

## **A Successful Experiment in Participatory Science for Promoting Change in a French Industrial Region**

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### **Abstract**

The author and her team worked with the residents in an industrial area in France to produce a participatory epidemiological study about their health. The final report, drafted with input from the citizens, attracted the national press and the interest of many other polluted communities.

The survey is currently being used to promote environmental change by the residents, their elected officials, and local doctors. This reinforces the author's claim that rigorously designed participatory science can further citizen environmental initiatives and provide them policy-leverage.

### **Keywords**

participatory science; participatory epidemiology; environmental health controversies; knowledge justice

### **Introduction: Living with Pollution**

For years, residents living in the small towns bordering one of [France's largest industrial zones](#) have complained about health problems that they felt were linked to pollution from the myriad of nearby chemical plants, refineries, steel mills and logistics depots. Over the past two decades, the area, referred to as Fos-sur-Mer/Etang de Berre, has had many state-sponsored health studies conducted all [concluding that that there were no significant health problems or that further study was needed](#). To residents and local doctors, these findings were not credible, as they did not correlate with their experience. Instead these studies produced a kind of strategic ignorance or knowledge injustice and were used to validate policy inaction.

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Houses, industry, and poor air quality in the town of Fos-sur-mer. Photo by author.

In 2014, I was working in France on a project comparing how citizens shaped policy-relevant environmental science in different national contexts. Based on conversations I had with local doctors and key environmental informants regarding their frustration with the lack of credible health status information in their towns, I decided to conduct a participatory science experiment. My hypothesis was that, if residents were fully incorporated in the making of a rigorously-designed health study about their community, the study would be both relevant to them and could lead to improving environmental health outcomes for the local population. In contrast to the state health studies, which were often based on extrapolating regional data for

local conditions, my proposal was to acquire disease prevalence data via self-reporting: by directly asking people if they have ever been diagnosed by a doctor with various illnesses.

### A Community Health Study

With my team (epidemiologist, Alison Cohen, and anthropologists, Yolaine Ferrier and Johanna Lees), I conducted a [community-based participatory environmental health study](#) using epidemiological methods of analysis in two polluted towns in this industrial zone: Fos-sur-Mer and Port-Saint-Louis-du-Rhône. This kind of study takes its inspiration from the popular epidemiology work pioneered by Phil Brown and Edwin Mikkelsen but derives its method from public health, notably the [community-based participatory research of Meredith Minkler and Nina Wallerstein](#). The project was funded by the new [French agency for Food, Environmental and Occupational Health \(ANSES\)](#), which was established in 2007 and aspired to a model of collaborative expert assessment. They also set themselves apart from the establishment French health and environmental agencies by being more open and accessible to the public.



Using a local map, epidemiologist, Alison Cohen (left) and Barbara Allen consult with resident, Gerard Casanova, over neighborhood surveying boundaries. Photo by Yolaine Ferrier.

In 2015, we designed a health survey questionnaire based on many group meetings and interviews with residents and local doctors. Using the health questions of the local people as the basis of the survey, we went door-to-door (following a random generated pattern) until over 800 households representing almost 10% of the population had been surveyed. By randomly surveying households and carefully excluding illnesses for which there were small numbers, we maintained epidemiological rigor and privacy, which meant our study could later stand up to the scrutiny it later received by institutionally-situated state health service scientists. We initially publicized our survey in newspapers and on civic bulletin boards to let residents know we would be knocking on doors. Our response rate was 45%, meaning of the people that answered the door, almost half agreed to be surveyed.

The survey revealed that multiple chronic illnesses, such as asthma, cancer, and diabetes, were elevated when compared to national data. For example, adult asthma was 50% higher than the French population, cancer was highly elevated especially for women, and type1-diabetes (an environmentally triggered auto-immune disease) was 3-4 times higher than the national population. In addition, there was an increased prevalence of chronic illnesses such as skin conditions, eye irritation, nose and throat problems, frequent headaches, and nosebleeds. A majority of the residents (63%) reported at least one chronic problem that affected their daily lives.

We completed [a final report](#) in collaboration with the residents and local doctors, holding over 30 focus groups to analyze and understand the health data in the context of the lives of the townspeople. The focus groups enabled people to collectively make meaning from the numerical data and yielded dozens of recommendations for “next steps” towards health and environmental improvements. While some of the recommendations were aimed at confronting the industries that provided jobs and fed the local economy, many were creative ideas that would help them to mitigate the impacts of pollution and negative health outcomes. For example, they suggested that schools adapt outside play and sports activities to avoid peak air pollution times and episodic events. They are also pressing their local governments to cease street cleaning by mechanical blowing (which re-suspends harmful particulate matter) and to introduce green zones and more planting around the towns.

## Promoting Change

After presenting the final report to the residents in town meetings in January 2017, it was released to the public online. The press immediately began reporting on the survey, highlighting how its results differed significantly from the “official” state surveys that had found no health problems in these towns. By mid-February, the story of [the participatory survey had reached French radio and TV](#) as well as [French medical blogs](#).



Focus group being led by team members, Johanna Lees and Yolaine Ferrier. Photo by author.

In March, after our press conference in Marseille, the story of the study was picked up again by the French AFP (the equivalent of the Associated Press) and by the end of the month over 70 news articles, radio interviews and TV segments had run about our project. The media coverage led to over a dozen citizen groups and local officials from other industrial towns contacting us, wanting a similar study. For example, representatives of civic groups in the alumina refinery town of Gardanne contacted us about replicating our participatory health study and have already drafted their request to the state. In June 2017, a physicist and scientific advisor for an environmental group in the town of Lacq (a natural gas production area) sent us extensive documents regarding a new study the state health service planned to conduct in response to citizen concern about cancer. The residents were leery about this study given the state health service's past performance, and so with our help the group made a successful argument to the state to change their survey approach to a participatory study instead.

As an experiment to know the impact of participatory science on the lives of people living in industrial regions, this project thus far has had favorable outcomes. One of the town mayors has already used the study results to challenge the re-permitting of an industrial incinerator and the enlarging of another commercial incinerator that burns all the garbage from Marseille. The French Regional Health Service (ARS) released an internal report to us in March, concluding with a recommendation of more therapeutic support for chronic illnesses in the region, which was in direct response to the focus groups' request for more access to medical specialists. A group of doctors at the local hospital told us that they are proposing new research based on findings in the report. We are certain more outcomes are to come, both in local follow-ups to the study, and in other polluted localities' intent to apply this research framework to their health questions.

This project demonstrates that when people participate in a robust scientific study—from the initial questions asked to the final analysis—it can not only produce evidence that aligns with their observations in daily life but can also have policy reach. To allow people to help shape and produce science is a way to democratize science and create a kind of knowledge justice—knowledge about health from the perspective of the people for whom the science matters and can have impacts.

### **Author Biography**

Barbara L. Allen is a professor in the Department of Science, Technology and Society at Virginia Tech, National Capital Region. As a sociologist of scientific knowledge, she researches participatory environmental sciences and their intersection with issues of social justice.