The Center for Sociology of Innovation (CSI) is at present the coordinator of EPOKS - European Patient Organizations in Knowledge Society - a European research project on the action of patient organizations and of collectives of users. The project objective is to compare the forms of associative action in four European countries and as regards different health conditions (rare diseases, non rare diseases, Alzheimer disease, childbirth, and attention deficit / hyperactivity disorder - ADHD). EPOKS looks at the conditions of production and diffusion of lay knowledge, and at its statute. The aim is also to study the role played by the European coalitions of patient and user organizations in the design of new modes of knowledge and know-how governance, allowing them to promote their involvement in the fields of medical and health research. In this interview, Professor Vololona Rabeharisoa from the Center for Sociology of Innovation, presents the characteristics of the patient organizations and collectives concerned by the project, and outlines the resorts of the project, its objectives and how it is rooted in the tradition of dialogue with the associative sector established by the CSI.

Who are the organizations concerned with the research project EPOKS?

Vololona Rabeharisoa: All the patient organizations and all the user collectives, small and large, involved in the health sector insofar as they show an interest for research. We consider the health sector in the broad sense: thus, for instance, the questions related to childbirth or the issues related to disability enter the field of our research. The interest of patient organisations and user collectives for research appears in various ways. It may be in a direct way, for example when they are involved in fund raising or in the collection of biological material for research, or when they contribute to clinical trials. They may also be indirectly involved, for instance in the dissemination or the production of scientific information, or when they take part in discussion lists or in forums.

EPOKS is simultaneously led in several European countries. Why?

Vololona Rabeharisoa: EPOKS is conducted in four European countries: France, Ireland, Portugal and the United Kingdom. The project will compare the forms of associative action in these countries but will also compare various health conditions (rare diseases, non rare diseases, Alzheimer disease, childbirth, and attention deficit / hyperactivity disorder- ADHD). Our assumption is that the forms of collective action vary according to the countries and according to health conditions, even if it seems likely that the various practices influence one another.

Can this new research project be considered as an extension of the MAPO project (Mapping and Analyzing Patient Organisation Movements on Rare Diseases) carried out by the CSI in 2006?

Vololona Rabeharisoa: Yes, but EPOKS widens the perspective opened by MAPO. This first project allowed us to identify more than 600 French patient organisations involved in a way or another in research and presumably representative of the diversity of the existing forms of associative involvement in France. We then studied the strategies developed by patient organizations to serve their causes.
With EPOKS the attempt is to analyze the evolutions over a few years, to detect tendencies and movements in the dynamics of patient and user organizations in Europe. In the field of rare diseases for example, France has undoubtedly been a driving force in the mobilization of patient organizations all over Europe. Thus Eurordis was founded by the French rare diseases organizations, and now speaks for 30 million people concerned by rare diseases in Europe.

**How does research on patient organizations fit in the scope of the CSI's projects?**

**Vololona Rabevarisoa:** In a very general way, research conducted by the CSI aims to describe and analyze the relations between sciences, technologies and society. In this process, special attention is paid to the uses and the users of sciences and technology. The work of the CSI on health issues falls under this prospect, with an interest for the health system users - patient organizations in particular. The associative world is a dynamic milieu, which develops through its own self-observation, a milieu rich of interactions, attentive to the context in which it evolves. The relationships set up between researchers and associative representatives offer very much to learn. The issues emerging in the fields of health and medicine provide exemplary cases to feed the study of the relations between sciences, technologies and society. The analytical prism of the sociology of sciences and technologies reciprocally contributes to the improvement of the reflection about the social links in various situations related to health (disability for instance) and to shed new lighting.

**What are the relationship between the CSI and the patient and user organizations?**

**Vololona Rabevarisoa:** Our relations fall under a tradition of co-operation, of dialogue. This dialogue with patient and user organizations went without saying. Moreover, the CSI supported dialogue between the organizations through discussion groups organized in spring 2007. Around fifty organizations took part in these discussions. The restitution and the analysis of these exchanges were published in book entitled: « Se mobiliser pour la santé. Des associations de patients témoignent » (Mobilizing for health. Testimonies of patient organizations). Certain organizations refer to the work of the CSI; others request our intervention in their assemblies or their meetings. We even have, at the request of the associative milieu and in collaboration with it, elaborated training sessions on associative management at the Ecole des mines de Paris.

**Is the research conducted by the CSI useful for patient and user organizations?**

**Vololona Rabevarisoa:** The CSI undertakes sociological research in field of health for about fifteen years. I believe that the quality of our work is from now on recognized. This legitimacy acquired by the CSI reflects on patient organizations -some make use of the results of our research for that matter. It seems to me that patient organizations may benefit from the provision of built and global information on their branch of industry in various ways. For example,
it may contribute to reinforce the knowledge patient organizations have on one another, and for each one to better locate itself within the associative fabric. Certain associative models infuse in the general associative fabric. As a source of knowledge on the operation and the organization of the associative world, our work makes it also more visible and understandable for public authorities. Through its research work, the CSI thus contributes to make the associative action in health better known and recognized by decision makers and experts of health policies. In a certain way, it accompanies the movement of legitimization of the associative action, which notably led to promulgation of the August 2004 Law relating to public health policy, in particular of its title II "Medical Democracy".

Is the CSI involved in the policy process along with the actors of the health system?

Vololona Rabeharisoa: The relations between patient organizations, researchers, health professionals and public authorities are in full progress. As far as we are concerned, the expertise of the CSI researchers is requested by various organizations and institutions, for example the National Health Insurance or the French National Authority for Health. In these bodies, the specificity of our approach can contribute to reopen questionings, to reformulate issues and thus to renew the approaches allowing to define health public policies.

When will the results of EPOKS be known?

Vololona Rabeharisoa: In the course of 2011. It may seem long but data collection and analysis is complex and requires thoroughness. It is not only a question of drawing up statistical results but also of providing a qualitative sociological analysis of the movements which cross the associative fabric.

... and disseminated?

Vololona Rabeharisoa: In addition to scientific publications in French and international journals, we have planned to invite patient and user organizations to a meeting where a restitution of the results will be made, probably in the presence of representatives of public institutions. In January 2009, the meeting organized for the results restitution of the MAPO project had indeed allowed about fifty patient organizations to exchange during more than two hours. We thus want to renew this experiment that all the participants have found extremely instructive. And we will of course disseminate the results through the CSI's website.