference to cancer treatment. Much of the emphasis in studies appears to be on the diagnosis of cancer – and any patient researching the issue will immediately find alarming warnings about mistakes that are made.

Second opinions in breast cancer pathology led to altered surgical therapy in 7.8% of 346 cases

Not surprisingly, these warnings appear mostly on US patient advocacy websites, and also on the websites of cancer centres in the US that offer second opinion services.

AN ENORMOUS IMPACT

For example, one of the most widely cited studies examined the impact of a mandatory second opinion for surgical pathology when cases were referred to a major cancer centre, John Hopkins Hospital, in the US, during a period in the mid-1990s. The study found that such a programme could “result in major therapeutic and prognostic modifications,” and although the number of affected cases was not large, the authors considered that the rate of discrepant diagnoses “may have enormous human and financial impact,” (*Cancer* 86:2426–35).

Another study, on pathology second opinions for breast cancer, ‘confirmed’ the benefit of a pathology second opinion, noting major changes that altered surgical therapy in 7.8% of 346 cases. Complete correlation between the initial report and the second opinion was found in just 20% of cases. However, failure to confirm a malignant diagnosis occurred in only one case, but the authors note that benign diagnoses are seldom subject to a second opinion (*Ann Surg Oncol* 9:982–987).

This is a huge topic in its own right, but it seems to be the case that patients are not as likely to seek second opinions on pathology and scan results as they are about prognosis and treatment. “Questions about the diagnosis are seldom raised by patients,” says Jürgen Schultze, a radiation oncologist

at Kiel University in Germany. “As I am also trained as a radiologist, I do deal with false-negative and false-positive results, but the questions are normally raised by other doctors who are not convinced that the findings of the original radiologist are right.”

It is very rare to see a misdiagnosis of malignant or benign tumours adds Cardoso. “There is some controversy in the classification of some types of cancer – for example, you have a lot of discordance in grading in breast cancer and some pathologists do grade differently – and when you use techniques such as immunohistochemistry, you can get different results. I think, though, that pathologists are more advanced than clinicians in asking for second opinions among themselves – they have been in the habit for many years of exchanging slides when they are not sure about a diagnosis and will send them to experts around the world. It’s much less frequent that a clinician

will send a patient for a second opinion because he is not certain.”

Clearly, though, there is a big difference between routine checking of pathology specimens and images for quality control purposes, and referral to a centre where different imaging and pathology tests may be done as part of a new patient consultation. Another study on 148 women who went to the University of Michigan Breast Care Center for a second consultation following a mammogram found that 7% had more cancer in the same breast, or an undiagnosed tumour in the other breast. But this was after a one-day radiology, surgery and pathology consultation, with many patients receiving additional imaging, resulting in additional or different biopsies, additional follow-up imaging and changes to treatment in 30% of the women.

The superiority of the top multidisciplinary cancer centres as places for diagnosis and treatment is hardly a

MEETING PATIENTS’ NEEDS

A rare paper on the ‘motives, needs and expectations’ of cancer patients in the Netherlands seeking a second surgical opinion (*J Clin Oncol* 21:1492–97) found that motives differ greatly. The authors identified five relevant variables: anxiety disposition, dissatisfaction with the first specialist, preference for decision participation, need for more information, and hope and expectation that the second opinion would be different from the first.

A majority of patients (62%) were identified as having ‘internal’ motives, relating more to reassurance and certainty, while the remainder had ‘external’ motives, relating to negative experiences or unfulfilled needs.

Given that some full second opinion consultations are unnecessary and put extra strain on health services, they suggest strategies that could avoid them. These could include phone or e-mail consultation with an expert for the ‘internal group’, and improving communications skills – developing professionals as ‘educators and collaborators’ – to deal with the increasing information and participation needs of the ‘external’ patients.

surprise, although as referral centres they also tend to see the more complex cases, which could make discrepant results more likely. Major centres are also more likely to have access to newer techniques, such as gene-expression profiling, which can provide additional information relevant to cancer prognosis and treatment.

A milestone reported recently is the identification of a gene-expression signature for Burkitt lymphoma, which can distinguish it from Burkitt-like

WHAT OUR READERS SAY

CancerWorld asked readers what they think about second opinions. The respondents include medical oncologists, radiation oncologists, surgeons, radiologists, cancer nurses, pathologists, patient advocates, palliative care specialists and hospital administrators among others.

- 81% answered 'yes' to the question: should all cancer patients be given access to second opinions? A quarter of those who said 'no' also ruled out any special circumstances for a second opinion.
- 66% have asked patients if they would like a second opinion.
- 35% said cancer patients can easily obtain a second opinion in their country; 18% said bureaucratic procedures hinder the process; 16% said their system does not pay for a second opinion.

A comparison between Eastern and Western Europe showed similar levels of support for the right to a second opinion (80.8% vs 87.5%), but a big difference in easy access, with 54% in the West saying patients always have access in their country and 5% saying there is no such access. The equivalent figures for Eastern Europe are 30% and 33%. The remainder indicated access is limited by region, bureaucracy or cost.

lymphoma (reported in the *New England Journal of Medicine*, 8 June 2006). As Paolo Vigneri, a medical oncologist at the University of Catania in Italy, comments: "They sound alike and look alike but are completely different. Diagnosis really requires an experienced pathologist, but even some experts in this NEJM study misdiagnosed it. The therapy for the two is very different, but as an oncologist, if someone tells you it's Burkitt-like or not – that's it. They are fairly rare, but the problem is that rare diseases are always less rare than you'd like and once you've encountered one you never forget it."

Rare cancers are of course more likely to be referred for second opinions, but it is the now routine treatments that may be being ignored that are probably more disturbing for patients. Cardoso does see women who have had a mastectomy when they could have had neo-adjuvant chemotherapy and a tumourectomy at a multidisciplinary centre. She feels some isolated surgeons may not be referring patients for a second consultation because they may not believe in neo-adjuvant therapy or could be afraid of losing their impact. Similarly, Schultze in Kiel sees patients who have been told by their urologist that the only treatment on offer is radical prostatectomy for advanced disease, with 20% of men then having a local recurrence – whereas he says his centre can offer a combination of external beam radiotherapy and brachytherapy, with 97% local tumour control.

In Germany, concern about existing guidelines for testicular cancer not being adequately followed has led to a new second opinion project that could also be rolled out for other tumours (see box, p17). Other countries with fledgling second opinion systems include Denmark, which has an expert panel for patients and doctors; the health insurance is obliged to pay for the

treatment they recommend (see Masterpiece, *CancerWorld* September–October 2006), and Sweden, also with a recent oncology experts' initiative called 2ndview (see www.2ndview.se). There also several e-mail based question resources, especially in the US, such as 'Ask the cancer expert' at www.oncolink.com.

WHO GETS WHAT

No country appears to have a national system for managing second opinions for all conditions. Some healthcare insurers in the US have had mandatory requirements for second opinions on some procedures such as mastectomy and prostatectomy to try and reduce the cost of elective surgery and to prevent unnecessary procedures. Most countries with health insurance systems have formal or informal voluntary second opinion options that are paid for in whole or in part. Insurers in the US now promote it as a patient right.

So European countries with health insurance systems, such as Germany, will pay for all or some of the cost of second or even third and more opinions, although there does not appear to be a legal right anywhere. Indeed, the UK's National Health Service explicitly states there is no legal right to a second opinion, but "a healthcare professional will rarely refuse to refer you for one unless there is sufficient reason."

In practice, access to second opinions appears to vary widely across Europe. The Euro Health Consumer Index, produced by Health Consumer Powerhouse, has graded Europe's health systems using a three-tier system, and includes 'right to second opinion for non-trivial conditions' as one of the criteria. At present, it adds Belgium, Estonia, Ireland and Latvia to the UK as countries offering no right; other countries such as Greece, Italy, Spain and Sweden only score 'yes, but difficult to

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access due to bad information, bureaucracy or doctor negativism’. France, Germany and the Netherlands are among the countries with the highest rank for second opinions (and these countries also take the top three slots for consumer-friendly healthcare systems across all criteria). France and Germany also allow direct patient access to specialists (see www.healthpowerhouse.com).

But even in the best countries, access to a second opinion is more or less ad hoc – referral choices are entirely up to the first specialist, or can be sought by the patient via their own research or in discussion with their primary care doctor. In a survey of around 150 cancer patients from across Europe conducted at a European Cancer Patient Coalition masterclass in 2005, 50% of respondents said that bureaucracy was the main hindrance to getting a second opinion in their country. Only 13% said a second opinion was easy to obtain, 16% said it was available only from certain healthcare providers or in certain regions. Ten percent of patients said second opinions are never reimbursed in their country.

It is no wonder that patient advocacy organisations are playing a vital role as information brokers in the process. As Jesme Baird, medical director at the UK’s Roy Castle Lung Cancer Foundation, comments, “Patients use us like a second opinion – they call and say, ‘Here’s my stage of disease, and this is what my doctor says; does this sound right?’ All we can say is that it may be broadly right or wrong.” However, the copious information now available on advocacy and cancer agency sites gives patients plenty of

pointers on how to take steps to find an alternative consultation.

Baird adds that in a system like the UK, where access to healthcare is mainly through a primary care ‘gatekeeper’ (the general practitioner or GP), referrals to other specialists can take precious time and there is always the danger of vital notes and materials getting lost. “GPs may also only come across a few cases and know relatively few specialists,” she says. But as an oncologist herself, she adds that the two biggest advances she’s seen in lung cancer in recent years are the growth of multidisciplinary teams and the role of the lung cancer nurse specialist – the latter can act as a friendly second opinion source, she says. (And in the UK,

personal breast cancer information is available by e-mail from nurses at www.breastcancercare.org.uk). However, even in a big centre Baird says all options may not be explored or explained – in the UK, in particular, patients may not be told about a drug that is not funded and not in the hospital formulary.

Vinod Joshi, a restorative dental specialist who runs the Mouth Cancer Foundation, another patient group in the UK, says meeting other patients, even in an online forum, can be an important second opinion resource. “They can come to us without feeling they are jeopardising the treatment they have been offered,” he says. The fear that many have about ‘upsetting’

SECOND OPINION PROJECT

A project in Germany is aiming to iron out the differences in outcomes for testicular cancer that are still being seen despite long-established standard care guidelines. A network of 20 second-opinion centres has been established by the German Testicular Cancer Study Group in conjunction with a health insurer. The centres receive patient data and the treatment suggestion from the original doctor, and then recommend therapy according to evidence-based guidelines. The project will follow up patients after two years; it will focus on recurrence-free survival data and will compare intended, recommended and actual therapy.

Mark Schrader, assistant medical director in the oncology unit at Berlin’s Charité hospital, is coordinating the data management. “The problem with guidelines is that no one reads them,” he says. “We have seen a lot of issues, particularly in some regions and small towns, with diagnostic work-up, therapy and surgery. Now patients and doctors have an easy way to consult specialists at multidisciplinary centres. It is all done by software and e-mail.” Some 200 referrals have already been made.

The project has not been without problems. “The health insurer is so far only paying for five of the centres, the others are doing it for free,” says Schrader. “But the main problem is the urologists – they are worried that other experts will get all their best patients and they will earn less money.” The head of the German Urological Association has been particularly critical, adds Schrader. “There has been an unbelievable amount of tension on this project,” he says.

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Förnyad medicinsk bedömning - second opinion

2ND VIEW
IN CANCER

När man själv eller en nära anhörig drabbas av en allvarig sjukdom är det viktigt att ha tillgång till den bästa vården - så snart som det är möjligt.

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Ask an Expert

Ask the Experts

Welcome to the Johns Hopkins Avon Foundation Breast Center's "Ask the Experts" section of our website. Here you can send a question to us for review and consider for posting on the website in this section. This section is not intended for providing medical advice concerning specific medical care or treatment. (You are also welcome to use the "search" feature of [eOnco](#), our electronic medical journal, to access information on topics of interest to you related to breast cancer diagnosis and treatment.) This "Ask an Expert" section is divided into categories intended to make it easier to navigate. We hope you find the information helpful.

[View our Ask an Expert Forum](#)

Ask An Expert

Patient Care Guide

Welcome to the services section our Johns Hopkins Avon Foundation Breast Center website. Below you will find a listing of links that will provide you with information about the services we provide.

- Services available at the Johns Hopkins Breast Center
- Unique Programs of the Johns Hopkins Breast Center
- The Breast and Ovarian Surveillance Service (BOSS)
- How to Make and Supportment

Support Programs

The Breast Center is committed to helping you in all aspects of your recovery. The resources below are available to assist you. You may call them directly or ask your doctor or nurse to help refer you.

Partners in Survival Breast Cancer Support Group: This group is designed to provide a safe and caring place where women whose breast cancer has

Searching for certainty. Websites like these offer varying levels of information, including extensive lists of FAQs, e-mail response services and even contacts for telephone or full face-to-face consultations

their doctor should not be underestimated; Baird makes the point that unless actively encouraged, people can be very reluctant to seek another opinion. Joshi notes that it is not easy in the UK to be referred to a multidisciplinary centre outside of a patient's home region, or for patients to discover that treatment modalities may differ fairly subtly, say in the radiation fractions given. "These decisions can be affected by finance," he comments. He also feels strongly that oncologists should be open about drug treatments that are not funded in one area – such as cetuximab, which is available for head and neck cancer in Scotland but not yet in England. "It is better than not saying anything about it at all."

From the oncologist's perspective, Vigneri notes that patients need to bear responsibility too. "I have no problem with people seeking alternative opinions, but some go to places that are not well qualified and get answers they like better." The sheer volume of work that referrals can generate is also an

obstacle. "Doctors need to prepare an extensive letter detailing the clinical situation of the patient. This material also needs to be translated into English and coupled with copies of the necessary laboratory and radiological exams carried out to evaluate the patient."

If they do go to a centre that is not highly qualified and internationally recognised, "the end result might be confusing, unreliable advice with consequent conflicts between the patient, their family, and the different oncologists involved." Vigneri has also come across patients who have had surgery and, told they also need chemotherapy, delay treatment too long while they 'shop around'.

Another concern he has is when patients fail to seek a second opinion before enrolling on clinical trials, and then drop out. "This can be a huge waste of time for an oncologist."

QUALITY OF LIFE

Schultze at Kiel feels that a key issue that patients don't ask about enough is

the consequences of treatment and quality of life. "These questions are not raised much by patients," he says. "For example, prostate cancer is presently a problem, as we are in a phase where we have to make up our mind if someone needs treatment at all, and if so, what treatment to give. And we need to encourage more second opinions on quality of life in palliative care for conditions such as inoperable lung tumours and head and neck cancers where you can apply very harmful, aggressive treatments, but at what price?"

"Doctors often decide on a course of treatment easily, but we do not see the burden we are bringing to the patient – for us it is our surgery, for the patient it is the rest of his life."

It is a point strongly endorsed by Joshi. "Rehabilitation is an area that is not sufficiently addressed," he says, noting that, unlike some other cancer treatments, surgery for mouth cancer can be socially disfiguring and can create great functional difficulties. Surgeons, he

The fear that many have about 'upsetting' their doctor should not be underestimated

“For us it is our surgery, for the patient it is the rest of his life”

says, may opt to perform a procedure that is more comfortable for them than the patient, and there are major choices that can be made – such as restoring a hole in the mouth with a prosthesis, or surgically, which can make other restorative work much harder.

“Part of getting a second opinion should include speaking to a patient who has had that treatment and be comforted that people do get through it despite the disabilities. Suppose you have surgery to your mouth, and the surgeon says you should have a feeding tube to your stomach. Some people fear this additional treatment – the second opinion they need is from another patient who may tell them that without it you can’t eat, you lose weight and it’s the only thing that kept them alive.”

A second opinion could also extend to others specialists who are often not part of the ‘loop’ in the early days of treatment, such as gastroenterologists, who may be able to provide information on the chances of radiation damage to the bowel and subsequent lifestyle issues. Even if there is no alternative treatment, there could then be continuity of care for a patient group that currently receives little attention.

Like many issues in cancer, much opportunity lies in the multidisciplinary team. Paolo Vigneri says it is not uncommon where he works now in Sicily to be visited by patients who have had surgery and had no discussion with a medical oncologist beforehand. Having recently also worked at Bellinzona in Switzerland, which has multidisciplinary tumour boards, he has seen the value of patients meeting both parties prior to any procedure.

One of the strongest appeals for an automatic second opinion comes from the R.A. Bloch Cancer Foundation in the US, founded by Robert Bloch, who survived a terminal diagnosis of lung cancer and went on to live for another 26 years. One day, he was with a medical oncologist who said that he had never in his career treated a cancer patient without a second opinion, because being only human, he could make a mistake – and there is often no second chance. “My conclusion is that any doctor treating a cancer patient without a second opinion is not practising medicine, but trying to play God,” says Bloch on the site.

Recognising the importance of multidisciplinary decision making, Bloch’s foundation has pushed for patients to be present when their cases are discussed by such teams – to take forward the

thoughts of ex-US Supreme Court judge and breast cancer survivor Sandra Day O’Connor in a speech to the National Coalition for Cancer Survivorship back in 1994. “Let me tell you my dream... to have a consultation with all the experts available at the same time, who’ve already looked at these things, they’ve looked at everything, and they are all in the same room, and they are there to help you reach a decision.”

Dream may be, but the Bloch site has a list of about 100 institutions in the US that say they will provide a multidisciplinary second opinion ‘where doctors representing each discipline which could treat the patient’s cancer meet together at the same time with the patient.’

Now that is a gold standard to aspire to.

IN SHORT

- Women, especially breast cancer patients, are among the most likely to seek second opinions, probably because of the many different treatment options for breast cancer and its high visibility in the media.
- Computers networks are obvious second opinion enablers. The European Union’s e-Health action plan predicts that by 2008 the majority of European health organisations should have the technical capability to provide online teleconsultation services for second opinions and other needs.
- More than a quarter (29%) of US adults reported that they or a member of their family received a second medical opinion from a doctor in the past five years, according to a 2005 Harris Interactive survey. In 30% of these, the diagnosis differed from the original. Another Harris poll in 2006 found that 36% of US adults never get a second opinion and nearly one in ten (9%) ‘rarely or never understand’ their diagnosis.
- Australian researchers have found that ‘Googling’ symptoms on the Internet came up with the right diagnosis in 15 out of 26 cases (reported in the *New England Journal of Medicine*). At Duke University in the US, medical physicists are using a Google-like approach to compare mammograms with the most highly ranked images returned from a database.