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The entanglement of scientific and political claims:  
towards a new form of patients' activism

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# The entanglement of scientific and political claims: towards a new form of patients' activism

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## **Abstract**

Drawing on fieldwork in four condition areas (rare diseases, childbirth, Attention Deficit Hyperactivity Disorder, and Alzheimer's disease), this article shows that patients' organizations' (POs) engagement with knowledge is neither limited to a set of diseases nor restricted to biomedical knowledge. Their work on and with academic and experiential knowledge contributes to an understanding of their conditions and the problems they induce, and to the shaping of the causes they defend. This results in the production of new evidence for grounding research and health policies in their condition areas. The authors propose the notion of "evidence-based activism" to capture the centrality of knowledge activities in contemporary POs.

## **Keywords**

Patients' organizations, health activism, evidence-based activism, healthcare policy, ADHD, Alzheimer, rare diseases, childbirth

## INTRODUCTION

Over the past decades, social scientists have extensively studied the involvement of patients' organizations in biomedical research as illustrative of the upsurge of lay expertise and of the democratization of science and technology (see for instance Brown et al., 2004; Epstein, 1995; Rabeharisoa & Callon, 1999). Biomedical research however is not the only research area in which patients' organizations invest. Blume's (2009) investigation of deaf communities offers a seminal example: he shows that rather than embracing a biomedical framing of, and "solutions" to deafness, these communities turn to socio-linguistics with a view to assert sign language as a language on its own right, and as the pivotal ingredient of deaf culture. His and other studies suggest that patients' organizations and groups of activists' engagement with certain bodies of knowledge should be examined in light of the causes they defend. This article pursues this line of reflection: it looks at how patients' organizations and groups of activists relate issues of knowledge to their politics of illness, and how this (potentially) impacts on the structuring of research policies on their conditions.

We draw on fieldwork we undertook in four condition areas, namely rare diseases, ADHD (Attention Deficit Hyperactivity Disorder) and childbirth in France, and Alzheimer's disease in Ireland. Considering these four condition areas was motivated by concerned patients' organizations and groups of activists' contrasted positioning vis-à-vis biomedical research. French rare diseases patients' organizations massively engage with biomedical research to foster the development of cures, whereas the French group of parents of children with ADHD considers biomedical knowledge as one body of knowledge amongst many others pursued for a better understanding of the disorder. The French group of childbirth activists enters into the black box of medical evidence on certain birth practices to point to their limits and reveal their shadow zones, whereas the Alzheimer Society of Ireland mobilizes social sciences methodologies for expressing patients' views and reflecting on patient-centered care.

How to make sense of the variety of knowledge, and of knowledge-related activities undertaken by the patients' organizations and groups of activists mentioned above? One may argue that the conditions at stake and the national contexts play a determinant role. We take a different stance here. Rather than positing conditions and national contexts as givens, we look at how these groups problematize their conditions and picture the network of expertise and issues they deem relevant to target. Indeed, our fieldwork suggests that clarifying what their conditions are, what they are the cause of, and what issues should be addressed at an individual and a collective level, constitutes the main preoccupation of these groups. This implies a radically different view on knowledge for these groups and for the social scientists who study them: rather than contemplating knowledge as a mere resource "out there" which patients' organizations and groups of activists rely upon for defending their causes, knowledge (and what counts as such), should be considered as "something" to be produced and discussed. This article shows that patients' organizations and groups of activists collect and format concerned people' experiences to document what it is to have/live with their conditions. They simultaneously identify pieces of academic knowledge on their conditions, and weight it up against their "experiential knowledge" (Arksey, 1994; Borkman, 1976). This work on

and with academic and experiential knowledge contributes to sorting out, ordering, and articulating an understanding of their conditions and the problems they induce, for themselves and for specialists. This reconfigures the epistemic network they make themselves part and parcel of, and results in politics of knowledge that eventually transforms the modalities of research, and in the production of new evidence for grounding health policies in their condition areas. This is the reason why we suggest calling this form of patients' activism: "evidence-based activism" (Rabeharisoa, Moreira & Akrich, 2013).

The following sections of this article document and analyze these groups' "evidence-based activism", and the compound dynamic interplay between politics of illness and politics of knowledge it entails in the four condition areas we studied. Section 1 looks at French rare diseases patients' organizations' engagement with biomedical research. Thanks to a better understanding of their bio-clinical profiles and improved care strategies, patients now experience the extension of their life expectancy and a series of problems similar to those with which patients with chronic illnesses are familiar. So much so that these organizations now embrace a diversified range of knowledge, and promote their articulation via interlinked platforms associating biologists, clinicians, health professionals and patients' groups. Section 2 on ADHD looks at how HyperSupers, the French group of parents, strives to make sense of their experience of the complex, variable and individual manifestations of the disorder, and to articulate a multidisciplinary network of expertise associating neuroscientists, geneticists, behavioral scientists, child psychiatrists, psychologists, educational scientists, and pharmacologists, on this confrontational condition. In doing so, the group intends to connect different scientific communities around ADHD, which so far keep apart from each other. Departing from the classic picturing of childbirth activism as a feminist movement seeking to de-medicalize childbirth practices, Section 3 focuses on the strikingly intense and enduring effort of the CIANE, the French group of childbirth activists, in the critical reading of medical evidence on certain birth practices, and its confrontation to women's experiences they draw on a series of surveys. This highly sophisticated work on and with various species of figures and statistics questions medical evidence from the inside, as much as it challenges, from the outside, the range of relevant evidence on what "normal birth" should be. Section 4 looks at how the Alzheimer Society of Ireland reflect on the relevance of social sciences methodologies for collecting and expressing the views of people with dementia, and for putting them center-stage in the provision of services. Rather than simply mobilizing these methodologies, the organization's involvement in mutually informing politics of illness, politics of knowledge and politics of identity has required it to renew them.

Reflecting on the similarities and differences between the four condition areas we explored, the concluding section offers a few thoughts on whether the intervention of patients' organizations and groups of activists in the fabrics of knowledge entails a process of co-optation and institutionalization of patients' activism. Does "evidence-based activism" put patients' organizations and groups of activists at risk of losing sight of their identity and oppositional power? Though we should avoid romanticizing "evidence-based activism", our analysis suggests that it brings in uncertainties on what exactly relevant and legitimate evidence is, and therefore introduces a form of collective reflexivity on the shaping of research policies.

## THE DUAL DYNAMICS OF RESEARCH AND ISSUES: THE TRANSFORMATION OF RARE DISEASES ACTIVISM

On the two sides of the Atlantic, patients' activism in the area of rare diseases was originally motivated by the absence of cures for these lethal conditions (Asbury 1985; Brewer 1983; Crompton 2007; Huyard 2011/2). In France, the AFM (*Association Française contre les Myopathies* – French Association against Myopathies), created in 1958 by a few parents of children with Duchenne de Boulogne dystrophy, has played a prominent role in relating this deficiency of the drug market to specialists' ignorance and lack of interest in these diseases because of their rareness, and to the need for patients' and parents' groups to actively engage with biomedical research. Aimed at “knowing the enemy [the disease] for combating it”, as the former President of the AFM phrased the cause of the association, it articulates “therapeutic activism” (Epstein 1995) to “biomedical activism”. Since the mid-1980s, the AFM has established partnerships with the biomedical community (Rabeharisoa 2003). In the absence of a robust corpus of credentialed knowledge on neuromuscular diseases, the AFM has introduced families' experiences to biomedical practitioners with a view to start and sustain the research process (Rabeharisoa & Callon 2004). It has provided financial support to research teams, and has participated in the orientation of research policies on neuromuscular and other rare diseases in France through its annual call for research projects (Rabeharisoa & Callon 1999).

The model of engagement with biomedical research that the AFM has promoted has been adopted and adapted by a number of French rare disease patients' organizations. Drawing on interviews and ethnographic observations of twelve French rare diseases patients' organizations, all created after the AFM and contrasted in terms of their size, the nature and prevalence of their diseases, their resources and organizational features, we observed that even though these groups do not intervene directly in the definition and conduct of research activities as the AFM does, they nevertheless establish dialogue with researchers, scrutinize research hypothesis and findings, and circulate them to families and medical and health professionals. When asked about their motives for such an intensive acquisition and dissemination of scientific knowledge and enduring relationships with the biomedical community, they mention a series of interlinked problems which, according to patients and families, continue to hinder the “war on rare diseases”: the scarcity of information available on these conditions, the low numbers of clinicians who can accurately diagnose their diseases and provide care to patients, the complexity of rare diseases and the need for longstanding investments in research, and the need to ensure that research teams they ally with explore the topics they deem important for a better understanding of their pathologies. As patients' representatives we interviewed suggested, “war on diseases” is a multifaceted endeavor, implying a complex investigation for deciphering the diseases at stake and the problems they come with, including those resulting from the perceived deficiencies of the market, the research system and the medical and health institutions when facing rare diseases. This problematization of rare diseases has multiple and interrelated consequences on the research policies and politics of knowledge in this area. Two of them are particularly worth being highlighted.

Firstly, for a number of rare diseases, the dialogue between patients' organizations and specialists, though sometimes confrontational, gives shape to epistemic communities

gathering patients, researchers and clinicians around the collective exploration of diseases, and within which experiential knowledge and academic knowledge constitutes a seamless web of knowledge. One remarkable feature of these communities is that their contours, as well as their epistemic focus, progressively evolve alongside the knowledge, problems and issues brought in by the different parties. To take but one example, *SolHand Solidarité Handicap – Autour des Maladies Rares* (Association on rare disabilities and diseases), formed in 2008, brings to the fore questions that its chairwoman qualifies as “medico-social” and on which no research has as yet been undertaken. The formulation of these questions is partly enabled by the efforts that have been devoted to biological and clinical research. The results obtained have had the effect not of healing patients (cure remains rare), but of gradually adjusting the care they receive. The natural history of rare diseases has thus been altered. Some of them became chronic illnesses that generated unexpected problems, on the fringes of biomedicine. That is why *SolHand* claims for the need to mobilize rehabilitation therapists and researchers in human and social sciences in the production of knowledge focused on solutions to problems that patients encounter in their daily lives, such as chronic pain, fatigue, depression, disability, or inclusion in the job market.

Interestingly, this articulation of biomedical research to the production of knowledge on families’ day-to-day preoccupations and the adjustment of care practices now stands at the core of research and public policies on rare diseases. In 2000, patients’ organizations decided to coalesce within the French Alliance on Rare Diseases and asked for the creation of centers of reference for diagnosis and care in various regions of France. This resulted in the launching of a National Plan for Rare Diseases by the French government in 2004, and the creation and support to centers of reference which propose multidisciplinary consultations and assemble researchers, clinicians, and care professionals, for ensuring the continuity from research to the clinic, from diagnosis to treatments, social care, and information to patients and families. How exactly this articulation between biomedical research and healthcare is performed, and to what extent patients’ organizations act as full-fledged stakeholders in the functioning of these centers, remain to be explored. Suffice here to say that these centers design innovative platforms for research and care policies, within which a variety of academic and experiential knowledge and know-how are supposed to mutually nurture. This also led to the recently formed French Foundation on Rare Diseases, responsible for coordinating research efforts in this condition area, to include a social and human sciences chapter in its activities.

Secondly, the knowledge-related activities undertaken by patients’ organizations profoundly transform the qualification of rare diseases and open discussion on their classification. To take but one example, *Generation 22*, concerned with the 22q11 deletion syndrome, a complex syndrome involving heterogeneous disorders with multiple manifestations, has actively contributed to clarifying the clinical profiles of affected patients. In particular, drawing on families’ observations, it pinned down the high prevalence of schizophrenia in these patients compared to the general population. While French specialists have long been reluctant to consider the extending range of manifestations and co-morbidities of this syndrome, *Génération 22* has recently secured collaboration with a psychiatrics genetics team in Switzerland with an aim to explore the psychiatric disorders that accompany the 22q11 DS. Moreover, the association now



suspects that this syndrome may be less rare than previously estimated, for certain persons with schizophrenia may carry the deletion. By entering into the black box of complex biological pathways and entities that are still to be explored, *Génération 22* contributes, as much as similar organizations do (Navon & Shwed, 2012), in the emergence of an *ad hoc* disease category gathering “developmental disorders and deformity syndromes”, as French specialists provisionally term it.

#### **FIGHTING REDUCTIONNISM: THE POLITICS OF KNOWLEDGE OF AN ADHD GROUP**

Parents of children with ADHD often start to mobilize for fighting the lack of medical recognition of this disorder, and the stigmatization of children as “brats”, notably because of parents’/mothers’ supposedly bad parenting. Indeed, ADHD has long been, and still is a contested condition. Neurobiologists, child psychiatrists and psychologists, to cite but a few specialties, hold different views on the causes and manifestations of this disorder (Rafalovich, 2001). In France, certain child psychiatrists, with a psychodynamics background, even deny the existence of ADHD, arguing that it may “hidden” child or adolescent depression, or even epitomize “normal” child or adolescent evolution. Some of them worry about “over-diagnosis” of ADHD, which, from their point of view, are often “misdiagnosis” (Garcin, 2011). Social scientists have highlighted how biomedical practitioners, the pharmaceutical industry and parent’s groups have promoted a biomedical framing of the disorder for attesting its “reality” against the prevarications of certain credentialed experts. Two phenomena are said to support this biomedicalization of ADHD: brain images which trace the dysfunction of certain neurotransmitters in children with ADHD, and the efficiency of certain medications, namely Ritalin®, on inattentive and/or hyperactive children. This biomedicalization of ADHD raises concerns on the risk of social normalization and control over behaviors considered as non-desirable in performance-oriented societies (Conrad, 2007).

HyperSupers, the French parents’ group on ADHD created in 2002 after the launching of an electronic discussion list, soon realized that biomedicalization is not the one best way for understanding the disorder and caring for their children. Though the group manifests its interest in the neurodevelopmental make-up of ADHD, as attested by a conference it organized on this topic following its 2010 general assembly of families, and is happy with the development of drugs, it tirelessly questions what exactly ADHD is, and how to address the multifaceted problems it induces for the children and their parents. Drawing on parents’ testimonies, which point to the complex, variable and evolving manifestations of the disorder, HyperSupers steps back from any simple causal interpretation of the condition. Not only does it put forward the multi-factorial nature of ADHD, it also casts doubt on the fact that the causes and consequences of the disorder can be easily sorted out. The president of HyperSupers whom we interviewed a number of times insisted that neurodevelopmental, social and psychological aspects of ADHD are interwoven and impact on each other. From the outset, this politics of illness has come hand in hand with the group’s intensive efforts in collecting and articulating a variety of bodies of academic knowledge with an aim to open discussion on the bio-psycho-social framing of the disorder.

HyperSupers’ eclecticism and openness recently translated in its launching of the *Journée Ribot-Dugas*, a one-day annual scientific symposium named after two French

psychologists. What is remarkable with this *Journée* is that despite the reluctance of its scientific committee, HyperSupers has managed to gather specialists from very different backgrounds who are not used to dialogue with each other: neurobiology, cognitive sciences, education sciences, child psychiatry, psychology, pharmacology, epidemiology, and even psychodynamics. Issues as diverse as the neurological mechanisms implied in ADHD, the sleep disorders that sometimes occur, and even the role of Omega 3 fatty acids in alleviating certain “symptoms”, have been put on the scientific agenda. Rather than taking the side of one or the other scientific community, the design of the *Journée* allows HyperSupers to shed light on the complexity and uncertainty of competing scientific understandings of ADHD. For the association, this does not mean that anything goes however: in this and other occasions, the president of HyperSupers regularly calls for further clarification of the hypothesis and methodologies that underlie the research projects undertaken by different scientific communities. HyperSupers’ epistemic efforts have two main effects on the politics of knowledge in this condition area.

Firstly, confronting diverse scientific communities, which more often than not turn a deaf ear to each other, HyperSupers clearly intends to give shape to a multidisciplinary network of expertise and issues on ADHD. Though the association has historically established tight bonds with a few specialists who are sympathetic to its cause, it nevertheless strives to expand the bodies of knowledge it deems relevant to assemble around families’ experiences. It is too soon to tell whether this will renew research policies on ADHD, but one can fairly assume that the association is playing a crucial mediating role in the development of multidisciplinary approaches in this condition area. HyperSupers’ numerous publications provide evidence of the association “shopping around” with concerned people’s experiences as its compass. For example, the “Token economy method” it posted a few years ago on its website, advising parents to reward their children when they are doing well, and to draw their attention to alternative small tasks when they are “going into a spin”, was simultaneously nurtured by parents’ experiences and by psychological theories which show that children with ADHD tend to lose self-esteem because of the constant denigration of their behaviors. This does not prevent parents from considering other “solutions” to other problems posed by ADHD, such as neurofeedback for instance, a type of biofeedback which focuses on the brain and central nervous system: by placing sensors on a person’s head, it provides a display of brain activity, or “brainwaves” that can be monitored and retrained. Though neurofeedback it is not necessarily perceived as an evidence-based therapy by the wider medical community, and is much discussed within the association, it surfaces as one body of knowledge and practices at which the association is taking a close look.

Secondly, one major consequence that HyperSupers expects from its epistemic efforts is the shaping of what it calls a “multimodal cure and care strategy”. As suggested by the examples mentioned above, HyperSupers claims for the assemblage of medications, parenting therapies, educational methods, and even psychotherapies, adjusted to each child’ situation and its evolution. Such a strategy not only translates the association’s politics of illness; it also enacts its politics of knowledge insofar as it implies a continuing exploration and weighting up of the evidence basis of various cure and care practices. Thus, politics of illness, politics of knowledge and politics of care together constitute a

threefold action towards the recognition of ADHD as a complex disorder that cannot be reduced either to the biological, to the social, or to the psychological only.

#### **RAISING ISSUES AND UNPACKING EVIDENCE: THE KNOWLEDGE POLITICS OF A CHILDBIRTH GROUP**

Childbirth activism displays a configuration which contrasts with the conditions we analyzed, as it has often been described as a de-medicalization movement: drawing upon a survey of 19 organizations in England, the Netherlands and Germany, Tyler (2002) points to the existence of shared views on pregnancy and childbirth seen as “natural physiological life events that should be as free as possible from medical intervention” and on “the routine application of medical technology [experienced] as disempowering” (p. 139). More recently, other works stressed the emergence of a rhetoric of “choice” which should extend to the right to choose elective cesarean section (Beckett, 2005). Much of academic discussion revolves around the relationships between these movements and various waves of feminisms (Annandale & Clark, 1996; Reiger, 1999, 2000): for some, technology supports the obstetricians’ control over women’s body and is seen as alienating (Katz Rothman, 1982; Murphy-Lawless, 1998; Halfon, 2010); for others, technology can contribute to women’s empowerment by freeing them from biological determinism. Standard medical practices appear as an external factors which obey their own logic: depending on their perspective, women demand the possibility to opt in or opt out. Recent works have criticized this view by stressing that the way women can frame their choices is highly dependent on obstetrics itself, on its organization and on the knowledge it mobilizes to define appropriate practices (Crossley, 2007; Donovan, 2006; Spoel, 2007). Our observations in four European countries (Akrich et al., 2012) led to the conclusion that childbirth organizations have been indeed taking this criticism as a point of departure for their activism: one should argue that, at least for the last decade, they have tried to transform obstetrics from within, and that, to do so, they have drawn upon an extensive knowledge work seeking the integration of women’s experiences as a challenging or complementing source of obstetric knowledge. Drawing upon the French case in the following section, we describe this knowledge work and its implications on both research policy and health policy.

Created in 2003, the *Collectif interassociatif autour de la naissance* (CIANE) gathers about 40 French childbirth organizations: local support groups and national organizations focusing on specific issues (cesarean section, homebirth, post-partum depression etc.), some of these having emerged in the early 2000s from internet discussion groups which developed a scientific expertise and a culture of discussion articulating this expertise with personal experiences (Akrich, 2010) which has been crucial in the development of CIANE. The CIANE involvement into knowledge activities takes three forms that we examine below.

Firstly, they question current medical practices in the light of an analysis of scientific literature, and, amongst other actions, make it politically operative by participating in the elaboration of clinical guidelines organized by the HAS (High Authority of Health). They even took part in the determination of its work program by sending referrals on the issues they deem relevant. Drawing on its scientific expertise, the CIANE has thus provoked and participated in the elaboration of guidelines on topics such as induction, episiotomy, fundal pressure, indications for planned cesarean sections: the choice of the topics to be

tackled was linked to the informal knowledge that they gathered on women's experiences and especially on situations where women were confronted with professionals' decisions that they eventually found detrimental and possibly made on disputable grounds. To a certain extent, the CIANE approach can be understood as a way of re-opening all these individual failed debates between professionals and women: thus, the aim is to set up a space for negotiation where expectations of both parties can be framed in a stabilized and public way.

Secondly, they question the relevance of medical practices, authoritative discourse and credentialed knowledge from the perspectives opened by experiential knowledge: this strategy is not exclusive from the previous one as is illustrated by the critical analysis produced by the CIANE very early in its existence about guidelines on episiotomy produced by the College of Obstetricians. This analysis was elaborated drawing upon existing internet discussion groups: the groups called for testimonies, confronted them to the academic literature, and pointed to several complications of episiotomy that have been neglected both by the literature and the guidelines but have severe consequences in women's everyday life; it ended up by reframing the problem not as "the prevention of episiotomy", expression that naturalizes the intervention, but as "the prevention of perineal lacerations", which opens up a whole set of other policy options. Amongst these options, acting upon positions during labor seem relevant but the CIANE pointed to another difficulty, the oversimplification associated with experimental protocols of research which excludes gathering data on situations where women are free to choose their position. The de-medicalization vocabulary is indeed useless to describe what is at stake here: the mobilization and production of experiential knowledge allowed the group to deconstruct both the framing of the issue and the legitimacy of credentialed knowledge; it led to propositions for amending the guidelines but also raised some issues as regards medical research, thus trying to influence both health policy and research policy.

Thirdly, they put together existing but separated pieces of knowledge in an attempt to reframe issues at stake: it might result in a questioning of research policy as well as of health policy as can be seen in the following examples. In 2004, the CIANE asked to review clinical guidelines on the prevention of post partum hemorrhage (PPH) which appears to be involved into more than half maternal deaths. Again, they contested the use of the word "prevention", as the guidelines did not even mention the issue of what may cause PPH, to the exception of well-known risk factors that do not represent the majority of severe cases. The CIANE put together firstly, the fact that in France, the prevalence of PPH was higher than in other countries, and, secondly, that some scarce publications, including publications by midwives, formulate hypothesis about the role of medical practices and the administration of oxytocin during labor in the occurrence of PPH: as this practice is more frequent in France than in most countries, it is tantalizing to infer a correlation between the two facts. After months of efforts, they succeeded in convincing an administration to fund a research project which resulted in a first publication in 2011 in the BMJ confirming the existence of a link between the administration of oxytocin and PPH. Whereas, in this case, the different pieces of knowledge were all medical, in a more recent case, the knowledge they put together were much more heterogeneous: they elaborated a document developing a new approach as regards health professional insurance. Due to European legislation, midwives attending homebirths need to get a

professional insurance. In France, insurers take as a reference the insurance premium paid by obstetricians, amount which is not affordable for midwives. The CIANE analysis consists of a large diagram making visible the different kinds of risks, some specific to hospitals, some specific to homebirths, others common to both situations; the diagram is accompanied by a detailed argumentation based on medical knowledge but also on psychological knowledge or legal one, as the risk at stake is a litigation risk which does not confuse with a medical risk and depends upon varied factors. This document has been endorsed by the National College of Midwives and three midwives' unions. It aims at re-opening the debate about premiums' calculation, which has been closed unilaterally by insurers, not providing the calculation key but trying to demonstrate that the current one is neither adequate nor fair.

In all these actions, the CIANE does not appear as driven by a normative perspective, it does not claim for rights, it tries to build a users' perspective on obstetrics, its practices, its organization, borrowing the obstetric language itself: by doing so, it opens up a space of discussion and negotiation with other stakeholders.

#### **SHAPING THE CONCERNED PUBLICS: SOCIAL ENQUIRY IN AN ALZHEIMER DISEASE ORGANIZATION**

Emerging in the late 1970s and early 1980s, European Alzheimer's Disease patients' organizations resembled in many respects those in the US from where they were isomorphically imported. In both contexts, the cause around which Alzheimer's disease patients' organizations were initially mobilized was to provide support to carers of people diagnosed with the disease, not patients themselves who were deemed to have experienced a "loss of self" and thus to be liminal or non-persons (O'Donovan, Moreira and Howlett, in press). However, a significant difference between the early US and European Alzheimer's disease patients' organizations was their knowledge-related activities. The prioritization of proactive engagement in biomedical knowledge production in the quest for a cure that was a defining feature of US patients' organizations, as described by Patrick Fox (1989), was not replicated by the European organizations, including the Alzheimer Society of Ireland. Established in 1982, the Alzheimer Society of Ireland was the second Alzheimer's disease patients' organizations to emerge in Europe, and similar to its British counterpart established three years previously, its chief preoccupation was service delivery. The organization has since become one of the largest service provision charities in Ireland; in 2011, 86 per cent of its €17 million budget, most of which came from State grants, was spent on service delivery (Alzheimer Society of Ireland, 2012). Notwithstanding this prioritization of service provision, the Alzheimer Society of Ireland is now also engaged in intensive epistemic work producing and circulating facts and figures about dementia and its care, much of which is motivated by efforts to establish the condition as a national and European public health priority. The *Dementia Manifesto 2007 - 2009*, the "cornerstone of the Society's political lobbying campaign" (Alzheimer Society of Ireland, 2007) serves as one example; it was a synthesis of knowledge about priority issues for people with dementia and their carers generated by a National Consumer Summit, consultation with "stakeholders" and the commissioning of a position paper by a health economist. The organization is enmeshed in networks of biomedical expertise, including those at European level through its strong links with the European coalition of

POs Alzheimer Europe, but engagement in biomedical research is just one feature of the organization's varied repertoire of knowledge-related activities.

Social research has featured prominently in the history of the Alzheimer Society of Ireland's epistemic work. Motives for considering this species of knowledge have included encoding and formalizing the experiential knowledge of carers and the "costs of caring". However, in recent years, moves to redefine Alzheimer's disease patienthood and recognize the fully-fledged personhood of those diagnosed with the disease have presented the organization with profound epistemic challenges; it relies upon social research to represent patients' experiential knowledge and perspectives, but is simultaneously confronted with the limitations of those very social science techniques and with the need to innovate methodologically. These epistemic challenges are intimately connected with the political challenge of social enfranchisement of people with dementia within the organization. To understand the distinctive features and challenges of this Alzheimer's Disease evidence-based activism it is important to appreciate the significant and hybridizing shift that has taken place in the "cause regime" of the organization, which has included an expansion of the constituency the organization claims to represent to include both carers and patients. Similar to Alzheimer's disease organizations elsewhere, the Alzheimer's Society of Ireland has been transformed from a carers' organization to a carers' and patients' organization.

The organization has made the "turn to personhood" that problematizes knowledge about the disease that understands it as inducing a "loss of self" form of patienthood, knowledge that it and other organizations in the international Alzheimer's disease movement played a crucial role in co-producing and circulating (Beard, 2004). Much of the scholarship on what Nancy Scheper-Hughes and Margaret Lock (1986: 137) referred to as Alzheimer's disease's metaphoric "double", "the layers of stigma, rejection, fear and exclusion" attached to the disease, attributes blame primarily to its biomedical framing as a disease that gradually destroys the patient's brain and consequently their personhood (Kitwood, 1997; Basting, 2003). But equally, the more recent understanding of what it means to be diagnosed with dementia that recognizes the personhood of the patient tends to be attributed to the Alzheimer's disease biomedical enterprise's investments in new devices for early diagnosis and treatments aimed at delaying the progression of the disease (Moreira, 2009).

The Alzheimer Society of Ireland's research on telecare provides an illustration of how the organization has co-produced and subsequently problematized the "loss of self" patient identity and confronted the epistemic challenge of representing the perspectives of people with dementia. In 2007, the organization instigated a pilot project of telecare as a technology of independent living. The research evaluating the project framed carers rather than people with dementia as the users of the telecare technologies and as the actors whose perspectives the research sought to ascertain. The social disenfranchisement of people with dementia through their exclusion from direct participation in the evaluative study was compounded by the exclusion of many of them from the decision to participate in the pilot project and the installation of the telecare devices (Alzheimer Society of Ireland, 2010). A subsequent telecare project, the EU-funded INDEPENDENT - ICT Enabled Service Integration for Independent Living, is adopting a very different style of research by including people with dementia as research participants, rather than relying on their

carers as proxies. Explaining the intention to use the technique of ethnographic interviewing to generate knowledge of patients' experiences of the impact of telecare on their quality of life, a researcher involved in the project explained:

We will be doing a detailed assessment of the quality of life with people with dementia. Hopefully, we'll be working with them directly to understand their view of ...what is important in quality of life for them and how telecare might impact that. Now obviously we can do that with people with mild to moderate dementia. We have to work really carefully with people who are further on in the disease to see what is the best way of communicating with them to get this information. (Delaney, 2010)

Here we can see that social science techniques are not a given but are to be explored as potential voicing devices that can make the experiential knowledge of people with dementia visible and meaningful. As we have discussed in more detail elsewhere (Moreira, O'Donovan and Howlett, in press), the technique of the interview is embedded in a politics of subjectivity that views individuals as knowledgeable agents in their own social worlds. Such presuppositions may require revisiting the methodological innovations being crafted in this second telecare project of the Alzheimer Society of Ireland.

## **CONCLUSION**

Through the variety of cases we presented, we intended to demonstrate that patients' and activists' involvement in knowledge activities is not restricted to a limited set of diseases (e.g. those for which biomedical research is considered as a priority), but extends to all kinds of conditions, including those which still remain contested.

This involvement in knowledge stands at the core of patients' organizations' activities, and that is what we try to capture through the expression "evidence-based activism". Firstly, this expression sheds light on how patients' organizations define the causes they engage in: even if patients' organizations constitute around a shared condition or experience, this does not necessarily imply a straightforward definition of their claims. Sometimes, as illustrated by the case of the French association on rare disabilities and diseases, what the "shared experience" consists of is not given once and for all but emerges and changes in the course of the on-going transformation of people's lives in which medicine itself plays a significant role. Thus, the transformation of individual complaints into collective claims involves the collective production of knowledge and analysis of individual situations and its articulation to the existing medical and care system: without the constitution of such expertise – which largely draws on, and even renews, as seen in the Alzheimer Disease case, social sciences techniques – POs would not be anything else than support groups.

Secondly, this entanglement between knowledge work and political work is also at stake in the engagement of patients' organizations in medical research: as demonstrated in the case of 22q11 deletion and in the ADHD case, the active participation of patients' organizations to "research policy", or at least to the formulation of research issues they deem relevant cannot be separated from their continuous effort to get a grip on their condition, i.e. to understand what it is, how and why it affects people's lives, which can eventually lead to a drastic redefinition of diseases or the emergence of new nosographic categories.

Thirdly, patients' organizations engagement in science and in knowledge production is a key element in the building of relationships, even confrontational, with a number of other actors, and especially professionals and researchers: being able to go back and forth between people's experiences and medical knowledge opens new capacities of action for patients' organizations. As mentioned above, participating to the medical definition of the condition is one of these capacities as well as participating to the elaboration of guidelines, to the setting up of centers of reference, or to the definition of care pathways: more generally, this engagement with knowledge opens up new spaces for discussion and negotiation with involved actors and, in some cases, results in the building of epistemic communities.

Does our analysis suggest a move towards institutionalization of patients' organizations that would hinder their contestation power and "normalize" them as ordinary players in a game ruled by official authorities? Are POs instrumentalized as civil society representatives that give legitimacy to decisions still massively in the hands of the "real experts"? In other words, do we face a fool's game?

On the one hand, one could say that patients' organizations who engage in what we called "evidence-based activism" accept to use the language of "dominant" actors and that should be considered as a success for biomedicine and health professionals; there are probably some associated losses as the capacity to mobilize around more overtly political slogans centered around rights or as the fact that it tends to overcome issues such as social inequalities. On the other hand, we tried to demonstrate that it constitutes a powerful leverage which allows patients' organizations to penetrate others' territory, to redefine borders, to bring in new entities and new issues, so that the whole geography may be turned upside down in some cases. Research actions that some rare diseases organizations undertook were explicitly aimed at shaking the medical world which thought there was nothing to be done; pushing Alzheimer disease patients into the arena of discussion through the mediating tools of social research is not especially intended to please professionals nor policy makers; criticizing the way obstetricians frame interventions and questioning research methodology is generally perceived as rather aggressive by the professionals; forcing various disciplines to discuss about their understandings of ADHD is clearly to infringe what researchers and clinicians consider as their prerogatives. So, "evidence-based activism" is not, in our view, a soft version of activism that would facilitate the instrumentalization of patients' organizations more than other forms of activism would do: on the contrary, it gives them quite effective munitions to contest both medical "paradigms" and the organization of care.

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