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Through a maze of studies: health questions and ‘undone science’ in a French industrial region

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Near the city of Marseille is one of France’s largest industrial regions, home to over 400 industrial facilities. Adjacent to these facilities are towns whose residents have complained of myriad health problems, from respiratory illness and autoimmune disease to cancers. While human environmental health in this region has been studied repeatedly by state agencies and allied organizations, the studies focused on tightly constructed questions answerable within particular languages of expertise. This rarely translated into information that residents found relevant or credible in relationship to their own experience living in their polluted communities. We argue that these disciplinarily circumscribed health studies are conditioned by the way policy-relevant science is produced in France given the strong centralized state and its civil service elite. Thus many residents’ questions remain unanswered and the absence of answers produce a form of ignorance called ‘undone science’. We examine three studies paradigmatic of the kinds of health research that has been done in the region. We illustrate the disconnect between the profession-driven studies’ questions and outcomes, and the areas of greatest interest to residents. In concluding, we advocate for study designs which engage with local residents and attempt to fill the knowledge gap of their unanswered questions.

Keywords: undone science; environmental health; contested illnesses; science and technology studies; sociology of ignorance

Introduction

Interest in the democratization of science has grown in recent decades through increased public engagement in shaping knowledge about the natural world. The lens of environmental controversies and concerns makes participatory science, at times called street science (Corburn 2005), popular epidemiology (Brown and Mikkelsen 1990) or citizen science (Irwin 1995), more explicitly visible. Foregrounding of lay participation also makes evident the background: the exclusion of the public in the making of science, particularly at the institutional or state-agency level especially when the knowledge being made is about their own environment and health. This can translate into civic pressure to be included in the shaping of this environmental knowledge, from scientific agenda-setting and the formulation of research questions to the methodologies chosen and the construction of the proper frame of analysis as to ‘who’ and ‘what’ is included in the scientific research. Part of studying the dynamics of participatory science also includes attending to the production of ignorance, that is, knowledge that is secret, absent, manipulated, incomplete, ignored, constrained and undone (Frickel 2014; Frickel et al. 2010; Gross 2010). In this article, we focus primarily on the last definition of ignorance, undone science, which can be actively produced through selective attention or chronic inattention to certain questions and methods (Frickel 2014). In particular, we are interested in understanding the relationship between the

state, environmental health science, affected lay-residents and undone science.

Environmental sociology that focuses on participatory science often looks at North American case studies or citizen-science alliances to examine both the types of scientific knowledge and the dynamics through which it is produced. Drawing on over a year of fieldwork, this article focuses on government sponsored health studies and undone science in France which has had a series of environmental controversies regarding the effects of industrial activities on humans and their immediate surroundings (Calvez, Van Tillbeurgh, and Ollitrault 2015). Some of these controversies have occurred in the industrial region in southern France, just west of Marseille, on the Gulf of Fos (Allen 2014). While, in the United States, not knowing the status of health in a polluted community is often due to a dearth of studies or withheld data (Allen 2005, 2008; Liévanos, London, and Sze 2011; Brown 2007), in France, similarly located communities, in contrast, face a plethora of studies.¹ However, they have same outcome of very little resident-relevant knowledge; the health studies conducted rarely align with lay-people’s own observations or produce credible knowledge that answers their questions.

This article examines how state power, disciplinary expertise, and scientific authority, in the form of environmental health studies, co-produce types of undone science that fosters resident suspicion and mistrust. These expert-

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driven health studies do not satisfactorily answer the questions local people have about their health, resulting in knowledge gaps illuminated by what these studies do not say, or what is called undone science. In this article, we analyze three paradigmatic examples of these studies, and problematize their lack of connection to local concerns. Finally, the importance of nation-state contexts in the production of undone science will be highlighted, using France as an example. Social scientists who have studied comparative US/EU knowledge-making for public policy have noted that France represents the starkest contrast to the United States. This is due, in part, to the power of the central state in France and the fact that science for public policy is dominated by state or state-funded research organizations (Campbell and Pedersen 2014). Thus, the French case study of undone science will demonstrate that, even with numerous state scientific agencies tasked with health and environmental knowledge production, undone science remains a problem.

Controversy and activism in two French towns

The heavily industrialized region of Fos/Etang de Berre in southern France houses hundreds of chemical, gas and steel installations, including almost 50 Seveso high-hazard threshold facilities² and over 400,000 inhabitants in 31 municipalities.³ Many environmental problems and accompanying debates have occurred in this region in recent decades. Much of the conflict has centered on the siting of new facilities as well as the effects of pollution and other industrial externalities on humans and their immediate surroundings, particularly in the two towns closest to concentrated industrial facilities: Fos-sur-Mer and Port-Saint-Louis-du-Rhône.

Fos-sur-Mer is a small port city on the Gulf of Fos, a natural bay of the Mediterranean. Port-Saint-Louis-du-Rhône, another port town, sits at the mouth of the Petit-Rhône river, a site targeted for heavy development since the early colonial and industrial eras (Garnier 2001). Both towns are largely working-class with 10–20% of residents living in poverty, 14–17% are unemployed and less than 20% have a college degree [see Table 1].⁴

Locally, the Fos industrial maritime zone is home to 11 Seveso-classified facilities and two incinerators are situated on a landfill between the two towns. Besides the location of the port, another argument for the concentration of industry was the presence of the strong, northern Mistral winds that would disperse pollution southward into the Mediterranean (Perrin 1973). But wind streams have proved more complex and climate change has lowered their frequency and dependability (Najac, Boé, and Terray 2009). In Port-Saint-Louis, regardless of the way the wind blows the industrial plume of pollution either crosses or stagnates over the town.⁵

Unfortunately, residents have little control over the growth and type of industry in their towns due to French law. In 1965, a federal law was passed demarcating

the coastal part of this region as the Port Autonome de Marseille (now called the Grand Port Maritime de Marseille, GPMM). The largest port in France, the GPMM, encompasses not only the actual port of Marseille, but also the ports and adjacent land extending through Fos-sur-Mer all the way to the mouth of the Rhône River. The GPMM designation removed all decision-making authority from the residents and their elected officials and transferred it to the state – specifically the public–private partnership that comprises the GPMM (Garnier 2001). Historian Bernard Paillard in his book, *La Damnation de Fos* (1981), describes the state-driven technocratic transformation of the region as the embodiment of a Promethean myth that was, in effect, a Faustian bargain, whose cost was the denigration of local living conditions. The area has become what some have called a ‘sacrifice zone’ (Lerner 2010).

In addition to legal barriers, residents also faced cultural barriers to local activism. Unlike the United States, where environmental engagement could be seen as a coalition of individual interests (e.g. property values, personal health), French political culture highlights the defense of the common good by the state. In France, models of the public good exclude individual interests that are viewed as politically illegitimate (Lamont and Thévenot 2000). Environmental claims are framed as what benefits everyone (such as the greater good of France) rather than what benefits collections of individual or group interests. Thus, the prevailing ideology in France makes it hard for residents to protest the siting of new facilities because this kind of protest is considered acting in one’s self-interest or the interest of one’s local neighborhood or town.

The two largest siting controversies in the region in the last 15 years occurred in the industrial maritime zone of Fos: the siting of a large Gaz de France LNG (liquid natural gas) terminal on the Fos public beach (opened 2005) and the construction of an incinerator designed to burn all the garbage of Marseille, one of the largest cities in France (opened 2010). These were hugely unpopular projects for the residents of Fos and nearby towns, and served to catalyze community members on environmental issues even though their protests were not able to halt either project.

Additionally, the siting controversies in the region prompted residents to ask questions not previously vocalized: what was the combination of emissions from all the polluting facilities doing to their health? Daniel Moutet, president of the *Association de Défense et de Protection du Littoral du Golfe de Fos* (ADPLGF), the largest locally based nonprofit environmental group in Fos, who led major protests against the gas terminal and the incinerator, explains:

During the struggle against the incinerator, they [the residents] tried during public meetings to approach the issue of health. Then from neighbor to neighbor and word-of-mouth, they came to learn about pediatric cancers and other cancers. ... Whenever the association would try and

get more accurate information, individual privacy was an issue, and even through Fos doctors it has not been possible to have estimates of important pathologies.⁶

Port-Saint-Louis residents also organized against the incinerator, since the emissions plume would impact their town. Their local nonprofit group, *Collectif Citoyen Santé Environnement* (CCSE), joined with ADPLGF and other associations/organizations in trying to get health data from the state health service, whom they felt were not letting people know the region's health problems. 'In France, the old culture of administrative secrecy reigns', explains Gérard Casanova, the past president of the CCSE. To protest this perceived occlusion of health data, these activist groups occupied the outside terraces of the regional office of the *Agence Régionale de Santé* (ARS) (the French health service) several times in 2007 and 2009. Each time they were escorted away from the property by the regional antiterrorist police squad.⁷

Research methods

We conducted more than 40 interviews, including regional health and environmental agency officials, environmental group leaders, journalists, local medical professionals, city risk managers, current and retired industrial workers, town residents, and documentary film makers. These interviews were part of a larger project that examined public engagement in shaping policy-relevant science for environmental regulations in a French industrial region. The interviews were semi-structured and conducted in French. For most of the interviews, written consent was given, and the interview was recorded, transcribed, and then translated into English.

Some of our informants referred us to environmental health studies that had been done in the region. Our methods also included content analysis of all the studies we could find from the last 20 years. From these 12 studies, we chose the 3 for this article that were (a) most often referenced by our informants and (b) most representative methodologically of the types of studies done.

Persistence of asking and not knowing

Challenging legal and cultural barriers, residents continued to voice their questions about health: Are there elevated rates of cancers and cardiovascular diseases? What about asthma and other respiratory illnesses? What about the prevalence of autoimmune diseases, thyroid malfunctioning, and unusual symptoms observed anecdotally? Are pediatric illnesses or reproductive problems elevated in the region? Are their health problems related to air or other pollution? Gwénaëlle Thébaud, the Director of Major and Chronic Risks for the Mayor's office in Fos, explains:

[The residents] see their neighbors, their families, with diseases they have never seen before and they ask for answers, but it's difficult. The law requires industries to measure their emissions and not go above certain levels,

but for the population, there is a preoccupation about knowing the overall effects, the 'cocktail' effects, as well as secondary pollutants.⁸

In the United States, residents of polluted neighborhoods have also been frustrated by the lack of information of the health impacts of being exposed in a mix of toxic substances. Environmental policy and information about pollutants is focused on both sources of pollution and on lists of pollutants, rather than on cumulative health impacts especially for vulnerable communities although there is some progress on this in the United States (Sadd et al. 2011; Morello-Frosch et al. 2011). Additionally, with the exception of Community Based Participatory Environmental Health studies (Cohen et al. 2012; Minkler, Vásquez, and Shepard 2006) and other popular epidemiology work (Brown 2007; Corburn 2005; Allen 2003), there have been few avenues for residents to know the health outcomes and disease prevalence of living in polluted areas with an array of daily exposures.

Adding to their frustration, there are few opportunities for residents in France to voice their concerns to policy-makers because during regulatory meetings only recognized persons and associations are authorized to participate. The meetings typically have specific topics and questions must be kept within a tight time frame.⁹ This kind of technocratic decision-making privileges scientific expertise, separates facts from values, poorly aligns with democratic ideals, and fails to capture the complexity of environmental problems (Fischer 2000; Sarewitz 1996). Local residents recognize when they are 'out-gunned' by scientific experts (Harding 1991) and often see public hearings as a façade where the public is invited to lend legitimacy to ready-made decisions by technocrats and their industrial allies (Irwin 2005).

The French residents' frustration was also fueled, in part, by the numerous professionally driven health studies of the area that have been conducted over the past two decades. In comparison to many polluted communities in the United States, where residents often struggle to get a single health study conducted, this region has been host to many studies that illustrate some of the continued challenges of state-sponsored research and its inability to answer lay people's questions. In both government-agency-led studies and those led by state-funded academic medical researchers, the studies focused on tightly constructed questions answerable within particular languages of expertise, rarely addressing the questions that the residents had relevant to their own perception of their health and environment. As has been found in other critical analyses of science, the residents' lived experiences and first-hand knowledge of their environment and health were absent when the state institutions and their allied scientists designed their technocratic responses to the residents' concerns (Ottinger 2013; Kinchy 2012; Wynne 1996).

A short description and analysis of three of the major studies (Table 2) sheds light on the current state of local concern, including the role that public health plays in shoring up the nation state's interest and inequalities

Table 1. Socioeconomic characteristics of Fos-sur-Mer, Port-Saint-Louis-du-Rhône, and Bouches-du-Rhône.

	Fos-sur-Mer (<i>n</i> = 15,859) <i>Commune</i> (town)	Port-Saint-Louis-du-Rhône (<i>n</i> = 8579) <i>Commune</i> (town)	Bouches-du-Rhône (<i>n</i> = 1,984,784) <i>Département</i> (region)
Economics			
Prevalence of unemployment among residents 15–64 years (%)	13.5	17.4	15.2
Proportion of residents in poverty (defined as less than 60% of median income) (%)	9.9	20.2	18.1
Educational attainment			
No degree/diploma (%)	17.9	27.9	20.0
High school degree or technical high school degree (%)	18.6	15.3	16.8
Vocational/trade school degree (%)	31.8	27.6	20.9
Any higher education degree (masters, bachelor or professional degree) (%)	18.0	12.2	28.4
Housing			
Homeowners (%)	61.3	41.2	51.0
Public housing occupants (%)	15.7	43.6	15.3
Immigration			
Proportion who are immigrants (%)	5.3	8.6	10.1

Table 2. Overview of selected health studies conducted in the Fos/PSL region.

Health study	Institutional direction	Questions asked	Findings and answers
<i>Enquête Panoxy-Berre</i> childhood asthma study	Local officials, epidemiologists, university physicians	What are the short-term clinical effects on children's respiratory function in relation to air pollution levels? Are there correlations between air pollution, respiratory illness, asthma and allergies for children in the region?	Cough incidence rates increase within 24–48 h of higher levels of air pollution. Cough incidence rates in fence-line towns were almost double those in non- industrial towns. Asthma was not statistically correlated with pollution in this sample. It was difficult to analyze the relationship between asthma and allergies
<i>Evaluation Des Risques Sanitaires dans La Zone Industrielle de Fos- sur-Mer dans les Bouches-Du- Rhône</i> risk modeling study	Federal officials, environmental modelers, risk engineers and epidemiologists	What is the cumulative impact of many sources of pollution in the Fos/Etang region? What are the levels of exposure for residents? What is their 'health risk', according to the study's risk modeling calculations?	No significant risk due to pollution was found for this population, due to the uncertainties of risk studies. However, some pollutants were at threshold limits and should be monitored. Arsenic levels in local seafood were high, but these levels can also be found in other parts of the Mediterranean
<i>Pollution atmosphérique et hospitalisations pour pathologies cardio-vasculaires et respiratoires, et pour cancers dans le secteur de l'Étang de Berre, 2004–2007</i> study	Regional officials, epidemiologists, risk engineers	What is the relationship between industrial air pollution and cardiac illness, respiratory illness and cancer for residents of the region?	From statistical analysis of hospital admittances for cancer, cardiac and respiratory illness, there was evidence of elevated rates of cardiac illness and of higher rates of leukemia in men as compared to people in less polluted areas of the region

(Shim 2014; Waitzkin 2011) and the disconnect between the studies and the residents who feel that the relevant health science they are asking for remains undone. These studies also highlight environmental sociologists and science and technology studies scholars' concern that more studies do not necessarily equal participatory science or political change (Brown 2007; Kinchy and Perry 2012; Mah 2017; Ottinger 2011b).

Past health studies: the questions and answers of experts

In the past 20 years, more than a dozen studies regarding population health in France's industrial zone have been conducted. We discuss three of these studies that are representative of the types of studies, including questions and methods, pursued in the past. The first study, funded

by the health ministry and carried out by university medical researchers, uses primary data (e.g. surveys) to assess links between pollution and health (OREP 1996). The second study, funded and directed by the French environmental agency (similar to the EPA), models risks due to local sources of pollution (BURGEAP 2008). The third study, funded and led by the regional health agency, uses secondary data to assess pollution–health links (Pascal et al. 2011). All of these studies are state-sponsored with little or no design input from area residents.

The *Panox-Berre* childhood asthma study (OREP 1996), prompted by local officials and funded by the Ministère de la Santé (Ministry of Health), was conducted by epidemiologists and physicians in response to resident and elected representatives' concerns regarding industrial air pollution.¹⁰ Epidemiologists and doctors in the Marseille Medical School's Departments of Public Health and Respiratory Diseases collected survey data in the field on respiratory illnesses (e.g. asthma, allergies) and other health symptoms of school children around the Etang de Berre region. The region was divided into six 'polluted zones' which corresponded to local towns and two control 'non-polluted zones', two nearby cities located outside of the more industrial area. They examined correlations between air pollution exposure (i.e. NO₂, O₃, and SO₂) and respiratory health.

The results revealed a 'cough incidence rate' of 30% in the polluted zone, almost double that of the control cities. They also noted an increase in respiratory symptoms 24–48 h after elevated SO₂ and NO₂ pollution was measured. They found that asthma rates, though higher, were closely statistically correlated to allergies, and so concluded that asthma was likely attributable to allergies rather than pollution. In the presentation of their findings, the epidemiologists emphasized that there was no evidence of a causal relationship between pollution and respiratory illness, obscuring the meaningful observational findings of an elevated cough rate and directly countering the residents' lived illness experience.

While the *Panox-Berre* childhood asthma study was methodologically sound, aligning with the disciplinary practices of epidemiology, the hypothesis the scientists decided to test was whether asthma was related to allergies. This was counter to the residents' questions as to whether asthma was related to pollution. This example demonstrates a 'more subtle process by which a government response to undone science (...) creates new pockets of undone science even as the first-order undone science is addressed' (Hess 2015, 143). So even though the study concluded there was no causal link between pollution, asthma and respiratory symptoms – which answered, somewhat counter-intuitively, a question the residents asked – it opened up a new set of questions regarding why their children were experiencing higher cough rates than 'lesser-polluted' control towns and increased asthma.

The second study we feature is the *Evaluation des Risques Sanitaires dans la Zone Industrielle de Fos-sur-*

Mer dans les Bouches-Du-Rhône (ERS-Z) (BURGEAP 2008).¹¹ A group of risk engineers, epidemiologists and environmental modelers under the guidance of the *Direction de l'Environnement, de l'Aménagement et Du Logement* (DREAL; comparable to the US Environmental Protection Agency) conducted this risk modeling study in collaboration with several other government agencies. The study assessed the cumulative impact of exposure and associated risk of residents living in the area by modeling exposure, via inhalation and ingestion, for 28 pollutants and determining a 'quotient of danger' for different kinds of pollutant cocktails. Much of the final report consisted of lists of technical data and discussions of the many uncertainties regarding safe chemical thresholds that were unhelpful to residents looking for useful information regarding their questions on illness and pollution. The conclusion of the *ERS-Z* report stated that there was no significant risk for those living in the industrial region and that links between health and exposure could not be drawn due to uncertainties. They recommended further monitoring and study.

The discourse of risk has 'become a defining feature of late modern society public policy culture', and, according to Brian Wynne (2005), has a democracy deficit:

Thus institutionalized risk discourse reifies its constructed object twice over: once in defining the objective and universal meaning of public issues as risk issues; then in presuming that selected definitions or what is to count scientifically as risk are objective, natural and universal representations (70).

Risk analyses are a reductionist and convenient tool of governing bodies that tacitly assume a limited role for local residents to make informed decisions and hypotheses instead relying on black-box expert formulations (Wynne 2005).

Having worked on health risk evaluation studies carried out by the DREAL and other agencies in the previous decade, Jean-Luc Lasalle, a public health risk engineer, and his collaborator, physician/epidemiologist Laurence Pascal, knew that technical studies of risk were not the same as health studies and thus confused and frustrated the lay public. The residents 'found [the studies] very strange,' says Pascal, 'the population did not understand why these studies were conducted'. Lasalle adds:

We have begun to think about involving the population, but what is expected [by the state] are prospective risk studies – these are not the same [as epidemiological health studies]. In the studies in Berre and Fos, the population did not receive information about this study and its methodology before it was started – they just received the results two years later [referring to the *ERS-Z* (BURGEAP 2008) study].¹²

The Fos-sur-Mer risk manager, Gwénaëlle Thébaud, echoed the state's preference for risk studies or technical modeling and the residents' desire for actual health studies that address their questions. When asked if locals trust the studies done by the state,

most of them are going to say that the right things were not studied. As long as there are no studies begun from a human perspective, not just from calculated risk using threshold values, people will not trust these studies – because they say they are certainly sick.¹³

Unfortunately, risk analysis and risk management tools often dominate environmental arenas where the science is complex. Technical models appear to ‘resolve’ the problem of scientific uncertainty, while fundamentally misunderstanding the public’s questions. According to Wynne (2005), ‘the public mistrusts science when it fails to deliver but this mistrust is founded on misunderstanding’ (78). He continues:

The typical public’s concern over uncertainty is about ignorance – unanticipated and unknown consequences – not known uncertainties. [emphasis added] Yet authorities’ repeated and exclusive reference to risk assessment as a response to public resistance in effect denies this endemic state of ignorance ... [thus] the public’s mistrust reflects its continual experience of scientific denial of ignorance and of the limits of scientific prediction and control... (78).

In technical risk studies such as the *Evaluation des Risques Sanitaires dans la Zone Industrielle de Fos-sur-Mer dans les Bouches-Du-Rhône*, residents are not included until the dissemination phase of the study. They are not given a place at the table during the expert-driven design of such studies to frame their own issues regarding pollution and exposures and to negotiate the kinds of meanings that reinforce local knowledge and experience of health and environment. Effectively, ‘the quantitative risk frame in environmental health puts lay publics at a disadvantage from the outset and limits their ability to participate in and influence decisions when compared to scientists and other professionals’ (Corburn 2005, 27–28).

Following the unpopular ERS-Z study, and in response to residents’ concerns about how industrial air pollution may be affecting their health, Lasalle and Pascal, together with a scientific steering committee, designed a public health study to examine the association between atmospheric pollution (SO₂ and particulate matter [PM]) and hospitalization for three disease categories: cardiovascular disease, respiratory illness and cancer (Pascal et al. 2013). The study, released in 2011 and followed by a published article in 2013, was titled ‘*Pollution atmosphérique et hospitalisations pour pathologies cardio-vasculaires et respiratoires, et pour cancers dans le secteur de l’Étang de Berre, 2004–2007*’ (referred to as *Hospitalisations* study) (Pascal et al. 2011).

Due to both budgetary and methodological decisions made by the scientific team, the study used secondary data. This led to a number of limitations in the data and subsequent analyses. First, they only used certain pollutants that were measured at air monitors, which did not necessarily capture what community members were breathing (Brown et al. 2003). For example, a medical doctor and president of a local nonprofit health association

would have preferred to also have information on smaller, and potentially very harmful, particles such as PM_{2.5} and PM_{0.1} in addition to the PM₁₀ that was measured.¹⁴ Second, using hospital admissions as a way to ascertain rates of asthma, cancer and cardiac disease meant that only the most extreme cases of asthma, and not the total burden of disease, would be captured. The scientists admitted as much:

The lack of significant results for respiratory diseases most probably shows that hospitalization indicators are not the best indicators to evaluate the respiratory health effects of air pollution in adults in France. Asthma hospitalization rate in adults decreased slightly since 2000, and asthma disease is mostly taken care of by ambulatory management. Studies using emergency or general practitioner (GP) visits for asthma attacks could be more relevant (Pascal et al. 2013, 8).

The *Hospitalisations* study found no excess risk for either cancer or asthma hospitalizations due to living in polluted industrial regions, except for acute leukemia in men. However, the study did show a relationship between heart disease and SO₂ air pollution. In their conclusion, the authors recommended further education of doctors and more surveillance of current and retired workers for possible impacts of more concentrated workplace exposures. The study overall concluded that ‘the health situation of the population exposed to industrial air pollution is generally not a concern for respiratory diseases and cancers’ (Pascal et al. 2011, 45).

Many residents were, in the end, critical of this study and its findings. ‘It seems impossible not to have been able to establish a link between pollution and respiratory illness in the *Hospitalisations* study,’ says local activist, Gérard Casanova. He continues:

We know that this is not possible. In France, what has not been proven does not exist. As long as there are no studies and we do not know, there is no problem. As long as people do not want us to make this link here, there will not be any targeted studies.¹⁵

Frustration with the lack of health knowledge

In 2001, the town of Port-Saint-Louis welcomed two new general practitioner doctors, Vincent Besin, and his wife,¹⁶ who had both previously spent years practicing medicine in the city of Grenoble. For such a small town, they were ‘amazed by the number of rare pathologies, early deaths, and immunological diseases as well as the large number of cases of respiratory illness and chronic bronchitis’. Dr. Besin’s wife had many children as patients and was not prepared for the number of sick children and the severity of their illnesses. Dr. Besin decided to compile his own informal data on one of the illnesses, pediatric type 1 diabetes. ‘Out of a town of 8000 inhabitants, we should have one case – and only from my personal inquiries, I believe we have 25’.¹⁷ As for miscarriages and fetal abnormalities, Dr. Vincent Besin responded that the

genetic specialists at La Timone (the main hospital in Marseille) had told him that a great number of these cases come from around the Etang de Berre. No studies of either of these concerns have been proposed to date by the ARS, the state health authorities. Another general practitioner in the area, Dr. Philippe Le Merer, has also been frustrated by the lack of information:

I have pediatric cancers, leukemia, bronchiolitis in children in my office.

It is scandalous that ARS does not have the data. In France, it is impossible to get statistics related to disease ... The data are collected, but they are not disseminated. It has been like this for years!¹⁸

The ARS is also limited by their classification system. For example, some residents are concerned about autoimmune diseases, but these are not classified by the ARS or routinely documented. For example, type 1 diabetes, which in most people is an autoimmune disease sometimes triggered by environmental factors,¹⁹ is not tracked by the Observatoire Régional Santé (government health data tracking agency), which considers these data difficult to collect.²⁰ The critiques of local physicians, such as Besin and Le Merer, about the lack of state health data align with what Gross (2007) refers to as 'negative knowledge'. This form of 'undone science' refers to knowledge that state and industrial elites may prefer to keep 'undone' as it may lead to regulation or other decisions seen as negatively impacting industry (Hess 2015).

Lack of information about pollution exposure in these communities is also obscured by state practices. One example is air quality information, since air pollution is one of the main exposures residents worry about. Thirty monitoring stations in the Fos/Etang de Berre region each measure 1 to 7 pollutants depending on location. The Air PACA²¹ operational director, Xavier Villetard, explained that PM is recorded as a daily average, rather than hourly, so it is rare that EU standards are exceeded when averaged over a 24-h period. An air quality alert is only declared after 35 days of 24 h averaged PM excess. Thus the level and duration of pollution is set so high that, according to Villetard, an alert is only sounded 1–3 days a year in the region.²²

A few years ago, the mayor of Port-Saint-Louis requested that an air monitoring unit be moved to the town center. It was moved temporarily and Air PACA found daily significant peaks of PM between 10 am and 2 pm – the time when many people were outside and children were playing in the schoolyard. Thus, the residents confirmed what they had suspected. But, due to the equipment available and the reporting standards dictated by the state, the locals still only receive overall reports of air safety in the form of color indicators on maps. They can go to the air quality index website and view their overall air condition as a rainbow – from green (*très bon* or very good) to orange (*médiocre*) to red (*très mauvais* or very bad).²³ Activist Gérard Casanova expresses his

frustration at the local officials and industrial power in the region:

The communication of index maps of air quality reveals a lot. We do not have data on the town or station but instead we have some color. Communication at the level of the Port-Saint-Louis municipality is a public sign that indicates air quality, but with a delay related to the schedules of the people responsible for posting the sign. If we had communication with the schools regarding peak pollution, we could reduce fieldtrips during unfavorable periods and reduce the risk of exposure. The public communication of air quality reaffirms the industrial purpose of the area.²⁴

One unique and potentially more independent association/organization, the *Institut Ecocitoyen pour la Connaissance des Pollutions*, was founded in 2010 in response to the environmental controversies in the region, with the express mission of including residents in their pursuit of answers to environmental questions. This locally grown and maintained organization is funded by the city of Fos-sur-Mer together with five other local municipalities and has a variety of people on its governing board, including industry representatives, and a local chemist as president.

Recently, the *Institut Ecocitoyen* decided to pursue a more rigorous project aimed at producing detailed exposure data. Their study, called *INDEX*, will study laboratory samples (i.e. blood, urine) and medical histories of 120 individuals, including 60 in a control community.²⁵ The project, due to a labyrinthine path to institutional approval, has taken over 4 years to get off the ground, but they hope to begin in late 2016. They explained that their study is of pollutant exposures, and not a health study per se, as they are not attempting to link exposure to health outcomes. This strategy was because their governing board has both government officials and representatives from industry who would not agree to study health outcomes directly.²⁶ Even though they are a group created to produce environmental science for the residents, the way they bounded their exposure study produced intentional undone science, as the link between illness and exposure is one of the main questions the residents have.

Discussion of French and national contexts in knowledge production

To understand policy-related science in France, some comparison with the United States is useful. Campbell and Pedersen (2014) compared the field of policy research organizations (i.e. government research units, think tanks, philanthropy groups, business/political party research organizations etc.) in the U.S. and several EU nations, including France. They define this dynamic constellation of policy research organizations as *knowledge regimes*, 'the organizational and institutional machinery that generates data, research, policy recommendations and other ideas that influence public debate and policymaking' (3). In their analysis, the US *knowledge regime* is a lively marketplace of ideas where a variety of knowledge-

making and knowledge-shaping entities battle for influence among policymakers. There is a strong presence of private, including nonprofit, advocacy research, and both the executive and legislative branches of government are targeted for lobbying and influence. While the US *knowledge regime* generates a diverse array of analyses and policy recommendations, the economic, political and ideological alliances of many of the organizations make it difficult for outsiders and nonelites to be heard.

France's *knowledge regime* represented the starkest contrast to the United States as it is guided by a strong centralized state (Campbell and Pedersen 2014). State and semi-public research organizations heavily dominate policy-making knowledge in France. These organizations 'are oriented around the executive rather than the legislative branch ... because in France's presidential system legislation emanates from the ministries and the National Assembly is comparatively weak' (104). Furthermore, 'the expansive and permanent French civil service elite rarely seeks the assistance of outside organizations because it is confident in its abilities and has considerable in-house expertise of its own' (104). Additionally the state subsidizes many, if not most, of the nonprofit and activist organizations, often in the form of registered '1901 associations',²⁷ which can become dependent on this funding and be reluctant to challenge state decisions at any level.

The divergent functioning of state knowledge regimes in the United States and France also maps onto differences in 'undone science'. According to David Hess (2007):

Because political and economic elites possess the resources to water and weed the garden of knowledge tend to grow (to be 'selected') in directions that are consistent with the goals of political and economic elites. When social-movement leaders and industry reformers who wish to change our societies look to 'Science' for answers to their research questions, they often find empty space ... whereas their better-funded adversaries have an arsenal of knowledge to draw on. I call this the 'problem of undone science' (22).

Hess' definition describes the US adversarial battleground of policy-relevant scientific knowledge. In France, however, *dirigisme*, or state-led strong economic planning and control, is allied with state health and environmental agencies, tasked with producing the knowledge to fuel the nation's economic directive. The professionals in these organizations form the state's technical and political elite and are primarily trained at the prestigious *Grandes Ecoles*, which provide a direct pipeline to coveted public service positions (Campbell and Pedersen 2014). In France, undone science is knowledge that lies outside of the traditional science taught and accepted in the *Grandes Ecoles*. Thus, the science consistent with political and economic elites that Hess describes in a US context is done in France, by the French state, in service of *dirigisme*. The insular nature of knowledge and power in France contrasts with the 'Wild West' of powerful

moneyed interests and government lobbyists in the United States.

Conclusion

Although the role of the state and the production of exposure studies differ, in the French context and in the United States, the outcome is similar: communities are left without the knowledge to answer the questions and concerns they have about their health. Even in a situation like France where numerous health studies are conducted, undone science is still produced. Furthermore, the French residents' dissatisfaction with the numerous environmental and health surveys done in their region cannot be attributed to scientific incompetence. All three studies discussed in the previous sections were presented at academic conferences, cited in other publications, and even published in highly regarded professional journals. Following Brown and Mikkelsen (1990) critique of epidemiology, the problem, we argue, is with the research questions asked and the strict methodological protocols followed, given the context of the myriad of health issues confronting the residents. There is a failure of governmental, institutional and professional imagination when it comes to fully including local residents in shaping the agendas and questions of science, in part due to the adherence to an uninclusive and disciplinarily driven framing of environmental health studies.

For example, in the *Panox-Berre* childhood asthma study, the unquestioned disciplinary practice of relying on abstract statistical correlation rates rather than on data drawn from the local residents who actually experienced symptoms led experts to privilege allergies as a source of causation of asthma rather than exposure to industrial chemicals. Additionally, the epistemic culture of the bureaucratized French knowledge regime favored measurable explanations of single sources of causation over more accurate, but less certain, holistic explanations accounting for the totality of residents' environmental exposures. Similarly, the *Hospitalisations* study focused on respiratory cancers for ease of measurement through an analysis of hospital data, rather than respiratory conditions that local residents in polluted areas actually experienced. These respiratory conditions are considered harder to measure because there are a wide range of illnesses and symptoms and hospital admittance is not a common way to manage chronic conditions. In the *Hospitalisations* case, this disciplinary practice of sacrificing meaningful questions for measureable data left science undone.

Additionally, undone science can also occur on purpose or have an intentional side. According to Dr. Besin, the state designed studies where they could be relatively sure of the outcome, a 'tactical strategy' where they 'chose something to find to secure financing.' Furthermore, he speculated, it was lucrative for health agencies to have inconclusive results, or results already well-established elsewhere, to justify further study financing while at the same time not disrupting the power of industry in the

region.²⁸ The circulation of theories as to the lack of environmental health science in the region is further evident of resident mistrust of the state *knowledge regime*.

The three studies discussed in this article, which are illustrative of the kinds of studies conducted in the Fos/Etang de Berre area, developed their questions and methodologies in a very insular, discipline-driven ways, meeting internal professional standards for doing science, but largely missing the local questions, public context, and the collection of hard to get data. Residents understand their health and ask questions in ways that differ from professionals such as epidemiologists and risk modelers. Often, the experts create undone science by seeking to 'fit' localized conditions into a simple predetermined risk model according to disciplinary and agency practices rather than taking resident's experiences with their health and their surroundings into account. Furthermore, the studies' conclusions align with Besin's belief that maintaining the status quo, not environmental health knowledge, is the implicit goal of these studies.

A perusal of the questions of the locals versus those of experts highlights the different views and priorities (see Table 2) that lead to the undone science. Residents want to know the prevalence and types of illnesses in their community and if these are 'normal.' They want to know if pollutants have entered their bodies and their food supplies and what kind of damage may result. They want conclusions that err on the side of caution: not the caution that statisticians use when conservatively interpreting data at 95% certainty levels, but precautionary actions a parent might have when considering the health of their children. This runs counter to the narrowly focused questions and findings of the many scientific health surveys conducted in Fos/Etang de Berre. Furthermore, the closed disciplinary and epistemic practices of the French civil service elite privileges abstract, mathematical model-based, forms of analysis that make little room for considering the experiences or lay knowledge of local residents. Even more striking than the narrowness of the expert questions were the timidity of the conclusions, which often observed problems but concluded that there was little effect or need for concern – and suggested that more studies were needed in the face of uncertainty.

Local residents can add great value to environmental health science – both in kinds of questions and ways of knowing – that increases understanding of population health in polluted communities (Allen 2003; Brown and Mikkelsen 1990; Brown 2007; Corburn 2005). Through combining professional knowledge 'from above' with on-the-ground embodied knowing, a more strongly objective and relevant health science is created (Harding 1991). When local residents participate in the process of producing environmental health knowledge – developing questions, collecting evidence, analyzing data and dissemination strategies – they are producing the science that had formerly been left undone (Allen 2003; Irwin 1995, 2015).

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Notes

1. In the last 20 years, there have been more than a dozen human environmental health studies conducted in the region all funded by the state through its various agencies and affiliated organizations.
2. Seveso high-hazard threshold facilities are defined as those with highly toxic or combustible substances either stored or produced on site. Facilities are listed here (last updated June 2014) http://www.paca.developpement-durable.gouv.fr/IMG/pdf/Liste_des_47_Etablissements_SEVESO_cle5f136d.pdf.
3. Demographic data (source: Institut National de la Statistique et des Etudes Economiques, accessed 27 October 2015) for the Etang de Berre/ Fos basin: http://www.insee.fr/fr/themes/document.asp?reg_id=5&ref_id=15834.
4. Institut National de la Statistique et des Etudes Économiques. 'Résumé statistique – Commune de Fos-sur-Mer (13039), Département des Bouches-du-Rhône (13), Commune de Port-Saint-Louis-du-Rhône (13078)' <http://www.insee.fr/fr/themes/comparateur.asp?codgeo=COM-13039&codgeo=DEP-13&codgeo=COM-13078> (accessed 4 May 2016).
Note: It is unconstitutional to collect data on race, ethnicity or religion in France, but first-generation immigrant status can be documented.
5. Interview by B. Allen and Y. Ferrier with Xavier Villetard, operational director of Air PACA (the air monitoring authority) for the Western territory of Bouches-du-Rhône in his office in Martigues, 21 January 2014.
6. Interview by B. Allen and Y. Ferrier with Daniel Moutet at the ADPLGF office in Fos-sur-Mer, 8 January 2014.
7. Interview by B. Allen and Y. Ferrier with Gérard Casanova at a café in Port-Saint-Louis, 20 January 2014.
8. Interview by B. Allen and Y. Ferrier with Gwénaëlle Thébaud at IMéRA in Marseille, 28 January 2014.
9. These have many parallels to Department of Environmental Quality public hearings in Louisiana's chemical corridor where only 'technical' concerns were deemed relevant and more holistic commentaries regarding landscape degradation or noxious smells were considered irrelevant and stricken from the record that was used by policy-makers for permitting applications (Allen 2003).
10. This study is referenced as OREP (1996).
11. This study is referenced as: BURGEAP (2008) *Evaluation des Risques Sanitaires dans la Zone Industrielle de Fos-sur-Mer dans les Bouches-Du-Rhône*, Avignon: Burgéap.
12. Interview by B. Allen and Y. Ferrier with Laurence Pascal and Jean-Luc Lasalle at ARS headquarters in Marseille, 10 January 2014.
13. Interview by B. Allen and Y. Ferrier with Gwénaëlle Thébaud at IMéRA in Marseille, 28 January 2014.
14. Interview by B. Allen and Y. Ferrier with Dr. Pierre Souvet, President, *Association Santé Environnement France*, in L'Arbois, 16 December 2013.

15. Interview by B. Allen and Y. Ferrier with Gérard Casanova in a café in Port-St-Louis, 20 January 2014.
16. We interviewed Dr. Vincent Besin (retired). We did not officially interview his wife (currently practicing) and have her sign an IRB consent form, so we are not naming her.
17. Interview by B. Allen and Y. Ferrier with Dr. Vincent Besin at his home in Port-Saint-Louis-du-Rhône, 9 December 2013.
18. Interview by B. Allen and Y. Ferrier with Philippe Le Merer at his home in Ensues-la-Redonne, 28 January 2014.
19. See Hathout et al. (2002) and Beyerlein et al. (2015) for relationship between air pollution and type 1 diabetes.
20. Interview by B. Allen and Y. Ferrier with Stéphanie Guagliardo at ORS offices in Marseille, 13 February 2014.
21. Air PACA is the state-approved, non-profit entity tasked with air monitoring. PACA is 'Provence Alpes Côte d'Azur', the administrative regional subdivision comprising the Fos region.
22. Interview by B. Allen and Y. Ferrier with Xavier Villetard, in his office in Martigues, 21 January 2014.
23. For a quick overview of this kind of mapping system: <http://www.airpaca.org>.
24. Interview by B. Allen and Y. Ferrier with Gérard Casanova in a café in Port-St-Louis, 20 January 2014.
25. A brief description of the INDEX study appears in the *Institut Ecocitoyen* website at: <http://www.institut-ecocitoyen.fr/etudes/index/>.
26. Interview by B. Allen and Y. Ferrier with Philippe Chamaret at the *Institut Ecocitoyen* offices in Fos-sur-Mer, 9 December 2013.
27. An Association Loi 1901, named after a law made on 1 July 1901, is a nonprofit organization of two or more people who are organized around some objective or purpose. People must form this kind of association if they: collect member dues, have a bank account, fundraise, or undertake legal action. For the law, see <https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=LEGITEXT000006069570>.
28. Interview by B. Allen and Y. Ferrier with Dr. Vincent Besin at his home in Port-Saint-Louis, 9 December 2013.

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