PATIENTS IN THE HEALTHCARE ECOSYSTEM: INFORMATION CHALLENGES AND COMMUNICATION ISSUES

International colloquium, Paris, November 2014 (date to be confirmed)

CALL FOR PAPERS

Theme

Active, involved, informed, educated, mobilized, concerned, empowered: this is the ideal-typical figure of the patient, user, consumer and citizen in the healthcare sector. From fundamental or clinical research, to the practice of medicine, to politics, law, journalism, information or even communication related to health, not forgetting technological innovation and drugs, the patient is no longer considered as the passive recipient of care, but rather as an indispensable and omnipresent player in the healthcare ecosystem. This transition is in various ways fraught with information and communication challenges that pertain to the identity of the stakeholders, the ordering of relationships of distrust or trust that develop between lay and professional players, the nature of the information possessed, exchanged and distributed by and between the stakeholders, the information and communication tools mobilized, etc.

This is evident from a number of heterogeneous phenomena:

a) The multiplication of patient associations since the 1980s, which, in addition to providing information and support to patients, also take part in fundamental and clinical research in collaboration with researchers, doctors and research and healthcare institutions. These institutions have in turn developed, spontaneously or in an organized manner, partnerships with patient associations;

b) The rapid development of the "translational research" paradigm in life and health sciences, advocating direct and bidirectional relationships between fundamental research and hospital-based clinical research, particularly in view of providing better care to patients by integrating them at an early stage into the research and innovation process;

c) The implementation, at the regional, national and European level, of various mechanisms for the handling and involvement of patients and citizens in health policies for democratic, moral, ethical and also practical reasons;

d) Developments in the legal framework concerning the individual and collective rights of patients and the responsibilities of healthcare professionals;

e) The increasing empowerment of patients and citizens via:

1) An increasingly proven expertise thanks to the development of consumer health information, in tandem with the specialized medical information of healthcare professionals, in the wake of an increased coverage of health issues in the press and audiovisual media as well as the increased availability of health information on the Internet, which not only facilitates access to information but also the expression of lay people on the web and in the face of professionals;

2) Technological innovation and the use, whether in a medical framework or not, of specialized or consumer mechanisms (data banks, Smartphone applications, diagnostic or automatic warning devices, communicating objects, etc.), which enable patients to carry out diagnoses themselves or automatically and which profoundly alter the practitioner-patient relationship in prevention, monitoring, treatment, etc. This phenomenon, referred to as "mobile health" and "quantified self" is distinguished from telehealth, telemedecine or e-health, which will not be addressed here.

The international colloquium "Patients in the healthcare ecosystem: communication issues" has the general objective of providing insights into these phenomena, while constantly focusing on information and communication issues.

Contributors invited

The colloquium seeks to combine narratives of experience, reports on actions and experiments, testimonies and theoretical and empirical research within a single space of speech and dialogue. With an international outlook, it welcomes contributions from all countries and encourages the presentation of various national cases and international comparisons. The colloquium therefore aims to be completely open. It welcomes contributions from:

a) Representatives of patient and user associations

b) Healthcare professionals

c) Researchers in human and social sciences and hard sciences.

The colloquium is organized according to five thematic topics.

Patient participation in medical research and innovation: how should the information and communication effort be shared?

This topic aims to provide empirical and theoretical insights into the information and communication effort made towards the participation of patient associations in medical research and innovation. Committed not only to assisting patients but also in the fight against diseases without treatment (cancers, rare or orphan genetic disorders, AIDS, Alzheimer's, myopathy, for example), patient associations have made medical research and innovation a space for their legitimate intervention and action according to diverse intentions and modalities that go beyond the support and funding of such activities by these associations. Institutional alliances between associations and professionals in medical research and innovation are being forged: partnerships with establishments, participation in research projects, involvement in networks, etc. Roles, skills and various tasks are allocated and distributed among patient representatives and professionals, more or less affecting the process, content and dissemination of medical research and innovation: acquisition of scientific and medical knowledge by patients establishing their credibility and their recognition by experts; production of certain types of information by patient representatives, built jointly with experts and incorporated into the dynamics of research and innovation, dissemination of scientific information to various audiences, drafting of reports, contribution to the publication of scientific articles, etc. Apart from relationships and the mechanisms of developing closer ties with medical research and innovation, patient associations can on the contrary choose to cut themselves off from it in a logic of mistrust and challenge it, considering existing medical research and innovation as a threat to their cause and to public health, as is evident for instance from controversies over drugs. Strategies and actions for promoting information and communication are being deployed.

The contributions gathered on this topic may deal with various issues, studies and experiences. Some questions may be formulated as *non-exhaustive and non-restrictive* guidelines to translate its general approach:

a) What is the role of patient associations in the production of medical scientific information? What information and knowledge is integrated with the participation of patients in medical research and innovation?

b) How are patient associations concretely involved in the production of medical information and innovation? What tasks are assigned to them and by what means and processes are they carried out? Where does the contribution of patient associations to the information and knowledge production chain start and end in medical research and innovation?

c) To what extent can patient associations ensure the dissemination of medical scientific knowledge and innovations? To which audiences? Using which means? With what objectives?

d) Who acts as the spokesperson of patients in their relationships with medical research and innovation? On what basis and how is the legitimacy of representing a group of patients to players in medical research and innovation built?

e) How do patient associations build their opposition to medical research and innovation? What types of expertise do they rely on to challenge? Which "know-how" is their challenge underpinned by and for which audiences? With what impacts?

Patient and citizen participation and health policies: do, say and show participation

This topic deals with patient and citizen participation, both as individuals and groups, in their relationships with health policies from the perspective of the information and communication challenges that it underpins. Patient and citizen participation has become a social and political issue for democratic (representativeness, participation), moral and ethical (justice), and also practical (efficiency) reasons. Social uses of this apparently consensual notion in fact encompass multiple representations and realities depending on the context. Patient and citizen participation can be understood, in a vertical downward dynamic, as an objective that public health policies seek to foster by various measures. It is then characterized as the content of public policies and gives rise to a set of political measures. These measures have the distinctive feature of being largely modeled by concerns and actions related to information and communication considered as a prerequisite for participation: promote the dissemination of information and knowledge on health, educate the public, inform and consult with patients for their treatment, inform and empower patients suffering from chronic diseases, inform and communicate in view of prevention, etc. We can observe that different means of communication provide guidance for patient and citizen participation: websites, electronic information sources, training health professionals in communication, decision support tools for patients, advertising campaigns for prevention, documents and legal and administrative procedures (charters, forms, etc.), etc. Patient and citizen participation is also perceived, in an upward perspective, as health policy processes with the implementation of various mechanisms for patient and citizen involvement in the formulation of health policies, at the regional, national or European level, directly or indirectly. Specific and various tools guide this participation: committees, councils, public meetings, conventions and large-scale public consultation processes (Estates General), community health initiatives, online citizen forums, networks, alliances, platforms, etc. Participation is done, formulated and exposed to others all at the same time.

The contributions gathered on this topic may deal with various issues, studies and experiences. Some questions may be formulated as *non-exhaustive and non-restrictive* guidelines to translate its general approach:

a) How are the relationships between patient and citizen "information" and "participation" in health policies conceived and built? Who informs whom? Who participates in what?

b) How is the linkage between the fight against inequality in healthcare and patient and citizen information and participation in health policies construed?

c) Who acts as the spokesperson of patients in their relationships with health policies? What basis and how is the legitimacy of representing a group of patients to players involved in health policies built on? What roles do patient and citizen groups play in the democratization of health policies?

d) Participation as a value-added action of health policies: how to communicate about patient and citizen participation in health policies?

e) What is the role of information and communication tools in mechanisms of patient and citizen participation in health policies? Which types of information and communication tools are mobilized depending on the situation?

The patient's legal and legislative constructs: information and communication mutations

The evolution of the legal figure of the patient is superimposed over the concerns and mutations of the society with respect to the figure of the patient as a healthcare player. The aim of this topic is to examine the information and communication mutations that accompany the patient's legal and legislative constructs. Recognizing the patient and the user as a player in the healthcare ecosystem is reflected, among others, in the legal framework that defines the individual and collective rights of patients and users and the responsibilities of healthcare professionals to them. These rights are affected by information and communication aspects, whether this relates, for instance, to the patients' right to information about their health condition through access to medical records, the right to accept and refuse proposed treatments, the right to privacy and confidentiality, the right to be informed about the circumstances and causes of an accident, etc. The legal framework also sets out responsibilities for healthcare professionals and establishments: receiving the patients' consent by giving them the information necessary about their health condition (diagnosis, treatments, risks, drugs, etc.), for example. Apart from strictly legal and legislative developments concerning patient rights, the question of their appropriation and their knowledge and acknowledgement both by patients and users and by healthcare professionals is raised. The effectiveness of the defined legal framework, far from being automatic and reducible to its content, stems from all the mediations made for its implementation by all the stakeholders. The figure of the patient as a healthcare player, legally recognized, also implies the figure of the informed patient knowing their rights, the contact persons, legal bodies and processes at their disposal. The rights are moreover relayed by the concerned healthcare professionals and establishments who can implement codes of ethics, practices, actions and services in line with such rights. Finally, the patient rights meet with mixed reactions: assertions by professionals of increasing legalization, collateral modifications of professional practices (preparation of a medical record, selection of information, etc.), transformation of patient-healthcare professional relationships, etc.

The contributions gathered on this topic may deal with various issues, studies and experiences. Some questions may be formulated as *non-exhaustive and non-restrictive* guidelines to translate its general approach:

a) What are the past, present and future legal developments regarding patient rights with respect to the healthcare ecosystem, and how can we conceive these developments with respect to information and communication challenges?

b) What information and communication initiatives are made to promote patient rights? What knowledge do patients and users have on their rights? What representation do patients have of their rights?

c) How do legal developments affect healthcare professionals and establishments? What knowledge do professionals have of patient rights? What representation do healthcare professionals have of legal developments?

d) What becomes of the patient-doctor relationship in light of the legal developments of the patient as a player?

e) How are professionals involved (or not) in the promotion of patient rights?

Better informed, better equipped: towards an empowered patient?

This topic deals with the figure of the patient and user as a healthcare player in relation to two phenomena: a) the evolution of medical and health information, on the one hand; b) the development of specialized or consumer technologies at the disposal of patients and users for monitoring, prevention, diagnosis, treatment, etc., on the other. The former phenomenon is significantly influenced by the prevalence of online searches for heath information among Internet-using patients and users. The rapid propagation of this practice, facilitated by ease of access and expression, is furthermore intermeshed with the growth of information supply, both abundant and heterogeneous at the same time, such that different information registries coexist on the Web depending on the players involved (healthcare professionals, institutions, businesses, associations, consumer information sites) and the types of information produced and disseminated (medical information, prevention information, promotional information, experiential information and advice). This phenomenon is all the more interesting insofar as the infatuation for consumer information which characterizes it can also fuel the skepticism of healthcare professionals and public authorities engaged in the development of a competing supply, the implementation of controls over information, and the denial of information on the Internet. This borderline case somewhat calls into question what seems to be taken for granted, thus opening up a space for debate: what does the idea of an informed patient player signify? How? And for whom? The second phenomenon concerns the empowered involvement of patients and users in the management of their health, in the wake of the development of databanks, mobile information and communication networks and devices. "Mobile health" and "quantified self", a booming economic sector, are also promoted by public authorities against the backdrop of public expenditure cuts and ageing populations. Patient monitoring, diagnosis, remote administration of treatments, dissemination of health warnings, monitoring and follow-up of senior citizens, empowerment of users in terms of prevention, etc.: can we look forward or not to actually seeing the benefits expected of these technologies for health and the reduction of health spending and for whom? In this respect, this topic deals with "mobile health" and "quantified self", not addressing related concepts such as telehealth, telemedecine or e-health.

The contributions gathered on this topic may deal with various issues, studies and experiences. Some questions may be formulated as *non-exhaustive and non-restrictive* guidelines to translate its general approach:

a) The patient, the Internet and health: to be informed or not, and contribute to information, or not? How do Internet users negotiate their relationship to information about their health on the Internet? What health information supply and repositories are available on the Internet?

b) What is the impact of health information on the Internet on healthcare professionals and experts? What are the stakes of professional medical information in view of the boom in consumer information? Internet: obvious or underlying third-party of the singular colloquium?

c) How is health journalism affected or not by the Internet?

d) Which technologies for mobile health? Which economy for mobile health?

e) What are the challenges and perspectives for "mobile health" today and tomorrow? Tech savvy patients and users: from medical paternalism to the hyper delegation of responsibility to the user?

Patients and healthcare professionals in the face of multilinguism: coming to grips with a new reality

This topic explores the figure of the patient as a player by focusing on the dimension of language. With migratory flows growing exponentially, healthcare ecosystems are currently confronted with the massive phenomenon of the multilinguism of patients. This situation becomes a problem for healthcare ecosystems that strongly value the figure of the patient as a player: how to ensure the participation of patients whose language is either poorly or not at all represented in the healthcare ecosystem that receives them? how to fulfill the legal obligation of informing patients about their condition and the conditions surrounding them, when linguistic circumstances make information and communication between patients and healthcare professionals difficult? Furthermore, the efficiency of healthcare ecosystems is at stake, considering misdiagnosis, accidents that are likely to occur in such situations and the compensations to be paid to the victims. The question of healthcare ecosystems can overlook neither its international dimension, nor consequently the dimension of languages.

The contributions gathered on this topic may deal with various issues, studies and experiences. Some questions may be formulated as *non-exhaustive and non-restrictive* guidelines to translate its general approach:

a) How do healthcare ecosystems across the world tackle the increasing internationalization of their patients with different languages and cultures?

b) How are information and communication interfaces developed around patients, healthcare professionals and translation and interpretation professionals? Which information and communication tools are mobilized? How is translation and interpretation training adapted to healthcare issues?

c) Beyond the linguistic dimension, cultural mediation is often at play: how to communicate with patients with different languages and cultures in extreme situations (conflicts, inter-ethnic wars, etc.) or not? What lessons can healthcare ecosystems draw from this in terms of intercultural communication?

d) Legally, fundamental linguistic rights are recognized with regard to healthcare as in other fields. What exactly are these rights? To what extent are they applicable and applied? Are patients informed of their rights in this area?

e) Access to information on the Internet varies from one language to another: are we informed in the same manner in English, French, Russian or Chinese when it comes to health issues? How do information asymmetries influence patient representations? What about the localization of information that various actors adapt according to the target patients? How does the multilingual digital healthcare space work?

The following information must be provided when responding to this call for papers:

1) The contributor(s)'s first name(s), surname(s) and affiliated institution(s)

2) The contributor(s)'s email address

3) Nature of the contribution: a) narrative of experiences, reports on actions and experiments, testimonies; b) theoretical and empirical research

4) Title of the paper

5) Thematic topic of the paper

6) Paper abstract (not exceeding 3,000 characters, the abstract must clearly state a) the subject matter of the paper, b) the issue addressed, c) the methodology and empirical content, d) main conclusions

7) Submission format: pdf, doc, docx, odt or rtf

8) Language: French or English

Address for submissions:

sante.communication@cnrs.fr

Evaluation schedule and procedure:

1) Opening date for submissions: March 7, 2014

2) Closing date for submissions: April 11, 2014

3) Expert assessment of the papers by the scientific council: April 16 to May 14, 2014

4) Response to applicants: June 2, 2014

5) Confirmation of applicants: June 18, 2014

Website: www.iscc.cnrs.fr

Members of the international scientific committee

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Members of the organizing committee

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Members of the sponsorship committee

Arnaud Benedetti, communication director at the French National of health and medical research; Jean-François Delfraissy, director the French national research agency on AIDS and viral hepatitis; Dominique Dupagne, doctor, founder of atoute.org; André Syrota, Chairman and CEO of the French National of health and medical research.