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Building collectives via the Web? Information and mobilization on cancer websites

Madeleine Akrich, Cécile Méadel, Catherine Rémy

INTRODUCTION

In this article the authors analyse the construction of cancer patient profiles through websites offering information on the disease. For reasons explained below, it seems that in France a largely traditional definition of patients prevails, regarding their relationship with members of the medical profession: patients entrust therapeutic decisions concerning themselves to their doctors, and their active participation is engaged only in so far as it is a necessary part of the treatment. Yet this patient profile has changed profoundly in other fields over the past twenty years, primarily through the action of patient organizations.

Patient organizations, initially focused mainly on mutual support, have now succeeded in obtaining recognition – especially in the case of chronic diseases – of a form of patient's "expertise" which is more than pure medical knowledge. Based on their early experiences, these forms of intervention have been diversified and are situated between two extremes: on the one hand, organizations whose position is complementary to that of the medical world, as they provide psychological and social support for patients without encroaching upon medical prerogatives; and, on the other hand, organizations that claim to occupy a key position in the organization of healthcare and the definition of treatment, and which are therefore often in conflict with the medical world whose supremacy they challenge (Rabeharisoa & Callon, 2000). In France the latter tendency has been increasing and some organizations are expanding into new fields. They are claiming the right to participate in the formulation of health policies, care protocols and research orientations. These trends concern mainly the pathologies of Aids and other chronic, rare or genetic diseases. (Barbot, 2002; Carricaburu, 1993; Rabeharisoa, 2003, 2006). The "epistemological" position of patient organizations indicates a clear dividing line between the two approaches: when an organization acquires the means to analyse and interpret medical knowledge in relation to patients' preoccupations, and considers itself as a source of knowledge that warrants consideration in the elaboration of research and treatment strategies, it clearly corresponds to the second type.

The world of cancer nevertheless seems to function according to a more traditional model. Originally many patient organizations were created as "charities", whose main objective was to support and inform patients. Some have been, or still are, advocacy groups supporting specific demands of patients, but on issues peripheral to the general organization of care and treatment: the announcement (the way patients are told that they have cancer) treatment for pain, socio-economic aspects, etc. Some contribute substantially towards supporting

research but the roles are strictly separate: while the general public is mobilized through fund-raising, professional experts decide on fund allocation. In short, French cancer organizations are hardly a threat to the authority of medical professionals who made a concerted effort to standardize protocols on a national scale in the 1990s, leaving little space for debate on the subject (Castel & Friedberg, 2004).

This situation is very different from the one prevailing in the United States. For the past twenty years the Health Social Movements have developed a far more militant approach to the work of non-profit organizations in the field of cancer. Apart from providing their members with support, cancer organizations fight on every front: for recognition of rights, participating in health policy-making, setting the research agenda, demanding quality care, evaluating treatment strategies, analysing the causes of cancer, and so on. There is not a single area in which these organizations have not contributed specifically (Brown Phil, 2004). At the origin of these movements there seem to be a few strong personalities who have been able to make the connection between personal experience and political issues – something unknown in France in this domain:

They made public their own experience of breast cancer and their encounters with the medical system and, in so doing, redefined breast cancer as a political concern. (...) all four women presented their own histories in accounts which did not separate the physical and emotional experience of breast cancer from detailed information about the status of scientific research and clinical procedures. (Anglin, 1997)

The work by these organizations is instrumental in the construction of new patient profiles and the transformation of behaviours and practices (Barbot, 2006). Direct action on public policies and patients' rights, elaborating and disseminating documents, tools, guidelines and information for the public, and direct support to individuals are all ways in which collective mobilization transforms patients and their relations with the medical world.

Alongside these movements, or in parallel with them, the spectacular development of the Internet and its uses seems to be a vector of this trend. It affords access to the scientific literature and is a window onto organizations and practices in other countries. The interested public can therefore draw on references other than the French medical community. The Internet also makes other forms of engagement visible and proposes different models of militant organization. Finally, its interactivity and the interaction it allows for can facilitate the formation of specific points of view and new ways of articulating individual experience to collective positions (Akrich & Méadel, 2007).

Doctors are aware of this and fear the potential subversion of traditional knowledge and hierarchies. The usual accusation regarding the upsurge of the Internet concerns the proliferation of information which is claimed to often be erroneous and misleading rather than being helpful to patients. Our study was funded by the National Cancer Institute to answer this very question on the nature and quality of cancer-related information on the Internet.

In parallel with this potential change from the outside, it seems that the oncology community is also evolving. In particular, in dialogue with patients it appears to recognize the uncertainty which remains, despite the advancement of new knowledge. Thus, oncologists have switched from 'not saying anything' to 'speaking in uncertain terms' during consultations (Ménoret, 2007). In other words, it seems that even in one-to-one conversations between doctors and patients, a space of discussion and negotiation is opening up.

In the rest of this article we characterize the profiles of cancer patients as they appear on a large number of French websites. Many sites belong to non-profit organizations; others are

initiatives by the medical profession; others still are produced by professional organizations linked to the media sphere. Apart from a general review of the competencies and rights associated with patients, on the role of information in determining their capacities to act, and on the place granted to patients and their families to express themselves, the sites related to patient organizations raise specific questions. For instance, what are the forms of engagement pertaining to cancer, in the French non-profit organization movement? In particular, how can the division of tasks that each organization institutes between doctors, patients and itself be characterized, and how does it articulate its support activities with its activism?

In parallel, we examine the role of the Internet in shaping this engagement, and the forms of writing peculiar to the Web. This writing has the characteristic of affording the possibility of a multiplication of enunciators and thus of facilitating encounters and the formation of collectives, that is, individuals talking in the same voice with specific aims. In what way do the uses to which the various "authors" of websites put these possibilities allow for the creation of new knowledge, the emergence of new collectives, and the performance of new actor configurations?

To answer these questions, our presentation is divided into three parts:

- First, we consider the status and format of medical information, as delivered on websites. In particular, we examine the designated enunciators, the authority on which their information is based, and the *mise en scène* of the context of enunciation. What position is assigned to the recipients of this information? Is there space for uncertainty and debate?
- In the second part we characterize the presence of laypersons' and patients' talk. In particular, we examine its possible link with that of professionals, and that of "science". Are there any forms of articulation between individual experiences and collective forms of expression?
- Finally, in the third part, we analyse the patient profiles that each website constructs in its public, both through the proposed content and through the modalities of action afforded by the site itself. We consider the "patients", their possibilities to act and the competencies attributed to them. How does the site describe a patient's relations with healthcare professionals? What choices does the patient have? What leeway does he or she have to define him- or herself through the site itself? What are the relations between the patient profile, that of the activist and that of the donor of funds?

Our analysis is based on a varied sample of French websites, selected from a set of 30 sites. Some US sites are used as a contrast, to explore dimensions unknown in France and to broaden the spectrum of possibilities.

I. VARIOUS MODELS OF MEDICAL KNOWLEDGE

What information is proposed on websites intended for patients? It is important to point out that even though the aim of cancer websites is to talk about the disease, they do not necessarily focus on its medical aspects. On some the activities organized by the collective, concerning the disease, are discussed: support operations (e.g. the dreams come true for

young patients of *Arc en ciel*), planned encounters with others, life within the organization, fund-raising, and so on. Others provide information on the disease but concerning its psychological, legal and social rather than medical aspects (e.g. data sheets on patients' rights drawn up by *Jeunes Solidarité Cancer*, and surveys on patients' quality of life). For some of them the explicit aim is to support patients in hospital (*Ametist*). Others are personal sites which recount the lost cause of a patient, very often a child. In this vast corpus, we selected sites which devote a significant amount of space to informing non-professionals on the disease: definition of cancer, explanation of its mechanisms, possible treatments, screening, prognostics, etc.

There is more than one approach to achieve the explicit objective of informing patients and supplying them with knowledge on the disease, even though cancer websites as a whole are far more homogeneous than websites in other areas of health. By highlighting the differences, it is possible to construct a typology of these information formats, based on several criteria: the rhetorical type, with its guarantee of authority; the way in which the enunciator is presented; the choice of the explicit or implicit recipients, and the position assigned to them. For this purpose we distinguish four main types of information, which we have called: the lesson; framework information; dialogical information; and engaged information.

To illustrate each of these four particular types of website we use an example, although the sites are not necessarily confined to a single type of information; with the multiplication of pages and enriched menus they do not always correspond to a "pure" information model.

THE LESSON: INFORMATION IN THE FORM OF A MONOLOGUE

In this first type, the lesson, information consists of established, timeless and unquestioned truths. There is no place for uncertainty on definitions of the disease, the validity of treatments, the quality of care, etc. For instance, the *Arc* site specifies that "knowledge evolves daily" but then presents an objective, rigid, timeless, decontextualized form of knowledge. This intangibility is materialized by the form in which the information is presented: very often downloadable PDF documents.

Brochures à télécharger

Thèmes généraux:

- Le cancer
- Comprendre comment une cellule devient cancéreuse
- Les cancers professionnels
- Hérité et Cancer
- Les leucémies de l'enfant

Prévention, dépistage et suivi:

- La prévention du cancer
- La mammographie
- Le tabac
- Les examens de dépistage
- Les marqueurs biologiques du cancer
- Le frottis cervico-vaginal
- L'auto-examen des seins

Traitements:

- La radiothérapie
- La chimiothérapie
- La greffe de moelle osseuse
- L'hormonothérapie

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Yet this is not the rhetoric of a scientific article, the question of certification is not mentioned and the language is suited to its implicit public. This type of information focuses on scientific results and not knowledge production. The authors' specific work consists in producing these truths in a language accessible to the layperson. But these enunciators, who have made a huge effort at translation, are not presented; they are anonymous and absent. It is science that is talking and its authority has no need for guarantees.

On the Arc site, in a brochure devoted to prostate cancer, the disease is described in totally objective terms: the actants are the biological entities, tumours, cells, medical actors (doctors, gastro-enterologists, urologists, etc.). The patients are present in two forms: most often as an indistinct entity, "the patients", who, like a statistical entity, have several behaviours and characteristics ("patients may have diarrhoea, patients have side-effects, patients follow a diet"). More rarely, the patient is individualized when he or she has contact with the doctor – "the doctor takes the patient's general condition into account" – but he or she does not for all that have autonomy or the capacity to express a personal point of view. Whether plural or singular, the patient is always in a passive position.

We note that in the Arc's brochures, the addressee is mentioned only in the introduction, when the purpose of the document is presented: "the purpose of this document is to review **with you**¹ the symptoms, diagnosis and treatment of prostate cancer". Everywhere else the "you" disappears and the reader becomes implicit: this is the person who wants to learn about cancer, without his or her relationship to the disease being clarified. And like the objectified patient in the brochures, the reader has no leeway: the PDF file is closed and allows no connection to be made with other sources of information; the reader can only learn the lesson delivered. The contract is explicit and repeated: "know cancer better to conquer it better".

¹ Our emphasis.

The patient and the addressee are therefore called to the same position of observation: learn medical authority's lesson to behave as it sees fit (as it expects).

FRAMEWORK INFORMATION: THE PASSIVE PATIENT

In the second type of information, that we have called framework information, the patient is likewise inactive but is better represented. The information is as closed as in the first type, the doctors' expertise is not called into question, and uncertainties are rare or even absent. Yet the profile of a patient does appear in several respects, not only as the good subject of medicine, but also as the reader to convince, the patient to advise, and the information-seeker to satisfy.

In the data sheets of the organization *Europa Donna*, a "European coalition against breast cancer", the discourse on medical knowledge is presented as a certainty: unique, sure, unquestioned. Even though a doubt is sometimes expressed, it is in the conditional:

The advantage of this technique may be to avoid the unwanted side-effects of an axillary curage. When the lymph nodes removed and analysed are not invaded by cancerous cells (we also say they are 'negative'), the sentinel node technique may make it possible to avoid an axillary curage in 50% of patients whose tumour is smaller than 3 centimetres and 70-80% of patients whose tumour is smaller than 1 centimetre.

But the slight doubt introduced here is not explained further and all the reader understands is that everyone (but who?) should not be convinced by the virtues of the sentinel node.

Despite the closed nature of the information, the model does not however correspond to the popularized brochure. Unlike the "lesson"s in the first type, *Europa Donna's* data sheets use the forms of certification of scientific texts:



The sheets are signed and the author is situated, the article is dated, the place of publication is indicated, and links are proposed. Unlike the first model, this one implies a reader who expects the guarantors (of the validity of the information) to be explicit. The enunciator is clearly indicated and so is the addressee. In the following sheet on Tamoxifène, a drug which reduces the risk of relapse, the information is presented as a series of questions by a patient, answered by a doctor.

Réponses sur le traitement au Tamoxifène

Par le Dr. Marc Espié
Hôpital Saint-Louis Paris

Bulletin N° 2 - 06/2000

aurais-je à nouveau des règles à l'arrêt du Tamoxifène ?

Le Tamoxifène peut induire un arrêt des règles qui doit normalement être réversible à l'arrêt du traitement. La grossesse est contre-indiquée pendant la prise du Tamoxifène en raison d'un risque de toxicité pour le fœtus. Une grossesse est envisageable à l'arrêt du Tamoxifène.

Est-ce que ça fait grossir ?

Dans les études comparant les femmes traitées par rapport au Tamoxifène aux femmes non traitées par cette molécule, il ne semble pas y avoir davantage de prise de poids chez les patientes prenant du Tamoxifène par rapport à celles qui n'en prennent pas. Beaucoup de patientes se plaignent,

When the sheet is considered as a whole, it is obvious that the doctor-author drew up the list of questions, and not the patients or their representatives. This is simply a rhetorical approach that the author has chosen to make him- or herself understood. The organization itself does not intervene directly as a collective able to provide information, to ask questions, set hypotheses or even propose interpretations. Its members act only as professionals and not as participants in the organization (their professional status appears on the articles and one has to go into the masthead of the website to see that they have functions in the organization). Thus, the site proposes explanations of patients' positions, preferably by recognized professionals or through "scientific studies" on patients' behaviours.

Europa Donna prides itself on representing patients, mainly through its capacity to designate the representatives who will not only talk with authority but will also be able to take into account the patients, the questions they may have and the things they have difficulty understanding, and thus to guide them better.

Hence, this is no dialogue between the holder of the knowledge and the pupil, for here the patient or layperson has no space available to intervene. The relationship between the enunciator and the addressee remains asymmetrical. The patient is only represented by an authorized mediator – unlike the case of the first type of information.

DIALOGUE INFORMATION: INFORMATION THROUGH INTERACTION

The third type of information, that we have called dialogue information, is slightly more open to possible interaction around certified medical information on cancer. It is possible here, if not to engage in debate, then at least to establish a form of dialogue, non-fictional this time, between the medical authority and the patient. No longer simply an addressee, the patient becomes a legitimate enunciator. There is thus an attempt to take into account the patient's position and the questions that he or she may have.

The homepage of the breast cancer website www.cancer-sein.net informs us that it is produced by a loose collective (in that it is unclear how it is organized, who leads it, and even if there actually is a real structure) steered by medical institutions, with a scientific committee and author-contributors, all of whom are practitioners. Yet the enunciator does not only talk

from her position as an unquestionable and unquestioned expert. After the first page one finds three types of enunciator. The first is clearly established: she answers the questions listed on the left of the screen and which are supposed to interest the visitor, in the form of a text or oral recording. This enunciator is however never explicitly presented, nor identifiable; she talks authoritatively, simply and affirmatively, expressing no doubt; she is neither a doctor nor a patient. The second enunciator is the visitor embedded in the site, and with whom we assume the other visitors identify since they have to use the same way of formulating their questions. In this case, there is some degree of confusion between this enunciator and the addressee. Finally, we find a third type of enunciator on certain pages: women who have had cancer and whose testimony has been recorded and divided into short sessions, placed next to the questions they address.

The screenshot shows the website www.cancer-sein.net. The navigation menu on the left includes: 1 Interventions chirurgicales, 2 Chimiothérapie, 3 Hormonothérapie, 4 Radiothérapie, and 5 Le ganglion sentinelle. The main content area is titled "Je suis un traitement de chimiothérapie, puis-je continuer à travailler ?". It contains the following text: "Cela dépend du traitement que vous suivez et de l'emploi que vous occupez. La poursuite d'une activité professionnelle est une bonne attitude évitant une rupture sociale et facilitant la reprise d'une vie normale à la fin du traitement. Cette décision vous appartient. Vous devez également vous organiser avec votre employeur pour aménager votre emploi du temps en fonction du traitement." To the right of this text are two video testimonies: "Marianne, 51 ans, Cancer diagnostiqué à 39 ans (durée : 1 minute 23 secondes)" and "Véronique, 47 ans, Cancer diagnostiqué à 37 ans (durée : 1 minute 09 secondes)".

We do not know much about these women, apart from a black and white photograph, a first name, their age and the age of their cancer, but this presentation creates a very sharp contrast between the universal enunciator, who is absent, and these "physically" present enunciators on the Web. The fact that what they say is not accessible in a written form, and can be grasped only in the continuity of a recording, strengthens the contrast with the other information formats on the site. On the pages for professionals, even when the information is formulated as an oral recording, it is always accompanied by a transcription. In contrast, when the patient talks her speech is always attached to the person and is therefore related to a form of subjectivity.

CONTEXTUALIZED INFORMATION: INFORMATION IN ACTION

The fourth type of information is like the expert knowledge model, in which an expert expresses him- or herself, based on the sole authority of the scientific literature. However, in this model the information is configured differently. Here the source of the information is the patients themselves and not professional knowledge. This configuration does not exist on any of the French-language sites that we studied. It corresponds to the status that US organizations attribute to information, especially the two very large organizations that we studied: the American Cancer Society (ACS) and the National Breast Cancer Coalition (NBCC).

The visitor seeking information on breast cancer on the ACS website finds an offer addressed specifically to her. Even the explanatory sheets on cancer go further than the dialogue-information described above. The visitor who wants to know everything about breast cancer first has to situate her level of knowledge; does she want information that is general, detailed or more specialized? Next, she has the choice between several formats: general explanations on cancer, a more specific consultation on her case (the decision tool that will help her to understand her treatment better and to interact with her doctor), optimistic accounts by former patients, precise information on therapeutic options, etc.

Learn About Breast Cancer

Learn about **Breast Cancer**, risk factors, prevention, treatment, and more. You can also read stories of hope from people whose lives have been touched by cancer.

[Choose another cancer topic](#)

[All About Breast Cancer](#)

Get answers to all your questions about this disease.

[Treatment Decision Tool for Breast Cancer](#)

Learn about your treatment options for this type of cancer.

[Other Information Sources](#)

Browse other Web sites on cancer, books on cancer and related information on our site.

Learn More

[Stories of Hope](#)
Discover what others have faced, how they have fought, and what they have learned about life and love in their experiences with cancer.

[Talking About Cancer](#)
Learn how to talk about your experience to people who are close to you and those outside your inner circle.

[Treatment Options](#)
Learn what types of treatment are available, their risks and benefits, the possible side effects, and how to manage them. Learning about your options and discussing them with your doctor can help you with these important decisions.

As on the sites considered above, the information produced by the patients themselves – for example their participation in forums – is disconnected from the part of the website strictly devoted to the presentation of knowledge on the medical aspects of the disease. But here the patient-visitor is represented at each stage of her search; the information is formulated in relation to her – or even the multiple hers that she may be – to give her the possibility to understand and participate (as the following section title indicates: "News you can use"). Like the readers, the enunciators are multiple: besides the experts, clearly situated on the side of the organization and its members, are patients, doctors and politicians who all express themselves to answer the questions put to the organization

These two US cases seem particularly interesting because they propose a way of expressing patients' points of view with authority, anchored in collectively accepted claims. This integration of patients into the actual organization of information and its rhetoric has two characteristics: the renewal of information, and its articulation to the organization's objectives. The information proposed is not closed and rigid, as in other models. The articles are dated, the dates of revision are indicated, and syntheses of the current state of research are proposed, with an extensive, recent and updated bibliography.

The plurality of authors and the renewal of the knowledge proposed (or at least the spirit of providing updated information) do not generate a fragmentation of the site or an effect of

cacophony because they are organized in line with the organizations' main political orientations. The two organizations are interested not only in care for patients; they also take a stand in major controversies on the subject. On its site the NBCC explains the positions it defends.

POSITION PAPERS

Abortion and Breast Cancer Risk

It has been hypothesized that surgical and spontaneous abortions increase breast cancer risk. However, the largest and most reliable research studies show that there is no association between either kind of abortion and risk of breast cancer. Based on the science described above, NBCC does not support any public policy efforts that imply such a link exists.

Access to Investigational Interventions Outside of Clinical Trials

Access to investigational interventions outside of clinical trials undermines the clinical trials system and the principle of evidence-based medicine. It has the potential to seriously harm individuals and raises important issues of fairness. For these reasons, the National Breast Cancer Coalition (NBCC) believes that access to investigational interventions outside of clinical trials should be allowed only in very limited circumstances.

Breast Cancer Advocate Involvement in the Research Process

Breast cancer advocates who are trained, educated and represent a patient constituency must be meaningfully involved in all aspects of decision-making that affect breast cancer research. This is the only way to ensure that funds are effectively spent and adequately address the causes and prevention of breast cancer, develop optimal treatments and cures for breast cancer, and focus on the best possible means to eradicate the disease.

Breast Self-Exam

If the visitor to the website has questions on self-palpation of the breasts, her point of view will correspond to that of the organization, contrary to that of many professionals, but she will also know what the right questions to ask doctors are, what their position in the controversy is, or the groups she can contact for support or to join them. She may even receive the ad hoc training enabling her to become an effective activist in the struggle for other forms of screening.

In this model of contextualized information, everything is done to give the patient the capacity to act, so that she can absorb what she is told – even if she needs to ask questions or to complete the information with other sources – and react to the information she receives, whether from the website or from a doctor.

To our knowledge this type of information, which empowers the patient by equipping her with knowledge directly correlated with her own questions, experience and life history, does not exist on French websites (it was not found on any of the 40 sites that we studied). In the lessons, the information dispensed on these sites seems to range from a position in which the patient is objectified, to limited forms of representation, from the most projective, framework-information, to the least prescribed forms in dialogue-information. Their aim is nevertheless to talk to laypersons and to be heard by them. How do they achieve this?

II. PROFESSIONALS' TALK / PATIENTS' TALK

We have just seen that the medical information proposed on French sites is relatively closed. Yet, without having the striking impact of the information on US sites, the dialogue-type of information illustrates the existence of more moderate positions in which patients and their points of view are not disregarded. In this section we are going to consider in more detail the question of patients' talk on websites devoted to cancer. We will see that certain

mechanisms grant visibility and legitimacy to this lay talk. Does this mean that the medical profession's ascendancy is being undermined? Is there a production of "lay" knowledge capable of competing with or destabilizing professional knowledge?

PATIENTS' TALK PRIVATIZED

French patient organizations act in a context in which certified information is valued. On the whole, this certification enables professionals to control content, and makes it possible to avoid the problem of uncertainty in scientific knowledge. How do organizations manage the tension between certification of information and free speech for patients, afforded by the Internet? One way may consist in *privatizing* access to patients' talk. Even though this privatization precludes wide dissemination of what is written, it also enhances a feeling of belonging to a community, by clearly delineating an inside and an outside.

This is the case, for instance, of *Ensemble contre le GIST* ("Together against GIST"), an organization set up to provide information and to bring together patients with GIST (Gastro Intestinal Stromal Tumour), a very rare form of sarcoma in the digestive tract. The organization's website is constructed around a demarcation between two spaces: a space open to visitors, offering general information on the disease, and a forum reserved for members. Most of the informative articles are signed by doctors on the scientific committee. In no way is this central role played by experts undermined by the laypersons' talk, which is limited to a small group of individuals.



The image shows a screenshot of the website for 'Association Française des Patients du GIST' (AFP-G). The header features the organization's logo, which consists of several hands holding each other in a circle, with the text 'ENSEMBLE CONTRE LE GIST' around it. Below the logo, the text reads 'Association Française des Patients du GIST' and 'ENSEMBLE CONTRE LE GIST'. A navigation bar contains links for 'AFP-G', 'Ensemble contre le GIST', 'Informations GIST', 'Recherche scientifique', 'Informations AFP-G', 'Espace Membres', and 'Liens'. Below the navigation bar, there is a login prompt: 'Pour accéder à cet espace, veuillez rentrer votre login et votre mot de passe'. This is followed by a 'Login' input field, a 'Mot de passe' input field, and a 'Valider' button. At the bottom of the page, there is a footer with links for 'Accueil', 'Plan du site', 'Nous contacter', and 'Mentions légales'.

THE PATIENTS' TALK JUXTAPOSED

Other websites limit this encounter between professional talk and lay talk, by creating a clear *separation* between the two spaces. Lay talk does exist, but the architecture of the site makes it difficult, if not impossible, to use what is said beyond the "official" space in which it is expressed.

This is the case for example of the private site *Doctissimo* which offers medical information. One section of the site focuses on cancer. For each type of cancer the visitor has access to information in various forms: popularized articles, educational sheets, videos, tests,

brochures and forums. This multiplication of media is organized around a clear distinction between, on the one hand, professionals who provide a wide range of information on the disease and, on the other, anonymous individuals who have only a pseudonym and no authority. No real value is attributed to the patients' talk; the forums are designed above all as places of communication and interaction, based on a model of mutual help rather than advocacy or imparting knowledge.

Le sein dans tous ses états

De la puberté à la ménopause, les seins sont l'objet de toutes les attentions et de toutes les peurs. La découverte d'une grosseur est l'objet d'un retentissement psychologique très élevé. Sans la négliger, sachez cependant que la plupart des lésions du sein sont bénignes.



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[Le cancer du sein avant 35 ans](#)
[Les maladies bénignes du sein](#)
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[Les traitements de la ménopause](#)
[représentent-ils un danger ?](#)
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Tous les traitements du cancer

Adriablastine	Cisplatine	Gliadel	Natulan
Alimta	Cisplatyl	Herceptin	Navelbine
Alkeran	Cosmegen	Hexastat	Nipent
Ametycine	Daunoxome	Holoxan	Nolvadex
Amsalyo	Depo-prodasone	Hycamtin	Novantrone
Anandron	Depocyte	Hydrea	Oncotam
Aracytine	Deticene	Estracyt	Oncovin
Aredia	Doxorubicine	Immucyst	Ostepam
Arimidex	Efudix	Iressa	Orimetene
Aromasine	Eldisine	Kessar	Paclitaxel
Avastin	Eligard	Kidrolase	Pamidronate
Belustine	Eloxatine	Lanvis	Paraplatine
Beromun	Enantone Ip	Ledertrexate	Prodasone
Bicnu	Endoxan	Leustatine	Prostadirex
Bigonist	Epirubicine	Lipiocis	Sprycel
Bleomycine	Erbitux	Litak	Sutent
Bondronat	Estracyt	Lucrin	Tamofene
Caelyx	Etopophos	Lysodren	Tamoxifene
Campto	Etoposide	Mabcampath	Tarceva
Capsion iodure I131	Eulexine	Mabthera	Taxol
Carboplatine	Fareston	Megace	Taxotere
Caryolysine	Farlutal	Metastron	Tykerb
Casodex	Farmorubicine	Methotrexate	Vepeside
Celltop	Faslodex	Methyl Gag	Vincristine
Cerubidine	Femara	Miltex	Xeloda
Chloraminophene	Fludara	Mitoxantrone	Zoladex
Cisplatine	Fluorouracile	Muphoran	Zometa
Caryolysine	Flutamide	Myleran	
Casodex	Gammanorm	Myocet	
Chloraminofene	Gemzar	Nafoline	

► Discutez-en sur nos forums 

[Un membre de votre entourage ou vous-même venez d'apprendre le diagnostic. Vous avez envie d'échanger vos points de vue avec d'autres personnes dans votre cas. Parler du cancer n'est pas toujours facile, nos forums vous sont ouverts](#)

The invitation to participate in the forums appears at the bottom of the page and leads to a space separate from that of official information. The idea is clearly to exchange opinions with other people in the same situation. In other words, it is limited to encounters between laypersons. Consequently, none of these discussions feed into the debates in the professional space.

PATIENTS' TALK AT THE HEART OF THE SYSTEM

While certain French websites privatize access to patients' talk or limit it to a secondary role, others transform it into legitimate and indispensable discourse.

This is for instance the case of the website of *Essentielles*, a breast cancer patients' organization. The importance of lay talk on the disease is established from the home page. The structure of this page, on which the presentation of personal experiences is set next to access to the forum, highlights the "active and enlightened" patients that each visitor can easily learn more about at a click. A small boxed section on the right of the screen, on the same level as access to the forums, informs the visitor that: "Essentielles.net was born from

the wish to enable women affected directly or indirectly by breast cancer to meet one another, by providing them with a space of information and communication tools to talk about and share their experiences and to break the isolation and taboos created by the disease". It is thus the site as a locus of interaction that is promoted, rather than the site as a provider of general, disembodied medical information, even though such information is also present.



Cancer du sein des femmes témoins
(Emmanuel Cuzin)
Ce livre donne la parole aux femmes atteintes d'un cancer du sein. Simples et directes, elles racontent un moment de leur vie, leur lutte contre la maladie, avec des mots du quotidien. Elles expriment sans tabou leurs émotions et leurs peurs, leurs questions sur la vie et son sens. [Commander](#)



Itinéraire d'une amazone
(Annick Parent)
Ce livre relate une expérience : celle d'une femme atteinte d'un cancer du sein, qui est passée par toutes les étapes de la maladie, de son dépistage à sa guérison. Elle évoque avec une certaine acuité ses sensations, ses sentiments, ses relations avec sa famille et le milieu médical qu'elle pensait connaître pour l'avoir fréquenté en tant qu'agent hospitalier, puis en tant qu'aide-opératoire en chirurgie esthétique. [Commander](#)

Lumières pour l'espoir
[03/09/2007 16:19:00]



Retrouvez toutes les infos pour participer aux lumières pour l'espoir 2007 dans la rubrique [Association / La vie de l'association](#)
[Archive des autres éditos](#)

Les forums de discussion

Voici les fils de discussion que nous vous proposons. Retrouvez les messages les plus récents en haut de chaque fil.

Les thèmes	Nb msg	Dernier msg
Inquiétudes	4357	17/09/2007
Problèmes cheveux et yeux	2005	17/09/2007
Grossesse et cancer du sein	549	17/09/2007
Echanges (pistes, livres, adresses, etc.)	753	17/09/2007
Ecrire	351	17/09/2007
A nos étoiles	1486	17/09/2007
Brèves de cancer	841	17/09/2007
Joyeuses Fêtes	815	17/09/2007
Cancer du sein inflammatoire	2267	17/09/2007
Des nouvelles des filles ?	1713	17/09/2007
Traitements et kilos	653	16/09/2007
Taxotère	1654	16/09/2007
Soutien du conjoint	1276	16/09/2007
Hormonothérapie	876	16/09/2007
Récidives	861	16/09/2007
Non-reconstruction, aussi un choix	94	16/09/2007
ALD, Sécu et prise en charge	676	16/09/2007
Ganglion Sentinelle	158	16/09/2007
Arimidex	2095	16/09/2007
Reconstruction	2772	15/09/2007
Rencontres Essentielles	2660	15/09/2007
Chimio FEC	1380	15/09/2007
Métastases	2924	15/09/2007

associée à la maladie

[25/07/2007] Prévention in vitro d'une prédisposition à des cancers

[25/07/2007] Avastin(MD) reçoit un avis positif en Europe comme traitement de première intention du cancer du poumon au stade avancé

[08/07/2007] Nouvel outil de recherche sur le cancer du sein

[08/07/2007] Pour une meilleure prise en charge des dépenses en longue maladie

[27/06/2007] Le cancer du sein plus dangereux avant 35 ans

[27/06/2007] **Cancer du sein : les traitements de demain**

[23/06/2007] Francis Larra élu nouveau président de la Ligue nationale contre le cancer

[23/06/2007] Nouvelles thérapies pour les patientes atteintes de cancer du sein.

[07/06/2007] Cancer du sein avancé : une avancée thérapeutique

[Archives des news](#)
[Archives HTML](#)

Essentielles.net est né de la volonté de mettre en relation les personnes touchées directement ou indirectement par le cancer du sein, en leur fournissant un espace d'informations et des outils de communication pour évoquer et partager leur expérience et

The *Essentielles* site is based on the model of a community: that of women suffering from breast cancer and, more generally, all women in so far as they could contract the disease. The governing board of the organization is composed of patients only or of (female) relatives of patients.

This community model appears clearly on the forums, which are highly active and cover diverse subjects, from the disease and doctor-patient relations to questions of day-to-day life. The participants express themselves, interact and sometimes virulently criticize the medical profession, in particular.

Some excerpts:

I feel like flying into a rage

[68512] posted on 24/01/2007 09:14:00

by simusette

it's disgusting!!

i was supposed to have my appointment with my onco in december, and when i phoned in june for the appointment the secretary told me to call back in september, which i did, and then she told me: mr randria's in a consultation, i don't have his diary, call back later, so now my visit's overdue and i don't dare phone anymore!!

this really gets to me!!!!

even my dog's vet sends me a letter proposing a date!!!

it's not fair

simusette

to simusette

[72049] posted on 03/03/2007 09:34:00

by dandoune007

hi,

I was browsing on forums and I came across the patient forum....

I had my first breast cancer in 2003 (a second one in 2004 and a third in 2006).

At the time the surgeon more or less imposed his oncologist on me (at the time I didn't even know what an oncologist was!).

My relations with this oncologist were very strained²: very cold, always in a hurry, no human contact, impossible to get answers to my questions, etc. I was just a file among many!!! I'd walk out of there totally depressed...

Considering my condition, three doctors (from a different specialty) advised me to change oncologists: it's doable. You just have to make an appointment with a new onco and he'll get your file transferred ...

I did it, with no regrets: part of the healing is through one's relations with a doctor and through the interaction ... and with the DIALOGUE that's established. **For God's sake, it's not just a common cold that we've got, it's a matter of life and death!**

² My emphasis.

Check out all the oncos available near you, and then choose...

Good luck

effect Fec100

[85771] posted on 08/08/2007 20:51:00

by Caracol

well yeah **there is a trick**, Emend ! Mary do you know why they didn't give it to you? I thought that it was part of the Fec "standard pack", but it seems that it's quite new.

In any case **people who've used it tend to say** that Emend's very effective for nausea. I had it for my 3 Fec100, and apart from the horrible taste that ruined my appetite, I had hardly any nausea.

But Emend will only be useful for your next chemo. In the meantime I don't know what to advise you, maybe anti-nausea bracelets, those that press on an acupuncture point on the inside of the wrist, between the two tendons, about two finger-widths down from the hand. If you don't have bracelets you can always try to massage this point.

Good luck!

The patients relate their experience. In so doing they often criticize the medical professionals' attitude – described as cold, distant, inhuman, authoritarian –, urge other women to react – to "take things in hand", change doctors –, or give advice relative to treatment or daily life – many messages concern side-effects and "tricks" to alleviate them. This lay talk moves into areas traditionally reserved for professionals, and provides a counterpoint to the general information given on the website, which is produced in collaboration with doctors and remains relatively "rigid". The charter specifies that "the site was originally a personal initiative and receives no institutional nor laboratory sponsorship. This guarantees it total independence and impartiality". On the other hand, thematic files are created with the collaboration of experts (surgeons, oncologists, geneticists, etc.) who are asked individually

to write articles, depending on the subject. On the *Essentielles* website, lay talk is thus recognized and active, even if this is not reflected in the experts' space by a dynamic presentation of knowledge.

The website of the organization *Anamacap*, which supports prostate cancer patients, proposes a different model. Patients are described as important speakers and knowledge on the disease is presented as evolving. This characteristic singularizes the *Anamacap* site on the French scene. The approach is defended from the home page. For example, in the "Communication" section, which reports on conferences and various scientific meetings, the chairman of *Anamacap* recounts his meeting with "an eminent professor":

This summer in Virginia I met Dr Charles Myers, who's currently the leading prostate cancer specialist in the world (who himself has prostate cancer in an advanced stage). Here are the drugs and diet that he recommends after a localized treatment, to delay any relapse. You'll see that all the recommendations are supported by scientific research. This will enable you to address the subject seriously with your doctors. I've had the opportunity to once again specify that ANAMACaP does not give advice; it informs on practices in France and especially abroad. Roland Muntz.

The organization provides evolving information that patients can use in consultations with their doctor. Patients are defined as actors in their own right in so far as their treatment is concerned. This active view of the patient is also materialized on the site by the appeal for everyone to express themselves in the forums. In the middle of the home page, two sections are presented side-by-side: "The latest articles" and "Your most recent accounts". This juxtaposition is repeated at the bottom of the page, with "Glossary: did you know?" and "Most recent messages from the forum". The site designers have thus linked the imparting of knowledge with patients' talk. It nevertheless seems that *Anamacap's* objective is not attained, as there is very little activity in the forums on the site.

Accueil L'Association Le Cancer Le Dépistage Les Traitements Nos Services Contact

rechercher ok



JE M'INSCRIS !

► Devenez adhérent de l'ANAMACAP et bénéficiez à travers notre site Internet d'informations pratiques, d'échanges sur notre forum et d'un livret sur la maladie qui vous sera remis dès votre inscription.

Ne restez plus seul !

Un mot sur le Cancer de la Prostate

"Le cancer de la prostate est devenu le premier cancer en France avec environ 50000 nouveaux cas par an actuellement.

Lorsque la tumeur paraît localisée à la prostate, trois facteurs (au moins) doivent être pris en considération afin de déterminer la nature du traitement : l'extension locale (en particulier en dehors de la capsule et aux vésicules séminales), le "score de Gleason", évalué sur les biopsies de prostate, et le taux sanguin de PSA (un marqueur tumoral).

Plusieurs études récentes indiquent qu'il faudrait également tenir compte d'un quatrième facteur : la vitesse d'élévation du PSA dans le sang.

En effet, pour les patients chez lesquels l'ablation de la prostate a été décidée, les chances de guérison diminuent clairement si le taux de PSA augmente de plus de 2 ng/ml par an avant l'intervention, et ce, de manière indépendante des trois autres facteurs. De même, dans une autre étude réalisée chez les patients considérés comme de bon pronostic sur les trois premiers critères (c'est-à-dire une tumeur qui ne franchit pas la capsule prostatique, de score de Gleason inférieur ou égal à 6 et dont le taux de PSA est inférieur à 10 ng/ml), il semble bien que l'on puisse se passer de traitement du cancer de la prostate en se contentant d'une simple surveillance si le temps de doublement du PSA est supérieur à 3 ans.

Ces données récentes ouvrent de nouvelles perspectives, à la fois pour éviter des traitements parfois traumatisants à des patients qui ne le nécessitent pas, et aussi pour proposer des traitements plus importants aux patients qui sont à haut risque de rechute malgré le traitement local."

Le Président

LES DERNIERS ARTICLES

- » Conseils kiné pour l'incontinence
- » Surveillance active du cancer
- » Implant pénien : le guide TITAN
- » Compte-rendu de l'AG 2006
- » Ajout d'articles dans la documentation

VOS DERNIERS TMOIGNAGES

- » Forum international
- » En Allemagne...
- » Absurdité de la vie et malédiction ...
- » tjs pas d'érection après 3 ...
- » prostate

[Cliquez ici pour témoigner!](#)

COMMUNICATIONS

SYMPOSIUM février 2005 – FLORIDE : Voici quelques communications du symposium sur le cancer de la prostate qui s'est déroulé en février 2005 à ORLANDO (Floride). Les nouvelles ont été rapportées par mon ami Christian LIGENSA, qui est mon alter ego de l'association allemande des patients. La traduction a été réalisée par notre collègue alsacien, Roland HOSSENKOPPHUSS. Si vous avez des informations sur notre maladie, n'hésitez pas à nous les communiquer pour être diffusées : info@anamacap.fr.
=> Lire la note sur le Symposium (PDF, 15ko)



PUBLICATIONS

Nous vous conseillons les ouvrages suivants :

- "La prostate après 40 ans", Professeur Guy VALLANCIEN, Edition Rocher
- "Cancer de la Prostate, prévenir détecter et traiter", Professeurs Olivier CUSSENOT, Georges FOURNIER et Monsieur Roland MUNTZ, Editions John Libbey
- L'ANAMACaP préconise la lecture de ce livret adressé à chaque membre de l'association.*
- "Les hommes aussi ont leurs secrets", Professeur Guy VALLANCIEN, Edition Rocher, Collection Equilibre
- "Tout savoir sur la prostate", Professeur Bernard DEBRE, Edition Faure, Collection Tout savoir sur...
- "Cancer de la prostate", Professeur Vincent RAVERY, Edition Springer, Collection Monographie

The two examples above show that patients' talk is effectively visible and promoted on certain French websites. For instance, as regards side-effects, patients express themselves, question the medical profession, advise one another, and so on. Yet even though there is dialogue and debate, to believe that lay knowledge is thus constituted would be a hasty conclusion. On closer inspection of the forums, the main locus of expression of patients' talk, we see that they are badly organized and hardly legible. There are few or no syntheses or overviews, which would be essential to translate particular issues into general terms and produce transmissible knowledge on the disease. In the third excerpt from the *Essentielles* site, for example, the participant tries to synthesize information circulating on forums to substantiate what she has said ("people who've used it tend to say"), which illustrates the plethora of available information. We also find messages or attempts to synthesize messages, highlighted by the participants themselves. Yet there is no identified spokesperson for this patient talk. The absence of a spokesperson complicates the shift from an individual to a collective level. It also makes it difficult to modify the usual positioning of the patients' talk vis à vis the professionals' talk.

In general, on the sites studied, it appears that patients' talk has a limited impact on the production of official knowledge and the medical profession's ascendancy. Are these organizations thus trying to anticipate the medical profession's reactions to the proliferation of uncertified information? Although we cannot answer this question fully, we note that certain organizations privatize the space reserved for lay interaction, and that those which expose this talk are not equipped with tools to transform it into more general statements, that is, to translate it from the individual to the collective level.

III. THE RECIPIENT'S MODES OF ACTION

In the preceding sections we focused primarily on the definition of the patient's relationship to knowledge or, more precisely, to the mutual co-definition of the patient and of the different forms of knowledge. We observed that in France many sites establish a clear distinction between two worlds: that of medical knowledge, implicitly or explicitly based on scientific references, presented as unquestionable facts, and to which the "public" has access only through a professional screen, and that of patients' subjective and local experiences, which cannot obtain real access to the status of knowledge.

The way in which an articulation between these two spaces is organized, or not, varies and outlines different positions: the *ARC* site proposes almost no articulation; that of *cancersein.net* establishes supposedly professional/lay interaction as a framework for the formatting and enunciation of lay knowledge; and the *Anamacap* site is characterized by patient-experts' critical perspective on knowledge. These different models also suggest different models of action for the patient-recipients thus represented.

In this section we complete this overview by endeavouring to provide partial answers to some of the questions raised at the beginning of the paper. If we posit that the transformation of an individual's relationship with the medical world is based on "equipment" for action, provided by authorities that need to be identified, including many non-profit organizations, it is crucial to analyse cancer sites in particular. One of the characteristics of websites is precisely that they are not content simply to describe or prescribe possible actions; they get people to do things. Browsing these interwoven texts requires actions from the visitor. Although these actions are embedded in the site architecture, their sequence is always the result of the user's interaction with the site. Moreover, in certain cases these websites afford possibilities for action with distant effects: one can react in a forum, propose an article, join an organization, donate funds, etc.

This description of action enables us to encompass the different components of the site more broadly. Until now we have concentrated on spaces devoted mainly to medical information, intended for patients, and on those that welcome an input by the people concerned, the patients and their families. In other words, we have focused on a particular addressee, the patient. Analysing sites from this new perspective, we see a multiplicity of addressees emerging.

PROFILES OF INTERNET USERS AND FORMS OF ACTION

Five main addressee categories can be identified: the patient, the potential patient, the member of a "community" of fate, the donor, and the activist.

The **donor** is easy to identify: he or she is addressed directly and unhesitatingly shown what to do. On the *ARC* site, we could say that donors are the main addressees. From the home page a multitude of elements converge towards the donor: the central appeal – "support research" – against an orange background, the only injunction on the page; the short film designed to rid the potential donor of any reticence concerning the effectiveness of research; the many marks of certification ("general interest campaign" label, C, BVQI, public utility); and the central part presented as a window onto the functioning of the *ARC*, designed to erase the memory of past irregularities.

Association pour la Recherche sur le Cancer

ARC, reconnue d'utilité publique - 94803 Villejuif Cedex - Tel: 01 45 59 59 59.

Accueil Documentations Aidez la Recherche Presse Chercheurs

Actualités

L'arc obtient le label de "Campagne d'intérêt général"
En savoir +

LYON : l'ARC au 100^{ème} Congrès des Notaires
En savoir +

Dernière mise à jour le : mardi 4 septembre 2007

Missions et activités

- Financement de projets de recherche
- Aide à la formation des jeunes chercheurs
- Pôles du réseau ARECA
- Prix Scientifiques

Fonctionnement

- Organisation
- Conseil d'Administration
- Instances Scientifiques
- Statuts

Rapport d'Activité 2006

- Rapport de gestion 2006
- Comptes 2006
- Annexe aux comptes 2006
- Rapports du commissaire aux comptes
- Orientations et prévisions 2007

Cherchons, nous trouverons !

l'Arc se voit attribuer le label de Campagne d'Intérêt Général

AGRÉÉE PAR COMITÉ DE LA CHARTE don en confiance

Certifié par EVOL

Infos légales Plan du Site Liens Contacts FAQ

The visitor who is captured by the invitation and responds by clicking on the orange rectangle, is presented with a series of very concrete propositions, equipped to enable him or her to act – including via the most direct intermediary available, on-line payment.

Your support is essential for the advancement of research

On-line donations

Donations by post

Automatic debit order

Life insurance

Bequests

Donations

All help the ARC

On the ARC site, as on many other sites that establish the donor as the addressee, very little information in terms of orientation of the funded research is given on the precise use of the funds. This disconnection corresponds to the traditional division of tasks and competencies.

The **potential patient** is the person to whom the prevention campaigns are addressed. He or she is also engaged and oriented towards action proposed by and on the site. An example is *Doctissimo*, which has created a series of tests for visitors to assess their personal risk of contracting cancer, and which indicates what each individual can do to reduce the risks. The *Ligue contre le Cancer* site likewise proposes a personalized health monitoring service based on a similar combination of action both on and off the website. The site thus becomes the vehicle through which individual action, deployed over time, is organized.


Suivi Santé Personnalisé

Il est aujourd'hui reconnu qu'il existe un lien direct entre notre alimentation, notre mode de vie et le risque de cancers.

Ainsi, la Ligue contre le cancer m'accompagne avec des conseils pratiques, des astuces personnalisées autour des grands thèmes de la prévention cancer.

► **Mon bilan**

- **Mon alimentation**
Description de 1 à 3 journées de repas
- **Mon activité physique**
Inventaire de mes activités physiques quotidiennes, domestiques, sportives
- **Mon mode de vie**
Mon comportement face au tabac et à l'alcool

[Je m'inscris ►](#)

► **Mon accompagnement**

Suivant mon profil, je reçois des emails avec de l'information, des conseils personnalisés et des astuces.

[Je m'inscris à la newsletter de la Ligue ►](#)

Accès membre ►

identifiant :

mot de passe :

mot de passe oublié ?

Comment ça marche ?

[Infos ►](#)

L'édito

[Lire ►](#)




Retour sur le site de la Ligue ↵

Je m'inscris à la newsletter de la Ligue ►

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The forums present on many websites appeal to the visitor as a potential member of a "**community of fate**". This appeal is not necessarily organized as such by the site designers; it appears through the topics of the various chats – "need", "request", "help", "panic", "?" –, which are all appeals sent out to companions in misfortune. As we have seen, the *Essentielles* site is built around its forums, but this policy goes much further, in a very explicit way. From the home page, the visitor is invited to become a "member of the site". A "community" is thus formed. By clicking on one of the forums listed on this page, the visitor is on the "Community" page, also accessible at the centre of the menu placed at the top of the site. There she is encouraged to participate in expanding this community by inserting a link to the site from her own site.

On the home page of the www.cancerdusein.org website, the mobilization of the visitor, or her transformation into an **engaged individual**, appears as the leitmotif. This engagement is the aim of a series of injunctions and possible actions converging towards this objective. For example, a short questionnaire is supposed to test the Internet user's knowledge on the "pink ribbon" worn during breast cancer month, the organization's main action. This relates directly to the model of solidarity engagement around AIDS. Messages urge visitors to participate in the event. A series of videos, grouped together under the title "personalities involve themselves: mobilizing talk against disease", presents each person's approach and particular

meaning attached to engagement. The "news" section lists the institutional actors or firms that participate in the operation and enable individuals to join the movement in various forms: by buying a special edition pen, ordering bracelets, etc. This aspect has a low level of representation on most French sites, in sharp contrast with US sites, where a range of possible actions for engagement is deployed: donations, participation in events, voluntary work for the organization, and activism in the full sense.



Finally, the **patient** profile is present everywhere, but primarily through the medical information described above. As we have seen, on most French sites this information sets patients in a position of exteriority regarding the knowledge itself and their relative submission to the holders of such knowledge.

THE COMBINATION OF PATIENT PROFILES

As noted in the introduction, in the US the emergence of movements active in the field of cancer has been facilitated and even allowed for by forms of articulation between formerly separate domains, from personal life experiences to critical analysis of the healthcare system and the organization of research. Hence, the importance of examining this possible articulation, now that we have identified the different forms of engagement in websites.

From this point of view, the difference between French and US websites is striking. Most French sites have one or two main types of addressee, exceptionally three. Very significantly, the articulation between these different addressee profiles is virtually non-existent. The sites organize a form of juxtaposition, using the possibilities afforded by the Web, to delineate the separate spaces more clearly than on paper.

For example on the www.cancerdusein.org site, the two lines of the menu on the home page relate to the engaged person, and to the patient, respectively. But there is no link between the two. Once the visitor has entered into a particular space, there is no communication apart from the double bar present on each page.



The ARC site is based on an equally strong and clear dichotomy. Sometimes mediation does exist through the potential patient profile and the role of prevention. Acting for prevention may mean adopting a position between the patient and the activist.

Apart from juxtaposition, certain sites deploy a mediation strategy. This is obvious on *Essentielles*. Next to the community, one finds the organization. The mediation between these two spaces relies on the fact that the members of the Board of Governors, who represent the organization, are above all patients. "Political" declarations are formulated as the expression of a particular person (not clearly identified, so that anyone can relate to them), in a forum. The "we" can be constructed only on the basis of the "I", defined by this community of fate. We can probably assume that this is a transitory situation. The mechanisms for participation and intervention, which the government and parliament have encouraged and even initiated, could produce patient movements in which the collective's engagement is more strongly articulated to individuals' experience and self-expression.

From a totally different perspective, *Doctissimo*, the health site frequented most by the general public, mixes discursive approaches (educational, scientific, emotional, critical, even ludic – with tests –, etc.), multiplies the number of speakers (doctor in white coat, journalist, expert interviewed, etc.), and diversifies the mediums (video, text, schemas, oral, etc.). As a mass media site, it wants to appeal to as wide a public as possible, but as a modern medium its aim is also to draw individualized audiences. The multiplication of sections is intended not to increase the range of knowledge and its specialization in an encyclopaedic perspective, but to allow for different interpretations, depending on the readers' supposed expectations, capacities and competencies.



Le cancer

Doit-on dépister le cancer de la prostate ?

Chaque année, la journée nationale de la prostate tente de convaincre les hommes de se préoccuper davantage de cet organe méconnu. Mais cette année, cette campagne intervient en pleine polémique sur l'utilité même du dépistage du cancer de la prostate.



Cancer de la prostate

Venez en discuter
sur nos **FORUMS**

Voir aussi notre dossier :

[Zoom sur les cancers masculins](#)

Cancer de la prostate, les hommes en danger

Chaque année, plus de 40 000 hommes sont touchés par le cancer de la prostate. Plus il est détecté tôt, mieux il est traité. Ainsi un dépistage est recommandé après 50 ans. Quelles sont les techniques de détection et les traitements ? Les conséquences sur la vie quotidienne des malades ? Un dossier sur le premier cancer masculin.

We could criticize the internal contradictions of the site that opens its home page on cancer with the controversy over the usefulness of screening, and then explains on another page that the same screening is indispensable. But this liberal approach to the treatment of information as a market that should propose products to suit each person's taste, has the effect of broadening the viewpoints of patient-readers and the range of their possible opinions – to the extent that just next to "certified" information, the reader is invited to debate the subject.

As we have seen, from the first page US sites establish equivalence between all the possible patient profiles: the activist, information-seeker, member of a community, and so on, without any distinction in the style or format.

Find out what we're doing,
and how you can help.
 Learn more. Speak up. Take action.

[Replay](#)

I need information for . . .

Patients, Family, & Friends
Survivors
Health Information Seekers
Professionals
Donors and Volunteers

Learn About Cancer

Join the Fight Against Cancer

- ▶ Donate
- ▶ Participate in events
- ▶ Volunteer your time
- ▶ Advocate for change

Find ACS in Your Community

Enter ZIP:

Search using city and state >>

Donate Now

Find It Fast

- ▶ Cancer Facts & Figures
- ▶ Statistics
- ▶ Research Programs and Funding
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Recent News

Managing Your Cancer Experience



Get help making treatment decisions, understanding the effects of treatment, finding treatment centers and doctors, coping with side effects, and talking with others.

Everywhere, including on the specialized explanatory pages, the same combination is maintained and the visitor can easily switch from one position to another: being ill and engaging in a local committee; relating one's story and training to become an activist, and so on. In this perspective, supplying the patient with information (or as a patient training to be an activist), is a way of participating in the organization's public action:

NBCCF believes that being informed can help you get better care. Patients who know more about their care choices tend to worry less and get better results. If you live in the United States, you can get excellent breast cancer care. But you could also get care that is wrong for you. This can happen even with good insurance and good doctors. Some breast cancer patients get very poor care. NBCCF is fighting for a better system. But for now, you need tips for getting care that is right for you.

CONCLUSION

As we reach the end of this analysis, one conclusion is obvious: on the whole, French websites that propose information on cancer correspond to the traditional definition of the

patient-professional relationship that gives medical professionals virtually unquestionable authority. These professionals are systematically mobilized to certify the knowledge imparted on the disease. Although doctors today express their uncertainty during consultations, information on the Internet is still monopolized by professionals, or the people relaying them, who tend to "set" it or at least not to present its more dynamic dimension. Laypersons' talk does have the possibility of emerging on many sites, where it is sometimes even presented as indispensable, but the mechanisms studied stop halfway. This talk is often confined to mutual help or, on more open sites, is privatized or not synthesized. It seems that the absence of translators or spokespersons strongly inhibits the emergence of lay knowledge in oncology. Moreover, the forms of action proposed to the patients or visitors of cancer sites are oriented primarily in two directions: a donation only, without any possibility of discussing the allocation of funds; and the creation of a community which provides its members with solidarity and support. Once again, the traditional French model remains intact: patient organizations provide support and popularized information, above all. The French situation is therefore not comparable to that in the US where patient organizations have been able to develop a militant approach.

Should we conclude that French cancer organizations' mobilization of the Internet is futile? This needs to be qualified by two observations. First, through their presence on the Web, non-profit organizations and other groups have prompted professionals to take an interest in this tool, and thus to recognize the existence of a new space of expression competing with that of traditional medicine. The financing that we have obtained from the INCA is an illustration of this, among others. Second, the possibilities afforded by writing on the Web have allowed for the emergence of a legitimate lay talk, and sometimes one that is even recognized as being as important as the organization itself or as information given by professionals. Such mechanisms as forums, question pages, spaces for accounts of personal experiences, or embedded video sequences – have made patients and some of their claims visible. Even if the shift from the individual to the collective is not observed, patient collectives are beginning to take root and individual talk is sometimes of critical importance.

- Akrich, M., & Méadel, C. (2007). De l'interaction à l'engagement: les collectifs électroniques, nouveaux militants dans le champ de la santé. *Hermès*, 47, 145-154.
- Anglin, M. (1997). Working from the inside Out: Implications of Breast Cancer Activism for Biomedical Policies and Practices. *Social Science & Medicine*, vol. 44(n°9), 1403-1415.
- Barbot, J. (2002). *Les Malades en mouvements : La médecine et la science à l'épreuve du sida* Paris: Balland
- Barbot, J. (2006). How to Build an "Active" Patient? The Work of Aids Associations in France. *Social Science & Medicine*, Vol.62(3), 538-551.
- Brown Phil, S.Z., Sabrina McCormick, Brian Mayer, Rachel Morello-Frosch and Rebecca Gasior Altman (2004). Embodied Health Movements: New Approaches to Social Movements in Health. *Sociology of Health & Illness*, 26(1), 50.
- Carricaburu, D. (1993). L'association française des hémophiles face au danger de la contamination par le virus du sida. *Sciences Sociales et Santé*, XI(3-4), 55-81.
- Castel, P., & Friedberg, E. (2004). Institutional Change as an Interactive Process: The Modernization of the French Cancer Centers, *SCANCOR Institutions Conference*. Stanford University.
- Ménoiret, M. (2007). Informer Mais Convaincre : Incertitude médicale et rhétorique statistique en cancérologie. *Sciences Sociales et Santé*, 25(1), 33-54.
- Rabeharisoa, V., & Callon, M. (2000). Les associations de malades et la recherche. I. Des self-help groups aux associations de malades. *Médecine Sciences*, 16, 945-949.
- Rabeharisoa, V. (2003). The Struggle against Neuromuscular Diseases in France and the Emergence of the "Partnership Model" of Patient Organisation. *Social Science & Medicine*, 57(11), 2127-2136.
- Rabeharisoa, V. (2006). From Representation to Mediation: The Shaping of Collective Mobilization on Muscular Dystrophy in France. *Social Science & Medicine*, 62(3), 564-576.