

From plan to practice

The French Cancer plan of 2003 raised expectations among the public and patients. This article, which looks at how a key measure is being implemented in practice, was one of several stories that earned **Paul Benkimoun** recognition in the 2006 ESO Best Reporter Awards.

Bad news will always be bad news, but the way it is told makes a big difference. Throughout the year, some 37 pilot schemes running in 58 institutions have been trying out a novel way of breaking the news of a cancer diagnosis that was developed in conjunction with patients. It aims to improve the conditions under which patients are notified of their condition and told about the treatment they will be given. As the pilots started gradually, full results are yet to be obtained. And the pilot schemes are set to be extended to all the sites treating cancer during the second half of the year.

In 1999, the *White Book* of the National Anti-Cancer League carried testimonies from people who were disgusted by the off-hand or brutal manner with which they were told of their illness. A symbol of the battle of patients, the improvement of the conditions under which news of the diagnosis is notified, was number 40 in a list of 70 measures of the Cancer Plan, launched in March 2003 by [President] Jacques Chirac.

A budget of 3.2 million euros was allocated, amongst other things, to pay for the creation of new nursing jobs. Another 15 million euros were set aside to extend the scheme in 2005, a sum that will have to be revised in 2006. The project was geared up to include 25,000 to 30,000 patients throughout the year. Ten months into the trial, some 15,000 people have taken part in the system, which is piloted by the National Cancer Institute in tandem with the

National Anti-Cancer League and the Directorate of Hospitalisation and Care Management.

“YOU DON’T KNOW ANYTHING”

The trial relates to the notification of the diagnosis, or its confirmation, but also to “the proposal for a treatment plan” decided at a multidisciplinary meeting, and to “the provision of a team of carers” including a psychologist and a social worker, as laid down in the specifications.

Patients can find familiar contacts within the system, and in the case of the reporting nurse, somebody who is more accessible than a doctor.

“The consultation with the nurse is a sort of ‘emotional catharsis’ for the patient and a time when medical terms will be translated into less academic language than is used by a

doctor,” said Professor Henri Pujol, president of the National Anti-Cancer League. “We feel physically, and also intellectually, diminished. We don’t know anything when faced with the doctor, the one who knows,” commented Henri Gontier, a member of the patients’ committee at the Institut Paoli-Calmettes (IPC) in Marseilles.

“In the case of tumours whose location is highly symbolic, such as the brain, you cannot just say straight out: You have a brain tumour,” explains Dr Olivier Chinot, of the neuro-oncology unit at the Timone University Hospital, in Marseilles, who is highly involved with paramedical staff in these trials. “Often patients do not ask the prognosis.”





Le Monde

Watchdog. Articles like this, which explore how far commitments to cancer patients are actually being translated into better services for all, put pressure on health services to deliver, and let patients and their families know what they have the right to expect

“They or their family ask us,” elaborates Soazic Duval, a nurse in the same department. “Bearing in mind the loss of independence that results from brain cancer, we have to take into account from the start the friends and family of these patients, who are often young,” adds Bruno Tivoli, the hospital executive who implemented the new system at la Timone teaching hospital.

Patients are also more likely to speak to the nurse about matters deemed ‘delicate’, or too banal to raise with the doctor. It is at this point that many patients discover that, in addition to causing them to lose hair from their head, chemotherapy often causes the loss of pubic hair. The matter of wigs is frequently broached.

As a by-product of these pilot schemes on the notification of cancer diagnoses, doctors have learned the value of information gathered by paramedic staff. “We had not sufficiently questioned the ambulance drivers, who take patients home, about the sickness caused by chemotherapy,” acknowledges Dr Jacques Camerlo, trial coordinator at the IPC.

“A TURNING POINT”

A notification system also calls for a *rapprochement* between hospital doctors and their colleagues on the outside. The general practitioner (GP) is, in fact, involved in informing the patient of the diagnosis. “A general practitioner from Marseilles told me: ‘When I refer a patient to the Institut Paoli-Calmettes [specialist cancer centre], don’t you think that I have held a patient notification consultation?’,” says Dr Camerlo. “The GP needs to be informed very quickly,” urges Dr Christine Bara, from the National Cancer Institute, who states that three-quarters of patients go to see their GP immediately after the notification consultation.

The pilots of the project know that making the scheme universal will not be simple. Even in Marseilles, often cited as an exemplary case, things have not always been simple. “Some doctors from la Timone University Hospital have had the honesty to say that they did not want to take part. Some give their agreement, but only send us one follow-up sheet per month,” says Professor Pierre-Henri Juin, who has been coordinating the experiment there for a year.

It is clear that there is a need “to proceed gently and with flexibility”, as Christine Bara says. “It is a question of a qualitative approach. We must avoid a purely administrative application of the system,” she adds. If you try to act on the frequent request from patients that notification consultations should no longer be held on Friday, leaving them on their own throughout the weekend, then you will probably have to take into account the problem of availability of doctors.

Flexibility is required, but also determination. “Patients have worked on this for four or five years. Therefore they are expecting changes. This will be a turning point in the relations between doctors and patients,” predicts Professor Pujol. He agrees with Dr Bara that further consideration needs to be given to four areas: paramedical consultation, the interaction between the local community and the hospital, the identification of psychological and social needs, and the personalised treatment plan.

Some practitioners look further ahead. “We will undoubtedly have to come up with an end-of-treatment system, as patients often collapse psychologically when they are no longer cared for as closely as during the treatment stage,” observes Professor Dominique Maraninchi, director of the IPC and chairman of the science board of the National Anti-Cancer Institute.

Marie-Noëlle, 48 ans, opérée en février :
 « Quelles sont mes chances de vraiment guérir ? »

Marie-Noëlle, 48 years of age, operated on in February: “What are my chances?”

She knew it as she pushed open the door to her GP's office. In fact, she knew it when she felt a lump as she examined her breasts one day in September 2004. Marie-Noëlle M., 48 years of age, was operated for breast cancer on February 4th, at Martigues Hospital.

One month later, Marie-Noëlle pushes open the door of the consulting room at the Institut Paoli-Calmettes in Marseilles, a regional anti-cancer centre, where Jacques Camerlo is waiting for her. This doctor coordinates the local pilot programme for the new cancer notification system. “We are going to go back over everything and reformulate everything,” he announces.

Before starting to examine her, Jacques Camerlo talks to her about her illness: “Breast cancer is a common disease which affects one in nine women. It can be cured and removed if various stages and treatments are complied with.” Marie-Noëlle interrupts the stream of explanations and details: “No-one ever explained that to me,” or “that’s not much fun,” when the subject of chemotherapy is broached.

She has clearly thought about her illness a great deal. Some questions are very specific: “*Am I going to have a wig?*” Other questions are more fundamental: “What are my chances of really getting better?”

Jacques Camerlo answers, without beating about the bush: “The treatment that you will have will make it possible to get rid of the disease. We will have done everything in order for you not to need to come back to see us. You will have more than a 70% to 80% chance of it not coming back.”

Marie-Noëlle’s two sons, aged 27 and 25, are very well-informed, as is her husband. “I want my children to continue with their lives as normal,” she says. “I don’t want them to be watching over me too much.”

A little later, she confides: “I am a worrier by nature, especially about others.” Jacques Camerlo tells her: “Take care of yourself first. Your day-to-day, social and emotional life must continue normally. The side-effects of the treatment are temporary and reversible.”

“Call me”

The doctor describes the different stages of the six-month treatment plan awaiting Marie-Noëlle –

chemotherapy sessions every three weeks, then daily radiotherapy for four to six weeks. He gives her the names of the doctors who will be involved. He then tells her of the various possible side-effects of the treatment, and the symptoms that she should watch out for – particularly any signs of a fever, as the treatment will severely compromise Marie-Noëlle’s immune system. “I am going to need a computer to remember all that,” she quips.

Having summarised her forthcoming phases of treatment in a document entitled “Theoretical treatment plan”, which he gives her, and having dictated in her presence a letter to the doctor who referred her, Jacques Camerlo introduces Marie-Noëlle to Jean-François Cailhot.

Cailhot, a nurse, coordinates the care of women being treated for breast cancer at the Institut Paoli-Calmettes. “Whatever the problem, call me, I will put you in contact with the people you need,” he says, giving her his card.

The nurse asks Marie-Noëlle what is the main problem that she is concerned about. “Losing my hair”, she answers immediately, adding: “I have already found out about wigs.” He tells her that her hair will start to fall out at the start of the second week of treatment, and mentions the various models of wig, reminding her that a hairdresser is available at the Institute.

Next subject: side-effects. His advice relates to everyday life: “You will be given drugs, but we cannot predict how you will react. Try not to plan too many activities during the three days following the chemotherapy session,” he stresses.

Mentioning the possibility of a fever, he recommends: “Somebody must be available to bring you here 24 hours a day, 7 days a week. You must keep the phone number of a taxi or an ambulance on you and a packed suitcase. It doesn’t happen often, but ...”

He reminds Marie-Noëlle that a psychologist and a social worker are at her disposal, and that she does not have to pay for her transport to the Institute for the chemotherapy sessions. He concludes by giving her an information leaflet on breast cancer.

Feeling a mixture of resignation and satisfaction, following this initial contact with those who are going to steer her through her six months of treatment, Marie-Noëlle prepares to return home. She will soon be back.