

Call for multidisciplinary papers on

**“The patient’s place in the health system”**

**For the January-March 2017 issue**

This call for papers is of interest to researchers in the fields of sociology, anthropology, geography, political science, history, law, public health, psychiatry, economy and philosophy, as well as to professionals involved in social welfare.

Papers must be submitted before **June 30, 2016**.

Little mention was made of patients in either the public debate or legal texts until the 1980s in France. The exception was documents setting out behavioural guidelines for physicians (code of ethics: *primum non nocere* or respect of medical secrecy) or organisational guidelines for private practice (“freedom of choice”, “freely established rates”, etc.). In reality, the patient was seen as the *object* rather than the *subject* of treatment and care. At best, the term “global vision” was often used when referring to patient care. This more “humanistic” approach was a reaction to the increased focus on the technical aspects of medicine, to the detriment of a patient-centric approach.

By the end of the 1970s, user groups - quite rare at the time and often systematically led by doctors - started to emerge as part of the trend for consumer movements in general. But the presence of individuals or groups active in the health system did not make itself felt – and this was not without difficulty – until the HIV epidemic struck. This disease hit young, educated people, who, with no sign of a cure in view, immediately seized on any scientific information on this pathology in worldwide circulation at the time. Their needs were instrumental in shaping new objectives that challenged traditional paternalistic medicine, namely: the sharing of information and participation in the decision-making process for treatment (including palliative care), respecting patients’ autonomy and finally adapting the

hospital routine to meet patients' needs (hospitalisation and medication). This helped open up new perspectives such as self-help, preventative healthcare as well as inequalities in healthcare provision.

All these changes, if not fully implemented, revolutionised attitudes and behaviours to be subsequently reflected in the law. These fell into two categories, either the “norm” or more progressive practices. The objective of the present call for contributions is to determine how far this movement has progressed up to the present day.

The 4 March 2002 act on patients' rights and the quality of the healthcare system has certainly ushered in innovation, despite the existence of legislation prior to this (such as the Huriet Law protecting the anonymity and the safety of persons participating in biomedical research adopted in 1988). The 2002 act determines “the right of the individual”, “rights and responsibilities of users”, “participation of users in the running of the health system”. This legislation introduced new concepts previously absent from the legal arsenal, such as access to medical files, the right to refuse treatment and compensation for medical errors. It also provided opportunities for patient/user representatives to work alongside public health policy stakeholders with a view to establishing a so-called “health democracy”.

Other measures soon followed, giving more consideration to the patient. One such example was the attention given to end-of-life issues and ethics (*22 April 2005 act on patients' rights and end-of-life situations*; the 5 July act on rights and protection of persons undergoing psychiatric care). Another focus area was a coordinated care pathway (consolidating the respective roles of the “referred” general practitioner” and the “treating” practitioner and training of both). At the same time, references to the patient in public discourse became essential. In 2009, the law referred to as “Hospital, patients, territories” (*Hôpital, patients, santé, territoires*) made more use of the term “patient”, going as far as to include it in the title of a text mainly focusing on health system organisation and hospital system operations. This law also aimed to “make care pathways easier to understand” or to “reinforce health democracy institutions” created in 2002. These measures were set up to improve “personal health care for all” and “accompaniment for the chronically ill”. On paper at least, references to the patient were everywhere. The bill for the modernisation of our healthcare system (passed in parliament on 17 December 2015) included several measures aimed at making patients' lives easier (right to privacy, group action, actions against refusal to accept treatment) and also connecting patient representatives with the activities of the ARS (Regional Health Agencies). That said, the law did not address the doctor-patient relationship in the strict sense of the term.

Rhetoric and anecdotal experiences apart, what is the state of play today in terms of action taken and solutions created for these different areas? Which of the stated intentions were actually implemented and how?

The same question may be asked about the legal and practical measures implemented in this respect. Which category of patient has seized these new opportunities to become

actively involved in managing their own lives, their own health and the health of others – and how? And are professionals and institutions involved? Is this a help or a hindrance?

This same question may be applied to a more general context: is the patient profile identical compared to previous decades? Can we see changes in patients' expectations and behaviour – or not? What is the impact (or potential impact) of the many forms of digital technology innovation granting patients' access to their own health data, allowing them not only to manage their healthcare and treatment, but also to circulate massive volumes of data that up to now had been protected by “medical secrecy”? How do carers adjust to these innovations? Are certain categories of patients (the chronically ill, for example, or on another level, “intellectuals” or “young people”) more capable of keeping up with these changes?

These developments concern the public health sector only. It would be interesting to explore how the carer/patient relationship operates in the medical-social sector, which has very specific features. In some respects, this sector was already well in advance with regard to legal endorsement of users' rights and their ability to voice their opinions, although the process was rather formal. A key example is the representation of residents in care homes for the aged, which became compulsory from 1985 onwards. The medical-social aspect is one of the focus areas of national and regional health conferences – the extent to which they have developed this area of interest now remains to be measured. Sectorial institutions such as the CNSA (“*Caisse nationale de solidarité pour l'autonomie*”) continue to ponder these questions of respect and consideration for people with diminished independence; despite some experimental developments, the individuals and families concerned have no opportunity to voice their opinions regularly. Professionals and medical social services interact with individuals in care (and their families) allowing limited scope for expression. Compared to the disability sector (where families have been actively involved for longer; the 2005 act puts strong emphasis on the respect of the individual) this area is less active.

Another category of questions covers access to information. More specifically, does unequal access to digital data lead to new forms of social inequality in the healthcare sector? When it comes to introducing forms of “health democracy”, to what extent are users and the associations that they represent willing to take on new responsibilities conferred on them at national level? Which focus areas are given priority?

Finally, developments concerning patients and their place in the health system are not restricted to France. Although national cultures vary greatly in this respect, information sharing is quick because most countries are undergoing similar technical changes concurrently. Comparisons and studies of cases outside France could provide valuable additional insight. At the same time, it would also be useful to review policies compiled and developed by the European Union.

Consequently, the possibility of receiving medical care in the different EU member states raises the issue of the development of cross border-healthcare solutions along with the emergence of the “consumer/user”, more discerning, rational and informed.

This call for papers defines three core topics.

## 1- **Health care institutions and professionals – recognising the patient as a person**

After 20 years' effort defining the patient as a person and patients' entitlement to freely express their wishes via a number of different channels, we can reflect on what has really changed for the patient. To this end, an overview of the current situation is timely in the light of developments over the last two or three decades.

We suggest examining questions that are both specific and varied, either seen from the patient's perspective or based on observations made by professionals:

- How do patients and their families access information at different stages on the healthcare pathway? Who are the current information providers? How have they established their legitimacy?
- How are patients' wishes taken into account at the different stages of their lives, both in and out of care?
- When it comes to care, have coordination procedures among professionals and care services improved?
- How is patient support organised? By a single general "treating" practitioner? By a coordinated team of carers? Through specific support programmes?

Current practices and policy outside and in France can be examined from several standpoints:

### - *Patient/user rights and their implementation*

It took time for both patients and healthcare professionals to understand the measures introduced to empower patients. Indeed, the texts themselves lacked precision and application of case law was at times necessary to define clearer limits. It is highly probable that some health professionals were opposed to endorsing the concept of patient autonomy. Some compulsory measures were implemented as a formality only, thereby casting doubt on their real effectiveness. These included patients' entitlement to information on their state of health, the right to participate in the decision-making process or the option to assign trustworthy individuals for this purpose, the fundamental right to social welfare, respect and dignity, equal access to healthcare for everyone, respect for privacy, pain management end of life support for young hospitalised patients, etc.

### - *Healthcare established*

Healthcare establishments are now obliged to make introductory pamphlets available with a view to providing patients or the general public with personalised information and fostering patient-healthcare professionals exchanges, to providing access to medical files and to appointing a mediator in the event of conflict. How are these new compulsory measures implemented? Who are involved – administrative or medical departments? In what

circumstances? How do hospital representative bodies such as the CRUQPC (commissions in charge of relations with users and quality of healthcare) and the CRCI (regional commissions for arbitration and indemnification) operate? Did they meet with opposition? Does the role played by these bodies really give users a say? What is the contribution of these bodies to a collective effort? Can comparisons be made between developments in private and public sector establishments (“profit vs. “non-profit”)?

- *Developments in medicine itself*

This new patient-centric approach has not only led to new medical practices, it has also led to new medical knowledge. A key example is medical procedures directly involving the patient (e.g.: injectable medication “on the patient's demand, according to his or her needs”). The input provided by patients (individual users or user groups) based on their experience and personal observations has served to enhance scientific knowledge.

How does medicine take advantage of the mass production of patient data? How are these data compiled and processed by public or private players (a key example is research for the pharmaceutical industry)? Have these data contributed to progress in scientific research aimed at improving biomedical techniques or therapeutic approaches?

It would also be interesting to explore whether economic players (pharmaceutical industry, private insurance schemes) take advantage of this new autonomous patient/user profile to reposition their products in the market, thus enhancing their image (participation in chronic illness management programmes, developing self-medication solutions, changing generic drugs strategy, etc.).

## **2- Development of skills, behaviour, attitudes and patient obligations**

Professional healthcare providers concur that there has been a dramatic shift in patients' attitudes in recent times, not only as a response to specific changes in healthcare systems but also with the emergence of new demands – comfort for example – and new ways of accessing information. At the same time, this access to information, progress in therapeutic education and promotion of healthcare used in combination are all factors that empower patients. We could even consider the possibility that a patient-expert profile has emerged, capable of negotiating his or her treatment, co-managing his or her illness or even competent to find his or her way around the complicated health system. At the same time, because of these changes we could argue as to whether there is a conflict between the patients' wishes (or even entitlement) to become an “expert” on one hand and an imposed obligation to acquire this expertise and to become actively involved in their own healthcare on the other.

*How do patients keep abreast of their own health?*

The physician is no longer the sole source of medical information – the Internet provides an exhaustive and easy means of access. There are notable exceptions to the ban on

advertising prescription medicines to the general public. There is also an abundance of simple, easily accessible literature enabling the general public to understand the impact of these preventive measures, to gauge the urgency and meaning of symptoms, to envisage the therapeutic solutions offered by formalised medicine, even going as far as to compare these solutions to a “standard”. In the case of some pathologies, user associations play a key role and further research into this point is required. However, not all categories of the population have the same ease of access to information and do not use it in the same way. Can discrepancies in this area be more clearly identified?

*Currently, what are the most common type of requests?*

It is believed that the most common requests addressed to healthcare professionals are: appointment availability, repeat prescriptions, etc. Have they changed over time? Demands for information evaluating the performance of healthcare providers has developed in France but this is at a slower pace than in other Western countries. What can we learn from these changes and how are these perceived by healthcare professionals?

What importance do patients give to proximity to the different kinds of healthcare professionals and services, to transparency of care pathways and to the personalisation of patient-professional interaction, etc.?

Have these changes impacted on medical practice, decision-making and organisation of healthcare? Particular attention should be given to a certain category of patient profiles: people in situations of exclusion, chronic or long illnesses, the aged and their families and end-of-life cases, etc. Can we observe a certain shift in patients’ attitudes to prevention, self-medication and the management of long-term illnesses?

*Choices and “empowerment” for patients-contributors?*

For several years, there has been demand for “empowerment” of patients vis-à-vis the healthcare system. The patient has the power to make personal choices and these will have a knock-on effect on global health costs. Health education campaigns (e.g.: “*Les antibiotiques, c’est pas automatique*”<sup>1</sup>) influence his or choices. It would be useful to explore how patients (who are also “contributors”) exercise this choice: choosing to “consume wisely”, to appoint a “highly-rated” general practitioner. Other choices include investing in complementary health coverage (insurance or complementary mutual health insurance scheme) in addition to “national health” medical coverage for which there is considerable choice. Furthermore, the wide range of group employee protection schemes subscribed to by employers and the different income-based solutions available would need to be considered. We can above all question the rationale behind contributors’ choice of complementary health insurance and its financing from a qualitative angle.

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<sup>1</sup> The catchphrase – *Les antibiotiques, c’est pas automatique* – was the title of the campaign first launched in 2002 with the aim of decreasing antibiotic prescription in France by 25% over a period of five years. In particular, the campaign targeted the treatment of viral respiratory infections in children, which accounted for 40% of prescriptions written. Since 2002 the campaign has been repeated every winter for the duration of the viral respiratory infections epidemic season.

### 3- “Health democracy” and users’ roles in the operation of the health system

As a consequence of the HIV epidemic in the 1980s, some individuals with chronic illness and longer term needs expressed the desire to become stakeholders in healthcare policy. We ask whether such wishes remain relevant and we will consider if it has grown in stature or diminished in the course of the democratisation process at different territorial levels.

The role of user associations has expanded in many different directions; some of these focus on a single pathology or situation (disability for example). Others have positioned themselves in a broader, more “public relations” context; new places for interaction, where they are clearly invited to act in an advocacy role and speak out – at national health conferences, for example – now recognised by the media.

We wish to review the situation on the following:

#### *Role, place and operations of associations*

Has the role of these bodies evolved over time and is the French situation different from the international context?

#### **User representatives workshops** (“*La fabrique de représentants des usagers*”)

Who becomes involved in the activities of these types of associations and their *fora* and how is policy disseminated to the wider public? Which domains are fully covered and which ones require attention? How are points of view made known? What is the role played by professionals, especially physicians?

#### *Healthcare system and user interaction – how it works*

At the local, regional, national and European level, procedures for interaction and discussion have been set up. In which areas are patients-users particularly active (interpersonal counseling, mediation with the medical profession and its expertise, claims concerning the operation of institutions, policy trends, access to care, cost of healthcare)? “Success stories” may provide valuable insight. Which changes to local or national decisions and policies have been sought and obtained by the users? In certain concrete cases what sort of results did these users obtain?

#### *Users and ethical issues*

Finally, in recent years there was considerable renewed debate on bioethical issues. End-of-life questions resonated with many but discussion also covered other issues such as the ethics of reproduction.

Insight can be provided for both general decisions and practical application. During these exchanges how are these patients questioned, listened to and supervised? To what extent

is input from patients requested and valued (on the subject of future development, for example?)

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The ethical charter for this publication and instructions for authors, including editing standards, are available at:

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