Forms of Involvement of Patient Organisations into Research
An Overview of Different Models

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Introduction

It is a great honour and a pleasure for me to participate to this STAGE Opening Conference, and I would like to thank the organisers of this event for their invitation.

My contribution to these two-days discussions is on the participation of patient organisations into research activities on the diseases they are concerned with.

Patient organisations are increasingly visible on the medical scene. In particular, they are more and more concerned with research on their diseases. They contribute substantially to the funding of scientific and clinical research. More importantly, some patient organisations participate into the orientation of research, into debates surrounding the very doing of research, and even into the production of knowledge on their diseases.

Of course, the involvement of patient organisations into research depends on the research system in each country, on the characteristics of each disease, on the history of each organisation. An increasing number of monographs provide with rich and detailed case studies. They are all displaying strong evidences that we are currently witnessing a general movement toward the participation of patient organisations into any sort of activity they are concerned with, including research activities for which they are not a priori responsible.

This movement certainly illustrates the co-production of knowledge between lay people and the so-called « experts », on which many scholars in science and technology studies have elaborated. It is clear indeed that patients are less and less passive, and scientists and clinicians are no more the exclusive experts on the diseases. But more importantly, this movement participates to the development of a scientific and technical democracy, through the emergence of new social actors who now intervene into research activities. This is what I would like to reflect upon today. What I would like to focus on is the social identity claim that stands at the core tenet of this movement, through a profound reconfiguration of the relations between clinicians and scientists on the one hand, and groups of patients on the other hand. More precisely, I would like to stress on the emergence and the development of patient collectives, through the participation of their members into the definition of what their diseases are.

My communication is twofold. I would like first to provide a few historical milestones for understanding the links between patient organisations' identity claims and their participation into research on their diseases. I will show that these links manifest the culmination of the

long-lasting self-help movement that has helped, over more than fifty years, to reshape the relations between experts and lay people. Self-help has rapidly disseminated within the domain of health and medicine. So my first objective in this communication is to provide an overview of the different models of patient organisations that have been, at least partly, inherited from the self-help movement.

My second objective is to show that these different models give raise to contrasted forms of engagement of patient organisations into research. I will draw upon different experiences to illustrate my purpose. I will show that each form lies upon a particular conception of patients' role into the production of knowledge. And each conception of this role depends on the answer given to the following questions: in what extent the definition of the disease – as a constituent element of patients' identity – is negotiable? Who are legitimate to take part into these negotiations?

In my conclusion, I will say a few words on the consequences of this movement on the research system, but also on the political challenge that it leads to, that is the recognition of proliferating forms of patient collectives.

1. Different models of relations between professionals and patients

Let's begin with the question: why do some patient organisations engage into research? As I said previously, to answer this question, it is necessary at least to give a rough outline of the history of the self-help movement. And the reason for that is because patient organisations share with that movement an essential claim: the importance of users' experiences in the understanding of their situations, and in the search for solutions to their problems.

Self-help is a very rich and diffuse movement. So what I will say will be necessarily sketchy. My aim is to point to different models of relations between specialists and lay people that self-help has helped to set up. I will first depict the historical trends along which self-help has developed within the domain of health and medicine, and then, I will enter into details of different patient organisations models.

1.1. A few historical milestones

Self-help was born as a grass-root movement. All writings pinpoint its start in the US in 1935 with the birth of Alcoholics Anonymous. These groups were created by alcoholics for alcoholics in a twofold opposition to the psychiatric institution: first against its bureaucratic functioning which made it difficult to deal efficiently with urgent and local situations; and secondly against the psychiatric conception which imputed responsibility for alcoholism to the individual alone, thus overlooking his or her family and socio-cultural environment. Alcoholics Anonymous therefore developed an alternative therapeutic principle to the psychiatric cure. This principle is based on two claims:

(i) Given the intimate experience that alcoholics encounter with alcoholism, they have an irreplaceable expertise on what alcoholism is;

(ii) Exchange of experiences between alcoholics is an alternative therapeutic to the somehow

aggressive psychiatric cure that was the only solution proposed to them.

It is this distanciation vis-à-vis the professional milieu, through the recognition of users' experiences as a form of expertise on the one hand, and the exchange of experiences between users as the main therapeutic principle on the other hand, that can be found in any self-help group.

These claims disseminated rapidly within the domain of health and medicine in different countries by the 1940s-1950s. But what is worth noticing is that it is the idea of exchange of experiences between individuals suffering from the same diseases that was primarily privileged by patient organisations. This led to the development of a first model that can be called « mutual-help model ».

Although this model was, and is still dominant, it was challenged in the 1960s-1970s. Talk groups were criticised for turning in on themselves, and refusing to articulate their problems in the public space. In a sense, a more assertive activism was advocated. In the US, the civil rights movement in the 1960s and the women's liberation movement in the 1970s prepared the ground. Militant self-help groups proliferated. In the domain of health and medicine for instance, parents of disabled children formed groups so that their children's handicaps would not lead to social discrimination; patients suffering from rare disorders and their families united to ensure that they were not forgotten by the medical profession. These organisations paved the way for a second model that can be called « advocacy model ». Their focus was no more exclusively on help, but on self. They were fighting for public recognition, and for putting their specific problems onto the agenda of those politicians and professionals who were supposed to be dealing with them.

This advocacy trend expanded, but it also transformed by the end of the 1970s when it encountered a particularly virulent consumerism. Although the most extreme forms of consumerism rapidly became marginal, it brought the idea of users' empowerment to the fore. This idea soon spread beyond the consumer movement. In particular, it was manifested throughout the 1980s and 1990s in the birth of numerous patient organisations demanding not only the right to information on activities concerning them, but also the right to intervene in these activities. What is interesting is that this claim for patients' participation echoes Alcoholics Anonymous' original claim: the importance of users' experiences in the definition of their problems, and the legitimacy of their intervention into activities concerning them. This led to the development of a third model that can be called « self-description model ». It is based on an identity claim: patients no longer accepted the idea of being defined in a negative way in relation to experts and professionals.

To summarise, we can say that the self-help movement has helped reveal and legitimise three claims enabling us to understand patient organisations' activism:

(i) A claim that could be qualified as epistemological, for the experiences that patients talk about between themselves to be considered as expertise in its own right on their diseases;

(ii) A political claim for their diseases to be given a particular attention by political and professional authorities;

(iii) An identity claim for them no longer to be reduced to the simple role of passive patients, but to be recognised as active partners in debates and practices concerning them.

Each of these claims corresponded to the historical emergence of a specific patient organisation model: mutual-help model, advocacy model, and self-description model. Although these models are somehow related to one another and may co-exist within one particular organisation, it is interesting to describe them separately since each of them lies upon a particular conception of patients' identities, and of the relations between patients and professionals. I will now turn to this point.

1.2. Patient organisations models

Let's begin with the mutual-help model. What are the main characteristics of this model?

The first characteristic has to do with the nature of the patient organisation. It bases its authority on mutual recognition and exchange of experiences between alter egos. If this principle disseminates so largely within the domain of health and medicine, it is because it is well suited to a variety of diseases that it helps to give attention. This is notably the case for rare disorders and for chronic diseases. Patients suffering from rare disorders and their families are used to think that they are alone with their problems unless they have the opportunity to meet with other patients and their families who have the same conditions as they have. By gathering, patients and their families endow themselves with a collective identity through their mutual recognition. As for patients with chronic diseases, they know what it means to live with the diseases. By uniting, they benefit from the little « hints » they give each other for coping with pain or emergencies.

More generally, this mutual recognition and help principle is crucial for it helps to define the main features of a patient organisation. It is a collective made up of volunteers who suffer from, or who are at risk of the same disease or condition, whose authority is based on the lived experience of its members, which is self-governed, and which provides free mutual assistance. These four features are now largely admitted as distinctive characteristics of patient organisations in regard to other kinds of therapeutic groups. More importantly, although these four features now sound very obvious, it is worth noticing that they laid down the historical foundations for patient organisations' activism, for they helped individual patients to federate around the progressive recognition of their own collective force.

The second characteristic of the mutual-help model is concerned with the collective action it develops. It is mostly focused on social and emotional support between patients on a daily basis. Professionals, who rely on patient groups as auxiliaries, as long as these groups stick to social and emotional aspects of the disease, and do not intervene into technical aspects of medicine, frequently seize upon this principle. This means that co-operation between patients and professionals is characterised here by a division of labour and very strictly defined competencies, where patients have the function of providing social support, mutual-help and emotional aid, while specialists define and manage technical and medical interventions. Patient's world and professionals' world are considered as two radically different and yet

complementary worlds, although this complementarity is obviously not free of conflict.

If we now turn to the advocacy model, we get a very contrasted picture.
The definition of what a patient organisation is in this model is slightly different from the one promoted by the mutual-help model. Indeed, as I said previously, the advocacy model is a watershed into patient organisations movement, for it leads them into the field of political protest. From the point of view of advocacy groups, mutual-help groups are no more than enlarged private spheres, depriving their members from seeing the structural nature of their problems. In this model, diseases, for instance, are more than privately shared conditions. They are collective causes that worth public consideration. As a consequence, patient organisations are no more exclusively defined as groups of individuals suffering from the same diseases, but as collectives that fight for the recognition of their diseases.
As far as collective action is concerned, this model forces patient organisations to define their own position in the public space, and especially in relation to institutional actors. Two different positions actually emerge. The first one consists for patient organisations to urge institutional actors – be they politicians or professionals – to put their diseases onto their agenda. How this should be achieved is often a matter for fierce discussions. But what is important to keep in mind is that patient organisations actively call upon those who are supposed to be in charge to take up their responsibilities vis-à-vis their diseases. This is very much the case for certain AIDS organisations, and more generally, for patient organisations, which fear that their conditions might lack public interest for one reason or another.
There is a second position that results from the development of advocacy claims into communitarian claims. The quest for the recognition of their diseases prompt certain patient organisations to assert for their collective identities rooted into their conditions. And they consider that these conditions are not negotiable. This is the direction taken by some disability organisations. They claim for a complete emancipation from any form of knowledge and intervention other than those they develop themselves and for themselves on the basis of their own experiences. This rejection is particularly sharp against specialists' knowledge, considered as the most pervasive and therefore dangerous form of alien knowledge. In his study of deaf communities who refuse cochlear implants for instance, Stuart Blume nicely demonstrates that what those people fight for is the perpetuation of deafness as the basis of their communities. They do not want deafness to be defined as a disease or a handicap. They do not want deafness to be cured or corrected. They want it to be recognised as the very constituent of their identities. « Deaf we are, and deaf we will stay », could be their motto. More generally, such a claim manifests the refusal of normalisation by turning differences into positive and self-asserted identity elements.
Let me finally describe the third model called « self-description » model. This model departs radically from the previous ones. What are its main characteristics?
First of all, its authority is based on the irreplaceable expertise that those who suffer from a disease draw from their own experiences. In contrast to the mutual-help model, this is not just

a matter for recognition and support between alter egos. What are at stake are their collective competencies for contributing to the definition of their disease. This self-description capacity is best depicted in the case of orphan diseases, on which patients are the only experts because professionals turn away from these pathologies. By gathering, patients and their families constitute a collective identity through the capitalisation of their experiences.
Secondly, collective action is focused here on the objectification of this experience-based expertise, and its circulation throughout the scientific and clinical milieu. This is what distinguishes this model from the classical advocacy model and from its communitarian ramification. In contrast to the classical advocacy model, patients do not content to plea for specialists' intervention. They actively disseminate their experiences and initiatives to help nurture specialists' knowledge and direct their decisions. But in contrast to the communitarian model, patients do not argue that their intimate experiences are the only accurate expertise on their conditions. They do assert for collaboration with specialists, so that their diseases eventually become objects of shared investigations and interests. This is understandably a crucial point in the case of orphan diseases.

To summarise, a mutual-help patient organisation is a collection of individuals who suffer from the same condition, who group to talk together about the social and psychological aspects of their lives with the disease, but who leave the definition of what the disease is up to specialists. An advocacy patient organisation is a collective that fights for public recognition of their disease. It might actively search for specialist' engagement into the definition of, and action on the disease, arguing that this is specialists' responsibility. But it might also actively exclude any form of negotiation with specialists. In this latter case, it claims that its members are the only ones who really experience what their condition is made of, how different they are from what « alien » people think – be they specialists. Hence, the patient organisation develops a sense of collective identity that cannot but be threatened if it is worked out from the outside. In the self-description model, the disease is somehow and open entity, and the pre-eminence of experts and professionals on the definition and the management of the disease is no more accepted. Hence the importance of procedures for securing patients' pole position, and for objectifying and circulating their experiences. I shall revert to this point later on, with the original example of the French Muscular Dystrophy Organisation that Michel Callon and I have studied for about six years now.
I have presented these three models in a very sketchy way. There are of course many crossings between them. In the case of orphan diseases for example, mutual-help, advocacy, and self-description might go hand in hand, for the quest for social existence partly depends on the objectification of the disease on the basis of patients' shared experiences. But what I intend to stress on is the key questions around which these models develop: in what extent the disease is negotiable as a constituent of the identity of a patient organisation? Who are legitimate and responsible to participate into the definition of, and action on the disease? This helps understand why research activities progressively become important stakes for patient

organisations. I will now turn to this part of my communication.

2. Different forms of engagement of patient organisations into research

The role of research activities into the shaping of new entities, be they humans or non-humans, and of new relations between these entities, has been well-documented by science studies. It is therefore not by accident that patient organisations progressively get interested into research. Research is one important locus where the diseases are qualified both as objects of investigations, and as means for identifying those who are concerned with these investigations.

There are contrasted forms of engagement of patient organisations into research, depending on whether they develop around one or the other previous models. So here again, I will describe different configurations.

2.1. Auxiliary and lay-expert configurations

The first two configurations that I will describe are the auxiliary and the lay-expert profiles. These profiles derive from the mutual-help model. To recall it briefly, a mutual-help patient group is a collection of individuals suffering from the same disease, focusing mostly on social and emotional support between members, and leaving the definition and management of the disease up to the specialists.

When such an organisation is a stakeholder into research activities on the disease it is concerned with, it traditionally relies on delegation. This means that the patient organisation leaves it up to its scientific council (or to outside experts if it does not have one) the task of defining relevant research themes, promoting them in the research community (through procedures like calls for tenders for example), choosing laboratories to support, distributing funds between selected teams, evaluating their results, disseminating knowledge and practices. All the patient organisation does in this respect is to appoint experts to do the work (it usually chooses people with the soundest reputation), and to allocate a budget to the funding of research. The patient organisation is what is called a direct payer. This form of involvement into research manifests the auxiliary role that the patient organisation usually plays vis-à-vis the professional milieu. The patient organisation acknowledges its own scientific and technical ignorance, and supports specialists who are supposed to know the best.

Many patient organisations have adopted this form of engagement into research, particularly when they are at the start of their support for research and have to define their subjects and identify laboratories (ex: the French Cystic Fibrosis Organisation at its beginnings), when knowledge on their disease is embryonic and needs researchers interested in it in order to develop, or when there is already a professional milieu constituted around the disease (ex: the French Multiple Sclerosis support groups).

However, there is an intrinsic risk to this model. The patient organisation leaves everything up to the will and projects of the professionals, ends up abandoning all initiative, and finds itself dispossessed of all influence. To take the example of the French Cystic Fibrosis Organisation,

it is clear that although it benefited from the virtues of its action as a direct payer in the early years of its support for research, it has now reached the stage where its room for manoeuvre vis-à-vis the scientific and clinical milieu is severely reduced and complicates the necessary re-orientation of its action. To avoid this risk, some patient organisations have opted for a second form of engagement into research that features an increasingly frequent continuation of the pure strategy of delegation.

This second form is what is called acquisition of academic expertise. Instead of entrusting specialists, patient organisations acquire themselves the knowledge required to dialogue with researchers on an equal footing. This alternative is essentially the outcome of the activism of some patient organisations which, faced with the urgency and the gravity of their patients' situation, challenge the specialists' prevarication by defying them on their own ground. Within Act-Up for example, certain activists have become what Steven Epstein calls lay-experts, taking place beside certain specialists against other specialists in controversies around clinical trials. They have thus become members of the professional milieu in their own right.

Although different from the auxiliary configuration in that certain members of the organisation take an active part into research activities and debates, the lay-expert configuration still maintains a clear-cut between those who are willing to participate into the production of knowledge on the disease, i.e. experts and lay-experts, and those who are not, i.e. lay-lay patients, to borrow from Steven Epstein. The frontier between patients and professionals is reproduced within the patient organisation itself. This might seriously threatens the raison d'être of the patient organisation. Lay-experts might progressively loose sight of their problems as patients by adopting specialists' s quarrels. What is at stake here is the preservation of patients' identity. In the case of Act-Up, this provoked, a couple of years ago, schisms within the movement between lay-expert patients and lay-lay patients. This might explain why alternative configurations have progressively emerged, articulating patient organisations' identity claims, and the doing of research on the diseases.

2.2. Emancipatory configuration

An alternative configuration to the auxiliary and the lay-expert profiles stems from the advocacy model. To recall it briefly, although the advocacy model stands primarily on the field of political protest, it has consequences on the field of production of knowledge. Indeed, by claiming for public attention, patient organisations are unavoidably doomed to articulate the reasons why their diseases worth specific consideration. In other words, patient organisations cannot but be « voicy » on what their diseases are.

Certain patient organisations actively assume that this should be specialists' endeavour. As far as research is concerned, this is notably the case when patient organisations fear that their diseases might be put on the fringe in public research budget discussions for instance. In this case, patient organisations act as classical lobbying groups, defending their interests in the political field.

Others, and those are the most interesting for my purpose today, articulate identity claims

and debates on who have the authority to elaborate on their identities. I will return back to the disability movement, or at least to some of its chapters, to illustrate this point. Disability organisations usually fear that their people be not only stigmatised, but also normalised by specialists' interventions. Some disabled people feel that normalisation is a pervasive mechanism for denying them the full status of human beings and/or citizens because of their handicaps. Correcting deafness by cochlear implantation for instance is considered as an unbearable social oppression by deaf communities I mentioned early on, for it points to deafness as an annoying burden for normal social life. What these communities claim for is that society transforms in order to be able to accept and respect these people as they are. Here is where the issue of research is prominent.

For their goal to be achieved, disability organisations work out to demonstrate the positive and non-negotiable nature of their differences. They reject professionals' knowledge, for they consider it not only as alien knowledge, unable to formulate what these differences are, but even worse, as negative knowledge, only able to describe these differences as deficits. They thus advocate that they are the only ones who are legitimate and competent to say what it is to be a disabled person. This claim gives raise to a research strategy that they call themselves emancipatory research. The wave of disability studies relies upon this strategy. People like Tom Shakespeare and Colin Barnes in the UK develop this research trend within university research centres. This kind of research displays specific features, amongst which:

(i) Disabled people are the first knowledge producers within these research centres;

(ii) Their research activities are intimately linked to political activism;

(iii) They mostly nurture their research work with disabled people' s narratives. These narratives are not intended to be objectified in one way or another. They are produced to be and to remain subjective descriptions of what it is to be disabled people;

(iv) Last but not least, their research is most exclusively social science-like research. They radically refuse to enter into medical and para-medical topics, for they consider that these topics distract from the main question, which is what it is to live as disabled people.

These features are enacted in various degrees. But what is important is that they aim, together, to lay down the foundations for a disabled people' s world on what disabled people say. Deaf communities who refuse cochlear implants are an extreme point in case. A recent and very well done TV broadcast deploys their strategy for documenting that deaf people' s world is not reducible to oral people' s world. They fight for the perpetuation of their world. They reject any form of scientific and medical intervention on deafness. They actively disseminate and singularise deaf language as a language on its own right, that naturally fits to their people, and that cannot be substituted to, or complemented by oral language. In this respect, they come to consider a simple visit to a specialist as a threat against their collective identity.

2.3. Partnership configuration

In contrast to the auxiliary and lay-expert configurations, the emancipatory solution is thus a radical way for freeing patient organisations from specialists' hands on the definition of

their diseases, and for preventing any alien intervention into their conditions. Yet, there is an another alternative to the monopoly of specialists, that nonetheless claims for collaboration between patients and experts. This is what is called partnership configuration.

This profile derives from the self-description model. Self-description lies on the importance of patients' experiences in the qualification of their diseases and in the definition of solutions to adopt. Patients' experiences is what makes them at once unavoidable – they know what it means to live with the disease – and different – their needs, dictated by the intimate contact they have with the disease can be different to what professionals assume they are. However, in contrast to the emancipatory configuration, patients do not claim an exclusive knowledge on their diseases. What they are looking for is partnership with specialists, so that they can engage in mutual learning whose outcome is a definition of, and action on the disease that incorporates patients' s experiences and initiatives, and that can stand as a legitimate object of collective interest. Let me illustrate this with the case of the French Muscular Dystrophy Organisation (AFM).

The AFM originated in the fact that at the time it was created in 1958, MD were orphan diseases. Because MD were mostly unknown (very few cases were encountered), and highly frightening (they generated severe handicaps, and rapidly led children suffering from these pathologies to death), professionals turned away from them because they highlighted their powerlessness. This disinterest, in turn, maintained the state of ignorance because it paralysed all efforts at carrying out research on these diseases. This had a dramatic consequence: because there was no organised body of knowledge, there was no care and no cure. To be a MD people was to be a living-dead, almost a non-human. Patients and their families soon realised that their very existence depended on their capacity to assert for the existence of MD as a clinical entity. And for that to be achieved, they could not but draw upon the only available knowledge: the one they have incorporated through their daily experiences with the disease.

Note that this configuration is very different from any of the previous ones. The situations I have described so far are all based on the pre-existence of two groups of individuals: group of patients on the one hand; group of professionals on the other hand. In 1958, there was no specialist on MD, or at best very few and isolated ones, and there was no patient per se, for people suffering from MD were not even considered as human beings, abandoned as they were by physicians, and sometimes by their own relatives. Therefore, the AFM' s objective was not that much to fight for a specific identity. It was, first of all, to make MD people recognised as individuals. And if it targeted the professional milieu, it was because being recognised as patients unable them to say « We are not monsters. We are people suffering from specifically dramatic pathologies ».

As far as research is concerned, although the partnership between patients and professionals seems obvious, especially in the case of the AFM, it is difficult to implement. This is because it profoundly challenges the division of tasks and prerogatives between experts and lay people. So partnership between patients and professionals cannot be simply decreed. It needs procedures that make one' s understanding of the disease perceptible to others. This is

notably crucial as regards patients' experiences.

If patients are to be considered « experts of their own experiences », their knowledge of the disease has to be formalised so that it can be circulated and discussed outside the private sphere. Now, the problem is that lay people do not usually develop tools for formalising their knowledge as professionals do. The originality of the French Muscular Dystrophy Organisation is precisely that it has progressively invented instruments for doing this. Drawing from the AFM experience, what are the main procedures that patient organisations have to set up in order to organise partnership with professionals?

First of all, they need to capitalise their members' experiences in order to provide a description of the disease as an entity on its own. Patient groups within the French Muscular Dystrophy Organisation for example, collect films, photos, narratives, compare them, and write documents on the basis of which it is possible to address questions to professionals. This primitive accumulation and objectification of patients' experiences is crucial in the case of orphan disorders, for it helps formulating a demand that does not exist elsewhere.

Secondly, patient organisations need to set up procedures that ensure that their contribution into the production of knowledge on their diseases will continue on the long run. In this respect, working groups within which patients are systematically associated are necessary. But more importantly, the very structure of the patient organisation is a crucial issue here. Of course, clinicians and scientists need autonomy in order to explore new avenues. Nonetheless, the respective roles of the scientific council and the board of administrators have to be clearly stated. In particular, the fact that the power of decision is in the hands of the board of administrators is a prerequisite. This of course is not easy, and conflicts frequently emerge. But the benefits of the mutual learning between patients and professionals cannot be ripped of if the patients' interests are simply subordinated to the professionals' projects.

Finally, patient organisations need to ensure that institutional actors will not withdraw from their pathologies because patients are managing so well on their own. This is a very important political issue. The engagement of patient organisations into research should not equate that they act in lieu and place of institutional actors. To say it roughly, everybody has to do its job. But of course, the question is what should be done by patient organisations and what institutional actors should do? This is not an easy question to answer. For sure, patient organisations help formulate new demands that are not perceptible through a top-down mechanism. For these demands to be translated into collective interests, patient organisations invest into infrastructures. The French Muscular Dystrophy Organisation for example has set up gene banks, technical facilities and plate-forms that help inscribe MD into the realm of genetic diseases. But for this initial effort been sustained, institutional actors should do their job. This is for instance the case for orphan drugs, for which the European Parliament has given incentives to pharmaceutical industry. What are at stake here are the responsibility and accountability of every actor within the research and health system.

Conclusion

To conclude my presentation, I would like to point briefly to some consequences of patient organisations' activism on the research system, and in the political field.

The different experiences that I have mentioned all along my communication show that patient organisations are now key-players into the research system. Patient organisations' power derives, at least partly, from the self-help movement, that has helped to reveal and legitimise an essential claim: patients are competent on their diseases because they are those who experience them. This claim is crucial for two reasons. First, it endows patients with specific position vis-à-vis professionals: patients are those who know what it is to live wit the diseases, and therefore they are concerned with any action and decision on the diseases. Secondly, this claim is both intended to the outside – and notably to professionals and politicians – and to patients themselves. It fosters patients' self-consciousness that they are not only individuals in front of institutional actors. They are also collectives which share the same conditions and which are therefore legitimate to articulate a collective discourse and action on those conditions.

This has three major consequences on the research system. The first consequence is a profound reconfiguration of patients' and professionals' prerogatives and competencies. The articulation between patient's needs and professionals' objectives is now an unavoidable issue, that impinges upon the way research priorities are decided. But there is more. The mutual learning between patients and professionals that has been developed by organisations such as the AFM radically transforms the very doing of research itself. It manifests strikingly in the emergence of new professional practices and careers. Some researchers, who are working with the AFM for instance, are both geneticists and paediatricians, constantly moving back and forth form the bench to the patient's bed, nurturing their research with patient's observations and vice-versa. Patients are themselves transformed by this tight co-operation, becoming at once objects and subjects of a collective investigation.

The second consequence of patient organisations' activism on the research system is the emergence of research themes and structures that could not have developed through classical research policy procedures. This is the case of the Genethon, the research structure that had been set up by the AFM in 1990. The French public authorities could not have taken the decision to invest into systematic mapping of the human genome at that time, because the French scientific community was very reluctant. The pharmaceutical industry could not have done it either because research on MD did not correspond to a clearly formulated and payable demand.

The third consequence of patient organisations' activism on the research system is that diseases that have not been perceptible so far now become objects of collective interest. This is notably the case for rare and orphan diseases. This sheds light onto the political dimension of patient organisations' engagement into research.

I have stressed, all along my communication, on the intimate links between patient organisations' identity claims, and their engagement into research. The position that a patient

organisation develops vis-à-vis specialists translates the very identity it fights for. The variety of identity claims is an important political issue. It is so for institutions. It questions traditional framing and frontiers between the general welfare and particular interests, between those who are willing to intervene into the definition of these identities and those who are not, between those who know and those who do not. Institutions cannot but consider this proliferation of debates that challenge the nature and the scope of their actions.

But the proliferation of identity claims is also a crucial issue for patient organisations themselves. The stake here is: what does it mean to be a collective concerned with a particular disease or condition? This is a heated question within patient organisations' movements. To illustrate this, I would like to mention a last example.

Last year, I attended the European Conference on Rare Disorders that gathered numerous European patient organisations in Copenhagen. During a plenary session, one scientific officer from the European Community celebrated quite enthusiastically the ever-growing collaboration between patient organisations and the scientific milieu. Suddenly, somebody interrupted his speech, and said with an angry voice: « Research is, and should not be, our main concern ». This interjection was followed-up by fierce discussions at the backstage. It appeared that this person spoke for a patient organisation concerned with a severely handicapping genetic disease. And she was very alarmed by the fact that focusing on research might dilute the disease into a complex arrangement of problems and interests, and thus divert from the main objective that is to fight for living as dignified subjects with the disease and its disability consequences. What is interesting is that patient organisations' engagement into research profoundly questions not only institutional politics, but also patient identity politics. We should bear this in mind in order to enrich our understanding of the pros and cons of the relations between the so-called experts and lay people.