

# Science and Engineering Ethics

## ICT, Genes, and Peer-production of Knowledge to Empower Citizens' Health

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<b>Abstract:</b>	<p>The different and seemingly unrelated practices of ICT devices used to collect and share personal and scientific data within networked communities, and the organized storage of human genetic samples and information—namely biobanking—have merged with another recent epistemic and social phenomenon, namely scientists and citizens collaborating as "peers" in creating knowledge (or peer-production of knowledge).</p> <p>These different dimensions can be found in joint initiatives where scientists-and-citizens use genetic information and ICT as powerful ways to gain more control over their health and the environment. While this kind of initiative usually takes place only after rights have been infringed (or are put at risk)—as the two cases presented in the paper show—, collaborative scientists-and-citizens' knowledge should be institutionally allowed to complement and corroborate official knowledge supporting policies.</p>	

# ICT, Genes, and Peer-production of Knowledge to Empower Citizens' Health

## 1. Introduction

The different and seemingly unrelated practices of Information and Communication Technology (ICT) devices used to collect and share personal and scientific data within networked communities, and the organized storage of human genetic samples and information—namely biobanking—have merged with another recent epistemic and social phenomenon, namely scientists and citizens collaborating as “peers” in creating knowledge (or peer-production of knowledge) (Benkler and Nissenbaum 2006; Ball 2012). These different dimensions can be found in joint initiatives where scientists-and-citizens use genetic information and ICT as powerful ways to gain more control over their health and the environment.

These practices are deeply changing epidemiological research and surveillance towards what can be called citizen “veillance:” an attitude of cognitive proactive alertness towards the protection of common goods.

This paper illustrates two Italian initiatives where citizens and scientists through knowledge and technology have joined with the goal of protecting environmental health in potentially highly polluted contexts. These are the “Fondazione Bioteca Sarroch” (Cagliari, Italy), located near an oil refinery and petrochemical plant, and the project “PM<sub>2.5</sub> Firenze” for the control of particulate matter pollution in the city of Florence. In both situations, citizens—namely scientists and lay-experts—started a knowledge-based initiative to re-establish their rights to health and environment (which are constitutional rights in Italy and in most European countries).

## 2. From public health surveillance to participatory epidemiology

The contemporary concept of ‘public health surveillance’ has changed over time as an attempt to draw the boundaries from other uses of the word ‘surveillance,’ where power implications are more apparent (Subramanian 2003). In the 20th century the concept of surveillance as the monitoring of disease occurrence in populations was developed in contrast to surveillance meant as close observation of persons exposed to a communicable disease in order to prompt isolation and control measures. Also, while the attempt was made to maintain the concept relatively ‘neutral’ towards its potential policy outcomes, at the same time the policy need existed to frame surveillance as the factual basis for “rational decision-making,” namely information for action (e.g., in allocating resources, in choosing priorities, in predicting future needs) (Declich & Carter 1994, 289). However, as methods and measures in public health have often been developed, especially in the field of infectious diseases (Gainotti et al. 2008), in connection with legal acceptance of compulsory measures and strong limitations of fundamental rights, a more direct and active involvement of the public was deemed necessary.

These attempts to make public health needs more compatible with human rights and democratic procedures have triggered a turn towards a more participated epidemiology, namely the application of participatory methods to epidemiological research and disease surveillance. Participatory epidemiology is based on conventional epidemiological concepts, but uses participatory methods to solve epidemiological

problems. The practices related to lay expertise, and especially expert patients, have thus merged with the dynamics of public health surveillance.

Framing surveillance as participatory in public health—as well as in other public life domains—has been a strategic move towards more democratized practices by directly involving the observed subjects. Including people in surveillance operations (e.g. in emergencies),<sup>1</sup> however, does not necessarily entail that they are given any power or control, and often has just meant using individuals as a source of information.

Indeed, not all forms of participation are alike, and the mere participatory nature of surveillance does not justify its overall legitimacy. Participation per se is not a significant sign of a paradigm change in surveillance if the powers involved are not re-considered, re-balanced, and re-legitimized. In this respect making public health surveillance participatory as to its means neither implies that its goals are disclosed to, known and controlled by, participants nor that these can be justified in terms of socially recognized rights and values. Participation should be a way to achieve some common goods that can hardly be protected in more traditional forms. The (often combined) fields of health and environment protection are amongst the most frequent domains for citizens to engage in (legitimate forms of) surveillance.

Efforts by communities to monitor industry's effects on air quality have been amongst the most widely performed activities of this type of participatory surveillance. Communities have used a variety of devices to watch the environmental impacts of neighboring industrial facilities as ways for political empowerment and with an eye to intervention (Huey and Fernandez 2009; Ottinger 2010). However, these activities have been mostly described as forms of 'sousveillance,' namely as 'the watching of the watcher by the watched,' a symmetric, but bottom-up form of surveillance, where hidden control remains the main component.

### 3. From biobanks to genetic digital networks

Starting in the 1990s, biobanks, namely the storage and use for research purposes of human biological materials and information, have become crucial for research and therapeutic uses, and their related commercial exploitations. In the normative puzzle that has taken place around their ethical and legal framing, the concepts of autonomy, privacy, and property have been played not only as rights and/or protecting measures for citizens, but also as ways to prevent citizens from participating in decisions concerning research and its potential benefits (Tallacchini 2015).

The beginnings of the storing of biological samples and information oscillated between ethical unawareness about potential applications, and the attempts to regulate the new practices through normative categories aimed at excluding individual donors from participation in research. The newness of the situations and the general unpreparedness towards them largely explains why the subject-patient-donor could not enter the normative picture (Skloot 2010).

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<sup>1</sup> See, in this issue, F. Andritsos, Future surveillance: the citizen in the loupe or in the loop?

Through time, normative frameworks concerning biobanks have been shaped in the US and in Europe by mixing legislative and/or judicial pieces, and official opinions of ethics bodies (Office of Technology Assessment 1987; European Group on Ethics in Science and New Technologies 1998).

In the US the regulatory issues have been primarily debated, mostly through court decisions, as a contrast between privacy and property (OTA 1987). A series of famous judicial cases in the US <sup>2</sup> have also widely inspired the European legal approach. In the first renowned court decision (*Moore v. Regents of University of California*), in 1990, the California Supreme Court portrayed the uses of human biological materials as a dichotomy between privacy and property. Concerned about the potential consequences of individuals selling their biological materials, the judges established that while research institutions and corporations may acquire these for free, and then patent and commercialize them, individuals are only entitled to abandon or donate their own biological samples. In a famous quote, followed by several other U.S. courts, the California Supreme Court stated that “the round pegs of ‘privacy’ and ‘dignity’” cannot be forced “into the square hole of ‘property’;” thus implicitly assuming that profit could be the only reasons for private individuals to be interested in scientific research. This legal imagination remained quite pervasive for a few decades.

In Europe the normative framework has avoided dealing directly with the property derived from the human body –considered as a non-marketable entity that as such cannot give rise to financial gain<sup>3</sup> and has mostly made use of the concepts of individual dignity, autonomy, privacy, and anonymization of information and materials (EGE 1998; Gottweis, Kaye, *et al.* 2012). In both cases, however, private and public life have been sharply separated in relation to scientific research. Having framed the issue in terms of protecting private life and granting researchers control over biological information and materials, regulators have *de facto* excluded other forms of potential involvement for citizens. Therefore, citizens’ concerns have been pre-defined and constrained within the limited scope of their private lives and anonymized identities. All other potential interests, such as participating in public decisions about research and contributing to defining the social goals did not enter the normative design.

Towards the end of the millennium a few biobanking initiatives, especially in Europe, were started as top-down, often State-driven initiatives led by scientists and experts, where citizens were only entitled to informed consent – that, in some cases, such as the Icelandic Health Sector Database, was just presumed (Winickoff 2006). Some arrangements excluding citizens turned out to be mostly unsuccessful and generated public distrust while the paradigm of privacy and de-identification was showing its limits (Erlich *et al.* 2014).

The unpredictability of the future research uses of biological materials has made the meaning of informed consent ambiguous because what donors are asked to consent to can hardly be anticipated and specified. Wide and even blank consent has been presented as a potential solution (Lunshof, Chadwick, Vorhaus, Church 2008), but the issue is still debated.

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<sup>2</sup> *Moore v. Regents of University of California* (Cal. App. 2 Dist. 1988; *Regents of University of California v. Moore* 51 Cal. 3d 1990); *Greenberg v. Miami Children’s Hospital* (264 F. 10 Supp. 2d 1064 S.D. Fla. 2003); *Washington University v. Catalona* (437 F. Supp. 2d 985 E.D. Missouri 2006).

<sup>3</sup> Council of Europe, *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine*, Oviedo, 4.4.1997, “Article 21 – Prohibition of financial gain: The human body and its parts shall not, as such, give rise to financial gain.”

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4 However, other unresolved tensions concern the relations between citizens' engagement in research and  
5 the legal protection of privacy. For instance, the proposed European new regulation on data protection,  
6 <sup>4</sup>while introducing more stringent standards for data protection that according to scientists will limit  
7 research through cancer registries, <sup>5</sup> does not take into account citizens' willingness to collaborate with  
8 researchers. Also, several communities in polluted areas, where official statistics are not considered as  
9 reliable, ask for the data on cancer incidence to be updated and, in absence of that, have to set up their  
10 own (sometime naïve) cancer case findings. <sup>6</sup>

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14 Starting in about 2005, some experimental exercise with Direct-to-Consumer tests was triggered by a new  
15 technological and social dynamic made possible by the Internet. These activities, led both by the for-  
16 profit and not for-profit sectors, have given rise to genetic social networks and new forms of engagement  
17 for users (Gutmann 2012). They are showing that, rather than being mostly concerned about privacy  
18 and/or abstract ideas of autonomy, users seem more focused on contributing to knowledge production, on  
19 having access to information and its re-use, and on sharing decisions and potential health benefits.

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22 The turn towards more participatory and participants-driven initiatives in genomic research is radically  
23 altering the relations between researchers and participants, while it is also encouraging genetic freedom  
24 and knowledge as an autonomous educated citizen choice (Saha, Hurlbut 2011; Hernandez 2012).  
25 Participants are now seen as *partners* in scientific research and as *peers* in knowledge production. Indeed,  
26 the expression 'peer production' rather than 'crowdsourcing' appears as more appropriate to this situation  
27 that does not simply solicit participant contributions, but "genuinely shares those contributions as freely  
28 as possible" (Ball 2012). These initiatives, <sup>7</sup> where scientists and citizens contribute to research as actors  
29 of research and peer-producers of knowledge, are exploring the potential for broad anthropological  
30 changes (Lunshof *et al.* 2008; Church *et al.* 2009; Kaye 2012).

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33 A range of new activities have called for "occupying science" (Saha and Hurlbut 2012)—citizens'  
34 willingness to engage in scientific decisions in analogy with citizens occupying the places of financial  
35 power. From genetic social networks to online collection of self-reported data, to participatory  
36 epidemiology, these activities are radically modifying the quantitative impact, timing, and methods of  
37 research (Lee, Crawley 2009; Gibson, Copenhaver 2010; Eriksson *et al.* 2010). Public involvement in  
38 genetic research has been increasingly perceived and promoted as implementing the idea of scientific  
39 citizenship, respecting individual dignity, reconciling individual and public health (Gottweis, Lauss 2010;  
40 Saha, Hurlbut 2012; Tallacchini 2015), and showing that issues of privacy and autonomy need to be  
41 reconceived and redefined in the light of new forms of agency and claims to knowledge —e.g. access to  
42 raw data (Lunshof, Church and Prainsack 2014). The imagined ways of shaping biobanking activities and  
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51 <sup>4</sup> European Commission, *Proposal for a Regulation of the Parliament and of the Council on the protection of*  
52 *individuals with regard to the processing of personal data and on the free movement of such data (General Data*  
53 *Protection Regulation)*, Brussels, 25.1.2012, COM(2012) 11 final, 2012/0011 (COD).

54 <sup>5</sup> EURO COURSE and ENCR Working Party, *Position paper on the Commission's proposal for a General Data*  
55 *Protection Regulation*, September 2012, [http://ieaweb.org/wp-content/uploads/2012/12/2012-10-5-ENCR-](http://ieaweb.org/wp-content/uploads/2012/12/2012-10-5-ENCR-EURO COURSE-Position-paper-on-the-proposed-EU-Data-Protection-Regulation.pdf)  
56 [EURO COURSE-Position-paper-on-the-proposed-EU-Data-Protection-Regulation.pdf](http://ieaweb.org/wp-content/uploads/2012/12/2012-10-5-ENCR-EURO COURSE-Position-paper-on-the-proposed-EU-Data-Protection-Regulation.pdf) Accessed July 16, 2015.

57 <sup>6</sup> See D. Fagin, *Toms River: A Story of Science and Salvation*, Island Press, Washington DC (reprint edition) 2015.  
58 In Italy some communities have used the cancer reimbursement data from the National Health Institution as an  
59 indicator for the number of tumors (see *Codice 048: cosa ne dicono gli epidemiologi*, [http://www.epiprev.it/codice-](http://www.epiprev.it/codice-048-cosa-ne-dicono-gli-epidemiologi#epidemiologi)  
60 [048-cosa-ne-dicono-gli-epidemiologi#epidemiologi](http://www.epiprev.it/codice-048-cosa-ne-dicono-gli-epidemiologi#epidemiologi), online preview. Accessed July 17, 2015).

61 <sup>7</sup> Such as the Personal Genome Project, <http://www.personalgenomes.org/> Accessed February 26, 2015.

directions, as well as the imagined relevant values for citizens, appear remarkably different from what is emerging in joint scientists-citizens initiatives.

#### 4. Peer-production of knowledge and trust: two case-studies

Health is a highly political domain, not only in terms of social welfare allocations, but also for its connections to the environment, environmental politics, and industrial policies. Environment and health are intertwined domains where knowledge production by citizens (citizen science) has often complemented, and sometime contested, official knowledge. Moreover, as said, significant changes are happening in how scientists and citizens relate and become partners in performing research (Wicks, Vaughan, and Heywood 2014). Finally, health represents a major sector where citizens are willing to become more knowledgeable and empowered in order to make decisions defined as better informed, more autonomous and personalized. In web-mediated initiatives, health and health data have become a way for citizens and researchers to reject legal restrictions, for instance as to the sharing of genetic information; and to introduce new rights, first of all access to raw genetic data as a new (moral) individual entitlement to knowledge (Lunshof, Church, Prainsack 2014). Indeed, an increasingly broad agreement exists about open knowledge: whenever information exists, it has to be made as widely available as possible.

The two cases presented here below allow reflection on some possible elements for considering citizens-based surveillance activities as useful and legitimate. Indeed, citizens' vigilance or veillance initiatives have become knowledge practices for proactive alertness towards the protection of common goods and new ways to establish and maintain trust between citizens and institutions rather than hidden forms of "spying" on others.

What seems to characterize both examples is the combination of several factors not systematically connected in other similar experiences. First, while population genetics has been deployed together with the biobanking of human biological samples and information, so far biobanks have been used (at least in epidemiology) as an instrument for the better understanding of the interplay between environmental (in a broad sense, e.g. diet and lifestyles) and genetic factors in disease causation. Biobanks have not been established as instruments for surveillance on third parties' behavior, but they can better achieve the goals of biomonitoring and molecular epidemiology, that epidemiologists have advocated for a long time for preventive health reasons (Perera and Weinstein 1982).

Second, environmental data and genetic knowledge merge as correlates for supposed associations between levels of pollutants and genetic modifications potentially leading to diseases.

Third, the forms and the subjects of knowledge production-and-use involved in these activities aim to generate knowledge and power. Indeed, the specific empowerment fostered by environmental and genetic surveillance depends on the meaning of the gathered data. Knowledge generated through direct collaboration between scientists and citizens is both trusted by participants and relevant for authorities (and industry).

ICT aggregating data about individuals to create populations that can be acted on are critical in transforming data into interventions; and social networks, not only give interested people the ability to

connect to each other and with scientists, but also to transform rarefied scientific activities into social movements.

Finally, unrelated citizens from different places are learning very quickly how to use knowledge and technology as forms of power. While in the first case (Sarroch) the population was guided and encouraged by authorities to take advantage of environmental and genetic knowledge, in the second case (Florence) citizens started the initiative: and the tendency is towards more complete citizens' control over both the techno-scientific and the political dimensions.

#### 4.1 The Fondazione Bioteca Sarroch

In 2006 the Sarroch Environment and Health Project was launched by the Municipality of Sarroch (Sardinia, Italy), which hosts a power plant and the second largest European oil refinery and petrochemical park—together with several universities, cancer prevention institutions, and non-profit epidemiological organizations. The project lasted for six years and received one million Euros from different public institutions.<sup>8</sup> It encompassed a complex set of epidemiological investigations and surveillance intended to identify and quantify the environmental health risk for the local population. In fact, the industrial estate produces a complex mixture of air pollutants, including benzene, heavy metals and polycyclic aromatic hydrocarbons.

A fixed air quality station was set up and several monitoring campaigns took place, including three large surveys of respiratory disorders in childhood, two panel studies on asthmatic children, and a bio-molecular study of DNA adducts, and a study of the cardiovascular effects of industrial noise on the adult population. Detailed reports of the health profile of the population were also published (in 2006 and 2013).

Pollution in the Sarroch area was precisely characterized. The first phase of the project was dedicated to air quality and gaseous pollutants responsible for respiratory disorders. Epidemiological and environmental surveillance of benzene and polycyclic aromatic hydrocarbons (PAH), metals and other constituents of the mixture of pollutants in the area required a different study design. Due to the small size of the population (around 5,000 people) traditional cohort studies have a very low statistical power.

Therefore, in the second project phase, the research team decided to dedicate their efforts to design a biomonitoring study – to characterize the population exposure spectrum and to quantify selected molecular risk indicators. Since 2008 the study documented an adverse effect on children's respiratory health of the mixture of air pollutants in the area, notably sulfur dioxide hourly peaks levels above 100 µg/m<sup>3</sup> (Rusconi *et al.* 2011, Peluso *et al.* 2013, Barbone *et al.* 2015).

The Sarroch scientific results were not challenged by industry that, instead, agreed to discuss them in their scientific and civic contexts. The data supported the request for stricter rules on emission reduction that the Ministry adopted in its revised authorization (Autorizzazione Integrata Ambientale, AIA) issued on

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<sup>8</sup> Namely, the Municipality of Sarroch (about 60% of the total investment); the Ministry of Welfare, project RF-SAR-2006-387926, and the Ministry of Education, University and Scientific Research, projects 2006131039 and 2007252HT8 (for the remaining 40%).

February 2009. The implementation of the new rules produced a significant reduction of the yearly emissions of sulfur dioxide: since 2009, only five episodes of high peaks in four years of monitoring were registered by the Sarroch Environment and Health Project. Moreover, as a consequence of the new policy and of industry compliance, the time trend of ambient concentrations for this pollutant showed an important reduction from 2009 onward (Cecconi 2015).<sup>9</sup>

Since the beginning, the research group launched several initiatives aimed to improve communication and participation from the Sarroch community. The original research group, mostly composed of epidemiologists, was enlarged to include experts on communication and participation, sociology of science, ethics and law.

The project was welcomed with a high participation rate (above 90%) in the surveys. On December 2009 the idea of setting up a public biobank was discussed by the Municipality and the researchers, and was presented to the population. The biobank represented a techno-scientific tool to empower the population in self-monitoring their health/exposure and to check the results on DNA adducts over time, as well as an open way to produce citizen knowledge to be compared with institutional and industry data and results.

Even though scholarly work has primarily associated biobanking with genetics, especially when dealing with ethical issues, it has to be clarified that the epidemiological value of biobanking is mainly related to non-genetic markers. One of the main values of biobanks is that markers are stored in a specific moment and can be analyzed in the future together with prospectively collected information. Precisely these features represent the added value in the Sarroch surveillance project.

It was immediately clear that the mainstream visions and existing regulations for biobanks could not meet the needs and goals of the Sarroch population. The project is framed as a civic initiative; it looks at population health and collective well-being; no individual benefits are expected besides empowering the community in its struggle for a better environment.

The main shift concerned the current understanding of biobanks, conceived to favor researchers' needs and commercial exploitation of genetic materials and information. Inherent in the concept of Bioteca—a word that in Italian evokes a public library (biblio-teca)—is its public destination: an independent foundation, collectively owned by citizens, and located in the village. In 2010, the Municipal Council approved the by-laws of the Bioteca Foundation and the new body was officially recognized on August 27th, 2012.

The by-laws of the Bioteca Foundation state that environment and health are a collective endeavor, and that the biological samples supplied by the exposed population are stored for research aimed to improve population well-being in a clean environment.

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<sup>9</sup> More precisely, the trends in sulfur dioxide were 18 µg/cm annual average in 2008, 8 µg/cm in 2009, 6 µg/cm in 2010, 7 µg/cm in 2011, 6 µg/cm in 2012, 5 µg/cm in 2013, 4 µg/cm in 2014, with exceeding over the limit of 350 µg/cm hourly max of 68 µg/cm in 2008 and zero in the following years. The prevalence of asthma, according to hospital records, was above the regional average about 25% (males and females) in the period 2001-2005, and was similar to the regional average in the period 2006-2010.



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4 The project and the activities of the Fondazione Bioteca cover the whole population of Sarroch. The  
5 Fondazione is an independent body with its own financial budget and can participate to national and  
6 international calls for grants. However, although research hypotheses can be traditionally produced by the  
7 scientific community, the research protocols, design and management are to be discussed with the  
8 Fondazione Bioteca board of trustees.  
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11 The project and the activities of the Fondazione Bioteca cover the whole population of Sarroch. The  
12 Fondazione is an independent body with its own financial budget and can participate in national and  
13 international calls for grants. However, it has to be clarified that the Fondazione is not a research  
14 institution and researchers are not part of it. In order to get access to the biological data stored in the  
15 Bioteca, researchers, belonging either to traditional scientific or to participant-led bodies, have to submit a  
16 research protocol. The Fondazione will approve the protocol and provide access the stored materials and  
17 data according to the by-laws.  
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21 The population controls scientific investigations through the Fondazione. To this end, all citizens are by  
22 definition entitled to participate in the initiative, but they are asked to agree to their membership, without  
23 being obliged to provide their samples. Supporting the initiative and exerting their related rights within  
24 the Foundation does not automatically require citizens to provide their biological materials.  
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27 Getting acquainted with the initiative and gaining trust towards it represents an essential part of the  
28 experience. Only through *ad hoc* informed consents participants may agree to be involved in specific  
29 research. Therefore, citizens can freely participate with different degrees of engagement. They can opt-in  
30 in the project, and become aware and knowledgeable about it, before deciding to become directly  
31 involved in the investigations they are interested in by donating their samples.  
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34 Participants' rights encompass rights to information, to access their data (including raw data), to track  
35 their samples when used in research, to contribute to decisions about research uses of biological materials  
36 and information (De Marchi 2011; Tallacchini and Biggeri 2014).  
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39 An ICT website (and a participatory platform under construction) is meant to add a further dimension to  
40 citizen engagement, providing citizens with their private space within the Bioteca, with direct access to  
41 their data and signed documents, to research and publications, to local and non-local education initiatives,  
42 to shared spaces for discussion.<sup>10</sup> The project aims to combine scientific evidence and civic will to care  
43 for a cleaner environment and, on the public policy side, to push for more strict emission levels.  
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47 The veillance activities performed in Sarroch, though primarily supported by researchers and  
48 administrators, acted as a powerful tool to improve the environmental and health situation in Sarroch.  
49 Improvements did not simply come from the validity of science, but they were rather the result of a  
50 broader and active idea of knowledge, technology, and the law, and their potential in complementing or  
51 strengthening more traditional legal means—often implemented only afterwards. Indeed, what is  
52 important in the Sarroch experience is the ongoing dialectic interaction between the exposed population  
53 and industry. The project provides information to the municipality that, on behalf of the citizens, can  
54 effectively and preventatively use it during the negotiations with industry, as established by the Italian  
55 legislation.  
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60 <sup>10</sup> See <http://www.fondazionebioteca.it>. Accessed February 26, 2015.  
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The Bioteca may provide citizens with further preventative instruments to maintain healthy conditions. The existence of the physical structure and the planned implementation of an ICT platform as its virtual representation and as a civic space have the potential to establish a stronger sense of connection amongst citizens, and to make the project adaptable and exportable to other communities with similar conditions.

Currently, the Fondazione is funded by an Epidemiological Agency to host biological specimens—under its rules, namely citizens’ engagement and participation —related to a biomonitoring study in the polluted area of Civitavecchia.<sup>11</sup> A similar agreement concerns the high risk area of Brindisi.<sup>12</sup>

Paradoxically, even though the biological samples from the Sarroch population have not yet been stored in the Bioteca, the establishment of the Fondazione Bioteca *per se* had a profound impact on the Sarroch political scene, as the initiative itself appears as a relevant game change.

#### 4.2 PM<sub>2.5</sub> in Florence

What happened in Sarroch has rapidly triggered other Italian initiatives,<sup>13</sup> where aware and engaged citizens have taken the lead in proposing environmental health projects.

In 2012 one citizen with the aid of two lawyers set up an air quality monitoring station for particulate matter (PM<sub>2.5</sub>) in the city of Florence. The device was located in his home courtyard and a dedicated website showing online real-time data on PM<sub>2.5</sub> ambient concentrations was launched.

Epidemiological studies have established that a correlation exists between particulate matter levels and respiratory chronic diseases such as asthma, bronchitis, emphysema, as well as cardiovascular diseases and tumors. Moreover, as to its indirect effects, particulate matter is the vector for highly toxic substances such as polycyclic aromatic hydrocarbons. Smaller particles are more dangerous for human health as they penetrate deeper into the respiratory system. This is why environmental monitoring is performed for particles with a diameter of less than 2.5 µm (PM<sub>2.5</sub>). While scientists mostly agree that the limit for PM<sub>2.5</sub> concentration should not exceed 10 µg/m<sup>3</sup> as annual average, the accepted levels vary in different countries and according to different institutions. Although WHO has established a health effect threshold of 10 µg/m<sup>3</sup> for PM<sub>2.5</sub>, the European Union (EU) accepts higher levels, which is hardly justifiable from a scientific perspective.

Florence is one of the Italian areas where the EU air quality standards are not met. The most recent available epidemiological data<sup>14</sup> reported that the EU limit of 50 µg/m<sup>3</sup> of PM<sub>10</sub> particles for a maximum of 35 days per year had been exceeded by an average of 59.5 days per year—which accounts for one additional death per semester.

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<sup>11</sup> F. Forastiere, C.A., M. Davoli, Letter. Quale valutazione epidemiologica per i siti inquinati in Italia? *Epidemiol Prev* 2014, 38, 1. More information can be found at <http://atlanteitaliano.cdca.it/conflitto/conversione-della-centrale-termoelettrica-di-torrevaldaliga-nord-di-civitavecchia>. Accessed July 17, 2015.

<sup>12</sup> See <http://atlanteitaliano.cdca.it/conflitto/centrale-termoelettrica-a-carbone-federico-ii-brindisi> Accessed July 17, 2015.

<sup>13</sup> See, for instance: Centralina di Milazzo, <http://www.incendiomilazzo.it>. Accessed February 26, 2015; Centralina di Manfredonia, <http://www.ambientesalutemanfredonia.it>. Accessed July 17, 2015; Biomonitoraggio Civitavecchia, for information: [c.ancona@deplazio.it](mailto:c.ancona@deplazio.it).

<sup>14</sup> EpiAir2 Project, funded by the Italian Ministry of Health, for the period 2006-2010.

Citizens have lost confidence in the data produced by local authorities. Data appeared clearly unreliable after most sensors were removed or relocated in areas where pollutant levels were clearly lower than in most parts of town. The main monitors have been located in widely green polluted areas, namely in the Boboli Garden (Giardino di Boboli) at Palazzo Pitti, and in the garden of the Istituto Agronomico per l'Oltremare. Only one monitor was validly located, though in an area with lower population density.

Despite several meetings and repeated requests, the Regional Environmental Protection Agency (ARPAT) did not restore the air quality monitoring network. On the contrary, the citizen environmental monitor respected the currently validated methods for background monitoring. It was located in the center of the residential area (ZTL), close to the railroad station, but directly exposed to vehicle traffic.

The PM<sub>2.5</sub> project was funded by private citizens. As soon as the initiative was reported in the press, several citizen committees and a non-profit social enterprise started collaborating and, following the Sarroch case, discussing the need for the population to store their biological samples.<sup>15</sup>

The overall rationale of the project is to complement the existing inadequate institutional monitoring system, and to plan a biomonitoring study. The design is a matched cohort study in which each resident in the monitor neighboring area is matched to between two and four controls living in an area with low PM<sub>2.5</sub> exposure, chosen to be amongst relatives and friends of the resident – i.e. matching by gender, age, and social class.

The website, built to display the data, and to aggregate and connect citizens around the initiative,<sup>16</sup> shows the graphs of automatic updates for 2-minutes, hourly, daily, weekly, and monthly values, and it compares them with those provided by the ARPAT Air Quality Network. Citizens are in charge of managing the monitoring system, while the scientific part of the study is performed through collaboration with scientists belonging to non-profit organizations, controlled and crowdfunded by committed citizens from all over the country.

The monitor analyzes a variety of plots corresponding to several issues on air pollution, and compares the data with those produced by the ARPAT network. Some scientific publications are currently using the data provided by the monitor to critically assess the coverage of the ARPAT, and to discuss the effectiveness of the policies adopted by the Florence Municipality. The data obtained by citizens and researchers showed that in Florence, in the first months of 2013, the EU limits for PM<sub>2.5</sub> have been exceeded, with a long period of very high concentrations during the trimester December 2012 – February 2013 (six consecutive weeks above the limit of 25 µg/m<sup>3</sup>).

In 2010 the public prosecutor started a criminal trial against the city mayor, other mayors of the surrounding municipalities, and the governor of the Tuscany Region.<sup>17</sup> However, both the original trial court and the appeal court found that the charge—namely the administrators' unwillingness to adopt adequate policies to fight against PM<sub>10</sub>, and their ability to control pollution anyway—was not criminally relevant and ruled that the case be dismissed. Indeed, these outcomes raise doubts about the effectiveness

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<sup>15</sup> A. Biggeri, The Epidemiologists and the participant-led science, *Epidemiol Prev* 2014, 38 (3-4), 151-152; D. Grechi, Who is monitoring air pollution in Florence? *Epidemiol Prev* 2014; 38 (3-4), 154-158.

<sup>16</sup> See <http://www.pm2.5firenze.it>. Accessed February 26, 2015.

<sup>17</sup> Editorial. (2014). The smog trial in Florence. *Epidemiol Prev*, 38 (3-4), 153.

of intervening after the fact and of lawsuits based on criminal law—which has been seen as the main legal remedy for environmental disasters in the Italian system.<sup>18</sup>

As a matter of fact, the data produced through private monitoring for one year and uploaded in real time on the PM2.5 Florence website together with the official ARPAT data, though not completely identical, did not turn out to be radically different either. These results, while being reassuring from a public health perspective, made apparent that, in order to be trustworthy, scientific knowledge produced for public policy purposes not only has to be scientifically reliable, but also has to meet the requirements of transparency and accountability for administrative action. This means that the rationale for dismantling the traffic monitoring stations should have been shown to citizens, together with the evidence that this decision would not negatively affect the accuracy and quality of PM2.5 measurements.

Therefore, the Florence citizen initiative cannot be interpreted as a ‘false alarm,’ but instead as evidence that some essential requirements for public trust were missing in the relations between citizens and the public institutions. Indeed, the project showed how institutional knowledge production can and should interact with citizen science —often created in collaboration with scientists—in order to generate more reliable knowledge for more trusted institutions.

## 5. From rights restoration to health prevention

ICT devices and a variety of sources of knowledge—environmental sciences, epidemiology, genetics, etc.—have become available to citizens in expanding their abilities to protect their environment and health. The sharing of data through ICT platforms and interactive websites is proving crucial in changing the meaning, the scope, and the scale of citizens’ initiatives. Moreover, the rapid development of sensors collecting and connecting data from the environment and the body is increasingly enabling Do-It-Yourself (DIY) practices.

The cases of Sarroch and Florence are different in the way they have been conceived: the Sarroch project was launched by researchers and the municipality, acting to raise civic awareness and commitment, and to enable the population to be involved in the project; the Florence initiative was entirely citizen-driven, but was strengthened by scientific advice and collaboration.

While knowledge and technology become pervasively distributed, the situation is in flux on different fronts.

First, the status of citizen knowledge production, especially in the health domain, has gone well beyond traditional popular epidemiology and the most commonly accepted definition of citizen science. Despite all changes in the production and distribution of knowledge and technologies, and in the collaborative initiatives between scientists and citizens, the institutional perception of citizen science and its value seems to be quite limited, and still confined to marginally contributing to official knowledge (EC 2013).

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<sup>18</sup> M. Tallacchini, Science and Law in Courts, *Epidemiol Prev* 2014; 38 (3-4), 159-163.

Both cases show that citizen-driven science is still used in a quite reactive way, namely to restore rights after they have been violated (as in European countries health is a fundamental right). Citizen veillance activities should help monitoring and preventing damage to both health and the environment. However, for knowledge produced by citizens and scientists to be effectively and proactively used, recognized institutional status and mechanisms should be put in place.

Second, these private forms of veillance call for scrutiny as to their legitimacy. This implies that both their goals and the technical means used to pursue them have to be legitimate, and that their funding has to be transparent and possibly crowdfunded (Bindi 2014).

Legitimation for citizen-led veillance initiatives may depend on their contributing to re-establish lawfulness; while the means adopted should not infringe other individual or collective rights. Indeed, the cases illustrated derive their legitimacy from the need to restore a ‘right’ after a ‘wrong’ had happened. They both connect to contexts where rights have been denied, namely where institutional and legal mechanisms not only have failed to grant citizens’ rights, but also where unreliable scientific data have been used to hide a wrongdoing.

However, the potential exists for these initiatives to become preventative and complementary forms of knowledge production in the creation of policy as more legitimate and democratic ways to make decisions in the public sphere.

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