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**Evidence-based activism: Patients' organisations, users' and  
activist's groups in knowledge society**

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# Evidence-based activism: Patients' organisations, users' and activist's groups in knowledge society

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## **Abstract**

This article proposes the notion of 'evidence-based activism' to capture patients' and health activists' groups' focus on knowledge production and knowledge mobilisation in the governance of health issues. It introduces empirical data and analysis on groups active in four countries (France, Ireland, Portugal, and the UK), and in four condition areas (rare diseases, Alzheimer's disease, ADHD – Attention Deficit Hyperactivity Disorder, and childbirth). It shows how these groups engage with, and articulate a variety of credentialed knowledge and 'experiential knowledge' with a view to explore concerned people's situations, to make themselves part and parcel of the networks of expertise on their conditions in their national contexts, and to elaborate evidence on the issues they deem important to address both at an individual and a collective level.

This article argues that in contrast to health movements which contest institutions from the outside, patients' and activists' groups which embrace 'evidence-based activism' work 'from within' to imagine new epistemic and political appraisal of their causes and conditions. 'Evidence-based activism' entails a collective inquiry associating patients/activists and specialists/professionals in the conjoint fabrics of scientific statements and political claims. From a conceptual standpoint, 'evidence-based activism' sheds light on the on-going co-production of matters of fact and matters of concern in contemporary technological democracies.

## **Keywords**

Evidence-based activism, patients' and health activists' groups, expertise, healthcare policies, collective inquiry, technological democracies.

## **Introduction**

Over the last two decades, social scientists have renewed their interest in patients' organisations, users' and activists' groups in the domain of health and medicine. This is due to interlinked transformations that significantly affect the sector of health and medicine: 1) the growing reliance on EBM for defining and managing care protocols; 2) the proliferation of diagnostic and therapeutic targets, and the complex regulation of the markets of drugs and medical products; 3) the challenges to the power of the medical profession and the strengthening of mechanisms of accountability; 4) the increased involvement of patients' groups in biomedical research; and 5) the emergence of new legislative frameworks that recognise patients and users as stakeholders in health policies in Western countries. The complex interactions that patients' organisations, users' and activists' groups build with these processes have attracted the attention of social scientists. Combining perspectives from new social movement studies, science and technology studies, political sciences, sociology and anthropology of biomedicine, and organisation studies, special issues of journals (Brown & Zavetovki 2004; Landzelius 2006), as well as edited books (Löfgren et al. 2011; Hoffman et al. 2011), have examined issues related to the politics of illness, the shaping of collective identities, the relationship between experts and lay people, the democratisation of health, and the articulation between science, medicine and the market. Contributing authors of these publications have also engaged in reflection on the analytical concepts and frameworks that best capture the role of patients' organisations, users' and activists' groups in these compound processes.

This special issue takes this body of research a step further to put forward the concept of 'evidence-based activism' as a means to understand the development of modes of activism that focus on knowledge production and knowledge mobilisation in the governance of health issues. We argue that such modes of activism are reconfiguring the role and dynamic of patients' organisations, users' and activists' groups, and have broader consequences for the governance of the so-called 'knowledge society' in contemporary democracies. Before presenting our approach, we first contextualise our approach within the current research to delineate what exactly we mean by 'evidence-based activism'.

### **From 'war on diseases' to the dual shaping of conditions and health issues**

Amongst the transformations stated above, the involvement of patients' organisations in biomedical research has been pinpointed as a watershed in health activism. Rich and detailed

studies have documented the rationale that underlies this dynamic, and its consequences on the configuration and conduct of collective action associating patients and experts (Barbot 2002; Dodier 2003; Brown et al. 2004; Epstein 1996; Novas 2006; Rabeharisoa & Callon 1999; Rapp et al. 2001; Silverman 2011; Panofsky 2011; Stockdale 1997).

Firstly, these authors have stressed the emergence of new forms of activism in which patients' organisations no longer confine their activities to the provision of help to their members and/or to advocacy for their rights and interests, but actively intervene in 'war on diseases' with an aim at finding a cure. 'War on diseases' has clustered around life-threatening conditions such as cancers, rare genetic diseases and HIV/AIDS, to cite but a few, for which there has been no treatment, a situation that patients and activists have related to the lack of investments and/or focus in biological, clinical and therapeutic research. Patients' organisations have thus mobilised to intervene in biomedical activities with a view to launching and accelerating the 'quest for a cure'. In his pioneering work on Act-Up, Epstein (1995) coined the term 'treatment activism' to feature activists' concern with the fight against the disease. In their study of the AFM<sup>1</sup>, Rabeharisoa & Callon (1999; Rabeharisoa 2006) pointed to the organisation's shifting interests from directly helping patients and their families to manage illness towards being involved in research and clinical efforts to combat the disease, a detour that the AFM considered as a relevant and promising avenue for securing a better future for people suffering from myopathies. In contrast to previous patients' organisations, which formed around chronic diseases and were mainly preoccupied with helping patients to cope with their illness experience (Pierret 2003) and manage their illness trajectories (Corbin & Strauss 1988), Act-Up, the AFM, and similar organisations, targeted diseases themselves as the focus of their mobilisation.

Secondly, patients' organisations' concerns with disease and its exploration has entailed a redistribution of competencies and prerogatives between patients and credentialed experts. Certain patients and activists acquired scientific and medical knowledge, becoming what Epstein (1995) labelled 'lay experts', i.e. credible interlocutors of specialists. Patients' organisations also collected, formalised and circulated patients' experience as a legitimate body of 'experiential knowledge' (Arskey 1994; Borkman 1976) on their conditions, and became what Rabeharisoa & Callon (2004) called 'experts of experience'. This two-fold role played by patients' organisations, as 'lay experts' and 'experts of experience', has led to new forms of cooperation between patients and specialists in the production, discussion and

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<sup>1</sup>Association française contre les myopathies – French association against myopathies

dissemination of knowledge. This transformation extended the repertoire of styles of mobilisation enacted by patients' and users' organisations, adding to forms of contestation new modalities of articulation that bring together these organisations and specialists to negotiate the scope of epistemic arenas for their conditions.

Thirdly, studies of patients' organisations' engagement in biomedical research have revealed the evolving nature of patienthood (Landzelius 2006). It is argued that not only patients cease to be passive and take an active part in the understanding of their conditions (Barbot 2006), but also that this involvement requires engagement with their self-description. Rabeharisoa & Callon (2004), in the case of myopathies, noted how some families (and doctors alike) who formerly saw their affected relatives as 'defects of Nature', progressively considered them as full-fledged human beings suffering from genuine diseases, who deserved to be recognised and treated as such. Patients' organisations' contribution to the production of knowledge both transforms the epistemic nature of their condition *and* raises the social status of affected people. This sometimes results in a new form of social relations between patients, which Rabinow (1999) has labelled 'biosociality' to indicate their condition-focused, knowledge laden and transformative power, which can however extends across disease areas in manifestations of solidarity through public donations to research on a range of 'high profile' diseases. These transformations of patienthood also brought tensions into organisations and movements. Epstein (1995), for example, showed how certain activists' proactive encounter with researchers ended up in a schism between 'lay experts' and 'lay lay' patients within Act-Up, the latter arguing that the former eventually lose sight of 'grass roots' problems.

The modalities of engagement are underpinned by reflexive work which echoes, as much as partakes, a number of aspects in the dynamic of contemporary health and medicine. It sheds light on the uncertainty and fragmentation of biomedical knowledge (Berg & Mol 1998), which is particularly salient in contested condition-areas such as emergent environmental illnesses (Brown et al. 2004), or complex multi-factorial conditions like Attention Deficit Hyperactivity Disorder (ADHD), which is the focus of one chapter of this special issue. It also relates to the development of EBM that emphasises the importance of standards in guiding clinical work, leading to the transition from the 'clinical tradition' to what Dodier (2003) calls 'therapeutic modernity'. Thus, Cambrosio et al. (2006) have suggested that EBM standards are linked to the emergence of a distinctive type of objectivity, 'regulatory objectivity', that focuses on the establishment of conventions through collectively



concerted programmes of action, where patients and users play an increasing role. Drawing on Light's theory of countervailing powers (Light 1991), Timmermans & Berg (2003) proposed that assessments of clinical effectiveness are part and parcel of a redistribution of accountability within health care systems where third parties attempt to gain access to the 'black box' of clinical judgment. In sum, one of the key characteristic of this dynamic in the field of health care is that knowledge – and the collective negotiation of what counts as such – has become central to the governance of health care services, programmes and systems. This further supports patients' organisations, users' and activists' groups' contribution to the evaluation of the 'evidence-base' of collective decision-making in the shaping of health care services and health research policies (Moreira, 2010; see also the chapter on Alzheimer's disease in this issue). Patients' organisations' engagement in biomedical research thus offer a particularly interesting locus for social scientists to study lay people and their representatives' contribution to the fabric of 'knowledge society', and lay people' involvement in technosciences as a crucial issue for democratising democracy (Callon et al. 2009). Patients' organisations, users' and activists' groups have become key actors in this reflexive work by staging, weighting up, sorting, assessing, and reordering heterogeneous sets of information and data on their conditions and health problems they are concerned with.

If a number of studies have focused on how and to what extent patients' organisations, users' and activists' groups intervene into the fabrics and monitoring of health policies, few of them however have investigated the epistemic activities that these organisations and groups deploy to contribute to significant changes in issues at stake. Studies are mainly preoccupied with the representativeness of these organisations and groups, as well as their lobbying power vis-à-vis institutions. Baggott et al.'s (2004) research work on various health consumer groups in UK stands as one exception through their focus on how these groups' expertise endows them with political legitimacy and power to influence institutional change. We take this a step further and examine how patients' organisations, users' and activists' groups produce and mobilise evidence for transforming health issues *and in so doing* contribute to their governance.

We propose the term 'evidence-based activism' to capture the variety of patients' organisations, users' and activists' groups forms of engagement with knowledge. This means that rather than focusing only on patient organisations' interventions in biomedical research – as significant as this might be – we open the focus to a broader spectrum of knowledge-related activities. In this, the term also aims at drawing attention to the multiplicity of forms

of knowledge that these organisations and groups are mobilising, which includes biomedical knowledge but also health technology assessment, public health research or forms of judicial expertise. Most importantly, we coin the term ‘evidence-based activism’ to explore what we consider as an important shift in patient and health activism. We argue that ‘the quest for cure’ is no longer the exclusive motive that drives patients and activists to engage with knowledge. Many patients’ organisations, users’ and activists’ groups are striving to raise public health issues that they deem relevant and significant for those affected in the way they feel appropriate. Because of the interlocking of knowledge governance and health care organisation, knowledge is no longer a mere resource for grounding political claims; it is the very target of activism, in a process through which patient organisations' causes and political identity have to be continuously re-thought and re-worked. We expand on this form of activism in the next section.

### **What is ‘evidence-based activism’ about?**

In order to grasp the scope of the concept we are proposing, it is perhaps worth clarifying the use of key terms that underpin it. Drawing on our empirical observations, we use the term knowledge, be it credentialed knowledge or ‘experiential knowledge’, to designate statements on the nature of patients’ and activists’ conditions or situations. As mentioned above, these statements may be multiple, and even contradictory. ADHD for instance is conceived as a ‘brain disease’ by certain neurologists, a ‘behavioural disorder’ by certain psychiatrists, and a complex and multidimensional condition by parents of children who have ADHD. Expertise is the capacity of an individual or a group to produce propositions on whatever concerns the nature of the health issues at stake and on the way they should be dealt with. Those propositions are usually endowed with a degree of credibility underpinned by the recognised mastery of specific form of knowledge. Evidence results from the selection and articulation of knowledge statements in order to produce forms of expertise: it aims at providing robust knowledge on how patients’ and activists’ conditions or situations ought to be understood and treated. Evidence thus is a mediating tool between knowledge and expertise. The notion of ‘evidence-based activism’ allows to highlight first, the articulation between knowledge and politics which is central in this form of activism and second, the work which is necessary to perform this articulation.

Evidence-based activism as a form of activism can be conceived through the following conceptual model:

1. Patients' organisations which engage in evidence-based activism collect experiences and build experiential knowledge, and that is how they give shape to concerned groups and delineate their preoccupations;
2. They articulate credentialed knowledge with experiential knowledge in order to make the latter politically relevant, e.g. to capture other stakeholders' interests and raise health issues;
3. Through this process, they usually reframe what is at stake, destabilising existing understandings of conditions and problems and resulting in the identification of zones of 'undone science' (Hess 2009; Frickel et al. 2010), thus inextricably linking patients' organisations' involvement in politics of health to politics of knowledge;
4. The causes defended by patients' organisations, the definition of their conditions, and the identities of concerned people are the *outcome* of these knowledge-related activities rather than their causes;
5. To achieve these epistemic shifts, patients' organisations make themselves part and parcel of networks of expertise with credentialed experts and collaborate to some extent with health authorities as well as medical professionals, This leads them to adopt a 'reformist' rather than a purely confrontational perspective.

We expand on the components of this model in the next sections.

### **Shaping concerned groups and delineating their concerns**

Health professionals, political philosophers, and social scientists (Schicktanz 2012; Epstein 2007; 2011) have rightly pointed to the issue of representation: who are patients' organisations representing? What allows them to speak on behalf of the people they claim to speak for? The patients' organisations whose activism we describe here take these questions seriously by making them key components of their work of collecting experiences, opinions and suggestions from concerned people, be they members of their organisations or not.

They do this through rather straightforward means, such as the collection and analysis of data reported in the subscription form to their organisations, or the collection of stories

gleaned in support activities (help lines, internet forums, speech groups); in addition, they also engage in a rather sophisticated work, as is described in the chapter on Alzheimer's Disease (AD). In Ireland as well as in UK, AD societies mobilised social research methods – and even innovated in this matter – in order to represent the needs of the various people involved in AD care, informal as well as formal carers and the people with AD themselves, the latter posing a clear epistemic challenge to the researchers. It has resulted into various reports and position papers that propose a hybridisation of the kind of evidence that are taken into account in dementia care policy. This hybrid format is widespread characteristic of the experiential expertise produced by patients' organisations, and can, we suggest, be understood as the expression of their mediating role between concerned people and health care system, or of their dual involvement in support as well as in advocacy activities.

This work undertaken by patients' organisations, which can be considered as partaking to the development of 'technologies of democracy' (Laurent, 2011), plays an important role in opening the route to the policy-making table, especially but not exclusively in countries where the participation of patients, users, and consumers to the governance of health issues has not been much institutionalised. Thus, despite their lack of recognition by the Health Ministry, the Association for the Improvement of Maternity Services in Ireland (AIMSI) was able to bring to bear issues of maternity care by drawing on surveys of women's experiences of childbirth services.

By producing evidence on people's concerns in relation to their experiences of their conditions, patients' organisations achieve two goals at once: they gather and constitute an assembly of 'represented' people by giving them a voice through the mediation of tools they use to collect and analyse their experiences; at the same time, they legitimise themselves as representatives of these people while eliciting the emergence of health issues that they bring to the attention of other stakeholders.

### **Articulating experiential and credentialed knowledge and involving stakeholders**

To gain the attention of other stakeholders in their condition areas, patients' organisations not only document patients' singular preoccupations: they have to convince other stakeholders that they too are actually concerned. For this to be achieved, they try to link patients' problems to the network of issues in which these stakeholders are already caught. Patients' organisations thus devote a large amount of energy in articulating credentialed knowledge and 'experiential knowledge'.

Patients and activists do not simply align or oppose either of these two sorts of knowledge. Instead, they are engaged in collecting and confronting them as a key part of their activities. In connecting these two bodies of knowledge, patients' organisations are translating people's experience into the language of science and medicine and vice-versa, with an aim at rendering their situations perceptible not only to medical experts and health professionals but also to themselves. In doing so, patients' organisations progressively constitute a seamless web of pieces of credentialed knowledge and 'experiential knowledge' that crafts their focus of activity. For example, it was through a careful analysis of the clinical effectiveness – which is supposed to underlie professional's concerns – of procedures such as episiotomy or fundal pressure<sup>2</sup> that childbirth activists' groups managed to make room for women's experiences, drawn on surveys they conducted. They succeeded to the point that recommendations for clinical practices now clearly pose limits to the use of these medical interventions. Thus, patients' organisations, users' and activists' groups' reflection on what counts as relevant knowledge plays a significant role in managing accountability and regulating processes in health care.

In many instances, they also bring in bodies of knowledge which medical experts do not consider as central. This is notably the case when patients' organisations, users' and activists' groups' contemplate unsettled conditions such as ADHD and other similar 'illnesses you have to fight to get' as Dumit (2006) nicely puts it. In these situations, 'stating the fact of the condition' is a 'matter of concern' for those afflicted: connecting patients' experiences to a wide range of medical, paramedical and non medical knowledge entails the building of a large multidisciplinary community invested in the understanding of the condition. In the case of ADHD for example, the epistemic eclecticism of the French group of parents aims at asserting a definition of the disorder and its treatments which encompasses all aspects of parents' and patients' experiences, and which counteracts professionals' tendency to reduce the disorder to their specific domains of competencies.

However, patients' and activists' interest in knowledge is not restricted to these sorts of condition-areas, as uncertainty bears on the negotiation of how to articulate knowledge making and political cause. This means that even for certain diseases whose scientific and medical understanding is, at least temporarily, quite stabilised, patients' organisations, users' and activists' groups may raise health issues that they feel should be addressed, both at an individual and a collective level for the benefits of concerned people. Take Alzheimer's

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<sup>2</sup> An incision of the perineum and the posterior vaginal wall during labour.

disease, for example. There exists today a quite consensual scientific and medical definition of AD as a neurodegenerative disease that impacts on fundamental cognitive functions and comes with severe impairments and disabilities. Although certain areas are still controversial, such as the genetic cause of early onset AD or the mechanisms which underlie the development of AD compared to other dementia and ‘normal’ ageing, AD is very much put under the jurisdiction of neurosciences which are agreed upon as the main relevant body of knowledge on this condition. This does not prevent patients’ and carers’ groups to raise the issue of care, and notably to question the relevance and effectiveness of standard clinical guidelines *versus* person-centred care: to do so, they mobilise bodies of knowledge – notably from social sciences – different from the one which is considered as relevant from a medical point of view.

Thus, patients’ organisations’ expertise does not simply consist of juxtaposing experiential expertise and ‘lay’ expertise on formalised knowledge. Drawing on patients’ organisations’ reflexive analysis of their own activities, we suggest that, at least in the case of evidence-based activism, their expertise lies in their capacity to articulate various knowledges, so much so that what constitutes evidence for patients may also count as such for scientific and health professionals. As one member of the Alzheimer’s disease Society in UK declared about their expertise: *‘It brings together the expertise of carers with the skills and insights of health and social care professionals and the discoveries of scientific research.’*<sup>3</sup>

Conversely, patients’ organisations also develop a micro-politics of knowledge, through significant efforts to provide patients and their relatives with information about how to navigate within research and health care institutions and negotiate the management of their case with professionals. This implies translating scientific data into plain language, providing concerned people with background knowledge that support statements and claims, and producing ‘evidence’ that can be deployed in interaction with their various interlocutors. Rare diseases patients’ organisations, for example, equip their members with various knowledge-based tools for them to be able not only to manage their conditions, but also to raise issues of organisation and provision of diagnosis, medical and social care. A similar effort has been deployed by Alzheimer’s disease organisations, where information sheets have been produced to compile information on issues from coping with memory loss to statutory rights of people with dementia in their relationship with health care services.

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<sup>3</sup> Cayton, H. ‘Executive Director’s Message’, *ADS newsletter*, August 1996: p. 2.

## **Linking politics of knowledge to politics of health**

In the preceding section, we have described how POs articulate experiential knowledge and credentialed knowledge to mobilise a number of actors on issues primarily raised by patients. This work of ‘intéressement’ (Callon 1986) helps patients’ organisations to extend the list of actors and issues to be discussed, thus creating a collective space of debate. However, our suggestion is that this process goes even further, for it destabilises and questions both existing bodies of knowledge and care organisations. As suggested by above-mentioned examples, patients’ organisations’ politics of knowledge is *de facto* a politics of healthcare. By bringing in new issues, patients’ organisations reframe what is at stake and redefine the list of entities – organisations, biological processes, interventions, etc. – that should be taken into account. Not surprisingly, this may lead them to identify zones of ‘undone science’ (Hess 2009; Frickel et al. 2010), and/or of ignorance that should be investigated in order to bring to bear previously excluded issues.

Zones of ‘undone science’ may concern a variety of questions such as the prevalence of diseases, an issue that patients’ groups on AD and ADHD have tackled by commissioning or being associated to research; the costs associated to various organisations of care for individuals as well as for communities and the State, an issue on which the Alzheimer Society of Ireland commissioned health economists to produce policy papers; medical practices which obstetricians consider as routines not even worth being discussed, while having important, and sometimes damaging effects from the perspective of women. Identifying zones of ‘undone science’ may also lead to the opening of new complex scientific questions, as in the cases of some rare diseases we study in one chapter of this volume. In that case, the evidence brought to the table by a French group of families concerned with 22q11 deletion syndrome led to the investigation of the links between this syndrome and some psychiatric disorders, potentially redefining both the syndrome, its prevalence rate and its relation to psychiatric disorders. Similarly, the French childbirth organisation we studied put forward a hypothetical link between the use of oxytocyn during the second stage of labour and the occurrence of post partum haemorrhage, and pushed to the setting up of a research program which eventually confirmed this hypothesis.

In this, as we have been arguing, knowledge is not only a mere resource that patients’ organisations, users’ and activists’ groups carve out for promoting institutional changes. Through their engagement with knowledge, patients’ organisations are able transform the very definition of conditions and of issues at stake, both at and individual and a collective

level. We should stress however that our contention is that knowledge is not only part and parcel of today's politics; political action is also a mean through which epistemic changes, as well as new knowledge making procedures and institutions are promoted. Again, in the area of rare diseases, interlinked platforms (Keating & Cambrosio 2003) for research and clinical activities, associating medical and health institutions, patients' organisations, industry and regulatory bodies, stand as new institutional configurations which sustain significant changes in the production of knowledge on these conditions and in the nature of what counts as relevant knowledge.

### **Redefining conditions, causes and identities**

Such characterisation of patients' organisations' activities needs further contextualisation. The patients' organisations we studied belong to what Allsop et al. (2004) identified as 'condition-based groups', or at least 'experience-based' in the sense that they gather people sharing *similar* personal experiences in which medicine plays a significant role as is the case of pregnancy and childbirth. They neither belong to health access movements nor to constituency-based movements as described by Brown & al. (2004), i.e. they are not primarily defined by a political orientation, such as the defence of rights, access to care, or the fight against discrimination based on race, class, gender, ethnicity, sexual orientation etc. even if, at some point, they can take on board such a problematisation. They are interested in making sense of their experience and improving their life, in questioning the role of medicine and medical knowledge alongside other fields of expertise, and in elaborating concrete answers to issues related to their conditions. To some extent, they share a number of characteristics with Embodied Health Movements as conceptualised by Brown and colleagues (2004). However, as we already mentioned, the notion of 'evidence-based activism' entails a wide range of knowledge-based activities. More importantly, it places knowledge-related activities at the heart of patients' organisations functioning: indeed, their engagement in knowledge-related activities can be understood as a multidimensional exploration of their conditions, whose definition is at stake over this process, and whose political implications proceed from this process rather than the other way round.

This is especially striking in the case of childbirth activism which has often been studied as belonging to a wider feminist movement. The close examination of their current functioning presented in one of the chapters of this issue reveals that they are not driven by pre-existing 'ideological' slogans. In the case of the Irish childbirth organisation for instance, the absence of a shared 'ideology' amongst volunteers, as well as the lack of an institutional



demand for representation, created space for a politics of representation drawn intensively on the analysis of their surveys on women's experiences, tackling issues such as what matters to women (availability of information and consent, or pregnancy loss). In other cases, where activists' groups are urged to participate to the governance of health but do not fully control the agenda setting, we observed that the collective exploration in which they participate leads them to progressively reframe their objectives and claims. This is the case with the British elaboration of a consensus statement on 'normal birth'. Starting from a 'radical' perspective on 'normal birth' which excluded any medical intervention, activists' groups engaged into a collection of data in order to evaluate the occurrence of such non medicalised birth practices, which led them to progressively forge a slightly more flexible notion of 'normal birth' that would be workable, measurable and acceptable by professionals. In this process, their politics of childbirth came to be transformed. A similar dynamic is observable in the case of Alzheimer's disease, where knowledge work to make the person living with dementia the focus of therapeutic evaluation and quality of life research in turn entailed a complicated and sometimes conflicting hybridisation of the constituency the movement is supposed to represent (O'Donovan, Moreira & Howlett in press).

As 'evidence-based activism' also targets the definition of the condition itself, it is no surprise that health issues and the possible collective identity to which it relates might also be affected. Through 'evidence-based activism', patients' organisations explore concerned people's singular experiences and specific issues that echo their preoccupations. This involves back and forth movements between their members' situations and knowledge on seemingly comparable conditions. The chapter on rare diseases explicitly addresses this process of 'singularisation', and shows how patients' organisations' engagement in research encapsulates their reflexive work on the very notion of 'rareness' and on the relevant similarities and differences between their conditions and problems they encounter in regard to 'non-rare' diseases. Through this process of 'singularisation', patients' organisations formulate and experiment a new sort of relation between the particular *and* the general nature of conditions and causes. Rather than positing the existence of general causes which stand above patients' organisations' particular concerns and around which they may want to coalesce in order to demand interventions at a collective level, we examine how their epistemic efforts lead them to dig around *and* relate their singular problems to equally singular situations experienced by others. 'Evidence-based activism' thus helps to renew reflection on the fabrics of collectives and collective interests. In a similar vein, the chapter on Alzheimer's disease offers a look at how standardised care and person-centred care both

propose specific articulations between experiential and credentialed knowledge and expertise, and bring in different understandings of the process of singularisation *versus* the process of generalisation thereof (see also Moreira 2012).

Our contention is that the study of this process of singularisation (in contrast to the process of generalisation) is a fruitful way for understanding why and how patients' organisations, users' and activists' groups coalesce around (temporarily) related causes, and for gaining thick empirical and analytical insight into the dynamic of health activism. This, we hope, may help to open the 'black box' of health movements which are too often presented as *de facto* general new social movements in the domain of health and medicine.

### **Partnering with health authorities and medical professionals**

Although our focus so far has been on patients' organisations' activities, it would be inaccurate to see patients' organisations as isolated actors in their engagement in knowledge work. One aspect of 'evidence-based activism' that we address in this special issue is the variety of relationship that patients/users/activists establish with experts. Certain groups of patients and families concerned with rare diseases for instance develop full-blown collaboration with biologists, clinicians and industry, and contribute to the creation of communities of patients and specialists as actors in 'war on diseases'; other groups step back from biomedicine and call for social and human sciences research to address disability issues that they consider as important bottlenecks for patients' inclusion in society.

Not only patients' organisations, users' and activists' groups target different experts; they also adjust their encounter with these experts according to their priorities at certain moments in their history. In this respect, Blume's (2009) research work on deafness opened the way for a reflection on the variety of knowledge and credentialed experts that patients and activists ally with and/or oppose to. As he convincingly demonstrated, deaf communities' opposition to the medical professionals did not mean a systematic and total rejection of all credentialed knowledge. Instead, this meant an alignment with sociolinguistic research to establish that sign language is a language in and of itself, and to enhance the social and political recognition of deaf people as merely 'different' and not 'disabled'.

The proximity between experts and patients' organisations which results in some instances from these collaborations may lead to a blurring in the 'roles' and positioning of the involved actors. In the case of ADHD, for instance, certain specialists who develop close

relation with parents' groups and who share with them the same understanding of the disorder, come to defend their cause as much as families do. From this perspective, the networks of expertise that patients' organisations we studied form with credentialed experts share some features with what Haas (1992: 3) called 'epistemic communities', i.e. '*a network of people with recognised expertise and competence in a particular domain and an authoritative claim to policy-relevant knowledge within that domain or issue-area.*' Patients' organisations and experts they collaborate with participate to a joint epistemic and policy enterprise, through a collective investigation of the complex, multiple, and often uncertain links between knowledge, policy actions and their outcomes.

Unlike 'embodied health movements' (Brown et al. 2004), which also ally with sympathetic researchers but are associated with a confrontational culture and a larger social movement challenging existing forms of authority and power, patients' organisations which engage in 'evidence-based activism' do acknowledge the importance of scientific and medical collectives, but on the condition that they are considered as legitimate contributors to these collectives' activities and policies. To put it differently, they partner with these collectives with an aim at influencing their activities and policies by introducing their experience and concerns. They do neither simply oppose these collectives, nor do they merely become 'insiders'; rather, they act as *reformers*, with the ultimate goal of shaping the rules of the game differently.

This has consequences on the issue of medicalisation / demedicalisation. We argued above that patients' organisations which engage in 'evidence-based activism' do not simply stand outside of the medical world in a contesting and claiming position; they collaborate to a certain extent and on certain conditions with health authorities as well as medical professionals. As a consequence, one can reasonably ask whether childbirth movements – which have long been described as movements seeking for demedicalisation of birth practices – still deserve this labelling. In light of what we observed in four countries, we argue that the 'evidence-based activism' that these groups have embraced in the last years cannot be reduced to this problematic. Through the careful and expert analysis of medical literature and practices they develop, it becomes clear that what is at stake is much more a redefinition of obstetrics practices, with an aim at leaving room for women to take an active part in the decision-making process. As such, childbirth movements are no longer simply opposing a naturalistic or humanistic definition of birth to a medical one, but are trying to build an approach which revisits and articulates these different aspects.

A symmetrical analysis can be conducted on the issue of medicalisation. It has been argued (Barker 2005, 2011; Conrad 2007) that the emergence of a number of new pathologies such as ADHD or fibromyalgia corresponds to a reframing of social problems into medical ones. Forms of suffering that originate in poor conditions of life – whether they translate in disproportionate expectations on the individual performance, or in the incapacity of society to respond with humanity to the ‘normal’ dramas of existence – are put under the jurisdiction of medicine and transformed into treatable conditions. In this context, ‘evidence-based activism’ which articulates experiential knowledge to medical knowledge could be interpreted as enforcing this medicalisation trend, and depoliticising social problems thereof. The ADHD case suggests otherwise. Parents’ groups consider engaging with medical knowledge as a unique opportunity to get rid of the blame of bad parenting which, according to families, stigmatises them and offers nothing to solve the multiple problems encountered by the children and their parents, then to initiate a complete assessment of the child’s individual situation including all aspects of the trouble, and finally to elaborate a multimodal approach associating educational methods, psychotherapies, rehabilitation, medication and social care. For these parents’ groups, engaging with medical knowledge is conceived as a way for opening up an arena of negotiation with scientists, doctors, teachers and health professionals, and for scrutinising and ultimately acting upon social structures and processes which potentially lead to the exclusion of children with ADHD.

### **Evidence-based activism’s conceptual ambitions**

In the sections above, we outlined the key components that make evidence-based activism a distinct and significant form of mobilisation in the domain of health and health care. We suggested that these components work together to produce a form of activism that targets both epistemic and political issues and which, in this process, often transforms the very spirit of the organisations that deploy it: their cause, their constituency, their modes of activism, etc. Our attention to the dynamics of this type of activism is not solely motivated by a descriptive ambition but also by a conceptual ambition to explore the relationship between health, medicine and health movements in contemporary technological democracies.

We propose that evidence-based activism should be conceived not merely as a type of mobilisation in the domain of health but as partaking in the transformation of relationships between actors, groups and institutions, by actively contributing to the growing interconnection between previously separated spaces. From this perspective, evidence-based activism is part and parcel of the contemporary organisation of health care as described by

Clarke and colleagues (2009), contributing to the definition of medical practices, of medical research, and of care provision, by bringing to bear the figure of the patient. However, in so doing, they are confronted with the epistemic and political problems of representation that traverse contemporary biomedicine (Epstein 2007). This means that, in the process of producing knowledge on experiences and building a user's expertise on care organisations and medical practices, patients' organisations are also required to configure their members' abilities, equipping patients with knowledge of research practices, medical procedures and organisational formats. The mediating role that patients' organisations' play between knowledgeable patients and specialists is both a requirement for their involvement in the collective production of evidence, and a threat to their claim to such participation, making them liable to accusations of bias or corporatisation.

That evidence-based activism is not a confrontational form of mobilisation might sit uncomfortably with the focus of social movement scholarship in studying processes of conflict and contestation and its concern with progressive politics and social justice. Given evidence-based activism concern with knowledge, we find parallels between their strategies of reformist engagement and Stengers' s (2005) conceptualisation of the 'working with' the sciences to provide an opening to their social and political environment. Avoiding usual critiques of social constructionist analysis of knowledge making that traverse much of the so-called 'science wars', Stengers' interest represents an attempt to work with the traditions of modern science to re-invent or re-imagine them 'from within'. Again, there are risks associated with this strategy, as patients' organisations might be seen to become incorporated in others' agenda (Epstein, 2008). However, it is a consequence of having to articulate epistemic and political issues that patients' organisations are rarely able to stabilise their causes and become fully integrated. In the case of evidence-based activism, uncertainty works against assimilation and pacification around issues.

This propensity to generate political and knowledge uncertainties has effects on the way in which patients' organisations relate to their publics and to each other. Through an interactive and iterative articulation of experiential knowledge and formalised knowledge, patients' organisations contribute to the reorganisation of disease entities, clinical relationships and patients' identities. If, on the one hand, this mean they have to work hard at producing and maintaining the link between them and their members, it is also significant that this identity work becomes engulfed in fluid alliances with other patients' organisations and associated networks. These processes, which rely on joint moves of singularisation and

generalisation, make patients' organisations and evidence based activism privileged places to observe the dynamics of contemporary biomedicine, as their constructing linkages between different conditions and issues impinges on the framing and re-framing of what partakes in health care.

Another consequence of this is that it becomes difficult to ascertain boundaries of medicine and to study its expanding or diminishing remit. Rather than using a regional metaphor to describe how the emergence of medical categories comes to affect how persons interpret their situation and their relationship with others (Conrad 1992), we might instead want to draw on the image of the fluid (Mol & Law 1994) whereby a person, issue or object might be caught up in multiple, co-existing arrangements of the relationship between health, illness and politics. Again, evidence-based activism is a good site to investigate this multiplicity of biomedicine as patients' organisations engage with multiple issues simultaneously as a matter of course in their activities (Dodier & Barbot 2006).

### **About this issue**

This collection draws on a European research project called EPOKS (European Patients' Organisations in Knowledge Society<sup>4</sup>), whose objective was to study patients' organisations, users' and activists' groups' knowledge-related activities in four condition-areas – rare diseases, Alzheimer's disease, Attention Deficit Hyperactivity Disorder (ADHD), and childbirth –, and in four European countries – France, UK, Ireland and Portugal –. In addition, we studied European coalitions of patients' organisations, users' and activists' groups in the above-mentioned condition-areas, and notably knowledge-related activities they conduct in collaboration with their national and local level member organisations.

We chose the four condition-areas according to four criteria. Firstly, all four are considered as major public health issues in the four countries we examined. Secondly, all four benefit from patients' organisations, users' and activists' groups' intense involvement in knowledge-related activities. Thirdly, we were sensitive to the variety of knowledge and expertise that these organisations and groups mobilise, and notably to the fact that not all of them align with biomedicine. Fourthly, not all of them are stabilised from a scientific and medical point of view: ADHD for instance is the object of fierce controversies amongst specialists, whereas a more consensual definition exists for Alzheimer's disease. Our choice

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<sup>4</sup> This project benefited from a three-year financial support (2009-2012) from the 'Science in Society' initiative of the European Commission FP7.  
<http://www.csi.ensmp.fr/WebCSI/EPOKSWebSite/>

of childbirth warrants a specific mention here, for childbirth is not a condition *per se*. The reason why we included childbirth is two-fold: (i) childbirth, although considered as an intimate life event by activists' groups, is nonetheless strongly embedded in the medical realm; (ii) childbirth offers an interesting locus for studying activists' intervention in medical practices, and notably the critical appraisal of EBM that some activists' groups put at the core of their action.

Our approach was not to compare organisations and groups in light of the national contexts into which they evolve, nor did we compare them according to their organisational features. Although all those factors impinge on the politics of these organisations and groups, we approached them the other way around. We begun by identifying and analysing their modes of engagement with knowledge and the nature of evidence they mobilise, and then looked at how their epistemic activities transform the networks of expertise and issues to which they make themselves part and parcel of in their countries, as well as the content and scope of their activism. This approach stems from our hypothesis on the crucial role played by the epistemic work undertaken by these organisations and groups on their conditions and causes. This does not mean that we are not interested in similarities and differences between these organisations and groups, but that we consider these similarities and differences as the provisional outcomes of their reflexive work on their conditions and related issues. In addition, we observed that similarities and differences are also worked on by these organisations and groups through their alliances, notably within European coalitions, as well as through the circulation of experience and knowledge that they contribute to: quite pragmatically then, we looked at how these organisations and groups identify themselves vis-à-vis each other (if they do).

Our approach also consists of studying these organisations and groups as particularly interesting loci for addressing research questions on the role of knowledge in the shaping of political activities. We did not look at these organisations and groups for themselves, but for their contribution to collective actions that question the politics of health and the functioning of medical institutions. In doing so, we intend to take seriously into consideration the fact that these organisations and groups develop highly hybrid activities that cannot be simply be labelled advocacy or lobbying, opposition to, or alliance with institutions. Many scholars (Epstein 2008; Brown et al. 2004) rightly emphasise the hybrid or boundary nature of health activism and movements as one feature of contemporary patients' organisations, users' and activists' groups. This prompted us to look at how these organisations' and groups' range of

activities eventually change their public identification, and even for some of them, the boundaries of their membership.

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