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# On the multiplicity of lay expertise

## AN EMPIRICAL AND ANALYTICAL OVERVIEW OF PATIENT ASSOCIATIONS' ACHIEVEMENTS AND CHALLENGES

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## **ABSTRACT :**

The notion of the "expert patient" has become quite prominent in recent years. In many countries, patients are invited to sit on various committees with biomedical specialists to share their expertise on diseases and health problems with various institutions. This situation stands in stark contrast with the medical paternalism that prevailed not so long ago. How did this come to pass? What is the nature of the patient expertise that is being solicited? How have health policies changed as a result? These are the questions that we examine in this article. In light of previous and recent fieldwork that we have done, and a selection of case studies reported in the literature, our objective is to revisit a constellation of notions such as "expert patient," "lay expert," "lay expertise," "experiential knowledge," and "expert of experience" that are not only analytical tools for STS scholars and social scientists, but also part and parcel of today's institutional parlance.

This article is divided into four sections. In the first section, we focus on the production of experiential knowledge by patient associations. In the second section, we show how they also strive to transform the content of credentialed expertise in order to better align this expertise with their concerns. The third section illustrates "lay expertise in action" and addresses the following questions: What changes do patient associations bring to health policymaking? How do they achieve these changes? In the fourth and last section, we examine the institutionalization of the "expert patient," which manifests not only in legislation that mandates patient participation, but also in a variety of initiatives implemented by institutions to mobilize patient participation in medical research and health programs. In the conclusion, we suggest a few avenues for future research that may complement the corpus of knowledge on lay expertise on aspects that thus far remain less investigated.

## **KEYWORDS :**

expertise ; patient associations ; knowledget ; experience.

# Introduction

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The notion of the “expert patient” has become quite prominent in recent years. In many countries, patients are invited to sit on various committees with biomedical specialists to share their expertise on diseases and health problems with various institutions. This situation stands in stark contrast with the medical paternalism that prevailed not so long ago. How did this come to pass? What is the nature of the patient expertise that is being solicited? How have health policies changed as a result? These are the questions that we examine in this paper. In light of previous and recent fieldwork that we have done, and a selection of case studies reported in the literature, our objective is to revisit a constellation of notions such as “expert patient,” “lay expert,” “lay expertise,” “experiential knowledge,” and “expert of experience” that are not only analytical tools for STS scholars and social scientists, but also part and parcel of today’s institutional parlance.

We focus specifically on patient expertise in the context of actions undertaken by patient associations. It was indeed in this context that the notion of “patient expertise” emerged. We define a patient association as a non-profit organization that brings together individuals with concerns related to a specific disease, disability, or health problem (i.e. those who are directly affected and/or people close to them such as relatives and friends). A few points should be stressed here:

- Saying that a patient association is an organization implies that its functioning is formally defined and obeys rules, although possibly differing across countries; informal groups that emerge through social networks, for example, are not patient associations. It also means that a patient association explicitly endorses specific missions that play an important role in the orientation of its actions, and that can evolve over time. The missions of a patient association may range from providing mutual support to defending its members’ rights and interests to waging war on disease, which involves seeking not only a cure but also appropriate care and sound medical practices.
- Saying that it is a patient organization implies that concerned people as defined above (patients, relatives and friends) play a major role in the organization, in contrast to certain patient groups that have been created and run by professionals. We consider a genuine patient association to have internal decision-making power, even if it has a scientific and medical advisory board or occasionally seeks advice from professionals.

In what follows, we will draw upon empirical studies that we have accumulated over the last fifteen years, mainly though not exclusively in France, concerning patient associations as defined above. In these studies, we have deployed different methodologies: questionnaires filled in by representatives from several hundreds of patient associations, interviews with key members of patient associations, participation in events or activities involving these organizations, document analysis, and focus groups. In this paper, we focus on a limited number of organizations which nevertheless display a great variety in their size, their age, their resources, and the types of health issues they are concerned with. Later, we discuss general lessons from our research findings.

Analyzing patient expertise implies examining how patients become experts. Experts have the experience and knowledge necessary to assess a specific situation and to propose ways to improve it. By extension, expertise is also what experts produce in the form of assessments and propositions. Expertise is intended for specific audiences (e.g. institutions that commission the expertise, actors who must be convinced of the relevance of a proposition, etc.), and is oriented towards action. One question immediately arises: How can one ensure that an individual has the experience and knowledge necessary to make him/her an expert? This recognition can be more or less formal, but is often based on professional credentials which provide evidence that the candidate expert has mastered a recognized body of knowledge and has significant experience relevant to the issues at stake. How then can patients be considered experts, when they often have no professional credentials in medical and health sciences? The main point that we would like to document in this paper is that in order to be regarded as capable and legitimate experts, patients engage in intensive work to acquire competences and build specific bodies of knowledge.

In the 1990s, Steven Epstein's (1995) groundbreaking work on HIV/AIDS activists in the United States paved the way for novel inquiries into how lay people become experts. He coined the term "lay experts" to describe HIV/AIDS activists who sought to arm themselves with as much knowledge as possible to help patients gain access to experimental treatments. Epstein showed that to be recognized by scientific experts and drug regulation agencies as competent and legitimate interlocutors, these activists: (i) familiarized themselves with the language and content of biomedical literature; (ii) wove together moral and epistemic arguments; and (iii) took sides in controversies opposing scientists on how clinical research should be conducted. Epstein used the term "therapeutic activism" to describe the actions of groups of "lay" people who decided to interfere with debates usually confined to the scientific and medical milieu. Janine Barbot (1998, 2002) and Nicolas Dodier (2003) described similar dynamics with regard to HIV/AIDS activism in France. Being acquainted with the scientific literature, these "lay experts" did not function merely as "interactional experts" (Collins and Evans 2002) by discussing issues with scientists; more importantly, they managed to transform clinical practices and to impose activists as stakeholders in the design and monitoring of these practices.

Together with HIV/AIDS activist groups, rare disease patient associations are considered a major source of inspiration for the development of contemporary health activism. As we described in our own work (Rabeharisoa and Callon 1999b) on the French Muscular Dystrophy Association (i.e. Association Française contre les Myopathies; AFM), the situation was a bit different from the one described in the case of HIV/AIDS: the AFM's involvement in research was aimed at mobilizing researchers to investigate diseases that nobody knew about in France in the 1980s. Much like the HIV/AIDS activists, members of the AFM became acquainted with medical research through contacts with biologists and clinicians, visits to laboratories and medical consultations, and engagement with the scientific literature. Their conclusion was clear: research on muscular dystrophy was almost non-existent, and very few clinicians were aware of myopathies. Thus, the AFM found itself obliged to produce the first corpus of knowledge on myopathies to elicit some interest in the medical and scientific milieu. The AFM collected testimonies from parents of children with myopathies, made films, conducted surveys to produce the first clinical descriptions of these diseases, and assembled facts to be discussed with clinicians and researchers (Rabeharisoa and Callon 1998). Not only did the

AFM families became “lay experts” in the sense given to this notion by Steven Epstein (1996), they also became “experts of experience,” able to bring about new knowledge based on their experiences with the disease. By effecting a confrontation between concerned people’s experiential knowledge (Borkman 1976) with medical and scientific knowledge, the AFM raised new research questions, identified “zones of undone science” (Frickel et al. 2010; Hess 2009) to be investigated, and eventually brought about paradigmatic changes in the understanding of myopathies. For example, a group of parents of children suffering from SMA (Spinal Muscular Atrophy) were used to exchange their experiences and realized that the body temperature of their children was lower than the normal (36.5°C in average instead of 37.2°C). They alerted clinicians and asked them to figure out the potential causes of this phenomenon. After a series of clinical investigations, it turned out that this low body temperature was related to cardiac problems, though myopathies were not supposed to affect the cardiac muscle. This finding prompted the exploration of comorbidities and contributed crucial knowledge on a category of diseases called “cardiomyopathies” (Rabeharisoa and Callon 2004).

We thus can say that the notion of “lay expertise” aptly captures a phenomenon that emerged in Western Europe and the United States in the 1980s and 1990s: the mobilization of biomedical research by groups of people concerned with specific diseases or health problems, and the recognition of these groups as competent and legitimate interlocutors by scientific experts, at least to a certain extent. Since then, “lay expertise” and “lay experts” have become topical issues in STS and in different social science domains.

That said, the notion of “lay expertise” raises many debates within academia and beyond. Although the term initially referred to the acculturation of lay people to the biomedical world, today the latter often reduces lay expertise to lay people’s experiential knowledge. Such a reductionist view is consistent with the long-standing state of medical paternalism: some observers argue that if lay people develop expertise at all, it can only mirror their own subjective experiences of a disease. The notion that lay expertise could denote lay people’s command of scientific knowledge is considered to be a result of analytical confusion between the social roles and competences of experts and non-experts, of professionals and patients.

It is precisely this alleged confusion that we would like to revisit in this paper. Indeed, continuous debates on the definition of “lay expertise” indicate an ongoing controversy on the role that patient associations should play, as much as they point to disputes on the role of credentialed experts in the decision-making process. Our approach consists not of discussing notions and concepts *in abstracto*, but of analyzing actual practices developed by patient associations in order to provide some points of reference in the debate. Drawing on our empirical studies, we show that: (i) the expertise deployed by patient associations in their attempts to influence health policies and care practices very often results from back and forth between scientific and experiential knowledge; and (ii) what we mean by experiential knowledge should be pluralized. Experiential knowledge does not exclusively stem from subjective introspection into one’s life, but from observations accumulated day after day on the evolution of the disease, through practices that resemble scientific practices. It is through the mobilization and hybridization of different forms of knowledge that patient associations put themselves in a position to produce expertise—that is, to make propositions about the nature of issues at stake and how these issues should be addressed.

This paper is divided into four sections. In the first section, we focus on the production of experiential knowledge by patient associations. In the second section, we show how they also strive to transform the content of credentialed expertise in order to better align this expertise with their concerns. The third section illustrates “lay expertise in action” and addresses the following questions: What changes do patient associations bring to health policymaking? How do they achieve these changes? In the fourth and last section, we examine the institutionalization of the “expert patient,” which manifests not only in legislation that mandates patient participation, but also in a variety of initiatives implemented by institutions to mobilize patient participation in medical research and health programs. In the conclusion, we suggest a few avenues for future research that may complement the corpus of knowledge on lay expertise on aspects that thus far remain less investigated.

## Producing and articulating experiential knowledge to confront medical knowledge: the construction of “lay expertise”

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As mentioned previously, the capacity of patient associations and activist groups to influence the course of medical research and clinical trials resulted from an intense acculturation to scientific research. They did not involve themselves in scientific debates and activities for the sake of science (Arksey 1994; Barker 2005; Brown *et al.* 2004; Dumit 2006; Epstein 1995; Landzelius 2006; Rabeharisoa and Callon 2002), but because existing scientific knowledge and medical interventions failed to account for patients’ experiences and concerns. Accordingly, their main motive was to realign the content and methods of scientific and medical research with patients’ concerns. For their expertise to be acknowledged, they had to speak the language of the communities they targeted.

However, this engagement with scientific research is only one part of the story: in addition to mastering the scientific literature, patient associations must identify the problems they deem important to tackle on behalf of the patients they claim to represent. For this to be achieved, they engage in a two-fold endeavor: (i) the production of “experiential knowledge” (Borkman 1976) (i.e. knowledge based on concerned people’s experiences); and (ii) the confrontation of experiential knowledge with scientific and medical knowledge. The aim is to reveal potential gaps between these two bodies of knowledge that, from a patient association’s point of view, hinder the recognition of problems that patients encounter in their daily lives.

Interestingly, this form of patient activism comes with an inversion of the so-called “deficit model” (Callon 1999) which supposes that disagreement between experts and the public arise from a lack of information of the latter: correctly informed by the experts, the public cannot but agree with them. Not only do patient associations consider themselves to be “knowledge-able actors” (Felt 2015), but they publicly claim to be experts about their own



experiences; they also highlight credentialed experts' lack of understanding and/or deliberate ignorance of patients' situations. Therefore, the first role of patient associations as "lay" experts is to problematize those situations, with the goal of making them relevant and legitimate objects of inquiry. But how exactly do they proceed, and what are the nature and scope of the epistemic transformations they produce?

## Incorporating experiential knowledge into the medical understanding of diseases

Our first example is Génération 22, a small French patient association created in 1997 by families concerned with a rare chromosomal syndrome called 22q11 deletion syndrome, just a few years after the deletion was identified (Rabeharisoa *et al.* 2014). There exists today an international consensus on the complexity of this syndrome, which is characterized by multiple organic, cognitive, and psychiatric disorders. However, the mother who founded the association recalled that clinicians she visited in the late 1980s and early 1990s argued that her daughter's various disorders were in no way related to one another. It took her years to assemble facts on the complexity of the condition, and to collect and confront scientific and medical knowledge with families' experiences. Even after the deletion was identified, different specialists continued to work in isolation. Notably, a few families alerted the association about the incidence of schizophrenia in adolescent patients, a fact that some French medical practitioners considered with much doubts at the time.<sup>1</sup> The mother who created the association approached a psychiatrist: together, they conducted a survey which concluded that the prevalence of schizophrenia was indeed higher amongst those with the syndrome than amongst the general population. This prompted the launch of a psychiatric genetics research program on 22q11 DS and schizophrenia, in which the association participated. In this case, experiential knowledge not only contributed original observations, but also initiated a paradigmatic change in the understanding of the syndrome, which previously had been scattered among different and unrelated corpuses of scientific and medical knowledge.

Génération 22 then made contacts and engaged with French collectives of patient associations and experts which began to emerge in the 2000s to explore connections between chromosomal syndromes and psychiatric symptoms. Génération 22 and sister associations' demands for a multidisciplinary approach to these syndromes were taken into consideration by the French National Plan for Rare Diseases, a policy initiative of the French government in response to patient organizations' demand: one of its core missions is to establish referral centers that provide diagnosis, care, and research services for patients with specific health conditions. A few of these centers were categorized as specializing in "developmental disorders and deformity syndromes," an *ad hoc* category comprising different conditions which present significant similarities, despite having different traditional disease classifications.<sup>2</sup>

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<sup>1</sup> Notably because these medical practitioners addressed the 22q11 deletion syndrome according to their own specialties.

<sup>2</sup> For more details on the intersection of genomic and psychiatric classification, see Navon and Shwed 2012.

This case is emblematic of the struggles of French rare disease associations that had to advocate for patients in the absence of robust corpuses of scientific and medical knowledge about their diseases, and that were in a unique position to refresh medical knowledge and paradigms by drawing on patients' experiences (Rabeharisoa *et al.*, *op. cit.*).

### Ensuring that patients' experiences count in medico-economic evaluations of drugs and disease burden

The second example illustrates how patient associations revisit the politics of cure and care by proposing experience-based assessments of the effects of drugs on patients, and of the disease burden for patients and society at large. This is the case of AKU Society UK, a small British nonprofit created in 2002 and dedicated to supporting patients and families affected by a rare disease called alkaptonuria (Rabeharisoa and Doganova 2016). Alkaptonuria is a genetic disease resulting in the accumulation of homogentisic acid in the body due to the lack of an enzyme that breaks it down. This metabolic dysfunction causes the degradation of cartilage that damages joints. In the mid-2000s, AKU Society UK identified a drug called nitisinone as a potential treatment for alkaptonuria: nitisinone is prescribed for another rare metabolic disease that presents similarities with alkaptonuria. Previous clinical research conducted in the United States suggested that nitisinone could reduce homogentisic acid levels. Though patients who took nitisinone reported that they felt better, the clinical trials were inconclusive. But the CEO of the AKU Society UK hypothesized that the clinical endpoint then used - improved functioning in the hip joint - does not capture the whole story. Indeed, the clinical picture of alkaptonuria is heterogeneous. This prompted the charity to launch a consortium called DevelopAKUre, which designed a totally different trial: instead of the clinical endpoint tested in the American trial, DevelopAKUre targeted a "surrogate endpoint:" the reduction of homogentisic acid levels in the body.

Had the trial been successful, however, the British National Health Services (NHS) would have been reluctant to pay for the treatment. The cost per quality-adjusted life year (QALY), the main criterion for the pricing of drugs in the UK, would have been too high. Thus, in parallel with the clinical trial, the AKU Society UK commissioned an independent consultant to study the "real costs" of alkaptonuria for patients and families, and by extension, the NHS. The consultant conducted a survey on a small sample of "real patients" to collect "real life"<sup>3</sup> data on the costs of the disease, notably the costs of the multiple surgeries that patients have undergone, the costs due to inaccurate diagnoses and inappropriate care (multiple medical consultations and medications, including pain killers, anti-inflammatory drugs, and anti-depressants), and other indirect costs (e.g. lost wages and productivity). The study concluded that a "conservative approximation" of the total costs of alkaptonuria in the UK ranges from £1.4 million to 2.0 million per year, a figure comparable to the expected price of nitisinone, which may cost a few hundred thousand pounds per patient per year.<sup>4</sup> By comparing the

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<sup>3</sup> The expressions "real patients" and "real life" are those of the CEO of the AKU Society UK whom we interviewed.

<sup>4</sup> AKU Society UK has estimated the prevalence of alkaptonuria to be 1 out of every 250,000–500,000 people (see <http://www.akusociety.org/what-is-alkaptonuria>). At the time of its cost assessment, AKU Society UK had identified 62 patients in the UK and 3 in Scotland.

disease burden to the potential benefits of the drug from the vantage point of patients, AKU Society UK uncovered “missing variables” in the pricing of orphan drugs that the UK National Institute for Health and Care Excellence (NICE)<sup>5</sup> began to acknowledge.<sup>6</sup>

This case demonstrates how a patient association translates what it is like to live with a complex disease without an appropriate cure into medico-economic language, with the goal of convincing clinicians and health administrators of the benefits of considering patients’ experiences when evaluating a potential drug, to benefit not only patients, but also the health system.

### Confronting the rationale for medical interventions with concerned people’s experiences

The third case concerns the Collectif Interassociatif Autour de la Naissance (CIANE), the main French organization dedicated to issues related to childbirth. CIANE was created in 2003 out of a network of various groups: local associations devoted to supporting parents and defending maternity wards threatened with closure; national associations concerned with specific topics (e.g. caesarean section, postpartum depression, breastfeeding, etc.); and internet-based support groups. Among these latter groups, episiotomy was one of the most discussed issues. Many women complained about the impacts of this procedure and questioned its relevance; they compared episiotomy to sexual mutilation, and some contended that episiotomy should be considered a manifestation of obstetrical patriarchy. Members of these groups reviewed the literature on episiotomy, which revealed growing academic contestation of its utility. After the National College of Obstetricians elaborated guidelines on this topic, it sent them to CIANE for feedback prior to publication.

CIANE was quite upset by the new guidelines, which established a 30% episiotomy rate as an objective for practitioners. Indeed, CIANE had found no robust evidence to support this rate and assumed it had been a political compromise designed to avoid antagonizing practitioners. To prepare its reply, CIANE formed a working group and conducted informal surveys with members of its network. CIANE responded with a 15-page comment that expressed a number of criticisms. One crucial criticism was that the document produced by the College was purely technical and failed to incorporate women’s points of view. CIANE commented on a number of issues that had been ignored by the College, including informed consent, medical complications, and impacts on everyday life such as pain and sexual problems. CIANE argued that those issues pointed to the need for a restrictive episiotomy policy, considering that in most cases, the benefits of the procedure were not scientifically demonstrated.

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<sup>5</sup> NICE is the UK health technology assessment agency.

<sup>6</sup> “Decisions about whether to recommend interventions should not be based on evidence of their relative costs and benefits alone. NICE must consider other factors when developing its guidance, including the need to distribute health resources in the fairest way within society as a whole” (NICE, 2009, *Patients, the Public and Priorities in HealthCare*. CRC Press, Taylor & Francis Group).

Moreover, CIANE re-conceptualized the prevention of perineal lacerations (the primary justification for episiotomy used by many obstetricians) by pointing out that other medical practices likely induced perineal lacerations, and that other strategies (e.g. different positioning during labor) might help prevent them. Drawing on women's complaints on one hand, and on the analysis of medical interventions on the other hand, CIANE formulated a series of propositions on women's consent, professional training, and modification of medical protocols for the management of labor. For CIANE, episiotomy was only the tip of an iceberg of bad practices rooted in a lack of respect for women, whereas for the College of Obstetricians, it was just a matter of adjusting a rate of intervention. This case epitomizes how concerned people's non-medical experiences, once translated into medical language, cause professional conceptions of medical practices to be questioned.

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These are but a few illustrations, echoing numerous others reported in the literature of how patient associations come to intervene in the orientation of biomedical research, the organization of care, or the evaluation of treatments by contributing new forms of expertise that challenge existing frameworks. The specificity of the forms of expertise developed by patient associations resides in the production of knowledge that begins with inquiries into patients' experiences. Three main characteristics of the fabric of experiential knowledge are worth highlighting here.

First, experiential knowledge is deployed in a variety of domains. An understanding of the disease is one of them. Patient associations regularly collect and synthesize concerned people's experiences of a disease and confront corpuses of scientific and medical knowledge on its etiology, clinical picture, and manifestations with their own narratives. The list of conditions on which patient associations are working has expanded in recent years because they have deemed it necessary to consider potential causes of certain diseases (e.g. environmental causes of certain cancers; Brown *et al.* 2006; Wynne 1996), or because patients suffer from conditions that are ignored by biomedical communities and/or public authorities (Barker 2005; Dumit 2006) or are not documented in the scientific and medical literature. Experiential knowledge also concerns the rationale for medical interventions and practices, the organization of care, the assessment of patients' quality of life, the evaluation of disease burden, and more recently, the calculation of the costs and efficiency of drugs: it encompasses all aspects of the functioning of medical and health systems. The possibilities offered by the internet have been central in this development (Akrich 2010): it allowed geographically dispersed people to exchange knowledge about their health problems and has been at the origins of many patient organizations, especially in the domain of rare diseases; it also permits the development of surveys at a low technical and economic cost.

Second, experiential knowledge has transformative effects on the content of scientific and medical knowledge. Although not all patient associations produce such paradigmatic changes as in the case of *Génération 22*, they do introduce problems that concerned people actually experience and reshuffle knowledge on diseases and their consequences. Moreover, patient associations often rearticulate bodies of knowledge that are separated along disciplinary lines. We thus can say that experiential knowledge contributes new research

questions and novel elaborations of the problems encountered by concerned people and enlarges the scope of knowledge and issues to be addressed.

Third, patient associations collect and synthesize patients' narratives, conduct surveys, and produce statistics that transform concerned people's experiences into genuine knowledge. These tools used by patient associations to produce and visualize experiential knowledge are not completely alien to those used by the scientific and medical communities. That said, patient associations do not concern themselves with the alleged scientific rigor that governs the production of scientific knowledge, because they are adamant that patients' experiences are meaningful regardless of whether or not they are consistent with scientific facts. For instance, rather than suppressing one observation that looks extreme compared to others, they categorize it as "anecdotal evidence" (Moore and Stilgoe 2009) to illustrate the severity of a particular situation. In addition, patient associations often place figures representing quantitative analyses of surveys next to patients' qualitative narratives in their publications to ensure representativeness while valuing the singularity of each patient's experience (Akrich et al. 2014). Moreover, patient associations sometimes adapt scientific methodologies and even improve upon them when investigating phenomena beyond the reach of classic scientific tools. For example, when the Alzheimer's Society UK decided to include patients, and not only caregivers, as contributors, it decided to call on social scientists for help (Moreira et al. 2014). As traditional interviews would not always be possible with people suffering from cognitive impairments, researchers mobilized and invented new methodologies, such as the use of pictograms to capture patients' answers to questions about their experiences and expectations. In doing so, the Society empowered patients by giving them the capacity to express themselves—a capacity that would not have emerged otherwise. By and large, some patient associations can be quite inventive when it comes to tools and methodologies for exploring, visualizing, and circulating patients' experiences.

## Building epistemic communities: building networks of expertise, building expertise as a network

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To confront experiential knowledge with scientific and medical knowledge, patient associations engage in a lengthy and demanding learning process. Patient associations identify and contact scientists and clinicians, visit laboratories, read scientific and medical articles, attend academic conferences, and regularly update their knowledge thanks to the rapid development of the web. Some activists are scientists and/or clinicians themselves who work on diseases that run in their families, as is the case for Nancy Wexler with Huntington's disease (Wexler 1996) and founding members of the National Society for Autistic Children in the United States (Eyal 2010). Others decide to complement their educations: for instance, the President of HyperSupers (the French association for ADHD) returned to university to deepen her knowledge in psychology, and certain members of French rare disease patient associations have followed a curriculum on bioethics to address issues related to prenatal and

pre-implantation diagnosis. Collectively, these examples show that the notion of “lay expert” is not an oxymoron (Prior 2003), but refers to a “knowledge-able” person (Felt 2015) who masters knowledge about different facets of a disease without being a specialist in a scientific discipline such as neurology, immunology, psychiatry, pediatrics, endocrinology, etc.

This hybridization process comes with a risk that lay experts may progressively lose sight of their activist identities and turn into experts among experts, as was the case of certain HIV/AIDS lay experts who were fiercely criticized by “lay lay” activists (Epstein 1996). This is where patient associations’ engagement with scientific knowledge *and* experiential knowledge plays a decisive role: as both “lay experts” *and* “experts on their experiences,” patient activists are positioned close to *and* at a distance from the scientific and medical milieu. More importantly, this positioning helps patient associations structure epistemic communities (Haas 1992). These communities are networks of actors who share policy orientations (i.e. definitions of the problems at stake and possible solutions) and have relevant expertise on which these policy orientations are based. Epistemic communities therefore expand traditional biomedical communities to include representatives of concerned people. As we show in the next section, this does not occur without conflict. But first, we must examine how patient associations come to occupy this position.

### Patient associations as research coordinators: supporting the creation and maintenance of patient-centered epistemic communities

Many French rare disease patient associations provide (modest) financial support to research teams. Over the years, they have learned not to content themselves with merely providing research funding, but to identify specific research targets and monitor the research activities they fund. Patient associations select the teams they are willing to help, as well as the research policy instruments they deem consistent with their missions. One remarkable example is that numerous rare disease patient associations in France support PhD students and postdocs, with the goal of establishing and maintaining research communities to study specific diseases. For instance, VLM, the French patient association focused on cystic fibrosis, issues an annual call for PhD research projects on a series of topics selected by the board of administrators of the association (all patients and/or family members) and convenes the students it supports once a year to take stock of their research findings. As a consequence, an epistemic community of young researchers now exists in France, and VLM plays an instrumental role, not only as a research payer, but also as a research coordinator.

The existence of such patient-centered epistemic communities sometimes creates turmoil within scientific communities. The case of the AFM is quite telling in this respect. Some scientists and clinicians we interviewed made the decision to leave the epistemic community organized by the AFM because they felt that they no longer had the flexibility to pursue their own research agendas. Some of them even expressed concerns that fellow scientists and clinicians who continue to collaborate with the AFM are patronized by the association and are giving up their personal research objectives. This criticism is interesting because it opposes two conceptions of patient associations held by scientists: (i) that patient associations are research foundations that should be governed by scientists, and (ii) that patient associations provide funding for projects that correspond to their research interests.

Let us highlight two points at this stage. Firstly, cooperation between scientists and patient associations does not always go smoothly. Quite the contrary: scientists do not invariably share their prerogatives and are not always ready to acknowledge patient associations' expertise. Moreover, the decision to take or not take patient associations' expertise into account sometimes triggers disputes amongst scientists, as the example of the AFM shows: these disputes concern the role that patient associations should play, as much as the normative views on what credentialed expertise should be. Secondly, most associations are in a very different situation from the AFM or a handful of large associations; they have very few resources and cannot pretend to weight significantly on research programs. However, a survey conducted on 215 French patient associations (Rabeharisoa *et al.*, 2008) revealed that many of them play an active role in research by helping to constitute patient cohorts, to collect biological samples, to prepare clinical trials, or to raise money. In the next section, we will see that beyond direct interventions on the research process, patient associations use more subtle methods in order to push the production of knowledge in directions they consider relevant.

### Patient associations as mediators and specialists' partners in networks of expertise

The AFM is a large and wealthy association with the ability to provide significant funding for research projects and sustain a community of experts. Money, however, is just one part of the equation. Other patient associations have been able to provide forums that enable scientists and clinicians to discuss conditions that are much less publicized than rare diseases, and to raise awareness of the need for research and treatment. This is the case with HyperSupers, the French association for patients and parents of children suffering from ADHD. ADHD has long been an unsettled condition, the etiology, mechanisms and manifestations of which have been mired in uncertainty (Bergey *et al.* 2017). When HyperSupers formed in 2000, it confronted an environment characterized by fragmented scientific and medical expertise and heated controversies between different specialists, particularly neuro-pediatricians and child psychiatrists with backgrounds in psychodynamics. Rather than taking sides in those controversies, the association began to collect data on patients' and families' experiences and compare them against evidence from scientific and medical articles, and realized that different interventions, sometimes in combination, may benefit different children: what was needed was a "multimodal approach," implying that one single discipline could not capture the multi-dimensional nature of the condition. As a consequence, HyperSupers decided to establish a multidisciplinary network dedicated to synthesizing expertise on ADHD and related issues (Edwards *et al.* 2014).

Historically, HyperSupers has established tight bonds with a few specialists who are sympathetic to its cause. It regularly puts together scientific symposia and awards scientific prizes to gather specialists who typically do not dialogue with each other from diverse disciplines, such as neurobiology, cognitive science, child psychiatry, psychology, pharmacology, nutrition, epidemiology, education sciences, disability studies, and even psychodynamics. During these symposia, HyperSupers presents the results of various surveys it conducts on patients' and families' experiences of diagnosis and care, and fosters exchange among specialists on patients' and families' needs and expectations. These specialists form an epistemic community whose members are regularly invited by the association to make



presentations to families at its general assemblies. Within these various arenas, which resemble what Callon *et al.* (2009) called “hybrid fora,” patient associations function as mediators between concerned people and specialists, and amongst different specialists. In doing so, they contribute to raising the scientific, social, and political profiles of diseases to inspire scientific and medical communities to design research projects and treatment programs.

The case of the National Society for Autistic Children (NSAC) in the United States described by Gil Eyal (2010) illustrates an even more radical situation. When the organization was established in 1965, a number of individuals simultaneously belonged to the world of patients and to the world of scientists. Bernard Rimland, a father of an autistic child and a psychologist who had not initially specialized in autism, and Lorna Wing, a mother of an autistic child and a psychiatrist, are the most famous examples, but many other individuals also adopted the hybrid identity of “parent-activist-therapist-researcher.” All of these people shared a daily life experience of autism, experienced deep dissatisfaction with the way their children were considered and treated, and possessed intellectual and professional tools that gave them the credibility to articulate other models of autism. Schopler, a psychologist who had been working with the Society since the 1970s, developed a research model in which parents served as co-researchers and co-therapists, thereby enabling novel expertise to emerge out of parents’ and specialists’ engagement in a process of collective inquiry (Dewey 1927).

### Enlarging communities of knowledge beyond biomedicine

The examples we have presented so far illustrate the role of patient associations in structuring and sustaining biomedical communities for specific diseases. Biomedicine, however, is not the only sphere of knowledge that patient associations are willing to mobilize. The DingDingDong association was established by a young woman whose mother has Huntington’s disease. She underwent genetic testing which revealed that she too carries the gene for the disease. This news was certainly a shock to her, but she was even more outraged by the medical doctor she consulted, who described a terrible and inescapable fate that she was not prepared to accept. This prompted her to form DingDingDong, with the goal of demonstrating that there exists, *hic et nunc*, a life with the gene and the disease, a life that the medical doctor she visited wrote off. DingDingDong seeks to explore the ordinary lives of people with the gene and the disease, a *terra incognita* that biomedicine, according to the association, largely ignores. DingDingDong was established as the “Institute for the coproduction of knowledge on Huntington’s Disease” to connect social scientists and artists (writers, film-makers, photographers) whose mission is to inform professionals and the public about the lives of those affected by the condition. In contrast to many rare disease patient associations focused on seeking cures and whose epistemic communities are mostly biomedicine-oriented, DingDingDong focuses on the lived experiences of those affected by the disease, and privileges collaboration with social scientists and artists to convey an alternative vision of what it means to have the gene and the disease.

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In the first section of this paper, we showed how patient associations are engaged in a two-way translation process—between patients’ experiences and scientific and medical expertise



—that enables patient associations to make patients’ concerns understandable to researchers, practitioners, and decision-makers. In this second section, we have shed light on a related, though slightly different process by observing how patient associations enroll specialists in networks that they actively help coordinate and sustain, and turn them into concerned allies who produce new forms of expertise in close collaboration with patients’ representatives. Several characteristics of this latter process are notable.

First, patient associations identify and familiarize themselves with the networks of scientists and clinicians who are studying and treating their diseases, read their contributions, and make strategic decisions about whom to involve in their epistemic communities. Because of the fragmented nature of expertise and the conflicts that may traverse scientific and medical communities, patient associations have to make strategic decisions on whom they want to ally with. As the former president of the AFM once told us: “Scientists are not friends. They are allies we carefully select according to our own objectives.” The AFM is not a unique example, though. Stuart Blume’s (2010) groundbreaking work on deaf communities reveals that deaf people made the decision not to ally with the medical milieu which promoted cochlear implantation as a solution to deafness, not only because they consider that evidence on the improvement of quality of life with cochlear implantation is disputable, but also—and most importantly—because they considered deafness to be a non-negotiable element of their collective identity. Instead, they turned to sociolinguistics, which demonstrates that sign language is a language in and of itself that constitutes the very core of deaf culture. Groups like DingDingDong or the deaf community are sometimes portrayed as “anti-scientific.” Our analysis brings a different perspective: they do not reject Science (with a capital S); rather, they select scientific disciplines and perspectives that resonate with their expectations and thus shape specific forms of expertise. Even in the case of the “anti-vaccination movement,” scholars show that this “movement”, as a unitary Anti-Science one, is a construction of pro-vaccination groups (Blume 2006, Ward 2016, Ward et al. 2019) which do not reject vaccination altogether but rather question the undesirable side effects of vaccination and its individual and collective benefits. That lay discourses may either oppose scientific rationality or develop pseudo-scientific arguments is certainly worth being empirically documented: what exactly is this scientific rationality that some lay people contest, and what are those pseudo-scientific arguments they supposedly put together? These questions are core to standard STS inquiries. Our empirical investigation suggests that formal patient associations have learned that science is diverse, that scientific evidence is not self-evident, and that credentialed expertise is a delicate balance between scientific facts and political orientations whose relevance is constitutively open to scrutiny.

Second, activities involved in the shaping and maintenance of epistemic communities rely upon a range of instruments that contribute to the organization of academic realms, such as scientific conferences, calls for research projects, scientific and medical committees, and biomedical platforms. However, many associations have learned not to leave the governance of these instruments up to the scientists. For instance, they position themselves as (co-)organizers of scientific workshops, selecting the speakers and delineating the issues to be addressed, and the same goes for calls for research projects. Many patient associations today also have scientific and/or medical committees which they mobilize in advisory, rather than decision-making roles, thus limiting their power. As illustrated by numerous examples (Larédo *et al.* 1996; Rabeharisoa and Callon 1999a), the tensions that emerge as a result relate to a

larger question about the status and role of scientific experts. Finally, patient associations are becoming increasingly involved in the management of biomedical platforms and infrastructures; some associations even own collections of biological samples, as is the case of the AFM, which has created its own DNA bank. Such infrastructures constitute specific assets that cement the epistemic communities formed by patient associations.

Third, the constitution of such epistemic communities often entails mutual learning between patients and credentialed experts. It manifests through the publication of “white papers” on diseases and consequences, co-written by concerned people and professionals, and even the publication of co-written articles in academic journals: for instance, C. Gétin, the president of HyperSupers published an article in *European Psychiatry* together with a psychiatrist; Y. Caillé, the president of Renaloo - an association concerned with kidney disease - co-signed an article with sociologists in *Population*<sup>7</sup>. Mutual learning entails a process through which experiential knowledge and scientific and medical knowledge intermingle, and which transforms patients’ experiences and identities. For example, certain people with Asperger syndrome nourish their lived experiences by learning neuroscientific facts about the plasticity of the brain, and eventually self-describe not as patients, but as “neuro-diverse” individuals (Chamak 2008). We thus can say that patient-centered epistemic communities partake not only in a politics of knowledge, but also in an identity politics (Epstein 1987), with transformative effects on patienthood that may well be unexpected.

## Lay expertise in action: patient associations’ reshaping of health issues

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In the previous two sections, we have examined how patient associations engage in the production of experiential knowledge, and in the discussion of this knowledge within the epistemic communities they assemble to address patients’ problems. It shows that knowledges, including experiential knowledges, are not existing resources that patient associations merely mobilize to ground pre-given causes, but a set of statements that patient associations elaborate with the goal of proposing and testing definitions of conditions and consequences that suit them, and shaping solutions they deem appropriate. In previous work, we suggested calling this entire process “evidence-based activism” (Rabeharisoa et al. 2014).

To discover solutions, patient associations must confront institutional actors and policymakers. In recent years, a number of European countries have promulgated legislation mandating patient representation on institutional committees in the fields of medicine and health, such as France’s 2002 Act on Health Democracy. In this section, we explore how

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<sup>7</sup> Lecendreux, M., Gétin, C. and Keddad, K. (2011) P01-318 - Family healthcare and ADHD in France, *European Psychiatry*. **26**,320.; Baudelot, C., Caillé, Y., Godechot, O. and Mercier, S. (2016) Maladies rénales et inégalités sociales d’accès à la greffe en France, *Population*. Vol. **71**, 1, 23–51.

patient organizations navigate institutional arenas and give shape to health issues that are sometimes unexpected.

### The conjoint texturing of lay expertise and unfolding of unexpected novel health issues

The case of Renaloo offers an example of how a completely new framing of health issues emerges jointly with the production of lay expertise.. This patient association originated from exchanges on a forum created by a young woman blogger who was narrating her life with kidney disease and describing the benefits of a transplanted kidney she had received from her mother. From the outset, patients' experiences were core to Renaloo's mode of action.

Soon after its creation, Renaloo organized the "Etats Généraux du Rein," a large meeting where patients were asked to collectively produce a description of their situation. Using data from a large survey on patients' quality of life, Renaloo showed that transplant recipients live higher quality lives than patients on dialysis; the survey revealed, for example, that 50 percent of transplant recipients have access to the job market, compared to just 18 percent of patients on dialysis. The survey also revealed that access to kidney transplantation in France is lower than in other European countries and demonstrated that in the long run, transplantation is significantly cheaper than dialysis. This observation led to an investigation into the possible causes of poor access to transplantation in France and the means to increase it. The investigation showed that one major explanation was the paucity of living donors, which prompted Renaloo to fight for improved access to information about transplantation and for the law to be modified to extend the circle of potential donors beyond close family members to friends. As a result, the number of living donor transplants increased by 60% between 2012 and 2016, and comprised 16% of all transplants in 2016, compared to just 11% in 2012.

Another unexpected finding of Renaloo's survey was that people with poor educational backgrounds are less likely to benefit from a transplant. This observation triggered heated debates in the media. A close examination revealed the complexity of the issue. Because of their living conditions, disadvantaged people tend to develop cardiovascular diseases, diabetes, or obesity, which are associated with kidney disease and which are contraindications to transplantation; moreover, educated people have much easier access to the "right" interlocutors, who may advise them on the best options. The case of Renaloo illustrates how patient associations reveal unexpected problems and reflect on underlying causes while collecting facts and figures through independent inquiry. They then use this evidence to justify adding those problems to the political agenda and to develop appropriate solutions.

### Exploring medico-administrative categories and confronting health authorities using their own logic

Reshaping health issues they deem important sometimes requires that patient associations extend their expertise into domains alien to the core concerns of patients and their relatives. The case of VLM, the French association dedicated to fighting cystic fibrosis, studied by Pierre-André Juven (in press), is one case in point. VLM played a pioneering role in the creation of referral centers for cystic fibrosis in the 1970s, decades before similar centers were

established for other rare diseases in France. However, the very existence of these centers has been threatened by recent changes to the tariff system that regulates the budget allocated by the French public health insurance fund to public and private hospitals. The tariff system is based on the average cost of care for patients with a given disease or condition; for each patient, hospitals receive an amount of money corresponding to this average cost. For hospital budgets to be balanced, this amount of money must cover all aspects of care provided to patients.

VLM noticed that the referral centers for cystic fibrosis showed a big deficit and suspected that the tariff for patients suffering from this disease was based on an inaccurate appraisal of the care activities performed by the centers. With the help of a retired researcher in management studies, the association began to collect extensive data on the range of activities performed by the referral centers. They discovered that some activities performed with patients, such as therapeutic education, had not been taken into consideration by health authorities. The same goes for a series of activities performed when patients were not present, such as coordinating personalized home care. Altogether, these activities, which VLM considered essential for patients and their families, yet were not accounted for by the tariff, represented 62% of the time spent by professionals. This analysis opened a new space for negotiation and debate between VLM and the French health authorities, which were reluctant to revise the tariff for cystic fibrosis because they feared a snowball effect for other rare conditions.<sup>8</sup>

Interestingly, VLM developed a strategy perpendicular to the one adopted by other opponents of the French hospital tariff. Indeed, for many years, professionals as well as citizens have contested this tariff, mainly from an ideological point of view, denouncing the commodification of health or the perversion of the logic of care by an accounting logic. Rather than engaging in these debates, VLM instead chose to become a “super-expert” and to confront public authorities using their own logic.

### Ongoing inquiry and the accumulation of small changes in the shaping of health issues

The previous examples might lead one to think that for patient associations, reshaping the list of issues that they deem important to address, or at least putting certain questions onto the political agenda, is merely a matter of producing the relevant evidence and choosing the right strategy. Such a view contradicts the usual skepticism about the influential power of patient associations: health systems are often depicted as ocean liners with trajectories that are extremely difficult to modify; in this context, the interventions of patient associations are seen as ineffective at best; at worst, they are seen as legitimizing decisions made by public authorities with merely a semblance of democracy. Through another example concerning the main French organization dedicated to childbirth issues, we illustrate how the accumulation of small changes may eventually modify the trajectory of health and medical systems.

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<sup>8</sup> When Pierre-André Juven did his fieldwork, negotiations were still underway between VLM and the French public health insurance fund.

In 2004, CIANE was invited to review guidelines on the prevention of postpartum hemorrhage. The guidelines were developed to incorporate recent research findings and to promote the practice of injecting oxytocin into mothers immediately after delivery to provoke strong uterine contractions that close the blood vessels. CIANE criticized the way “prevention” was defined in the guidelines, which restricted it to drug administration and did not consider other factors that contribute to postpartum hemorrhage. France is a particular case, as the proportion of maternal deaths due to hemorrhage is significantly higher than in other countries. At the same time, the proportion of women receiving oxytocin to accelerate labor is also very high. CIANE was especially concerned by this medical intervention, for it appears to have important effects on labor by increasing pain and leading to medicalization that does not fit all women’s aspirations: once oxytocin is administered, women often need epidural analgesia and more careful monitoring. Putting these two facts together, CIANE began to wonder whether the administration of oxytocin during labor could increase postpartum hemorrhage, their intuition being that the drug might saturate receptors that inhibit the natural release of oxytocin after birth. They eventually obtained funding for a research project on this topic, which concluded in 2011; evidence revealed that CIANE’s intuition had been correct.

In 2014, following its strategy of initiating collective discussion about all issues related to obstetrical practices, CIANE proposed that the French High Authority of Health (Haute Autorité de Santé, HAS) should develop guidelines for “normal/non-pathological childbirth.” In December 2017, the published guidelines clearly state that: “It is recommended not to administer oxytocin in the absence of stagnation of dilatation, even if the frequency of uterine contractions is less than three per ten minutes,” and that the use of oxytocin must be restricted to specific clinical situations and moments during the birth process. These guidelines have accompanied tangible changes to previous practices: in 2010, nearly two-thirds of women had oxytocin injections, a figure that dropped to 52.5% in 2016. Between the 2004 guidelines and the 2017 ones, numerous related events occurred, some initiated by CIANE, that collectively contributed to the decrease in the use of oxytocin before the 2017 guidelines were released. It is thus fair to say that these guidelines were the collective result of intersecting events; the changes are not solely the result of CIANE’s actions. That said, CIANE, like many patient associations, made a specific contribution to the changes by translating people’s concerns into terms that were understandable to the actors it wanted to convince and mobilize. Ultimately, some cumulative transformations resulted from this lengthy and non-linear process involving multiple actors.

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Today, patient associations are broadly recognized as stakeholders in the governance of health policies. The cases we have presented enable us to flesh out what it takes and means for patient associations to fulfill this role.

First, patient associations embrace this role by deciding which issues are relevant to address and setting priorities that differ from those of the institutional actors typically involved in health policymaking activities. Being atypical experts gives patient associations an advantage in terms of innovativeness (Hounshell 1975); their unique perspective enables them to

question facts and routines that are taken for granted, deviate from established frameworks and make new connections. Patient associations are not content to echo patients' complaints or claims and wait for others to propose solutions; they actively identify issues and help formulate solutions by articulating experiential knowledge in the language of credentialed experts and policymakers. Although this "invasion" of others' territory does not occur without friction, it can also produce changes.

Second, converting a patient-centered perspective into elements that can influence policymaking requires the production of evidence: in areas other than health, influence can be exerted by other means, such as demonstrations, but in domains with strongly constituted expertise, and which concern specific categories of the population, the building of counter-expertise is critical. To do so, patient associations must familiarize themselves with the functioning and parlance of institutions to identify the right interlocutors and knock on the right doors; this know-how is not documented in textbooks; it is acquired through a long process of learning by doing.

Third, the capacity of patient associations to bring about change is facilitated by the existence of procedures that accommodate patient expression: without the 2002 Act on Health Democracy, which mandates the presence of patient representatives on institutional committees, French patient associations probably would have been less influential. Very often though, their influence is not immediate, nor does it result in major paradigmatic changes; instead, they tend to adopt a light-touch approach that leads to incremental changes over time that progressively open a space of possibilities.

## Towards an institutionalization of patients' expertise... but which expertise?

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HIV/AIDS activist groups, as well as rare disease patient associations, have greatly contributed to the public recognition of patients as stakeholders in health-related policies. In France, for example, the Téléthon (the TV fundraising initiative launched by the AFM in 1987) solidified the AFM's public identity as an organization governed by patients and serving patients, and yet capable of managing big research programs. Such a public identity sharply contrasts with charities devoted to research support and led by researchers that prevailed before the creation of patient associations like the AFM. The French association AIDES, which is concerned with issues related to HIV/AIDS, built an improbable partnership with an umbrella organization of family associations; in 1996, it formed a national collective of patient and user associations, the Collectif Interassociatif sur la Santé (CISS), which had a dozen members at its inception (Lascoumes and Bouchard 2017). The CISS was a pioneer in the promotion of patient associations' participation in the governance of health; in fact, the 2002 French Act on Health Democracy was a direct outcome of its relentless political mobilization. In many other countries, the role of patient associations is acknowledged, although within different organizational and legal frameworks (Baggott and Forster 2008; Keizer and Bless 2010).

By and large, there is agreement that involving patients in all aspects of medical and health policies may improve the quality of services provided by healthcare systems and strengthen democracy in the process. The notions that care should be centered on patients, and that their needs, expectations, preferences, and real-life conditions should be taken into consideration, have become indisputable. In addition, some actors argue that the experiential knowledge of those directly affected by a disease or a health problem may help prevent unnecessary medical examinations and treatments (as well as irrelevant research projects), thereby enabling better care and reducing healthcare costs to render health systems more sustainable.

This general trend toward the valuation of patients' perspectives manifests not only in the increasing role of patient associations in the governance of health issues, but also in the proliferation of initiatives being implemented in a variety of institutions. In what follows, we offer a few examples of these initiatives: we want to argue that the definition of lay expertise and the role of lay experts are at stake in these initiatives, but are not really discussed. We are still in a relative state of confusion where, depending on the case, lay expertise refers either to experiential knowledge or to scientific knowledge, can be the property of individuals, the result of the aggregation of individual experiences, or the outcome of a collective reflection. This confusion has political implications we want to highlight.

In countries like Canada and France, the recent development of the "patient-as-partner approach" (Karazivan *et al.* 2015) is one of those initiatives: at the University of Montréal, for instance, patients are recruited as staff members and contribute to the health sciences curriculum; they also participate as members of health care teams and co-researchers in research programs. Some French universities develop special training programs for patients who are willing to be acknowledged as "expert patients," either as patient representatives on health committees or as instructors in patient therapeutic education programs. All such initiatives are rooted in the ideas that patients have expert knowledge of their experiences, and that their expertise is highly valuable when it comes to developing a truly patient-centered approach to care. Very often, though not always, these expert patients are members of patient associations. That said, the very term "expert patient" places the focus on the individual expertise of the patient rather than the collective expertise that s/he may have gained as a member of a patient association.

Other initiatives relate to the rapid development of patient reported data and of outcome measures based upon these data (Greenhalgh 2008; Refolo *et al.* 2012). Interestingly, some initiatives originated in non profit organizations, as illustrated by the creation of the Patient Centered Outcome Research Institute (PCORI), an American funding institution that has already spent US \$2 billion in 2018 (Frank *et al.* 2014). Other initiatives were taken in the private sector, especially through the creation of platforms such as CureTogether or PatientsLikeMe (PLM), and more recently, the Open Research Exchange platform, described by PLM, its founder, as the "first Open-Participation Research Platform for Patient-Centered Health Outcome Measures." The main objectives of these platforms are to measure the quality of care in ways that are "relevant and meaningful to patients" and "to help patients, caregivers, clinicians, employers, insurers, and policy makers make better-informed health decisions." They do so

by developing questionnaires on patients' health status, feelings about their diseases, impacts of treatments on their lives, and the things in life that they value most and are eager to preserve. Typically, free expression is not accommodated, the objective being to offer researchers "robust tools" that they can exploit and use in a variety of contexts. In this case, professionals and researchers produce expertise about patients' experiences by pre-shaping experiences in order to produce data they can aggregate and interpret. The professionals and researchers remain the experts, whereas patients are data providers. Once this expertise is produced, it is shared with patients and professionals to help them make care-related decisions.

Scientific institutions also are receptive to the notion of the "expert patient." In 2003, INSERM, the main French institution dedicated to health research, launched a working group composed of representatives of patient associations and INSERM researchers with the goal of strengthening partnerships. In 2013, *BMJ*, a leading medical journal, launched a "patient revolution" (Richards *et al.* 2013; Richards and Godlee 2014) by taking a series of actions such as asking authors of research papers to document how they involved patients in the research process, asking patients to review articles, and inviting patients and patient advocates to join the editorial board and even to write articles. In 2015, *Research Involvement and Engagement (RIE)*, a journal entirely devoted to analyzing patient involvement in all types of research, was launched. Despite apparent similarities, *BMJ* and *RIE* rely on two different patient participation models. *BMJ* seeks to engage patients as experts of experience; these patients must be talented individuals, although they need not possess health sciences knowledge. In contrast, many researchers who publish in *RIE* favor a statistical model of representation and emphasize the need to gather samples that represent the diversity of the targeted population, thereby mediating lay expertise through research methodologies and analytical frameworks.

These diverse initiatives reveal two main trends related to the institutionalization of patients' participation. First, when institutions call upon "expert patients," they sometimes refer to representatives of patient associations, but more often to individual patients. Second, and consequently, institutional conceptions of "expert patients" result in multiple appraisals of lay expertise, even though lay expertise is said to relate to patients' experiences. In some cases, the production of knowledge and expertise remains in the domain of competences and prerogatives of researchers, with patients being considered only as data providers; this vision is associated with a statistical conception of representational capacity. In other cases, individual patients are supposed to be able to transform their experiential knowledge into expertise that is useful to specific communities (policymakers, health professionals, students, etc.), which could be considered as a "symbolic" form of representativeness. In yet other cases, "expert patients" are members of patient associations, which entails a political conception of representativeness: their expertise, rooted in their individual



experiences as much as the collective elaboration of issues by the patient associations they belong to, is what makes them patient representatives.

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To conclude, the notion of the “expert patient” is not expanded without potential backlash; as the saying goes, the road to hell is paved with good intentions. Each format of representation may have its own advantages and bring interesting data to the discussion; but when it comes to the fabrication of expertise, privileging individual patients over patients who are members of patient associations introduces the risk of undermining the work accomplished by those associations, and reintroducing medical paternalism by excluding from the public debate the experiential knowledge and expertise elaborated by groups of concerned people.

This is especially pernicious, as a common justification for dismissing patient associations is that they are groups of activists who are “militant” and lack “scientific objectivity” (Blease et al. 2018). Such an argument misses the point that all knowledge and expertise, including scientific knowledge and expertise, are situated (Haraway 1988), meaning that they are the product of highly political perspectives on the “relevant” questions to be tackled and the “appropriate” factors and “legitimate” actors to be taken into consideration—in other words, the framing of issues that are deemed important at the individual and collective levels. By re-evaluating existing framings from their own perspectives, patient associations renew the fabrics of and debates on issues of collective concern: the role of oxytocin in postpartum hemorrhage, the definition of endpoints in clinical trials of nitisinone for alkaptonuria, or of what it entails to organize care for cystic fibrosis patients would probably not have been studied and discussed without the intervention of patient associations. It is this potentiality that the institutionalization of the “expert patient” may threaten in the long run: there is a wide gap between expertise as the property of one knowledgeable and experienced individual, and expertise as the collective capacity to articulate policy recommendations drawing upon a variety of knowledges and experiences; any initiative that considers concerned people as data providers and places the elaboration of recommendations in the hands of professionals widens that gap and strongly bends the notion of “lay expertise” that we have highlighted in the previous examples.

## Conclusion

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In this paper, we have sought to present empirical observations and analyses of lay expertise and a constellation of notions—such as the “expert patient,” “patient participation,” the “patient-as-partner approach,” and “multi-stakeholder governance”—that have become part of the vocabulary of medical researchers and health institutions. In the footsteps of Steven Epstein, we have shown how lay expertise is a political concept that captures a form of patient activism grounded in

patient associations' involvement in the production and confrontation of experiential knowledge with scientific and medical knowledge (section 1), the building of epistemic communities assembled around patients' concerns (section 2), and the (re)shaping of issues that patient associations deem relevant and legitimate to address to best help patients (section 3). In addition, we have reflected on how lay expertise is mobilized in today's institutional settings and is sometimes reconfigured therein (section 4). Moreover, we have emphasized the multiplicity of lay expertise and the complex paths it follows to enter policymaking arenas.

At this point, one may wonder about the extent to which what we described in our examples is specific to the French context or even to the small bunch of studied cases. Surveys we conducted in 2006 and 2010 (Rabeharisoa *et al.*, 2008, 2011) on, respectively, 215 and 293 patient associations revealed that most of them invest quite a lot of energy in explaining and disseminating medical knowledge, in organizing conferences, and in supporting research in various ways. Contemporary patient associations do not consider that they should restrict their prerogatives to mutual aid; quite the contrary. Part of the empirical material we relied on had been produced in the context of a European project which revealed very similar phenomena in different countries (Akrich *et al.* 2012). Let us recall that the articulation of experiential knowledge with scientific knowledge has also been central in environmental health movements (Akrich *et al.* 2010, Allen 2004, Brown 1997, McCormick *et al.* 2003), emergent diseases (Arksey 1994, Dumit 2006, Lorient 2003), and at the intersection of the two (Capek 2000, Kroll-Smith *et al.* 2000).

Another concern related to the issue of generalization is that we may have missed cases where patient activism merely contributes to the medicalization or biologization of certain problems, and that certain patient groups use the language of biomedicine only to push forward some claims that are contested by health professionals (Barker 2008, Barthe *et al.* 2010, Conrad 2005, Fair 2010, Graham 2007, Spandler 2018). If this phenomenon is indisputable, medicalization/biologization is not a wrong in and of itself when patient associations have to fight to get their diseases recognized by biomedical practitioners and by health authorities, and to enroll them in the war on diseases. In doing so, some patient associations may succeed in transforming something rooted in people's experience into an object of inquiry and eventually into a medical concept, whereas others may fail. In this paper, we reported on patient associations which eventually managed to demonstrate the soundness of their expertise and propositions, often after long and tense discussions with professionals. If one were to sort out successes and failures, however, one should remember the principle of symmetry put to the fore by early sociologists of science (Bloor 1976): the success or the failure of a scientific proposition should be analyzed with the same kind of arguments. There is no criteria for setting apart successes from failures *a priori*, and that should be considered as the normal functioning of a form of scientific democracy.

This raises an additional question about the conditions that favor the development of lay expertise, the role of contexts in the integration of lay expertise into the making of health policies, and the global impacts of patient participation on the governance of health. At the very least, we may say that lay expertise requires an atmosphere of democracy to blossom and consolidate, and that it certainly impacts the democratization of health in a variety of ways. That said, there is no grand narrative to unveil here. Rather, what we have witnessed are complex dynamics at the intersection of a variety of initiatives and events with transformative effects on the politics of knowledge and the politics of care that are continually debated and developed. Amongst the most debated, three warrant further investigation.

The first topic is the alleged destabilization of scientific communities due to the increasing role of patient associations in the orientation, financial support, and monitoring of research programs. At stake here is a fundamental disagreement about whether researchers should collaborate with patient associations. A recent survey conducted by the working group formed by INSERM (the French institution dedicated to health research) composed of representatives of patient associations and researchers shows that scientists and clinicians who have collaborated with patient associations have progressively conformed their research interests to patients' concerns, which other scientists consider to be a breach of the academic ethos and quest for objectivity.

We think that it would be interesting to explore the scope of this phenomenon and to figure out whether it brings about novel orderings of scientific communities and trajectories. Such an exploration would extend analyses of what Callon *et al.* (2009) called "technical democracy," e.g. the ongoing reshuffling of the modes of production of knowledge as a democratic imperative.

The second topic relates to issues of justice. Notably, HIV/AIDS, rare diseases, Alzheimer's disease, autism, and cancers rank at the top of the list of conditions that benefit from patient activism. Such activism has influenced medical research and health policies on those conditions in many countries in Western Europe and North America. This raises questions about uneven access to public resources among patients with different diseases and health conditions due to the power of certain patient associations. These questions are being addressed not only by academics (Best 2012; Dresser 2001), but also by certain patient associations: some worry that certain collective interests may supersede others, and eventually threaten the democratic outreach of patient activism.

This issue warrants inquiries into how patient associations, though clearly and legitimately self-centered organizations, contribute knowledge, questions, ideas, and solutions that may benefit others. Some patient associations claim that achievements related to their diseases may help other patient associations; for instance, rare disease

patient associations often say that rare diseases may serve as “disease models” that can be used to study and combat common diseases with similar characteristics. But what it means to be a “disease model,” not only from a scientific point of view, but also from a social point of view, remains an open question. We may also look at umbrella organizations within which different patient associations coalesce, with an aim of achieving broader impact. More importantly, it would be interesting to explore how the politics of singularization that support the production of experiential knowledge and lay expertise may transform the traditional politics of numbers largely based on statistical reasoning, i.e. the logic on which public policies are grounded.

The third topic that might be worth exploring is the circulation of certain models of patient activism developed mainly in Western Europe and North America to other regions of the world. Studies on transnational activism show how coalitions of patient associations or activist groups engage in the production and/or discussion of knowledge and expertise in different condition-areas (Krikorian 2017; Rabeharisoa and O’Donovan 2014). It might be interesting to extend studies on how these coalitions situate themselves vis-à-vis large non-governmental and philanthropic organizations which are particularly active in certain regions, and how these coalitions give shape to expertise drawn on concerned people’s experiences (if they do). There is much to learn from global health studies, with significant opportunities to extend them by looking at certain regions of the world where multiple international institutions and private foundations take hold and introduce their own modes of action that may contradict groups of concerned people and even prevent them from organizing in a meaningful way.

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