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MEANS? 4S-EASST MEETING, BARCELONA, 2016  
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# Inquiries into experience and the multiple politics of knowledge

**KEYNOTE PLENARY 1: TO WHAT EXTENT IS EMBODIED KNOWLEDGE A FORM OF SCIENCE AND TECHNOLOGY BY OTHER MEANS?**

**4S-EASST MEETING, BARCELONA, 2016 AUGUST 31ST**

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## **ABSTRACT :**

Has patient experience or patient experiential knowledge the potential to constitute other means of doing science and technology? Does it represent an alternative to mainstream science? Has it the power to question it, to challenge it, to make it more "democratic"? To try to answer this question, I contrast two sets of configurations: the first one concerns patient groups and I will try to recap what we have learnt from what they do with experience; the second one is centred around activities of private actors as well as researchers or institutions who have decided to give patient experience an important role in research, promoting the notion of "patient centred care", the involvement and the participation of concerned people to research and research drawing on what is called "patients' reported outcomes".

In this presentation, I describe the different ways in which people's experience is enacted, how it is mobilized in knowledge production, and I reflect on the kind of politics it performs, and on the extent to which it could be considered as science by other means.

## **KEYWORDS :**

Experience, Patient, Patient Organization, Patient reported outcomes, Science.

For several years, I've been working on the construction of knowledge and expertise by people concerned with health issues, firstly inside internet groups of patients, and more recently in patient organizations.

It is of course from this perspective that I understand and translate the topic of this panel:

- Has patient experience or patient experiential knowledge the potential to constitute other means of doing science and technology?
- Does it represent an alternative to mainstream science?
- Has it the power to question it, to challenge it, to make it more "democratic"?
- Could it contribute to Donna Haraway's project of a "practice of objectivity that privileges contestation, deconstruction, passionate construction, webbed connections, and hope for transformation of systems of knowledge and ways of seeing"?(Haraway, 1991)

To try to answer this question, I contrast two sets of configurations:

- The first one concerns patient groups and I will try to recap what we<sup>i</sup> have learnt from what they do with experience;
- The second one is newer for me – I thank the convenors for giving me the opportunity to have a closer, if very preliminary, look at it – and it is centred around activities of private actors as well as researchers or institutions who have decided to give patient experience a quite important role in research. My curiosity has been aroused by the emergence of a rhetoric around the notion of "patient centred care", accompanied by the development of a discourse on the involvement and the participation of concerned people to research and of research drawing on what is called "patients' reported outcomes".

In this presentation, I describe the different ways in which people's experience is enacted, how it is mobilized in knowledge production, and I want to reflect on the kind of politics it performs, and on the extent to which it could be considered as science by other means.

# Patient organizations and knowledge

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For about 25 years, there has been a significant number of studies that have enriched our vision of the engagement with knowledge of formal or informal groups of people concerned by a health problem:

I think of course of Steven Epstein's contribution on HIV (Epstein, 1996), of Phil Brown and his colleagues' contribution on environmental health (Brown, 1997; Brown et al., 2004), of my colleagues, Vololona Rabeharisoa and Michel Callon's contribution on rare diseases (Callon & Rabeharisoa, 2008; Rabeharisoa & Callon, 2002), and of many others scholars that have been taking part to this effort .

These studies have highlighted the importance of patients' expertise based upon their experience (Borkman, 1999). Notion which is today largely taken up by professionals, researchers, policy makers as a legitimation of patient involvement into research or health policy making.

The importance taken by knowledge related activities in the functioning of patient organizations prompted us to forge the expression "evidence based activism" (Rabeharisoa, Moreira, & Akrich, 2014) which highlights the centrality of the articulation between knowledge and politics in this form of activism and the work which is necessary to perform this articulation.

This work may have various objectives. I would like to mention four of them.

- First of all, it's a matter of helping concerned people themselves, to allow each one to benefit from others' experiences, to share difficulties, doubts, experimentations, solutions, so that every one can recover or enhance his or her capacities of reflection and action.

The work performed by DingDingDong, an organization devoted to Huntington disease which calls itself "Institute for the Co-production of Knowledge on Huntington Disease", offers a striking example: they leave to others the fight for a cure and put their energy into inquiries in relation to a question directly linked to the development of genetic testing: how to live with a life whose horizon is a predicted and inescapable disaster? How to compose with the disease? (DingDingDong, 2015)

- Secondly, it is a matter of making certain issues visible in the public space: the history of organizations concerned with rare diseases, emergent diseases, environmental health problems is intimately linked to the collection of experiential data that could help people making sense and dealing with the problems they are confronted, and would help to constitute issues at stake and get other actors interested into these issues.

Beyond the objective of raising awareness, it's also a matter of identifying issues, of constituting matters of concern out of matters of fact.

The screenshot shows the Renaloo website interface. At the top, there is a navigation bar with the Renaloo logo and the text "Association de patients maladies rénales, greffe, dialyse". Below the logo are social media icons for Facebook, Twitter, YouTube, and RSS. A search bar is located on the right side of the header. The main content area features a news article titled "ACTUS > L'actualité sur Renaloo > Maladies rénales et inégalités sociales d'accès à la greffe en France : publication d'un article dans Population". The article discusses the publication of a study in the journal "Population" regarding social inequalities in access to kidney transplantation in France. The article text states: "La lutte contre les inégalités sociales de santé est un enjeu majeur de santé publique. Certaines de ces inégalités sont à ce jour peu documentées et donc peu présentes dans les débats. C'est le cas des maladies rénales et de l'accès à leurs traitements (dialyse et greffe de rein). Pour les patients qui peuvent en bénéficier, la greffe est le meilleur traitement de l'insuffisance rénale terminale, améliorant sensiblement l'espérance de vie et la qualité de vie par rapport à la dialyse. Mais l'accès à la greffe est contraint par des freins à l'inscription sur la liste nationale d'attente ainsi que par la pénurie d'organes. Pour la première fois en France, des disparités sociales dans l'accès à la dialyse et à la greffe sont mises en évidence et publiées dans Population, la revue de l'Institut National des Etudes Démographiques (INED). Les données, issues des enquêtes des Etats Généraux du Rein et QuaVIRrein montrent que quels que soient la tranche d'âge et le sexe, les personnes dialysées sont moins diplômées que les personnes greffées." The article is dated June 19, 2016. The website also features a sidebar with a "Communauté" section and an "Agenda" section listing upcoming events.

"Renal diseases and social inequalities in the access to grafts in France", capture of Renaloo website, accessed on 2016, August 25.

Renaloo is a French organization on renal diseases: they organized a large survey and found out that access to kidney transplant was correlated with patients' level of education. Nobody had anticipated such a result before the survey was completed, and this result contributed to the definition of the organization's program of action.

- Thirdly, it is a matter of discussing, arguing, negotiating with concerned actors: to transform institutions and established practices, patient organizations need to convince their interlocutors. Claiming that "diseases are rare but patients numerous", thus justifying that public authorities seriously consider this issue, has needed a meticulous inventory of thousands of dispersed diseases, and the gathering of patients.
- Lastly, patient organizations may engage themselves into some scientific research because of the absence of interest of academic researchers for research questions that they consider central for patients: for example, the French DES daughters organization launched in 2013 an epidemiological

study in order to find out whether or not the risk of getting a breast cancer was higher than in the general population. Two previous studies, in the US and the Netherlands, had shown divergent results. Thus, the importance for the French DES daughters to know what to expect in order to adjust their medical follow-up.

To produce these knowledge, patient organizations rely on a variety of “methods”: from very informal ones – discussion between volunteers in contact with people seeking help – to formalized surveys or even scientific research undertaken in collaboration with professional researchers.

One crucial point is that they don't content to produce knowledge based on experience, but articulate it to other forms of knowledge, and notably biomedical knowledge. Contrary to what have been sometimes suggested, they don't loose their soul by getting their nose into scientific affairs: it's precisely their capacity to articulate these two kinds of expertise that give them the capacity to act upon the health system and to transform it.

How did, for example, a French childbirth organization criticize guidelines on episiotomy? (Akrich, 2010)

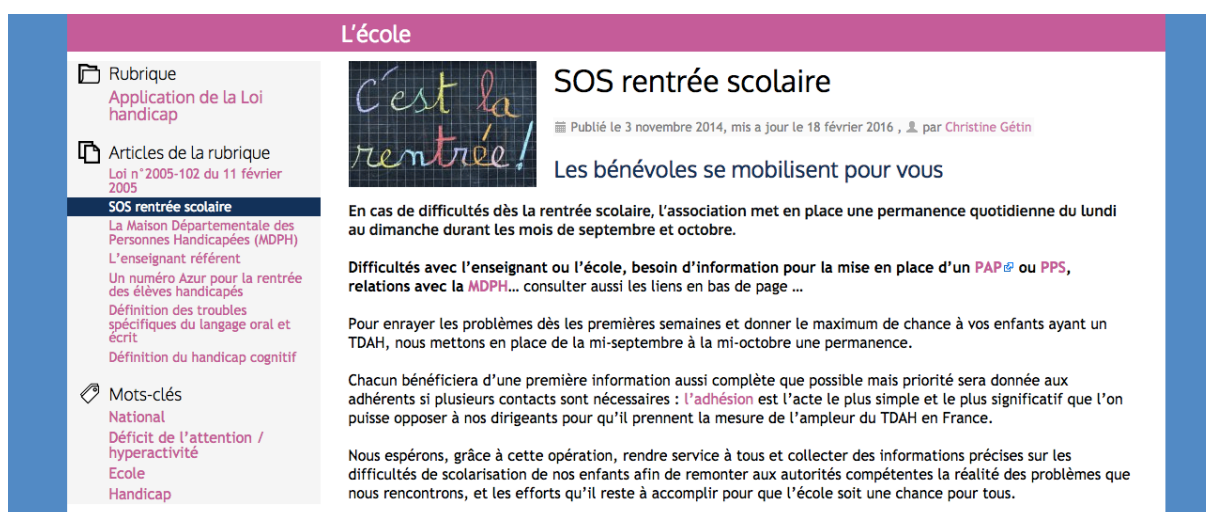
- They did a careful bibliographical review that allowed them to highlight the variety of practices;
- they gathered testimonies that showed several complications of episiotomy that, from women's viewpoint, have severe consequences on their everyday life, and that have been neglected both by the literature and the guidelines.
- They ended up by reframing the problem not as “the prevention of episiotomy”, an expression that naturalizes the intervention, but as “the prevention of perineal lacerations” that opens a whole set of other policy options, such as positions during labor, but that also points out the oversimplification associated with experimental protocols of research excluding the collection of data on situations where women are free to choose their position.

Experiential knowledge thus gives the perspective from which the situatedness of biomedical knowledge can be seen, and here the exercise of power on women's bodies on which it relies.



# Knowledge production as political activity

However, the production of knowledge shouldn't only be characterized by its outcomes: it is a political activity in itself in the sense that it seeks to engage the whole community not only as objects of this knowledge or as information providers, but also as active participants.



The screenshot shows a website interface with a purple header labeled 'L'école'. On the left is a sidebar with a 'Rubrique' section containing 'Application de la Loi handicap' and 'Articles de la rubrique' with a sub-item 'Loi n°2005-102 du 11 février 2005'. Below this is a highlighted 'SOS rentrée scolaire' section with details about the 'Maison Départementale des Personnes Handicapées (MDPH)', a 'numéro Azur', and 'Définition des troubles spécifiques du langage oral et écrit'. A 'Mots-clés' section lists 'National', 'Déficit de l'attention / hyperactivité', 'Ecole', and 'Handicap'. The main content area features a graphic with the text 'C'est la rentrée!' and a title 'SOS rentrée scolaire'. Below the title, it states the article was published on 3 November 2014 and updated on 18 February 2016, by Christine Gétin. The main heading is 'Les bénévoles se mobilisent pour vous'. The text describes a daily hotline from Monday to Sunday during September and October for school difficulties. It mentions 'difficultés avec l'enseignant ou l'école, besoin d'information pour la mise en place d'un PAP ou PPS, relations avec la MDPH...' and encourages parents to contact the hotline from mid-September to mid-October. The final paragraph states the goal is to provide information, collect data on school difficulties, and report back to authorities to improve the school environment for all.

<https://www.tdah-france.fr/SOS-rentree-scolaire-html.html>, accessed on 2016, September 8.

Here you can see an announcement for the “SOS Back to School Operation”, a hotline opened every September-October for parents of children with ADHD seeking solutions to urgent problems when their children return back to school. The twofold nature of the operation (providing help; producing knowledge) is made explicit in the last paragraph: ““Thanks to this operation, we hope to accomodate everybody’s needs and to collect precise information on the schooling difficulties encountered by our children, in order to bring back to the authorities the real problems to which we are confronted, and the efforts that are still necessary in order to make school an opportunity for all”, so that parents have the possibility to anticipate and adapt their testimony to the second objective.

In another register, as Tiago Moreira and his colleagues showed, the efforts deployed by Alzheimer Society UK to find innovative methods in order to hear the voices of those who can't speak anymore are a way of performing an organization which would not only be an organization of carers and relatives but also of patients themselves (Moreira, O'Donovan, & Howlett, 2014).

Besides, patient organizations often provide opportunities for people to express themselves in a discursive form: they organize spaces for collecting testimonies, or add open-ended questions to their surveys (Akrich, Leane, Roberts, & Arriscado Nunes, 2014). Thus, people are invited to adopt an active and reflexive attitude, and

to re-analyze their experience in light of the context suggested by the survey in a way that may contribute to the collective understanding of issues. We see that producing knowledge is indeed performing the collective.

To conclude this part, I want to return to my starting point, i.e. experience and science.

Two points about experience:

- Experience doesn't go without saying. It's not something which is out there once for all. It's always the product of some interaction that occurs either between human beings, via the mediation of a questionnaire or via the confrontation with other testimonies.

Experience is constantly reworked in these interactions and at a collective level, the elaboration of experiential knowledge and expertise out of experiences is the very process through which both the collective and the issues it has to face are constructed.

Working on/with experience is trying to find a way in the messy and dense web of events, thoughts, feelings, worries, that constitute everyday life of each concerned individual, by building connections with others' lives.

- In this quest, and that's my second point, science and technology are not alien; as many STS scholars have demonstrated, they are mediators in the relationship people entertain with their body and their disease, they participate in the constitution of their experience at the individual level; at a collective level, it's one way of building the connections I was just talking about.

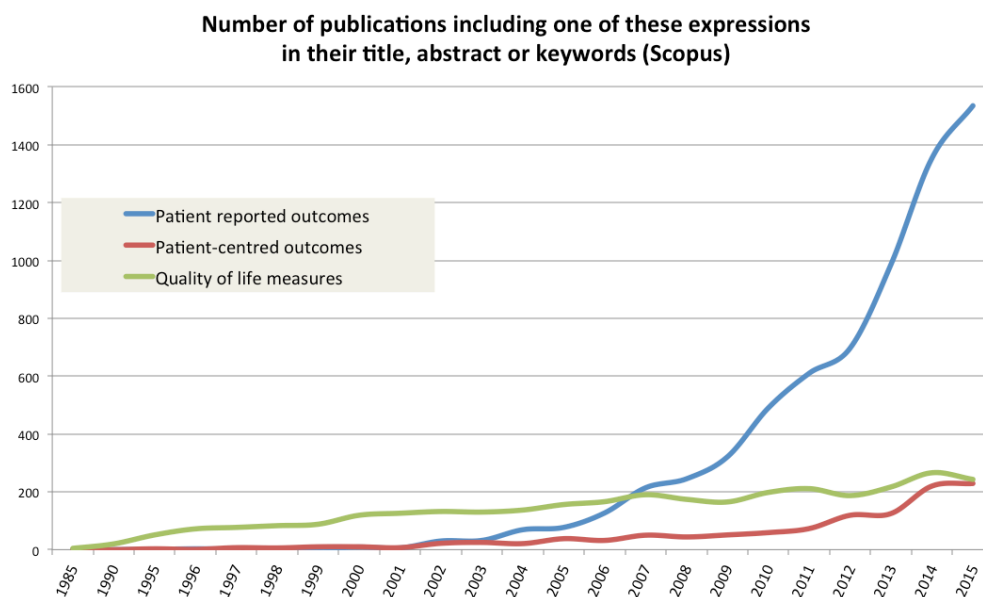
Should we think of these knowledge-oriented-activities as science by other means? I'm not sure, and I am even reluctant to use the expression "research in the wild" forged by Michel Callon and his colleagues (Callon, Lascoumes, & Barthe, 2009): in trying to put lay knowledge on an equal footing with expert knowledge and to analyse their interrelations, this expression runs the risk of reducing these activities to their contribution to science. That is the reason why I think it would be a "category error", to borrow from Bruno Latour (Latour, 2013): even in cases where a collective inquiry results into a scientific publication, patient organizations are not interested in scientific research for the sake of scientific research; what they are interested in is making sense of people's experience, building collectives, and providing opportunities and capacities for individual and collective action.

# Making science out of people's experience

Let's now turn to people who seek to inject patients' experience into scientific research.

Since the beginning of the 2000s, we witness the emergence of two sets of initiatives that can be put under the label of "patient centredness" in healthcare and health research.

Firstly, within research activities, it translates into the increasing use of patient reported data - and the development of outcome measures based upon this data. Interestingly, this move concerns public research as illustrated by the creation (2012) of PCORI – the Patient Centered Outcome Research Institute, an American funding institution that has already spent 1.4 billion \$ on this theme – as well as the private sector with the creation of platforms such as the well known Curetogether (2008) or PatientsLikeMe (2005), and more recently the Open Research Exchange Platform (2014), described by its creator, PatientsLikeMe, as the "first open-participation research platform for creating outcomes measurements".



Secondly, there is a pressing movement urging researchers and research institutions to associate patients to the governance of research, meaning to have them participating to the setting of research agenda, the elaboration of research protocols or various forms of assessment exercises. This tendency is reflected by the "patient revolution" undertaken by the BMJ in 2013, or the creation in 2015 of a journal: "Research involvement and engagement" entirely devoted to these issues.

The arguments in favor of such initiatives range from political to economic and epistemic ones:

- Experiential knowledge from those directly affected is supposed to improve the quality and relevance of research. Patient engagement is seen as a way to help health systems become sustainable, as it should reduce healthcare costs through the avoidance of unnecessary investigation, treatment, and irrelevant research projects.
- It's also considered as a democratic imperative: for the BMJ, a "fundamental shift in the power structure in healthcare and a renewed focus on the core mission of health systems" (Richards, Montori, Godlee, Lapsley, & Paul, 2013) is at stake: professionals need to accept that expertise in health and illness lies outside as much as inside medical circles.
- It is considered as the first steps towards a more desirable model of care: patient centred care which takes into consideration patients needs, expectations, preferences and real life conditions. Expressions such as "participatory research", "collaborative research", involvement, patient expertise, empowerment... are part of the quite positive rhetoric around this movement.

I'm not going to elaborate more on it; but I want to look at the practices which sustain this discourse with one question in mind: which patients/contributors, and what experience, are performed into these practices ?

One common feature to these different tools, and to procedures that aim to involve patients, is that they almost always target the individual patient. Numerous tools for collecting data from patients are questionnaires, whose aim is to determine the individual patients' health status, how she or he feels about the disease, the impacts of treatment on her/his life, and/or the things she/he values the most in her/his life and that she/he is keen to preserve despite the disease (Greenhalgh, Long, & Flynn, 2005). No space is left for free expression, since it is important for researchers to rely upon "robust" tools, that they can exploit and use in a variety of contexts: here, producing knowledge is about being able to aggregate data; together with the interpretation of data, this should remain in the hands of professionals and researchers.

If this did not come as a surprise, I was not expecting that the same would apply for procedures that aim to involve patients. I was lucky enough that the Research Involvement and Engagement Journal was created only a year ago, so that it was still possible to have a close look to the 36 papers published to date.

In almost all cases, involved people are individuals apparently without any strong engagement within patient groups. Everywhere there is an emphasis on the necessity to gather a representative sample of the diverse targeted population, but as can be

seen on these quotes, nobody is supposed to represent anyone else than her - or himself. Here, the model of representation is a statistical one.

“No individual is representative of the public or a particular patient group. (...) We do not choose individuals with specific expertise or personal qualities, have no “Job Description” and do not provide training or make training a requirement of participation.” (Jenner, Gilchrist, & Baker, 2015)

“The members of the RUG [Research User Group] are recruited on the basis of their illness experience – rather than educational attainment or prior research involvement – and thus they bring this ‘expertise by experience’ to the table. ” (Jinks et al., 2016)

What is meant by “experience” or “expertise by experience” is supposed to pre-exist to the situation in which it is mobilized. In this perspective, the questionnaire collecting patient data makes only the useful part of experience visible, in a standardized and manageable way. Experience is a property of the individual, something that allows her/him to have something to answer to the questions addressed to her/him.

What is true in this configuration is also true in involvement procedures: in particular, the question of whether these involved patients should receive a training is discussed. Some argue that it would ease the dialogue with researchers. Others think it’s not necessary and runs the risk of distorting patients’ views: as the BMJ puts it, it is “important to get the “authentic” voice of patients heard and not just that of an articulate minority” (Richards & Godlee, 2014); as a consequence, in a document explaining to potential candidates what is patient peer review, they insist on the fact that no medical and scientific training is needed (“Guidance for BMJ patient reviewers | The BMJ,” n.d.).

Indeed a twofold operation is performed through this definition of experience:

Firstly, a gap between scientists and lay people, between science and experience is re-enacted. In questionnaires, patients are expected to provide facts, feelings and opinions, but in contradiction with what is often claimed, not something that would look like an expertise.

In the same vein, here is an example of what experts seating on a Health Technology Appraisal Committee from NICE, the National Institute for Health and Care Excellence, say about patients’ written statements. These experts’ views clearly “theorize” patients’ contribution as opposed to scientists in a very traditional way, which draws upon old gender stereotypes.

**Table 1** The differences between 'evidence' and 'insights' from patients

The nature of 'evidence'	The nature of experiential knowledge
• Data obtained through systematic enquiry	• Knowledge gained through experience - insight
• Objective	• Subjective
• Rational	• Emotional
• Written in scientific and technical language	• Written in the patients' own words
• Mostly quantitative - statistics	• Mostly qualitative - stories
Apples	Pears

Excerpt from (Staley, 2015), p. 8.

Secondly, through the collection of patient reported outcomes, researchers position themselves as spokespersons of the patients, shortcutting other forms of representation, and especially those built by patient organisations.

Just an anecdote on this point: I recently had an interview with a researcher implied in a project of platform for the collection of patients' experiences and data. At some point, he told me: "I am suspicious of patient organisations". When I asked: "Why?" he replied: "Because they are activists." This is a bit ironic considering his engagement in an epistemic project with a strong and explicit political aspect.

I don't want to give the impression that researchers and credentialed experts people are just bad guys. But at least, what I can say is that they are involved into a "modernist" project that pretends to solve the problem of politics by doing science.

Despite the denegations – one paper out of three in Research Involvement and Engagement Journal uses the word "tokenism" to distance themselves from the practice this word qualifies – the revolution called by the BMJ might turn out to be more an endogeneization of politics, or a capture of the public, than anything else.

In this respect, the 1999 BMJ coverpage on patient partnership – which shows a domineering medicine, capturing the patient, forcing her/him to follow its steps and to be drown in its eyes, again using gender stereotypes – might be more representative of what is at stake than the 2013 triumphant coverpage.



## Conclusion

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To conclude, we end up with what can be seen as a paradox. The question raised at the starting of this presentation was more or less implicitly imbued with a positive connotation towards the idea that experience or experiential knowledge could be science by other means, thus opening up science to a more democratic and inclusive functioning.

At the end of the day, we are confronted on the one hand, with knowledge practices that cannot be considered as science but that have a reflexive and disruptive potential as regards science, and on the other hand, with scientific practices that are supposed to draw upon people's experience to build a more democratic science and health care but end up taking away any critical capacity from concerned people and shutting up any possibility of debate.

It raises two issues for us, STS scholars. Firstly, STS has put a strong emphasis on participation and democracy in science: but the road to hell is paved with good intentions; there is clearly a need to investigate the politics of participation which is embedded not only into procedures, but also into science itself.

Secondly, as I have suggested, the framing of the question raised in this session reveals a positive bias in favor of science. But if we were interested in democracy, then we should take more seriously the multiplicity of knowledge, and ask ourselves on what conditions it is possible to preserve / enhance people's capacities to engage into inquiries on matters they feel concerned with, and what kinds of institutions and procedures are needed to properly articulate these inquiries to scientific activity, that is to make it more open to the plural possible worlds.

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I thank Vololona Rabeharisoa for her careful rereading of this text.

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<sup>i</sup> By "we", I mean the group of researchers involved in the EPOKS project which I coordinated together with Vololona Rabeharisoa: M. Callon, C. Edwards, A. Filipe, E. Howlett, L. Maire, T. Moreira, J. Nunes, O. O'Donovan, F. Paterson, C. Roberts, M. Roriz, C. Satchwell, I. Tyler, F. Vergnaud.