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4.1 Final publishable summary report

4.1.1 Executive summary

EPOKS draws upon the statement that the last two decades have witnessed the increasing role of patient, user and civil society organizations (POs and CSOs) in the production and circulation of knowledge on diseases and health problems. Although there have been several case studies addressing the issue of POs and CSOs' involvement into the production of knowledge, few comparative studies across national contexts and condition areas are available. This is where EPOKS seeks to make an original contribution. Through a cross-national and cross-condition analysis, we aim (i) at deepening the understanding of similarities as well as differences between national organizations in France, Portugal, the U.K and Ireland, active in four conditions areas. These are the fields of rare and orphan diseases, childbirth issues, Alzheimer's Disease, and ADHD (Attention Deficit and Hyperactivity Disorder) and (ii) at reflecting on the form of activism they develop, as well as how they impact the governance of health issues.

Our project enabled us 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 mobilization in the governance of health issues. This concept denotes that knowledge is no longer a mere resource for grounding political claims; it is the very target of activism whose (provisional) outcome is the specification of what exactly people's situation is, and what it is the cause of.

Patients' organisations, users' and activists' groups which engage in 'evidence-based activism' display four main characteristics. Firstly, they situate themselves within the 'medical collective' they seek to influence. They are concerned with the framing of specific issues related to their condition, and with the elaboration of concrete answers. It is their engagement with knowledge that puts them in a position to raise and act upon issues that would otherwise have been out of their scope of intervention. Secondly, they collect and confront experiential and credentialed knowledge for making sense of their situation for themselves as well as for their interlocutors. Connecting these two bodies of knowledge, translating people's experience into the language of science and medicine and vice-versa, identifying zones of 'undone science', and/or of ignorance that should be investigated in order for them to formulate their intimate feelings, are crucial activities for them. Thirdly, they develop a variety of relations with experts. The network emerging from these alliances share some features with what is called 'epistemic communities', e.g. networks of people with relevant expertise who participate to a common policy entreprise, notably by investigating the multiple linkages between policy actions and their outcomes. Fourthly, through the work they undertake for framing their conditions and issues they are concerned, they may establish links with sister organizations and contribute to the generalization of causes thereof.

The same characteristics apply to the European patients' organizations we studied: our fieldwork helped us to demonstrate that 'evidence-based activism' allows these organizations to give shape and actively participate to the governance of European health strategies in their condition-areas, although health remains the domain of prerogatives of the Member States.

4.1.2 Project context and objectives

Context of the project

Those last decades have witnessed the increasing intervention of patients', users', and civil society organizations in activities and debates related to their condition. Some of them have become key players in biomedical research with an aim at fostering the war on their disease, a phenomenon that has attracted much attention from social scientists who have pointed to their shilfting role as passive patients to active lay experts. Other organizations, though not taking part in the biomedical entreprise, engage with knowledge, an activity that they put at the core of their mission. Rich and detailed case studies have been published on patients', users', and civil society organizations' participation to the production and circulation of knowledge, reflecting notably on how this impact on the politics of illness in various contexts. However, social sciences research is still needed to deepen our understanding of the form of activsim pertained by lay organizations' knowledge-related activities, and of the role played by these organizations in the governance of health issues, not only as social actors but also as epistemic actors. In addition, very few cross-national and cross-condition analysis have been performed so far: such analysis would document the growing entanglement between the governance of knowledge and the governance of health issues in contemporary societies, and the role of lay organizations in this process.

Our EPOKS project aimed at investigating these research topics. It stemed from a previous European Specific Action called MEDUSE, to which three out of the five partners of EPOKS took part. MEDUSE aimed to establish dialogue between various stakeholders on three issues with high political stakes: (i) the dynamic of patients' organizations in the European area; (ii) the emergence of new technologies and responsibilities for health care at home across diverse European systems and cultures; and (iii) cross-national and European perspectives on health safety agency. MEDUSE notably resulted into a conference gathering social researchers, patients' organizations (POs) and civil society organizations (CSOs), health professionals and health agencies. Observations and suggestions made durign the conference, together with the analysis of the literature, lead to the following statements which constituted the baseline for EPOKS project.

Firstly, the intervention of POs and CSOs in knowledge-related activities takes up different forms. The literature has documented their role as co-producers of knowledge through their engagement with specialists in activities directly related to biological and clinical research. Discussion during the MEDUSE conference also highlighted their role as connectors or translators between different species of knowledge, through the collection and circulation of data and information. In addition, discussion suggested that what is termed "knowledge" should not be restricted to lay and certified medical knowledge on diseases per se; knowledge extends to patients' rights, the functioning of health services, the availability of diagnostic and therapeutic tools, achievements of lay organizations on shared or similar issues, economic pressures, political decisions at the national and European levels, and even tacit knowledge and embodied know-how on policy-making within institutions, or on the best way for putting claims forward in different arenas.

Secondly, the way lay organizations are involved in the production and circulation of knowledge depends on the causes they intend to defend. In particular, their propensity to embrace or to challenge biomedical knowledge is highly sensitive to their vision of how much and to what extent the biomedical repertoire either exerts a domination that might threaten their struggles, or is amenable to transformations that might help them to campaign for what they are standing for. Some organizations may find it crucial to create tight relationships with biomedical practitioners, and to translate their experience and needs in the language of biomedicine. Conversely, other organizations may enter into the very details of evidence-based medicine (EBM) in order to point out its inconsistencies, and to be able to react to EBM-driven initiatives that they feel threatening for their causes.

Thirdly, the involvement of POs and CSOs in the co-production of knowledge does not take place in a void of collective and institutional actions. Lay knowledge is more often than not caught into a complex web of expertise, whose scope and degree of coherence depend on the conditions at stake. In certain cases, various forms of expertise progressively organize around the structuring of a corpus of biomedical knowledge to which patient organizations actively contribute. In other cases, the proliferation of actors involved, combined with multifaceted tensions between various forms of knowledge, creates predicaments and uncertainties for patient organizations.

Fourthly, the number of European coalitions has dramatically increased over the last years. Some factors, such as the expansion of evidence-based medicine and the globalization of innovation processes in the field of diagnosis, therapeutics and drugs, explain why local or national organizations coalesce at the European level. A number of factors, such as the diversity of health systems across countries or the maturity of civil society organizations in different national contexts, also counterbalance the trend towards European coalitions. The complex interplay between these various factors results in the diversity of European coalitions. Of particular interest for us here is a question on if, how, and to what extent these various Europeanization 'patterns' possibly contribute to a tendency for organizations to become increasingly similar, to a certain degree of standardization and harmonization of their frames of understanding and modes of knowledge production and dissemination.

Objectives of the project

EPOKS aimed at taking the observations stated above a step further. It examined national patients', users', and civil society organizations active in four conditions-areas – rare diseases, Alzheimer's disease, ADHD (Attention Deficit Hyperactivity Disorder), and childbirth –, in four countries – France, UK, Ireland, and Portugal –. In addition, EPOKS partners studied European coalitions active in the four condition-areas, namely EURORDIS (European Organization of Rare Diseases, Alzheimer Europe, ADHD Europe and ENCA (European Network of Childbirth Activists). The condition-areas were chosen according to four criteria. Firstly, all four are considered as major public health issues in the four countries examined. Secondly, all four benefit from patients', users', and activists' organizations intense involvement in knowledge-related activities. Thirdly, EPOKS partners were sensitive to the variety of knowledge and expertise that these organizations mobilize, and notably the fact that not all of them align with biomedicine. Fourthly, not all of them are stabilized 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. The choice of childbirth warrants a specific mention here, for childbirth is not a condition *per se*. The reason for its inclusion is two-fold: (i) childbirth, although considered as an intimate life event by activists' groups, is nonetheless strongly embedded in the medical realm; and (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.

EPOKS had four major objectives:

1. Characterizating patients', users', and civil society organizations' modes of involvement in the production of knowledge and expertise

As stated previously, the role of lay organizations in the production of knowledge depends on the form of activism they develop, as well as the causes they stand for. The nature of knowledge that they contribute to, the tools and procedures that they implement for collecting, shaping and circulating information and data, need to be empirically studied as regards the claims they put forward, and their modes of action. In order to achieve this first objective, EPOKS partners planed empirical case studies of national organizations in the four condition-areas they selected, to address two main questions:

- First, to what extent do the very nature of the organization and its functioning impact upon the way it conceives of knowledge-related activities? Certain organizations mostly act as information providers to their members, or as experience providers, as many self-help groups do. Other organizations may conceive their intervention in the production of knowledge as a way to complement, question, or oppose certified expertise as sometimes happens in advocacy groups. Still others may privilege social activities and delegate knowledge-related tasks to sister organizations.
- Second, how and to what extent the causes that lay organizations stand for influence their role in the production of knowledge? The generation of lay knowledge cannot be studied apart from the missions that these organizations have taken up, and the stakes they are facing.

2. Making a cross-national comparison between patients', users', and civil society organizations' modes of engagement in the production of knowledge

The roles of lay organizations as sources of knowledge depend not only on their internal features, but also on national contexts. Provision of care, organization of health services, functioning of regulatory bodies, recognition of patients, users, and lay people by medical institutions and political authorities, public awareness on issues raised by various activists, all impact on lay organizations' engagement in knowledge production. As a consequence, the role of lay organizations as interested parties in the governance of knowledge, as well as in the promotion of their experience and expertise in the governance of health and medicine, differ from one country to another. EPOKS partner decided to investigate and compare specific examples in which these issues of governance are at stake, and display similarities as well as differences in various national contexts. These examples might concern lay organizations' participation in:

- The production and circulation of various forms of knowledge onto which normative documents such as clinical guidelines or recommendations are elaborated.
- The collection and dissemination of various forms of knowledge through awareness campaigns aimed at sensitizing public authorities and the general public to specific issues.

- Conflicts of expertise about the provision of care or the administration of specific drugs or therapies.

These detailed examples aimed at documenting interactions and cross-fertilization between different forms of knowledge in various national contexts and condition areas. EPOKS parteners inteded to look at lay organizations' positioning vis-à-vis certified knowledge: do they stand on an equal footing with other experts? How do other actors in the domain of health and medicine consider experiential knowledge?

3. Mapping and analysing the network of expertise and issues to which patients', users', and civil society organizations participate

As mentioned earlier, patients', users', and civil society organizations tend to coalesce within larger movements. These alliances develop in various forms: some are formal whereas others are not; some are perennial whereas others are temporary; some include professional groups, whereas others exclude them. The way lay organizations intervene into the production of knowledge depends on their positioning vis-à-vis various stakeholders in these networks. This is why the co-production of knowledge is part and parcel of the governance of health and medicine. Besides, networking transforms their public identification: by allying with or opposing certain actors, including sister-organizations, whose expertise and claims they consider coherent or divergent with their own orientations, they are led to adjust their self-description and actions. EPOKS partners planned to describe the web of expertise and issues to which lay organizations participate, e.g.:

- To identify key actors in these networks, in particular those who play a major role in their structuring and articulation.
- To characterize the links between various patients', users', and civil society organizations active in these networks, and between lay organizations and medical research and health institutions, economic actors, regulatory bodies, etc.
- To highlight collective actions and positions which lay organizations ally themselves or which they oppose within these networks. This network analysis would be conducted both at the national and cross-national levels. Indeed, one can assume that networking is instrumental to the mutual learning between organizations from different countries, especially as regards forms of intervention into the production of knowledge.

4. Describing the dynamics of the "Europeanization" of lay organizations, and its effects on the governance of knowledge and the place of knowledge in the governance of health and medicine

Over the last years, European coalitions of patients, users and citizens have multiplied in the domain of health and medicine. Very little is known on the types of organizations that these European coalitions actually constitute. At the very least, it is fair to say that they are the locus for exchanges between various local and national organizations, and may, in certain circumstances, be the locus for elaborating common political positions and collective actions. The objective was not to study these European coalitions in-depth, but rather to capture their role in the shaping of certain forms of governance of knowledge in health policy-making. EPOKS partners planed to examine two mechanisms:

- Europeanization process "from below", e.g. through the ways lay organizations conceive their links with supra-national coalitions (if any), and envision the distribution of tasks and prerogatives between the national organizations and European coalitions as regards the promotion of lay experience and expertise in the definition and treatment of problems they are concerned with.
- Europeanization process "from above", e.g. through the forms of governance of knowledge and health issues that these European coalitions actually promote. A particular attention would be paid to the ways these European coalitions disseminate certain form of know-how that enforce patients', users', and citizens' empowerment, and transform their member organizations' capacity to engage with medical research and health institutions in their own countries.

4.1.3 Main S&T Results / Foregrounds

'Evidence-based activism': Patients' organizations, users' and activists' groups' engagement with knowledge and their role in the governance of governance of health

Over the last two decades, social sciences 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 (Sociology of Health & Illness, 26(6), 2004; Social Science & Medicine 62(3), 2009), as well as edited books (Lofgren, De Leeuw & Leahy, 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 reflection on the analytical concepts and frameworks that best capture the role of patients' organisations, users' and activists' groups in these compound processes.

Our cross-condition analysis of patients' organizations, users' and activists' groups pronouncements and actions enabled us to take this body of research a step further, and 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 dynamic of patients' organisations, users' and activists' groups, and are impacting on the so-called 'knowledge society' in contemporary democracies. Before delineating what exactly we mean by 'evidence-based activism', we first present the state of the art and our previous contribution to this literature.

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; Stockdale, 1997).

Firstly, these authors have stressed the emergence of new forms of activism in which patients' organisations do no longer content to provide help to their members and/or to advocate 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 rare genetic diseases and HIV/Aids[1], 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 in biological, clinical and therapeutic research. Patients' organisations have thus decided to intervene in biomedical activities with a view to launching and accelerating the 'quest for cure'. In his pionnering work on Act-Up, Epstein (1995) coined the term 'treatment activism' to feature activists' concern with the fight against the disease. In our study of the AFM (*Association française contre les myopathies* – French association against myopathies), we pointed to the organisation' s shifting interests from directly helping patients and their families to combating the disease, a detour that the AFM considered as a relevant and promising avenue for securing a better future for people suffering from myopathies (Rabeharisoa & Callon, 1999; Rabeharisoa, 2006). In contrast to previous patients' organisations, which formed around chronic diseases (Armstrong, 1993; Coppa & Boyle, 2003) and were mainly preoccupied with helping patients to cope and manage their illness trajectories (Corbin and Strauss, 1988), Act-Up, the AFM, and a few others, targeted diseases themselves and put them centre-stage of their mobilisation.

Secondly, patients' organisations' concerns with the disease and its exploration has come with a redistribution of competencies and prerogatives between patients and credentialed experts. Certain patients and activists acquired scientific and medical knowledge, and turned to be 'lay experts' (Epstein, 1995), e.g. credible interlocutors of specialists. Patients' organisations also collected, formalized and circulated patients' experience as a legitimate body of 'experiential knowledge' (Arskey, 1994; Borkman, 1976) on their conditions, and became what we called 'experts of experience' (Rabeharisoa & Callon, 2004). 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 dissemination of knowledge, and has impacted the dynamic of health activism. This is not to say that the contesting character of patients' organisations has totally disappeared, but that new modalities of articulation and confrontation actually bring together these organisations and specialists to negotiate the scope of epistemic arenas for their conditions and the nature of knowledge which circulates within.

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[1] At a time when the nature and scope of the epidemics have raised heated debates among specialists.

Thirdly, studies of patients' organisations' engagement in biomedical research have revealed the evolving nature of patienthood (Landzelius, 2006). Not only patients cease to be passive and take an active part in the understanding of their conditions (Barbot, 2006); their self-description also changes along their participation to research on their disease. For instance, we noted how some families (and doctors alike) who long saw their relatives who had myopathies as 'defects of Nature', progressively considered them as full-fledged human beings suffering from genuine diseases and who deserved to be recognised and treated as such (Rabeharisoa & Callon, 2004). Patients' organisations' contribution to the production of knowledge thus transforms the epistemic nature of their condition *and* raises the social status of affected people in the same move. This sometimes results in a new form of sociality between patients – one that Rabinow (1999) called 'biosociality' –, as well as of solidarity manifested by public donations to research on a range of 'high profile' diseases. We should not romanticise this move however: Epstein (1995) 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 loose sight of concerned people' s problems.

By and large then, patients' organisations' engagement in research has offered a particularly interesting locus for social scientists to study lay people and their representatives' contribution to the fabrics of 'knowledge society', and the increasing role played by techno-sciences in the dynamic of democratisation of democracy (Callon et al., 2001, 2009).

Not all patients' and activists' groups engage in biomedical research as did the organisations mentioned above however. But when looking at these groups' pronouncements on their websites, it is clear that knowledge-related activities are not alien to their missions. It is reasonable to argue that the development of internet tools has facilitated the circulation and access to various bodies of knowledge on a wide range of conditions, thus raising scientific literacy. Online communities of patients and activists have rapidly multiplied, some of them discussing credentialed knowledge and confronting them to people' narratives (Dumit, 2006; Radlin, 2006), and even becoming epistemic communities on their own as one of us demonstrated (Akrich, 2010). Beyond online forums, many 'classic' patients' organisations, users' and activists' groups also engage in a reflexive work on knowledge, know-how and experience, staging, weighting up, sorting, assessing, and reordering heterogeneous sets of information and data on their conditions and health problems they are concerned with.

This reflexive work echoes, as much as it partakes to a number of aspects of 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) for example, which is one the condition-area we studied. It also relates to the development of EBM that puts an end to the hegemonic domination of the individual clinician; somehow, patients' organisations, users' and activists' groups contribute to the transition from the 'clinical tradition' to what Dodier (2003) calls 'the therapeutic modernity', as much as they deploy a critical appraisal of this new 'medical regime', as our study of childbirth activism shows. Cambrosio et al. (2006) 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. Furthermore, 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. 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. This 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, as we demonstrate in the case of Alzheimer' s disease (see also Moreira, 2011).

We propose the term 'evidence-based activism' to capture the variety of patients' organisations, users' and activists' groups forms of engagement with knowledge, the intervention of some of them in biomedical research being a spectacular but extreme case on a broader spectrum of activities. This term also aims at drawing attention to the multiplicity of knowledge that these organisations and groups are mobilising, biomedical knowledge being just one sort amongst many others (EBM, health technology assessment, public health research, judicial expertise etc.). More importantly, we coin the term 'evidence-based activism' to explore what we consider as an important shift in patient and health activism. '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 for people to be treated (medically and socially) the way they feel appropriate. In this process, knowledge is no longer a mere resource for grounding political claims; it is the very target of activism whose (provisional) outcome is the specification of what exactly people's situation is, and what it is the cause of. We expand on this new form of activism in the next sections.

What is 'evidence-based activism' about?

To begin with, it is worth clarifying a series of terms that are sometimes used concurrently. Those are the terms 'knowledge', 'evidence', and 'expertise'. In our project, knowledge, be it credentialed knowledge or 'experiential knowledge', designates 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 featured 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. Another example we examined is Alzheimer's disease: what it is for patients may be different from what it is for their families and carers. Expertise denotes the capacity of an individual or a group to define health issues at stake and to reflect on the way they should be dealt with, this expertise being endowed with a certain degree of credibility due to the fact it draws upon the mastery of specific knowledge. Evidence results from the selection and articulation of knowledge statements in order to produce forms of expertise: it aims at providing proofs on how patients' and activists' conditions or situations ought to be understood and treated. Evidence thus is a mediating tool between knowledge and expertise.

This is not to say that knowledge is strictly objective and factual, and evidence purely normative and political: what we intend to emphasize is the process through which 'matters of fact' are turned into 'matters of concern' (Latour, 2005). 'Evidence-based activism' precisely entails patients' organisations, users' and activists' groups' reflexive contribution to this process. It is this process, and its transformative effects on the causes that patients' organisations, users' and activists' groups form around, that we explored in our project.

'Evidence-based activism' is crucial for unsettled conditions such as ADHD, e.g. for '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. Our contention however is that patients' and activists' interest in knowledge is not restricted to these sorts of condition-areas. 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 and individual and a collective level, for the benefits of concerned people. Take Alzheimer' s 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 (Moreira, May & Bond, 2009), 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 mobilize other bodies of knowledge than the one which is considered as relevant from a medical point of view, namely neurosciences. The concept of 'evidence-based activism' aims at capturing the role of patients' organisations, users' and activists' groups in the shaping of health issues that they deem important to tackle, and the work they undertake for sorting knowledge and producing evidence on what their condition is, and on how it ought to be taken care of.

Shaping health issues and governing health policies: activists' groups' positioning as 'insiders'

One significant characteristic of patients' organisations, users' and activists' groups which engage in 'evidence-based activism' is their reformist orientation: they situate themselves within the 'medical collective' they seek to influence. Unlike Embodied Health Movements (EHMs) (Brown et al., 2004), associated with a confrontational culture and a larger social movement which challenges existing forms of authority and power, they partake in – or at least aspire to – the construction and renovation of medical practices and care services along with health professionals, researchers, public institutions and political authorities. More importantly, they are less concerned with the expression of general claims than with the framing of specific issues related to their condition, and with the elaboration of concrete answers; they are, so to speak, pragmatically acting 'from the inside'.

A number of studies have looked at the emergence of new forms of governance of health policies (Coulter, 2002; Hogg & Williamson, 2001; Lofgren, De Leeuw & Leahy, 2011; O'Donnell & Entwistle, 2004), and have questioned how and to what extent patients' organisations, users' and activists' groups intervene into the fabrics and monitoring of health policies. Very few of them however have investigated the epistemic activities that these organisations and groups deploy for contributing significant changes in health issues at stake: above-mentioned 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: although these authors first and foremost studied the potential role of these groups in promoting institutional changes, they rightly evoked these groups' expertise which endows them with political legitimacy and power. We took this a step further and examined how patients' organisations, users' and activists' groups produce and mobilise evidence for shaping health issues *and* contributing to their governance.

The extent to which these groups are actually involved in policy-making activities depends on the degree to which the participation of patients/users/consumers to the governance of health issues has been institutionalised in each country. Despite national differences however, our case studies together suggest that groups which engage in 'evidence-based activism' adopt similar approaches. For example, although Ireland does not recognize patients' and activists' participation in the same way and to the same extent as UK does, the Association for the Improvement of Maternity Services in Ireland (AIMSI), like its British sister organisation, develops a strategy based on surveys among women in order to highlight issues and 'bring them to the table' of the Irish Department of Health and of maternity units. All the groups we studied put forward arguments underpinned by substantial evidence in order to challenge 'technical' statements mobilised by their interlocutors. It is the activists' groups' engagement with knowledge that puts them in a position to raise and act upon issues that would otherwise have been out of their scope of intervention.

The case of childbirth activism that we studied in this project offers an interesting example. Through the collection of EBM data and its confrontation to women's experience drawn on surveys they conduct, childbirth activists' groups come to produce evidence on the lack of clinical effectiveness of procedures such as episiotomy or fundal pressure[2], and to scrutinise medical practices that are massively used in certain countries: this results in the elaboration of recommendations for clinical practices that clearly point to the limits of these medical interventions. In doing so, childbirth activists' groups do not simply align with feminist movements that have fuelled childbirth activism; they also enter the 'black box' of childbirth practices and question the nature and place of obstetrical interventions. This has unexpected consequences on their own causes: demedicalisation *per se*, which was claimed by childbirth movements in the 1970s and 1980s, is now tainted with issues of best practices that may encompass, in certain situations, medical interventions that some women may consider relevant in their situations. This example highlights a number of interrelated aspects of 'evidence-based activism' that we develop in the following paragraphs: the compound nature of the knowledge that activists' groups mobilise, the fact that their causes and conditions, and even the contours of concerned groups may evolve through their work on and with knowledge, and the reframing of the medicalisation / demedicalisation debate.

Hybridizing knowledge: activists' groups as representatives of concerned people and as mediators between them and the health system

So far, we have insisted on the link between the production of experiential expertise by patients' organisations, users' and activists' groups, and their intervention in the governance

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[2] An incision of the perineum and the posterior vaginal wall during labor.

of health issues; in doing so, we have brought these groups closer to professional actors. In this paragraph, we would like to stress that although they comply with some 'professional' standards, they do not simply align on credentialed knowledge. Their involvement as patients' representatives translates into a specific and intense entanglement between credentialed knowledge and 'experiential knowledge'.

Following Allsop et al.' (2004) typology, the groups that we studied clearly identify as 'condition-based groups'. They do not however consider that their condition is settled once and for all; they actively contribute to its definition and transformation through the interplay between their experience and advances in medical knowledge. The patient organizations included in our proejct collect and confront experiential and credentialed knowledge for making sense of their situation for themselves as well as for their interlocutors. Connecting these two bodies of knowledge, translating people' s experience into the language of science and medicine and vice-versa, identifying zones of 'undone science' (Hess, 2009; Frickel et al., 2010), and/or of ignorance that should be investigated in order for them to formulate their intimate feelings, are crucial activities of patients' organisations, users' and activists' groups. These activities progressively constitute a seamless web of pieces of credentialed knowledge and 'experiential knowledge' that crafts patients' and activists' situation.

The case of ADHD that we studied is very telling in this regard. Parents' groups search, evaluate, and put together various bodies of credentialed knowledge in light of their experience, which in turn is reordered and expressed in a language that intertwines medical descriptions of the disorder and parents' narratives. The production of these mix statements on the condition is exactly what we mean by turning 'matters of fact' into 'matters of concern'. In the case of ADHD, parents' concern is about medical uncertainty that sometimes leads specialists to deny the very existence of the condition, whereas as parents, they do experience ADHD as a serious disorder.

The articulation between different bodies of knowledge is intimately linked to the issue of representation: who are patients' organisations, users' and activists' groups representing? What allows them to speak on behalf of the people they claim to speak for? This question, asked both by health professionals and political philosophers (see for example Schicktanz, 2012), receives a very practical answer from patients' organisations, users' and activists' groups. For these groups, representativeness stems from straightforward means, such as the collection and analysis of data reported in the subscription form to the groups, or the collection of narratives gleaned in support activities (help lines, internet forums, speech groups). It can also entail a sophisticated work on and with knowledge, as is described in our case report on Alzheimer's diseases groups. In Ireland as well as in UK, AD societies have mobilized, and have even renovated social research methods, in order to voice 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. This has resulted into various reports and position papers mixing up different species of evidence, articulating qualitative evidence with quantitative ones, 'objective' measures with 'subjective' accounts, etc. This hybrid format is a widespread characteristic of the experiential expertise produced by patients' organisations, users' and activists' groups, and can be understood as the expression of their mediating role between concerned people and the health care system, as well as of their dual involvement in support and in advocacy activities.

The hybridization and articulation between experiential and credentialed knowledge that patients' organisations, users' and activists' groups undertake witness the fact that knowledge is not a mere resource that these groups carve out for promoting institutional changes. Knowledge is also the target of their activism for defining their condition and related issues, and consequently, for deciphering the population that they intend to represent and serve. In the case of certain rare diseases, this can lead to the opening of new scientific avenues: it was the evidence brought in by a patients' group concerned with 22q11 deletion syndrome that led to the investigation of the links between this syndrome and some psychiatric disorders, potentially redefining both the 22q11 deletion syndrome (including its prevalence) and psychiatric disorders. As a consequence, the population formerly concerned with the 22q11 deletion syndrome may well extend to people with certain psychiatric disorders in the near future.

These different configurations offer an understanding of complex and variable arrangements of knowledge-related activities and political actions. However, our contention is that not only knowledge is part and parcel of today' s politics; political action is also a mean through which epistemic changes are promoted, and eventually institutionalised. Interlinked platforms (Keating & Cambrosio, 2003) for research and clinical activities, associating medical and health institutions, patients' organisations, industry and regulatory bodies in the area of rare diseases for example, 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.

In what precedes, we have focused on the work on and with knowledge which is needed to translate grassroots preoccupations into relevant policy claims, and which consists in making the former counts in policy-making arenas by producing evidence able to articulate experiential knowledge with formal/credentialed knowledge. But it should be emphasized that a 'symmetrical' move can be observed: patients' organisations, users' and activists' groups put significant efforts in providing patients, users and activists with information which helps them to voice their concerns and preoccupations at their individual level. This implies translating scientific data into a language that lay people can work with, and equipping them with evidence that support their demands in the dialogue with their interlocutors. Rare diseases patients' organisations for example equip their members (as well as professionals) with various knowledge and experience for them to be able to approach these conditions in an appropriate way, and to raise issues of organisation and provision of diagnosis, medical and social care.

Networking of expertise and issues: activists' groups' as part and parcel of epistemic communities

It should not be concluded from what precedes that patients' organisations, users' and activists' groups stand alone while engaging in their work on and with knowledge. One aspect of 'evidence-based activism' that we observed is the variety of relations 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 ally with medical doctors and researchers in social and human sciences with an aim at addressing 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. 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. They actually mobilised sociolinguistics to establish that the sign language is a language in and of itself, and that deaf people must therefore be considered not as 'disabled' people but as 'different' people who deserved full social and political recognition.

In some cases, such collaborations may blur the 'roles' and positioning of 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 turn into experts of the condition. Such alliances between activists and 'sympathetic' researchers have been already highlighted in the analysis of Embodied Health Movements such as environmental health movements (Brown, 1997; Allen, 2004); however these cases display an opposition between two groups of researchers, the first and larger one being constituted of researchers whose perspectives are aligned with the dominant epidemiological paradigm (DEP), whereas the second one being composed of researchers who ally with lay activists and challenge the DEP. The alliances established between the groups we studied and researchers do not necessarily display this oppositional structure, and even though they sometimes do, as in the case ADHD for example, they do not map on an opposition between the DEP and an alternative option.

Conversely, the network emerging from these alliances share some features with what Haas (1992) called 'epistemic communities', e.g. networks of people with "recognized expertise and competence in a particular domain and an authoritative claim to policy-relevant knowledge within that domain or issue-area" (p.3): they participate to a common policy entreprise, notably by investigating the multiple linkages between policy actions and their outcomes, in a context characterized by numerous uncertainties. The groups we studied often engage with their allied scientists into a joint enterprise which is both epistemic and political, resulting in the reframing of their causes and conditions.

Reframing conditions and causes

Patients' organisations, users' and activists' groups' engagement with knowledge results in a twofold dynamics. Firstly, it contributes to the definition of their causes and strategies; efforts they devote to represent their member's problems, needs and expectations come, by construction, with a reflection on the objectives towards which these efforts are targeted. In some cases, these efforts may even determine the causes that these organizations defend: the Irish childbirth organisation is an example of such a configuration in which the absence of a shared 'ideology' amongst volunteers, as well as the non-existence of an institutional demand, leave room for the emergence of a series of actions inspired by the results of the increasingly sophisticated surveys it undertakes: for example, as a survey revealed difficulties in accessing comprehensive information on the benefits and risks of a range of maternity related procedures, AIMSI decided to produce the *Healthy Birth Directory for the West of Ireland* (2011) and to launch of a campaign highlighting the inadequacy of consent procedures in Irish maternity units. In other cases, where groups are urged to participate to the governance of health and 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: the British elaboration of a consensus statement on 'normal birth' offers a striking example of the kind. Starting from a 'radical' perspective on 'normal birth' which excluded any medical intervention, the childbirth activists' group engaged into the collection of data in order to evaluate its prevalence; this led them to progressively forge a very different notion of 'normal birth' that would be workable, measurable and acceptable by professionals, and thus to deflect in a significant way their own politics.

Secondly, as 'evidence-based activism' also targets the very definition of the condition, it does not come as a surprise that health issues and collective identities may evolve. Indeed, 'evidence-based activism' involves back and forth movements between people's singular experience and broader issues that echo their preoccupations. Through this process, it is the singular *versus* general nature of conditions and causes which is formulated. Rare diseases organizations explicitly address this process: their engagement in research encapsulates their reflexive work on the very notion of 'rareness' and on the similarities and differences between their conditions and problems they encounter in regard to 'non-rare' diseases. Rather than positing the existence of general causes that drive patients' organisations, users' and activists' groups' politics, we examined how their epistemic efforts eventually lead them to generalise their concerns and to demand interventions at a collective level. In the case of Alzheimer's disease organizations, we notably looked at how standardised care and person-centre care both propose particular articulations between experiential and credentialed knowledge and expertise, and bring in different understandings of the process of singularisation-generalisation thereof.

Our contention is that the study of this process of singularisation-generalisation is a fruitful way for understanding why and how patients' organisations, users' and activists' groups coalesce around (temporarily) common 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. One point which is worth noticing is that although EHMs and 'evidence-based activism' share certain characteristics, especially the centrality of knowledge issues in the definition of causes and the entanglement of expert knowledge with 'experiential knowledge', EHMs mainly focus on activists' challenges to the restrictive definition of their condition and do not really address the organisation and provision of care, whereas 'evidence-based activism' questions what exactly their condition is the cause of, and what sort of health issues are accordingly at stake.

To recap, 'evidence-based activism' entails patients' organisations, users' and activists' groups' reflexive work on knowledge on their conditions or situations, and on evidence that enable them to give shape and to contribute to the governance of health issues that they deem important.

Revisiting the issue of medicalisation / demedicalisation

We have insisted on the fact that the groups we studied can be considered as participating to the governance of health issues: they do not simply stand outside of the medical world in a contesting position; they accept to collaborate to a certain extent 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 demedicalisation – still deserve this labeling. In light of what we observed in four European countries, we argue that evidence-based activism that these groups have developed in the last years can no longer be reduced to this motto: through their careful and expert analysis of the medical literature and practices, they have clearly contributed to the redefinition of obstetrics which has progressively left room for women to take an active part in the decision-making; they are no more opposing a naturalistic or social definition of birth to a medical one, but are trying to build a compound approach in which the articulation between these different aspects can be taken into consideration.

A symmetrical analysis can be developed as regards medicalisation: it has been argued (Barker, 2005 & 2011; Conrad, 2007) that the emergence of a number of new pathologies such as ADHD, fibromyalgia etc. corresponds the transformation of the experience of suffering into a treatable condition, due to modern expectations of individual's performance, or to the incapacity of modern societies to respond to 'normal' dramas of existence in a human way. In this context, evidence-based activism which articulates experiential knowledge with medical knowledge could be seen as mirroring this medicalisation trend. Our study of ADHD groups displays a contrasted configuration: the medicalisation of ADHD promoted by parents' groups appears as a unique opportunity, firstly, to get rid of a psycho-social interpretation which, according to them, fails to bring any solution to the multiple difficulties encountered by children and their families, secondly, to initiate a complete reassessment of each individual situation which includes all aspects of the disorder, and thirdly, to elaborate a multimodal therapeutic approach associating pedagogy, as well as psychology, rehabilitation and medical care. Interestingly, instead of resulting in a de-politicisation of ADHD, its medicalisation has opened up an arena for negotiation and action in which parents' groups scrutinize the potential exclusion of their children by actual social structures and processes.

To conclude this summary of our main findings, we would like to recall the approach we adopted in our project. Our approach consisted of studying patients' organisations, users' and activists' 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 intended to take seriously into consideration the fact that these organisations and groups develop highly hybrid activities that cannot be simply be labeled advocacy or lobbying, opposition to, or alliance with institutions. Many scholars (Epstein, 2008; Brown et al., 2004) rightly emphasized the hybrid or boundary nature of health activism and movements as one feature of contemporary patients' organisations, users' and activisits' 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.

Europeanization and Evidence-based activism

The last two decades have witnessed an efflorescence of EU lobbying organizations, including European civil society organizations. A recent estimate is that on a daily basis 15,000 EU Commission and parliamentary officials face 20,000 lobbyists; business organizations predominate, with civil society organizations constituting approximately 20 per cent of EU accredited interest groups (Coen, 2007). Patients' organizations too have been part of this 'rush to Europe', as attested by this quotation from a report by the Brussels-based consultancy firm FIPRA:

Today, patient groups matter more than ever. Their numbers have increased, they are more professional, and they have a louder voice in the healthcare debate, even sitting on regulatory bodies such as the European Medicines Agency (EMA). (FIPRA, 2010)

This is of particular significance because healthcare is a major area of the welfare state in which the EU has in the past had little involvement but one which has in recent years witnessed an increasing Europeanization of policy (Greer, da Fonseca and Adolph, 2008). Despite acknowledgements of the ascent of European patient advocacy however, very few studies have explored the species of organizations that European patients' organizations constitute, and the forms of activism they develop. Our EPOKS project is a research initiative that began to explore these issues.

Our study of European patients' organizations active in the four condition-areas we selected for our project – namely Alzheimer Europe, EURORDIS (European Organization for Rare Diseases), ADHD Europe (Attention Deficit Hyperactivity Disorder), and ENCA (European Network of Childbirth Activists) –, shows that these organizations cannot be considered as mere interest groups. They do of course lobby the European institutions to defend their constituencies' interests at European level, and sometimes protest against certain European decisions promoted by other civil society organizations like certain environmentalists which fight against animal experimentation or the dissemination of bio-products. More importantly however, and with the exception of ENCA, they contribute to the elaboration and the implementation of European health policies in collaboration with their national member organizations and various national and European stakeholders in their condition-areas. In particular, they collect, produce, format and circulate a series of data and figures pertaining to issues they deem important to be tackled at European level, notably the issue of availability of, and equal access to diagnosis, treatment and care. Our notion of 'evidence-based activism' thus aptly describes the form of action that these European patients' organizations develop. In this summary, we highlight how and to what extent 'evidence-based activism' allows these European patients' organizations to construct and sustain a Europe of patients and for patients.

Shaping European causes and building European communities of patients

We first raised the question: what exactly is a European patients' organization? One would intuitively answers that it is a group which represents all European patients suffering from one disease and/or concerned with one health problem. This definition however neither illuminates the reasons why patients come to coalesce at European level, nor does it clarify the modes of representation that these coalitions adopt. To examine these pending questions, we drew on della Porta's and Caiani's (2009: 25) notion of 'Europeanization from below', defined as Europeanization of and by civil society. We investigated how the European patients' organizations we studied formed, and how they formulated their claims. Our fieldwork unable us to demonstrate that all four organizations we studied were of grass-root origin, and that they undertook an important work for framing their condition as a relevant European cause and for organizing accordingly.

Alzheimer Europe was founded in 1990, at a time when national Alzheimer organizations already existed in different European countries. The rationale for grouping these national organizations within Alzheimer Europe was to scale up political advocacy in order to put pressure on Member States to design national plans on Alzheimer's disease. Alzheimer Europe does not intend to address any single problem that patients with AD experience in their countries – this falls under the prerogatives of national organizations –, but to be the exclusive legitimate interlocutor of European institutions on global policy matters related to Alzheimer's disease. Hence its representation monopoly of national Alzheimer organizations at European level.

EURORDIS intends to be the voice of patients with rare diseases in Europe. In contrast to Alzheimer Europe however, it had to render rare diseases visible as a relevant public health problem for Europe. EURORDIS was formed in 1997, on the basis of the 'concept of rare diseases' it elaborated after patients' experience. This concept denotes the fact that despite the heterogeneity of rare diseases, patients and families confront similar problems whatever their condition and their country of origin: difficulties for obtaining an accurate diagnosis, absence of treatments and dire provision of care, lack of robust knowledge and organized expertise. Gathering all individual patients and their representative organizations within a multi-constituency umbrella organization, and helping the establishment of national rare diseases alliances, were powerful means to advocate for the need for a European global strategy on rare diseases which, according to EURORDIS, altogether affect about 30 million individuals throughout Europe.

ADHD Europe was created in 2008. In an even more radical way than EURORDIS, it had to state the fact of ADHD as a European cause. Indeed, ADHD was, and still is, a contested condition. Priori to its official creation, the founding members of ADHD Europe began to identify families throughout Europe, and to collect their experience in the frame of a European-funded project called *'Knowing Me-Knowing you'*. This resulted in a statement that prompted the establishment of the European organization: children with ADHD and their families throughout Europe faced important burdens due the unsettled character of the disorder. ADHD Europe then argued for a European global initiative to address the disorder.

As stated earlier, ENCA stands as an exception. From its creation in 2003 onwards, it has been an informal network of individual childbirth activists and groups, and has not constituted a 'classic' organization. This has probably resulted from various considerations, one of them being that activists have put the focus on the empowerment of individuals (women and midwives alike), for them to be able to advocate for 'normal birth' in their national contexts. ENCA mostly acts at a transnational level, providing activists with scientific, legal and political evidence for increasing their capacity to mobilize. The other three organizations that we studied also undertook capacity building, along with community building (see our case reports). ENCA however displays a specific feature, in so far as it first and foremost intends to raise its activists' capacity to defend 'normal birth' in a quite liberal feminism orientation, without gathering them within a formal European community.

To recap, the four European patients' organizations that we studied gave shape to their causes and built communities of patients in the same move. Their representativeness stems from their ability to produce and mobilize evidence on the need for, and the relevance of a European strategy on their conditions. This entails that they are not pooling claims that national organizations put to the fore: depending on the state of mobilization on their condition in various national contexts, they define their conditions as cross- and transnational causes that would be best tackled at European level. In the next section, we elaborate on the form of activism that they develop for fulfilling their objectives.

'Evidence-based activism' and the construction of a Europe for patients

As we briefly mentioned earlier, European patients' organizations collect data and provide evidence for shaping the issues they deem important to address at European level. The *'Knowing Me-Knowing You'* project that ADHD Europe undertook prior to its inception served to collect families' experience throughout Europe in order to assert the existence of ADHD, and to argue for the need of what it called 'evidence-based' diagnosis and treatment that were much lacking in many countries. The other three European patients' organizations develop similar approaches. These approaches feature two significant characteristics that they share with national patients' organizations we studied.

Firstly, and again with the exception of ENCA, European patients' organizations are very much 'insiders' in the European political game. Not only do they learn the language of Europe and keep updated with the functioning of the 'cocktail circuit of the Brussels polity' (Lauhusen, 2004); they also familiarize with the constitutional principles of the European Union and the instruments conceived for its governance. Their involvement in actions and programmes promoted by different European DGs –mostly DG Health and Consumer, DG Trade and Enterprise, and DG Research – manifests their positioning within the European space. More interestingly, certain actions aim at raising their national member organizations' capacity to cooperate at European level. For instance, in 2006, EURORDIS coordinated a capacity-building programme called CAPOIERA funded by DG Research FP6, whose objective was to train various national rare diseases alliances on how to read clinical protocols, on the model of a training developed by the French Institute for Medical and Health Research. This action took advantage of the then new soft modes of European governance which promoted exchanges of experience and best practices between various national institutions and actors. One could thus argue that European patients' organizations contribute to make their national member organizations as legitimate and competent players at the European and the national levels.

Secondly, European patients' organizations engage in an intensive work for staging, comparing, confronting, circulating data, facts, statistics on healthcare services across European countries. This metrological work aims at proving evidence on the relevance and legitimacy of their health causes at European level. They regularly conduct surveys of their members, collecting data on their preoccupations, experiences and expectations, as well as information on the provision of care in their countries. In this 'evidence-based activism', European patients' organizations claim a unique and sophisticated expertise on issues ranging from patients' rights to drug treatments to the quality of social services in different national contexts. For instance, the strategic importance attached by Alzheimer Europe to its metrological work and mobilization of research evidence was emphasised during a 2011 conference presentation by its Executive Director in which he outlined various studies undertaken by the organisation in 'building a case for political action'[3]. One such study, undertaken between 2006 and 2008 and partly funded by DG SANCO, is EuroCoDe (European Collaboration on Dementia) that sought, amongst other things, to develop 'consensual indicators' on prevalence rates and guidelines for diagnosis and treatment. EURORDIS undertook similar surveys it called EURORDISCare which served as an argument for the European Commission to recommend the launching of national rare diseases plans in all Member States by 2013. The same goes for ENCA, although in a much less formal way: in order to answer its activists' questions, ENCA collects scientific, judicial, political and experiential knowledge to document their situation and to help them voice their concerns and demands in their countries. Some European patients' organizations like Alzheimer Europe or EURORDIS have been conferred with considerable epistemic authority by European institutions that repeatedly cite facts and figures produced by them, clearly a mark of their successful engagement in knowledge production.

To recap, the form of activism that European patients' organizations develop is based on an intensive metrological work whose objective is to provide evidence on the relevance of a European and/or transnational approach to their conditions. Some critics of the European construction would emphasize the fact that the Europe of patients and for patients that European patients' organizations give shape to is mapped onto the techno-scientific and neoliberal Europe. These critics however should be balanced with the efforts put by these organizations in the 'Europeanization from below', and in the articulation of original cross-national facts and data on issues like access to diagnosis, cure and care that European patients are concerned with.

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[3] Jean Georges, Dementia policy and planning in Europe – the NGO perspective, presentation at *Shared Priorities. The Dementia Agenda in Europe and Ireland*, 17 June 2011, Dublin.

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Silverman, C. (2011) Understanding Autism: Parents, Doctors, and the History of a Disorder. Princeton: Princeton University Press.

Stockdale, A. (1997) Conflicting Perspectives. Coping with Cystic Fibrosis in the Age of Molecular Medicine, Brandeis University

Timmermans, S., & Berg, M. The Gold Standard: The Challenge of Evidence-Based Medicine and Standardization in Health Care. Temple University Press: Philadelphia.

4.1.4 Website

EPOKS website http://www.csi.ensmp.fr/WebCSI/EPOKSWebSite/ provides:

- Presentation of the project's background, objectives and approach.
- A brief presentation of the EPOKS partners:
  - Centre de Sociologie de l'Innovation, Mines-ParisTech/CNRS/ARMINES, France
  - Centre for Social Studies, Coimbra University, Portugal
  - Department of Applied Social Studies, University College Cork, Ireland
  - Sociology Department at Lancaster University, UK
  - School of Applied Social Sciences, Durham University, UK
- Publications based on research undertaken as part of the EPOKS project (articles, book chapters & working papers).

4.1.5 Potential impact and wider societal implications

The potential impact of the project stems from, firstly, the dissemination activities we undertook, directed at POs as well as an academic audience, and, secondly, from the policy recommendations we drew on the project.

Relationships with POs and other concerned actors

From the project's inception, we have been very concerned with establishing a two-way relationship with the organisations we wanted to study. In fact, EPOKS drew upon a previous European specific support action, which consisted of the organisation of participative conferences, one of them being focused on patients' organisations : we already had established productive relationships with patients' organisations before we started the EPOKS' project.

Apart from the exchanges with them we had during our fieldwork – which were really important – three kinds of actions have been undertaken :

- The organisation of a participative conference « Health activism in Europe today » which took place in september 2011 : it was designed as a participative conference with the aim of involving POs in the discussion of our scientific findings ; apart from a number of POs representatives, we invited a few of fellow researchers working on similar topics, and a number of people from institutions that work with POs. The organisation of the conference combined presentations of our research findings, followed by workshop sessions that run in parallel with a limited nomber of participants in order to foster collective discussion and comparison between condition-based POs, and concluded by workshops reports discussed in plenary session. The reactions we gathered from the participants were really positive : they appreciated the opportinuty they had to step back from daily activities and to reflect more globally on their practices : they were quite inspired by the « evidence-based activism » scheme of interpretation that we presented.
- Project's participants gave 16 presentations in conferences gathering either POs only or a mixed audience comprising POs and/or other actors, such as public health specialists. (dissemination activities n°1, 3, 5, 8 , 9, 11, 13, 14, 15, 29, 33, 34, 36, 41, 42, 45)
- We also already published and plan to publish in the next months a number of papers intended for a non sociological audience, either for POs journals or websites or for 'professional' and public health journals. (publications n°2, 8 + booklet issued for the conference « Health activism in Europe today » ; four other papers are already planned).

Actions for academic dissemination of the project's results

Project's participants already published 6 papers in peer-reviewed journals, and 2 book chapters, 8 papers are already submitted or will be in the next weeks.

They participated to 33 conferences or workshops. EPOKS' partners also put together an open panel on the project's topics (Evidence-based activism: patients' organizations and the governance of health ; panel n°6 http://www.4sonline.org/files/open_panels_12.pdf) at the next 4S meeting in Copenhagen (17-20 october 2012) : it will gather 14 presentations out of which 4 will be draw on the EPOKS project. It will thus be a good opportunity to disseminate our findings and to discuss them with academics.

List of papers in the open panel n°6 :

Evidence-based activism: patients' organizations and the governance of health organized by Vololona Rabeharisoa, Tiago Moreira and Madeleine Akrich

- *ADHD in France and Ireland: Parents' groups' scientific and political framing of an unsettled condition,* Claire Edwards, Etaoine Howlett, University College Cork, Madeleine Akrich, Vololona Rabeharisoa, CSI Mines-ParisTech, Orla O'Donovan, University College Cork
- *3 decades of knowledge activism: An Australian healthcare consumer organisation*, Anni Dugdale, University of Canberra
- *Patients at the Zero Point: Uncertainty and Promises in Japanese Stem Cell Research*, Wakana Suzuki, Kyoto university
- *The voice of the silence: UK patients' silent resistance to the assisted reproduction regulations*, Ilke Turkmendag, Newcastle University
- *"Distributed expertise" and an opposition to the anti-vaccination movement in Poland. How the structures of knowledge are being challenged in the public debate*, Andrzej Wojciech Nowak, Adam Mickiewicz University, Poznan
- *Rearranging aetiologies and caring practices: Transgender in the making*, Esther Ortega, Universidad de Santiago de Compostela, Carmen Romero-Bachiller, Universidad Complutense de Madrid
- *Assembling Dementia Care*, Tiago Moreira, Durham University, Orla O'Donovan, Etaoine Howlett, University College Cork
- *Childbirth activism as evidence-based activism*, Madeleine Akrich, CSI Mines-ParisTech , Maire Leane, University College Cork, Celia Roberts, Lancaster University, Joao Arriscado Nunes, CES University of Coimbra
- *„Well, it's not healthy." Negotiating embodied knowledge and medico-moral definitions of obesity*, Theresa Oehler, University of Vienna
- *The dynamics of causes and conditions. Rareness of diseases in French and Portuguese patient organizations' engagement in research*, Vololona Rabeharisoa, Michel Callon, CSI Mines-ParisTech, Angela Marques Filipe, London School of Economics, Joao Arriscado Nunes, CES University of Coimbra, Florence Paterson, Frédéric Vergnaud, CSI Mines-ParisTech
- *From silence to epistemic empowerment: the creation of a collaborative device around stuttering*, Daniel Neves Costa, Centre for Social Studies, University of Coimbra
- *Pain, and Its Ventriloquists,* Kyra Landzelius, LIME, Karolinska Institutet

- *Re-presenting patient groups Today: from the US Orphan Drug Act to Rare Disease R&D Today*, Pei Koay, Center for Genetic Research Ethics & Law (CGREAL), Case Western Reserve University (CWRU)
- *Reframing Criticism in Mental Health. Patients' Movements in Switzerland (1970-2012)*, Virginie Stucki, University of Lausanne

Policy recommendations

Drawing upon our research findings, we suggest below a few policy recommendations that address three different topics:

- the role of POs as knowledge 'providers' within the governance of health issues
- the potential for renewing research themes and methodologies that POs can bring about
- the issues that would benefit from further social sciences input.

Enhancing POs epistemic potential

As demonstrated above, POs' involvement in policy making is largely supported by knowledge related activities which aimed i) at building representations of the experiences, needs and claims of the people on behalf of whom they speak, ii) at translating these claims into a language in which they can be discussed with other stakeholders in the health system, which implies the articulation of these claims with other bodies of knowledge such as 'evidence-based medicine', clinical knowledge, health economics etc.

Our contention is that both types of activities are crucial:

- the first one because it is the condition for health democracy to make sense : the deliberative ideal presupposes that viewpoints of concerned people must be expressed, but unless they are provided with instruments to voice their concerns, publics are left mute or in a plasma-like state ;
- the second one because it is the condition for creating a common world to patients, medical professionals, researchers, policy makers where 'matters of concern' can be shared, explored collectively, and where answers to be brought about can be discussed.

Consequently, we formulate two sets of recommendations, and a third one cutting across the formers:

1) Representation and knowledge building

- POs should be encouraged to develop a 'politics of representation', i.e. they should be given methodological help and financial support if needed.
- Research should be done on innovative methods mixing up quantitative and qualitative data: we observed that POs often try to produce rich and workable accounts of patients' experience by mixing up these two types of data, but it remains at a home-made level ; the articulation between these two types of data is difficult to achieve, especially when the 'qualitative' data is abundant and thus should be considered as quali-quantitative data.

- Their views should be more systematically taken in consideration in the elaboration of statistical surveys at the national or the European level which are generally based on a professional vision of what ‘matters’.

2) Knowledge capacity building

- Support should be given to POs in order to enhance their capacity to select and analyze relevant bodies of scientific literature. In some countries, education programs are set up either by public authorities or by POs themselves, but it should be extended both in terms of concerned countries and in terms of the covered disciplines: it often focused on biomedical knowledge, but judicial or economical knowledge can be crucial to POs and are as difficult to grasp as biomedical knowledge.
- Access to the literature should be provided: nowadays, it often depends on the access provided either by a POs’ member professional involvement in research or by ‘sympathetic’ researchers / medical professionals.

3) Creating a status for POs’ representatives

As evidenced below, the work performed by POs’ most involved members is extremely demanding: whereas the involvement of POs in health and knowledge issues is progressing in most countries and, as a consequence, the performance level which is expected from them, the human resources on which they can draw are not following the same path.

To take into consideration the collective benefits drawn from POs’ work, a status for POs’ representatives should be created that would allow them to combine more easily their professional/ family duties with their activities as volunteers. This status should provide them with the possibility of some work absences compensated by public funding or with a funding for babysitting; they should also benefit of the continuing education programmes with up-to date knowledge related to their associative missions.

Renewing sources of inspiration for research policy

The detailed case studies allowed us to describe the various modes of intervention of POs in research polic : whereas most of them support in many ways research and researchers, their capacity to influence research contents themselves is much more unequally distributed. Two points should be emphasized here:

- POs are able to identify zones of ‘undone science’, i.e. issues that they think would be relevant for patients/ users, but that are not investigated due to other constraints influencing the research–agenda setting. In some cases, they find the means in order to get research done, but there are still a variety of topics left unexplored. To overcome these limitations and put on trial potential sources of innovation, we suggest:

1. to organize a call for research ideas directed towards the POs: there already exists a handful of research instruments allowing consortia associating NGOs and research teams to get a joint research programme funded; but this presupposes that NGOs are already well integrated in a research network ready to answer to their queries. To overcome this limitation, a mediating device might be useful: it ought to associate a call for research ideas with a commission comprising a diversity of experts – from the

research sector as well as the POs' sector – in charge of the assessment of collected ideas and of issuing a call for research projects that would integrate these ideas.

2. to support the organization of workshops in which POs discuss their ideas with researchers and/or to support the participation of POs in scientific meetings, and the organization of sessions that would allow exchanges between POs and researchers.

- We demonstrated that POs' knowledge work partly consists of hybridizing and articulating experiential knowledge with credentialed knowledge. However, it generally left untouched the research methodologies: experiential knowledge can open up new issues but is hardly taken on board as such in research programmes. Meanwhile, the development of a few platforms such as PatientsLikeMe can be observed: they elicit the constitution of communities of patients which share pre-formatted data on their condition, its evolution over time and the effects of treatment, and which exchange through forums, the platform allowing any participant to circulate among this heterogeneous set of data. PatientsLikeMe is a private initiative and a business organization relying on the fact that big pharmas are willing to get access to the data and ready to pay for it: it acts as an opaque mediator between patients and industry. Despite the interest of this initiative, its private character – which might raise ethical and legal issues – limits its potential impacts in terms of knowledge production. The creation and development of such platforms should be encouraged by public authorities, as it might allow i) help to detect quickly and efficiently some public health issues, ii) open new venues for biomedical research and iii) favor the involvement of patients into their health management.

Potential contribution of social sciences

Our work also highlighted a number of issues that would deserve further investigation:

- we have been confronted to a great diversity of organizations as regards the governance of health issues, and especially as concerns the participation of POs. It seems that there does not exist any overview on this aspect. Taking a reverse perspective than the one we took, it would be interesting to make an inventory of existing mechanisms for the involvement of POs in the governance of health issues in European countries: the objectives would be i) to analyze the impact of such mechanisms on health policy as well as on research policy, and on the competences and actions developed by POs ; ii) to favor the circulation of experiences and the dissemination of 'best practices'.
- A similar inversion of perspective that would place researchers at the center of investigation would be illuminating: what are their motives for collaborating or for rejecting collaboration with POs ? What are, for them, the drawbacks of the participation of POs to the governance of knowledge? What would be the conditions that would make the collaboration feasible or more productive?
- As mentioned earlier, research instruments exist that allow consortia associating NGOs and research teams to get a joint research programme funded. Despite the interest for research manifested by the POs we studied, it seems unlikely that they already took part in such research programmes. An analysis of the kind of research, as well as the species of relationships between POs and researchers, that such programmes promote would be useful in order to deepen our understanding of the conditions, the nature and the outputs of such collaborations.

4.2 Use and dissemination of foreground

Section A

template A1: list of scientific (peer reviewed) publications, starting with the most important ones

NO.	Title	Main author	Title of the periodical or the series	Number, date or frequency	Publisher	Place of publication	Year of publication	Relevant pages	Permanent identifiers[4] (if available)	Open access[5]
A. Scientific peer reviewed publications										
1	From Communities of Practice to Epistemic Communities: Health Mobilizations on the Internet	Akrich Madeleine	Sociological Research Online	15 (2)			2010		http://www. Socresonline .org.uk /15/2/10.html	yes
2	L'expertise profane dans les associations de patients : un outil de démocratie sanitaire	Akrich Madeleine	Santé Publique	24(1)	Editeur SFSP (Société française de santé publique)	Paris, France	2012	pp. 69-74	http://www.sfsp.fr/ santepublique/pagint/ affich_art.php?cid=378	no

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[4] A permanent identifier should be a persistent link to the published version full text if open access or abstract if article is pay per view) or to the final manuscript accepted for publication (link to article in repository).

[5] Open Access is defined as free of charge access for anyone via Internet. Please answer "yes" if the open access to the publication is already established and also if the embargo period for open access is not yet over but you intend to establish open access afterwards.

3	Actores colectivos e os seus projectos para a saúde: o caso das associações de doentes em Portugal	Filipe, Ângela Marques	Eä- Revista de Humanidades Médicas & Estudios Sociales de la Ciencia y la Tecnología	1(2)	Published by the Institute for Health Studies, Society, Science and Technology (ISO-CYTE), Argentina		2009	pp. 1-48.	http://www.ea-journal.com/	Yes
4	'A vida como política? Debates contemporâneos sobre saúde, (bio)medicina e cidadania' [Life as politics? Contemporary debates on health, (bio)medicine and citizenship]	Filipe Marques Ângela	Oficinas do CES	338, Janeiro		Coimbra, Portugal	2010		http://www.ces.uc.pt/ publicacoes/oficina /ficheiros/338.pdf	yes
5	'Os novos actores colectivos no campo da saúde: o papel das famílias nas associações de doentes' [New actors in the health domain: the role of families in patient orgaziations],	Nunes Arriscado João, Filipe Marques Ângel, Matias, Marisa	*Alicerces*, Revista do Instituto Politécnico de Lisboa, IPL		Edições Colibri	Lisboa, Portugal	2010	pp. 119-128		
6	Troubling Mothers	Tyler Imogen	Studies in the Maternal	2(1)	Birkbeck University of London	London, UK	2010		www.mamsie.bbk.ac.uk	yes

B. Scientific publications (non-peer-reviewed)

8	EPOKS Project: Investigating patients' organizations and users' groups involvement in knowledge-related activities across condition-areas and national contexts	Akrich Madeleine, Rabeharisoa Vololona	The INNOVIA Foundation Newsletter	14			2011	pp. 4-7.	http://innoviafoundation .org/home/wp-content/uploads /2011/Newsletter_14.pdf	yes
9	Practising Childbirth Activism: a Politics of Evidence	Akrich M., Leane M., Roberts C., Nunes A. J.	Interdisciplinary Institute for Innovation Working Paper 12-MS-01.		Interdisciplinary Institute for Innovation	Paris, France	2012		http://www.i-3.fr/wp-content /uploads/2012/05/I3WP_12-MS-01.pdf	yes
10	Attention Deficit Hyperactivity Disorder in France and Ireland: Parents' groups' scientific and political framing of an unsettled condition	Edwards C., Howlett E., Akrich M., Rabeharisoa V.	Interdisciplinary Institute for Innovation Working Paper 12-MS-02.		Interdisciplinary Institute for Innovation	Paris, France	2012		http://www.i-3.fr/wp-content /uploads/2012/05/I3WP_12-MS-02.pdf	yes
11	The dynamics of causes and conditions. The rareness of diseases in French and Portuguese patients' organizations' engagement in research	Rabeharisoa V., Callon M., Filipe Marques A., Nunes Arriscado J., Paterson F., Vergnaud F.	Interdisciplinary Institute for Innovation Working Paper 12-MS-04.		Interdisciplinary Institute for Innovation	Paris, France	2012		http://www.i-3.fr/wp-content/ uploads/2012/05/I3WP_12-MS-04.pdf	yes
12	Les listes de discussion comme communautés en ligne : outils de description et méthodes d'analyse	Akrich Madeleine	Interdisciplinary Institute for Innovation Working Paper 12-MS-03.		Interdisciplinary Institute for Innovation	Paris, France	2012		http://www.i-3.fr/wp-content/ uploads/2012/05/I3WP_12-MS-03.pdf	yes

C. Book chapters

13	‘Os familiares de doentes e a emergência de novos actores colectivos no campo da saúde’ [Patient's relatives and new collective actors in health domain],	Nunes, João Arriscado; Matias, Marisa; Filipe, Ângela Marques	in M.E Leandro, P. Nossa,V. T. Rodrigues (org.), Saúde e Sociedade os contributos invisíveis da familia.		PsicoSoma Viseu	Viseu, Portugal	2009	pp. 467-486		no
14	‘The Irish Health Service’s Expert Advisory Groups: Spaces for advancing epistemic justice?’	Órla O’Donovan	in Hans Lofgren, Evelyne de Leeuw and Michael Leahy (eds),*Democratizing Health. Consumer Groups in the Policy Process*.		Edward Elgar	Cheltenham, UK	2011	pp. 97-110		no

template A2: list of dissemination activities

NO	Type of activities[6]	Main leader	Title	Date	Place	Type of audience[7]	Size of audience	Countries addressed
1	Presentation	Madeleine Akrich, Michel Callon, Vololona Rabeharisoa & Florence Paterson	Meeting: Report on research work done at CSI-Mines-ParisTech and to present EPOKS project.	30 January 2009	Paris, France	Forty French patient groups, researchers	90	France
2	Presentation	João Ariscado Nunes, Ângela Marques Filipe, Marisa Matias	"Participação em saúde e novas formas de governação: As associações de doentes em Portugal", presented at *X Congresso Luso Afro Brasileiro de Ciências Sociais, Braga, Universidade do Minho*	4 February 2009	Braga, Portugal	Academics		International
3	Presentation	Vololona Rabeharisoa	General assembly of SolHand (Solidarité Handicaps Rares)	25 April 2009	Paris, France	Patients and patients' organisations		France
4	Presentation	Angela Marques	"From biomedicalization of politics to the politization of biology: a perspective on patient organizations in Portugal", at *Estudos sobre a Ciência en Portugal: Rumos Contemporâneos ICS Lisboa*	27 April 2009	Lisbon, Portugal	Academics		Portugal
5	Conference	Vololona Rabeharisoa	3rd Symposium of the Fondation Groupama pour la santé - Vaincre les maladies rares	12 May 2009	Paris, France	Medical and health professionals, patient groups & health administrators		France

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[6] A drop down list allows choosing the dissemination activity: publications, conferences, workshops, web, press releases, flyers, articles published in the popular press, videos, media briefings, presentations, exhibitions, thesis, interviews, films, TV clips, posters, Other.

[7] A drop down list allows choosing the type of public: Scientific Community (higher education, Research), Industry, Civil Society, Policy makers, Medias ('multiple choices' is possible.

6	Seminar	Ângela Marques Filipe	"Bios or polis? The place of patient organizations in the contemporary Portuguese healthscape*". In Science, Technology and Society Research Group*	16 July 2009	Coimbra, Portugal	Academics		Portugal
7	Presentation	João Arriscado Nunes, Ângela Marques Filipe, Marisa Matias	"Research engagement, dissemination of activism and health governance: the case of rare disease organizations in Portugal" *9th Conference of the European Sociological Association, Lisbon, ISCTE.*	2 September 2009	Lisbon Portugal	Academics		Portugal
8	Other	Ângela Marques Filipe	Ceremony of the protocol for an observational study for the construction of a rare diseases patients' registry *at Calouste Gulbenkian Foundation* (invitation from the Portuguese Federation of Rare Diseases)	9 February 2010	Lisbon, Portugal	Patient organizations, Health professionals, Policy makers		Portugal
9	Workshop	João Arriscado Nunes	Expert workshop on citizenship and health *at the School of Public health - Lisbon.*	10 February 2010	Lisbon, Portugal	Academics		Portugal
10	Seminar	João Arriscado Nunes & Ângela Marques Filipe	“Childbirth unattended by the authority of science: Whether closing maternity wards or homebirth in Portugal”, *NECTS Seminar Cycle 2010: Knowledges in Dialogue, CES, University of Coimbra*	11 February 2010	Coimbra, Portugal	Academics, health professionals & childbirth organisation		Portugal
11	Conference	Ângela Marques Filipe	Doenças Raras: “Raras com Sentido – Informar sem Dramatizar”, *Portuguese Alliance of Rare Diseases / Colégio do Oriente.*	26 February 2010	Loures, Portugal	Patient organization, Students		Portugal
12	Seminar	Ângela Marques Filipe	Associating patients, governing health: new frontiers between biology and politics in Portugal" at *Faculty of Medicine - University of Porto.*	26 March 2010	Porto, Portugal	Academics		Portugal
13	Seminar	Ângela Marques Filipe	Seminar on patients' organizations and sociological research, in a health education programme at *University of Minho - Braga.*	9 April 2010	Braga, Portugal	Academics, health professionals		Portugal

14	Conference Presentation	Madeleine Akrich	First International Conference on Childbirth at the occasion of the ENCA (European Network of Childbirth Associations) Annual meeting.	29 May 2010	Sofia, Bulgaria	Patient organization		International
15	Seminar	Madeleine Akrich	Naissance et développement d'un mouvement d'usagers autour de la naissance Journée de la Société d'Histoire de la Naissance	12 June 2010	Paris, France	Historians and professionals		France
16	Conference	Vololona Rabeharisoa	Patient organizations' engagement in war on rare genetic diseases: Scientific activism and new forms of sociality, *European Human Genetics Conference, in conjunction with the European Meeting on Psychosocial Aspects of Genetics*	17 June 2010	Gothenburg Sweden	Academics		International
17	Workshop	Madeleine Akrich	European commission - DG Research Workshop: «*Encouraging new ways of doing research*»	16 July 2010	Brussels, Belgium	Policy makers		
18	Presentation	Angela Marques & João Arriscado Nunes	"As doenças raras, uma voz comum? Intervenção dos pacientes na saúde em Portugal" [Rare diseases, a common voice? Patient intervention in health in Portugal] *in VIII Jornadas Latinoamericanas de Estudios Sociales de la Ciencia y la Tecnologia "Ciencia y tecnología para la inclusión social"*	23 July 2010	Buenos Aires, Argentina	Academics		International
19	Conference presentation	Órla O'Donovan	«Alzheimer's disease organisations and technologies of "independent living": Tracking transformations in patienthood and organisational cause », *EASST010, Track 26: The Shaping of Patient 2.0*	3 September 2010	Trent, Italy	Academics	50	Ireland, UK

20	Presentation	Madeleine Akrich Vololona Rabeharisoa	“Evidence-Based Activism” in Europe, Comparing Patients’ and Users’ Organizations’ Involvement in the Production and Circulation of Knowledge across Condition Areas and National Contexts. Workshop « The Role of Patient and Professional Organizations for EU Health Governance »	21-22 September 2010	Brussels, Belgium	Academics		International
21	Seminar	Vololona Rabeharisoa	Les publics concernés. Mobilisations associatives dans l’espace de la recherche médicale, *Sciences de la vie en société : fascination, confrontation, controverses, co-évolution (Génopole – IFRIS)*, Collège de France	28 September 2010	Paris, France	Academics		France
22	Presentation	Tiago Moreira	Ageing in technological democracies, Communication and Innovation, Center for Healthy Aging, Københavns Universitet	28 October 2010	Copenhagen	Academics	50	Denmark
23	Presentation	Tiago Moreira	For a public neuroscience, Symposium 'Translating the Brain:Ethics, Publics, Prospects', University of Edinburgh	12 November 2010	Edinburgh, UK	Academics	20	UK
24	Presentation	João Arriscado Nunes, Marta Roriz, Angela Marques, Daniel Neves, Marisa Matias	"Advocating Rarity": Rare Disease Organizations in Portugal, comunicação apresentada na/o Anthropology and Health - Trends for the next decade, Coimbra	18 November 2010	Coimbra, Portugal	Academics		International
25	Presentation	João Arriscado Nunes, Marta Roriz, Daniel Neves, Angela Marques	“Humanizing childbirth”: The motto for childbirth movements and organizations in Portugal, *comunicação apresentada na/o Anthropology and health - Trends for the next decade, Coimbra*	18 November 2010	Coimbra Portugal	Academics		International
26	Seminar	Celia Roberts, Imogen Tyler	Department of Sociology seminar series	8 February 2011	Lancaster, UK	Sociologists, health researchers	25	UK

27	Seminar	Vololona Rabeharisoa	The Dynamics of Mobilization on Rare Diseases in France. Singularizing/De-singularizing Rare Diseases, *BIOS, LSE*	17 February 2011	London, UK	Academics		UK
28	Seminar	Madeleine Akrich	Technologies de l'information et de la communication et constitution de l'expertise dans le domaine de la santé, *Séminaire du Centre de recherche sur les médiations, Université de Metz*	14 June 2011	Metz, France	Academics		French
29	Presentation	Candice Satchwell	'Normal Labour and Birth': 6th Research Conference	14 June 2011	Grange Over Sands, UK	Midwives, birth activists, clinicians, academics	30 in session, several hundred at conference	International
30	Presentation	Celia Roberts, João Arriscado Nunes	« Valuing patients' experience: telling stories and producing figures", *EPOKS Conference: « Health Activism in Europe Today »*	15 September 2011	Lancaster, UK	Academics, patients' organizations		International
31	Presentation	Madeleine Akrich Tiago Moreira	« Engaging with evidence-based medicine and evidence-based policy », *EPOKS Conference: « Health Activism in Europe Today »*	15 September 2011	Lancaster, UK	Academics, patients' organizations		International
32	Presentation	Órla O'Donovan Vololona Rabeharisoa	« Engaging in cross-national exchange", EPOKS Conference : « Health Activism in Europe Today »	15 September 2011	Lancaster, UK	Academics, patients' organizations		International
33	Presentation	Madeleine Akrich	« L'expertise profane, outil de démocratie sanitaire » *Congrès de la société française de santé publique*	4 November 2011	Lille, France	Academics, professionals, policy makers		France
34	Seminar	Vololona Rabeharisoa	Formes d'activisme et nature de l'expertise des organisations européennes de malades : le cas d'EURORDIS (European Organization for Rare Diseases), *Séminaire de la Maison des Sciences Sociales du Handicap*	8 November 2011	Paris, France	Academics, professionals and disabled people		France

35	Presentation	João Arriscado Nunes, Marta Roriz, Angela Marques	Colectivos sociais como actores na Saúde em Portugal e na Europa: o caso das doenças raras e dos movimentos ligados ao parto no contexto português., *comunicação apresentada at Rumos da Sociologica do Conhecimento, ciencia et Tecnologica em Portugal, ISEG Lisboa*	9 November 2011	Lisbon, Portugal	Academics		Portugal
36	Conference presentation	Órla O'Donovan	"(Some) Irish patients' movements on the move to Europe", *New Agendas in Social Movement Studies*	26 November 2011	Maynooth, Ireland	Academic and activist	70	Ireland
37	Seminar	Vololona Rabeharisoa & EPOKS partners	'Evidence-based activism': Patients' organizations and the governance of health, *Institute for Social Studies of Science, Vienna University*	1 February 2012	Vienna, Austria	Academics		International
38	Seminar	Madeleine Akrich	« Nouvelles formes de mobilisations: les collectifs électroniques », séminaire Mobilisations et Identités collectives dans le champ du handicap et de la santé, EHESS-EHESP.	14 February 2012	Paris, France	Academics		France
39	Seminar	Vololona Rabeharisoa, Órla O'Donovan & EPOKS partners	Europe of patients, Europe for patients. The role of European patients' organizations in the Europeanization of health policies, *Symposium 'Unpacking Europe', COST Action Bio-objects and their boundaries*	29 February 2012	Lisbon, Portugal	Academics		International
40	Presentation	Angela Marques, João Arriscado Nunes, Marta Roriz	People, numbers and rarity: Biosocial platforms in Portugal and Europe, comunicação apresentada na/o ESRC Genomics Network Conference- Genomics in Society: Facts, Fictions and Cultures, British Library, London	23 April 2012	London, UK	Academics		International

41	Conference presentation	Órla O'Donovan	"Europeanization of and by patients' organisations' evidence-based activism", Patient organizations, health movements and medical research: varieties, effects and future civil society engagement in science, technology development and research policies	10-12 May 2012	Augsburg, Germany	Academic and patients' organisations	30	International
42	Presentation	Madeleine Akrich	« Patient organizations' contribution to scientific and technological democracy », Conference Patient organizations, health movements and medical research, Augsburg University	12 May 2012	Augsburg, Germany	Academic and patients' organisations	30	International
43	Seminar	Madeleine Akrich	« Mobilisations en santé et communautés électroniques », *Ateliers du lundi du département SES, Télécoms Paristech*	21 May 2012	Paris, France	Academics		France
44	Seminar	Vololona Rabeharisoa	From war on disease to 'evidence-based activism': Patients' organizations' engagement with knowledge in the area of rare diseases in France and in Europe, *Department of Thematic Studies: Technology and Social Change, Linköping University*	23 May 2012	Linköping, Sweden	Academics		International
45	Seminar Presentation	Vololona Rabeharisoa, Michel Callon, Angela Marques Filipe, João Arriscado Nunes, Florence Paterson, Frédéric Vergnaud	La mobilisation associative autour des maladies rares : quelques éléments de comparaison entre la France et le Portugal, *Assemblée Générale de SolHand (Solidarité Handicap autour des Maladies Rares)*	9 June 2012.	Paris, France	Patients and patients' organisations		France
46	Presentation	Angela Marques, João Arriscado Nunes, Marta Roriz, Daniel Neves	Normal birth and rare diseases: challenges for a politics of inclusion and difference, comunicação apresentada na/o IX ESOCITE 2012 "Balance del campo ESOCITE en América Latina y desafíos", Cidade do México	5 June 2012	Mexico City, Mexico	Academics		International

47	Presentation	João Arriscado Nunes, Marta Roriz, Angela Marques	Plataformas biossociais de doenças raras e os movimentos em torno do parto em Portugal, *comunicação apresentada na/o VII Congresso Português de Sociologia.*	23 June 2012	Porto Portugal	Academics		Portugal
48	Conference	Vololona Rabeharisoa	Shaping and governing health issues: The role of patients' organizations in the area of rare diseases, Symposium on 'Patients as collectives. Normative considerations and socio-political analysis of patients' organizations' role in healthcare and biopolitics', International Association of Bioethics Annual Conference	27 June 2012	Rotterdam, The Netherlands	Academics		International

Section B (Confidential[8] or public: confidential information to be marked clearly)

Part B1

The applications for patents, trademarks, registered designs, etc. shall be listed according to the template B1 provided hereafter.

NOT RELEVANT

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[8] Note to be confused with the "EU CONFIDENTIAL" classification for some security research projects

Part B2

Please complete the table hereafter:

NOT RELEVANT

4.3 Report on societal implications

See SESAM platform.