

A Project on Patients' Rights in Psychiatry: Managing Diverse Opinions

Tim Greacen, *Director of Research Unit, Maison Blanche Hospital, Paris: Laboratoire de Recherche de l'Établissement Public de Santé de Maison Blanche, Paris.*

Introduction

User groups in the public psychiatry sector in France claim that patients who consider their basic rights are being infringed have difficulty getting clear answers to their questions. They suggest that patients are not given access to useable information on these questions. Furthermore, many recent changes in French law may have created confusion as to what patients' rights actually are. Recent court decisions have insisted that it is the doctors' responsibility to prove that they have adequately informed patients about procedures, treatment options and risks. This year's March 4th law on patients' rights and the quality of the healthcare system has made accessing medical records and compensation considerably easier and has reinforced the position of user organisations throughout the system. In psychiatry, where an increasing proportion of patients are hospitalised without their consent, interpretation of these laws and legal decisions is complex. Putting the new rules into everyday practice in mental health services will take time.

The project

The current project came from a proposition by user groups to create a living document¹ aimed at helping users and personnel keep up to date with regard to users' rights questions in everyday situations. This "Patients' Rights Data Base" could be then used as a tool for personnel training as well as for training user representatives to better understand and defend patients' rights and service provision issues. The idea was to create a document that would be easily accessible to all stakeholders (patients, families, professionals, etc.), with both internet and paper versions.

Method

A three-step methodological approach was tested in a feasibility project initiated in early 2001. The first step involved identifying common subjects of complaint in letters received by the director of a major psychiatric hospital in central Paris² concerning the rights and liberties of patients in psychiatry. The second step was to interview members

¹ A 'living' document reflects the state of knowledge on a subject at a given time. The document is continually revised and improved as new developments happen in the area in question.

² Etablissement public de santé Maison Blanche

of user groups in order to identify eventual rights issues that might not appear in the written complaints. In the third step, each member of a mixed professional/user work group, using everyday terms as if they were replying to a user's letter of complaint, drafted responses to three test questions. The aim was then to discuss replies and to draft versions that would be acceptable to all participants.

If the feasibility project showed the chosen methodology to be sound, it was then intended to extend the project to include a larger sample of written user complaints from general as well as psychiatric hospitals and to involve a larger range of user groups to formulate complaints and answers that might not appear in these written complaints.

Results

(1) Analysis of written complaints by service users

105 letters were received from service users by the Director of Maison Blanche Hospital during the year 2001. After anonymisation by the hospital Client Relations service, each letter was classified by two investigators according to the nature of the complaint and using the two major patients' rights charters, the Patients' Rights at Hospital Charter (*Charte du patient hospitalise*) and the Mental Health Services Users' Charter (*Charte de l'utilisateur en santé mentale*) to determine classification criteria. As the number of different subjects of complaint or request was large with regard to the number of letters in the test sample, classifying the subjects by order of frequency was not meaningful from a statistical point of view. A larger sample would be needed if complaint frequency were to be a priority in the extended study. A further distinction was made between letters written by patients and those written by other users (relatives, friends, community members, etc.).

Five subjects of complaint or request appeared more frequently in letters addressed by patients:

- Patient wants to leave the hospital
- Patient wants to change doctors
- Patient dislikes living conditions at the hospital
- Personal possessions have been stolen
- Patient claims to be victim of aggression by other patients or by staff

In the 105 letters received, only two subjects of complaint or request addressed by relatives occurred more than once:

- Relative worried about continuity of care when the patient leaves hospital
- Relative wants access to family medical records

(2) Other subjects added by user group members

User group members considered that there were a number of additional priorities concerning users' rights that did not figure in the letters. They suggested that certain users might be unable or reticent to express certain complaints in writing. Other users might be unaware that their rights may not be being respected. Additional subjects prioritised by user group representatives included:

- Informing patients about the process and the treatments and seeking patient's consent
- Respecting user privacy
- Avoiding use of force and fear
- People with psychiatric problems being treated as people, considered as equals
- Easy access to quality healthcare
- Patients being able to keep in touch with the community even when hospitalised (visits, telephone, hospitalisation within the community)

(3) Test questions

One of the most critical steps of the feasibility study was to test the hypothesis that users and different professional groups would be able to produce consensual answers in everyday language to users' complaints and requests. To test this hypothesis, three trial questions were put to a group of six comprised of hospital managers, psychiatrists, nursing and user representatives³. Each of the three questions was chosen to represent a different level of difficulty and controversy. The research necessary to answer the questions being potentially time consuming (especially in the context of recent and extensive changes in users' rights legislation), only two questions were allocated to each participant. The three questions chosen were the following:

- Smoking at the hospital (a question considered by all members to be relatively non-controversial and easy to explain)
- Free choice of doctor (a difficult question in the French psychiatric context where the basic right for all users of the French health system to choose one's doctor is often in contradiction with the community psychiatry principle of proximity of care).
- Use of physical constraint (a controversial question in France).

³ The President of the FNAPpsy (National Federation of Patient and Ex-patient Groups in Psychiatry), the Director of Nursing, a Chief psychiatrist and the Director of finance and client relations of a mental health hospital; the Director of the Patient's Rights Unit and a Professor of Psychiatry in a general university hospital.

With the exception of hospital managers, who only produced the corresponding legal texts and did not actually formulate structured replies, analysis of the answers produced by staff and user representatives revealed largely similar rhetorical structures. As a general rule, all answers followed a similar logical pattern. They restated the user's case (e.g. *You have been put into a room with a heavy smoker and you would like them to stop*). They then stated the general principle (e.g. *Smoking is forbidden in public places to protect other people's health*), explained hospital practices and organisational imperatives that might make applying the general principle problematic (e.g. *People with major psychiatric problems can't be told to stop smoking from one day to the next*) and described service policy on the issue (e.g. *In this service, smoking is forbidden in the patient's room and smokers are asked to use the TV room. This is because there are no single rooms available and this is a closed service where patients may not go outside unaccompanied*). In the case of contradictory principles, the hierarchy of norms was made clear (e.g. *The anti-smoking law has more force than local smoking policy*). Letters in general concluded with a suggestion as to how the plaintiff might best get satisfaction (e.g. *Start by seeing the head nurse of your unit*).

However, although the way of arguing was similar from one answer to the next, different professional groups used different sorts of arguments to justify their position. Hospital managers referred to rights and duties described in legal texts. Psychiatrists referred to what is good for the patient from a medical point of view and used arguments based on medical or scientific authority (typically research results). Nursing staff referred to patient's rights and duties, to hospital policy and to organisational obstacles that make it difficult to apply the rules in a given service context. Users referred to basic human rights and alleged that institutions often abuse basic rights. Thus, for example, although the final responses to the question concerning smoking at the hospital were quite similar, the arguments used to defend that position were very different according to the professional profile of the person writing the answer.

With regard to the other two questions, significant differences appeared between groups concerning the actual answers. Hospital managers, psychiatrists, nurses and user groups did not necessarily agree, whether it be on the interpretation of the law or on the hierarchy of norms. User groups, for example, did not agree with psychiatrists on the use of constraint. Hospital managers were reticent to put down on paper the argument frequently used by clinical staff that organisational difficulties might impinge on patients' basic rights, be it temporarily or otherwise. With regard to the patient's right to choose their doctor, although all participants were well aware of and could describe the legal dilemma, the same question received very different answers from different professionals.

Conclusion: modifying the project

Feasibility studies can indeed be useful. They can save a lot of hard work if what appeared to be a good idea at the beginning turns out in reality to be far more complex or more difficult to achieve.

In the current action-research project, the main research objective was to identify common complaints from patients. These were then to be used as a basis for creating a

document aimed at making information about patients' rights more accessible to all stakeholders. We had included different stakeholders on the editorial team in order to find a common language in which best to convey this information. With regard to the research objective, our fear that accessing confidential hospital information on such a delicate issue might be a possible obstacle to the research project proved to be unfounded. Using the anonymisation process and getting the hospital managers involved in the project made the process considerably easier than planned. However, the action part of the project, arriving at some sort of consensus as to the content of the answers to the letters, was problematic. Briefly, we know what the problems are concerning patients' rights in psychiatry, but we don't necessarily know the answers or, if we do, we don't necessarily agree how to explain them.

As a result of the questions raised, the project itself has been transformed considerably. On the one hand, a compendium of legal texts and decisions related to patients' rights in mental health services will be assembled as a living document reference tool on Internet. Secondly, seven other mental health establishments from the WHO Collaborating Centre for Mental Health in France have asked to join a modified version of the project. As well as extending the analysis of patients' complaints across the eight sites and over a longer time period, two new aims have been introduced: firstly, to create a living document - "Answering Questions about Patients' Rights in Psychiatry" - that will allow different sorts of arguments from different sorts of professionals or users to co-exist in the same document and secondly to use this document as a training device to help different professional categories and user groups to understand the other stakeholders' point of view.

Clearly, commonplaces are the stuff of everyday explanation in current health care. It's the law. It's good for you. It's therapeutic. It's evidence-based clinically recommended. It's how it's done here. It's an organisational problem that we all will deal with as soon as we're able to but we ask you to live with it for now. It's a subject of debate between user organisations and professionals. The idea behind the new version of the research project is that the more we know about the sorts of commonplaces and arguments other stakeholders use to explain mental health laws, hospital rules and the ins and outs of service provision, the better we'll be able to make, understand and explain our decisions - whether we be patients, administrators or carers. Laws evolve. Some laws are the subject of debate, others seem to meet a general consensus at a given time, even if the arguments used to explain them differ. In both cases, this is important information for a patient who is unsatisfied with the healthcare they are receiving.