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## Research is in the air in Valle del Serchio

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### ABSTRACT

In this paper, we will present an ongoing Citizen Science (CS) project in environmental epidemiology in five European countries focussing on the Italian pilot study conducted in the Serchio Valley (Tuscany). The area is rich in natural, cultural and historic significance, but it also suffers from environmental contamination from a variety of sources, including industry, which is a health concern for the local population. The study is framed as a Post-Normal Science (PNS) project, applying, in particular, the idea of extended peer community (EPC). The research team looked for and encouraged the engagement of local residents in all the phases of the project, from the framing of the problem to the definition of the specific research questions, the research design, the collection and analysis of data, the dissemination of results, and the drafting of policy recommendations. We discuss the novelty of our approach, the progress so far, the different types of challenges encountered and the strategies adopted to deal with them. Besides the totally unexpected problems generated by the Covid-19 pandemic, we focus on the difficulty in conforming to the requirements of standard medical ethics, which do not take into account the peculiarities of projects such as ours.

### 1. Introduction

For many decades, there has been an increase in the forms of public participation other than those strictly related to representative democracy (*in primis* elections). They include a series of spontaneous initiatives in the most diverse of fields, which have evolved into a field of academic scholarship and have occasionally attracted the attention of regulatory agencies and political institutions on whose mandate such initiatives may have a bearing.

Following a disturbing and widely debated "crisis of trust", top-down initiatives were devised to encourage public engagement in issues of common concern including those that go under the name of Citizen Science (CS). This is an umbrella term that groups quite diverse experiences, which however, to a lesser or greater extent, all regard the traditional relationship between professional scientists and "lay providers of knowledge". This well-established trend will inevitably generate significant changes in the organization of research and in the way society in general conceives and uses knowledge.

We will present the experience of a co-created CS project in environmental epidemiology, a field where CS projects are still uncommon. The paper describes the research process, including opportunities and challenges, through three different lenses, which

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correspond to the professional fields of the three authors: an ethicist (AF), a sociologist (BDM), and a medical statistician (AB).

Section 2 briefly sketches the origins and development of CS starting from early experiences of citizen participation. Section 3 is dedicated to discussing the work undertaken in the *CitieS-Health* project, with a focus on the Italian pilot study, which applies the extended peer community concept of Post-Normal Science (Funtowicz & Ravetz, 1993/2020). Section 4 is devoted to the ethical aspects of CS, with the novel challenges and open questions in running a project for which clear legal norms are lacking in the Italian context. Section 5 describes the complications generated by the Covid-19 pandemic. Finally, Section 6 briefly summarizes some key aspects of our work.

## 2. Public participation and Citizen Science

Since Arnstein's seminal work (Arnstein, 1969), the literature on citizen participation has grown exponentially and it has addressed both theoretical and practical issues. This material covers an increasing number of experiences in a variety of fields of investigation and socio-cultural settings, most often in connection with policy-relevant problems.

While the expression "public participation" encompasses any kind of involvement of citizens in public matters, nowadays it generally refers to forms of engagement other than those typical of liberal democracies (namely elections, referenda, etc.) at a time when these are suffering from a loss of trust. The term expresses a form of dissatisfaction with the limitations of representation and promotes a quest for a "deliberative democracy" (Bohman & Reigh, 1997; Elster, 1998).

Popular discontent with the management of the *res publica* is nothing new, but for a long time, it concentrated on the architecture of political power, leaving aside other institutional arrangements. However, due to the centuries-long alliance between political and scientific institutions, the situation was unlikely to remain as such. A turning point was the BSE (Bovine Spongiform Encephalopathy) emergency (van Zwaneberg & Millstone, 2001), in the late 1980s and the 1990s, whose mismanagement brought to light the inadequacy, incompetence and occasionally the corruption of the political as well as the scientific establishment and the potentially perverse effects of their partnership.

To "restore trust", new institutions and policies were envisaged at both European and national levels, while bottom-up initiatives of civic involvement mushroomed in the areas of health and the environment, as well as many other policy relevant areas such as, among others, allocation and management of scarce resources, land-use planning, energy production, infrastructures and services design, technological innovation, and so forth. The partial novelty in this trend was that lay citizens not only claimed the right to have a voice in policy decisions, but also expected to be involved in the very processes leading to such decisions, including scientific research.

Thus, in the last decade of the past century, examples of public participation in scientific research projects increased significantly, triggered by dissatisfaction with current arrangements and favoured by the new opportunities devised by the establishment in response to the crisis of trust. Though not in the remit of this paper, we want to recall the field of community-led epidemiology and health studies, which gained momentum from the seminal experience of Love Canal in the 1970s (Fjelland, 2016; Gibbs, 1982) to recent cases such as the Flint water crisis (Carrera & Key, 2021; Pauli, 2019). Also worthy of at least a brief mention here are research projects and advocacy that have addressed health and environmental justice conflicts, a great and increasing number of which are reported in the Environmental Justice Atlas (EJAtlas, 2021) (see also, among others, Arancibia & Motta, 2019; Brown, 1992; Giatti, 2019; Martinez-Alier, 2003; Temper, del Bene, & Martinez-Alier, 2015).

In the literature, Citizen Science (CS) gained prominence as an umbrella term to indicate a large variety of different experiences, yet there is no common understanding from the part of the proponents on the role of the citizens in this enterprise, due to the variety of perspectives and criteria applied, both from a normative and descriptive point of view (Bonney, 1996; Froeling et al., 2021; Irwin, 1995). Formally at least, there is a general agreement regarding the purposes, which are the promotion and advancement of knowledge for the improvement of societal well-being and the achievement of the common good. Nevertheless, dissent becomes apparent as soon as one starts to investigate more closely the non-univocal meanings that different people attach to ideas such as knowledge, well-being, common good, etc. and the consequent discordant ways in which they assess their practical realization.

The key divide is in the role of citizens, conceived of as either "executive or creative", respectively corresponding to a relationship of either subordination or partnership with professional scientists. As Arnstein (1969) had already clearly recognized some half a century ago, the crucial issue is power. Among the many scholars of CS, Irwin positioned himself very clearly on the same trajectory, claiming that knowledge must serve the needs of society and its ownership must be shared (Irwin, 1995).

Overall, there is no doubt that CS has gained momentum in the last couple of decades, promoted by projects that have been funded by EU Research Programmes. Also, enthusiastic advocates have gradually won over sceptical opponents, especially in cases where strictly disciplinary approaches had proved unable to provide an adequate framing of the relevant policy issue, let alone an appropriate resolution. Yet, even for the former, it has not been easy to develop and deploy new research practices, which often clash with alternative views, consolidated traditions and of course, power strongholds.

When it comes specifically to the field of environmental epidemiology, CS projects, devoted to assessing the health effects of environmental conditions, are still rare, despite the fact health and the environment have long been matters of concern for citizens. This is hardly surprising because there is no fixed script for this new type of research and, although opportunities abound, challenges remain (Froeling et al., 2021). Under the current arrangements, project proposals are drafted and submitted by professional scientists, and citizen scientists enter the scene with their specific positions, only once funding has been obtained. Therefore, and perhaps more urgently than in other fields, projects need to be constructed in such a way as to allow changes in procedures in the face of possible new inputs, additional requests, or any unforeseen circumstances, whilst at the same time maintaining the original goals. Flexibility from the part of the research team - in both its professional and lay components - is a necessary condition for resilience, i.e., the capacity to react and adapt to constraints and/or unexpected predicaments. As we will see (Section 5), the Covid-19 pandemic was a far greater

challenge that anyone had foreseen, and indeed needed an unprecedented capacity of adaptation.

### 3. The CitieS-Health Project and the Italian pilot study

As evidenced in its mission statement, “CitieS-Health aims to put citizens’ concerns at the heart of the research agenda regarding environmental epidemiology by tackling health issues that concern them” (see <https://citieshealth.eu/about/>). Five pilot research studies on environmental stressors and health are being conducted in five European countries, namely: air pollution in Barcelona, Catalunya, (SP); noise in Ljubljana (SLO); heavy metal pollution in the province of Lucca, Tuscany (IT); city design in Kaunas (LT); wood burning in Amsterdam (NL).

The professional research teams comprise experts with diverse backgrounds and specializations, including epidemiology, public health, medical and applied statistics, environmental science, ethics, history, political science, sociology, science communication, social informatics and computer science, business management and law. The project was devised as a co-creation, meaning that citizens are involved in all its phases from the framing of the problem to the definition of the specific research questions, the research design, the collection and analysis of data, the dissemination of results, and the drafting of policy recommendations.

There are different types of data, retrieved from already existing sources (such as maps, health and pollution records, historical documents, etc.) and collected with a variety of methods and techniques (e.g., wearable sensors, networks of self-assembled monitoring sensors, mobile applications, surveys, interviews, focus groups, workshops). The collection of biological specimens is also foreseen in the Dutch pilot study (saliva) and in the Italian one (blood and urine).

In the following sections, we will concentrate on the Italian study.

#### 3.1. *Aria di Ricerca in Valle del Serchio: citizen engagement*

The Serchio Valley is in the northern part of Tuscany and it is an area with contrasting characteristics. On the one hand, it has important environmental, historical, and naturalistic assets with natural reserves, protected areas, and even some UNESCO sites. On the other hand, it has been the site of industrial installations, including a copper foundry with a potential risk of heavy-metal pollution. Environmental pollution has been documented since the 1980s, when an epidemiological study found a cluster of lung cancer deaths in the area surrounding the industrial plants (Biggeri & Marchi, 1995).

More recent (2007–2017) epidemiological data on the health status of the resident population confirmed a persistent excess risk of cardiovascular diseases – in particular coronary heart disease – and urinary system diseases – in particular, chronic kidney diseases (see [https://www.ariadiricerca.it/page.php?h\\_stato\\_di\\_salute\\_di\\_residenti](https://www.ariadiricerca.it/page.php?h_stato_di_salute_di_residenti)).

The effects on human health of chronic exposure to environmental pollutants from different sources have been a matter of local concern since the 1980s and the principal investigator (AB) has already been involved in relevant research. Thus, the idea to include the area in a proposal to be submitted to the EU was welcomed locally. Some local associations, in particular La Libellula,<sup>1</sup> were very active in raising awareness and facilitating contacts with local stakeholders; initially with public administrators, and later with the population in general, to diffuse information and encourage support for the initiative. The area selected for the study consists of eight municipalities of the Valley (Barga, Borgo a Mozzano, Coreglia Antelminelli, Fabbriche di Vergemoli, Fosciandora, Galliciano, Molazzana, and Pieve Fosciana) with a total population of 29,949 inhabitants (ISTAT, 2021).

As soon as the proposal was approved for funding, a series of preliminary meetings were held with interested citizens and some administrators on how to organise the research, so that as many residents as possible could be fully involved. The most concerned and active citizens, many of which but not all associated with the previously mentioned association La Libellula, joined a spontaneously created citizen committee (CC from now on) with the purpose of favouring constant dialogue and collaboration with the local administrators and the team of professional researchers. The option of adopting a formal structure was dismissed in favour of an open one, with the perspective of allowing and favouring access to as many fellow citizens as possible in order to facilitate and encourage their engagement in research activities and policy-related decisions.

This proved an effective choice. Indeed, whilst the “hard core” of those following all the phases of the project remained stable at some 15–20 people, in some key passages, such as the preparation of the study protocol or the presentation of some preliminary results, the number of people contributing to the discussion increased to 50–100. The majority are members of local associations that are mostly active in volunteer health care (19 in total) and quite mixed in terms of demographics.

In the first year of the project (2019) – which we call the citizen engagement phase – the activities undertaken had two main related purposes: 1. to explore the local citizens’ knowledge and concerns about environmental and health matters, and to plan an investigation addressing their main interests and worries, and 2. to make them partners in a co-created project.

One of the first steps was to set up a network of low-cost DIY sensors to monitor the concentration of respirable (PM10) and fine (PM2.5) particles (Brown, Gordon, Price, & Asgharian, 2013). Also, a questionnaire was prepared in collaboration with members of the CC and many volunteers from all the 19 local associations. It was distributed to 1025 residents, with 922 citizens compiling it, which is a response rate of 90%. Overall, the concerns expressed about health problems revealed a good knowledge of the most frequent diseases among the Valley’s population, as reported in previous epidemiological studies (see <http://www.cd.biostatistica.net/>), namely malignant tumours (particularly lung cancer), respiratory diseases and thyroid diseases, a finding possibly related to the many

<sup>1</sup> The association La Libellula had also signed the letter of commitment to the CitieS-Health project, when the proposal was submitted (<http://www.movimentolalibellula.com/>).

screening campaigns regarding endocrine diseases conducted in the past. However, the respondents were not familiar with the updated health profile emerging from more recent studies. A report prepared by the Tuscany Health Authority was presented to the local population in two public events, in October 2018 and July 2019 (<https://www.ars.toscana.it/2-articoli/4016-presentati-a-barga-i-dati-di-salute-aggiornati-della-popolazione-della-valle-del-serchio.html>). The report shows excesses above the regional average of cardiovascular diseases and chronic kidney diseases and a relative reduction in the incidence of some historical excesses in the Valley, such as those for malignant tumours and lung cancer, when compared with the regional average.

Our survey results also showed the existence of a strong tendency to associate environmental pollution with the perceived health profile (Durch, Bailey, & Stoto, 1997). With specific regard to heavy metals, widespread concern emerged regarding the recognition of their presence in the Valley, which may be attributed also to their use in the production cycles of certain industrial installations.

At the end of 2019, the discussion concerning the research questions was finalised and it was collectively agreed that the CS study should focus on chronic kidney disease, also in view of the possibility of implementing policy actions to reduce or eliminate exposure to heavy metals. A public event was dedicated to summarizing the epidemiological evidence, to presenting the results of the sociological survey, and to illustrating the research questions.

Besides the data to be gathered through the epidemiological study, other types of information and knowledge were deemed essential in a research project designed and conducted in collaboration involving professional researchers and citizens. Therefore, the latter were invited to share all types of relevant information and knowledge they possessed, both in the form of written documents and materials (newspapers cuttings, local chronicles, pictures, etc.), and of oral testimonies based on personal memories and experiences. Indeed, the Italian pilot study includes a specific task on the history of the industrial development of the Valley over more than a century with particular regard to the complex relationships between the copper foundry and the community. The historical methodology relies primarily on oral sources, besides the few primary sources available.

As previously stated with reference to Irwin (1995) scholarship, this type of organization in a research project is based on the idea that the knowledge produced must meet the demands and needs of all those affected by the problem under investigation and be conceived as their common ownership. A further inspiration of our work is the idea of extended peer community (EPC) introduced by Funtowicz and Ravetz (1992/2003), i.e. of a more extended and varied group than the restricted community of academic peers who traditionally assess the quality of the knowledge produced, including methods and results. According to the proponents, such an extension is appropriate in post-normal conditions characterised by “uncertain facts, disputed values, high decision stakes and urgent decisions” (Funtowicz & Ravetz, 1993/2020).

There is no doubt that for the inhabitants of the Serchio Valley, the quality of the air they breathe has been a matter of great concern for decades, together with the awareness that its assessment is surrounded by many uncertainties. In 2018, the first installation was put in place of what is now a network of four independent monitoring stations. Also, there have been several initiatives designed to highlight the urgency of policy-decisions for such a high-stake issue.

Most recently, in 2019, the copper factory mentioned above<sup>2</sup> submitted an industrial plan of investments, which became the subject of a participatory deliberative process (Bobbio, 2010), and which ran in the same period as the first phase of the *CitieS-Health* project. The plan, which included the construction of a bio-fuel energy plant in the premises of the factory, met with very strong local opposition and the mobilization of thousands of people: 9000 signed a petition and there were a number of public demonstrations and flash-mobs until the regional administration decided not to authorize the industrial plan in the summer of 2021.

No strong polarization appeared between the factory workers and the rest of the population and, generally speaking, concerns for health, environmental quality and job protection were shared across the overall local population, despite differences in values and priorities.

Our purpose when setting up the local study was to work with as large and diversified an EPC as possible, where different positions and perspectives can freely emerge in a non-confrontational setting. This does not mean conceiving the EPC as an arrangement where all differences are resolved, and consensus is reached. Sometimes this can be the case, but the underpinning rationale in having different actors expressing their positions is to clarify points of agreement and disagreement, so that conflicts are clearly recognised, and possible compromises can be found. Naturally, there are instances when this is not possible and defections from some actors are to be expected, due to dissatisfaction or just fatigue.

*Mutatis mutandis*, the dynamics of CS projects are not so different from those of traditional research, and management capacities are required, together with many other skills and experiences, for their successful completion. This is even more true when they apply to the area of Post-Normal Science. Referring to the classification of CS projects suggested by Haklay (2020,2022), our project is linked to all four of the typologies he uses (Fig. 1). According to the first one, proposed by the same author and colleagues (Haklay, Mazumdar, & Wardlaw, 2018), and in reference to types of activities, it is a “community/civic science” project, which moreover uses DIY devices. Considering Wiggins and Crowston’s typology (Wiggins & Crowston, 2011) based on primary goals, it fits into the “action-oriented” category. Using the 5C classification proposed by Shirk et al. (2012) the project can be denoted as “co-created”. Finally, in the typology proposed by Haklay himself a few years back (Haklay, 2013), the project belongs to level 3, which is to say “participatory science”.

### 3.2. *Aria di ricerca in Valle del Serchio: the epidemiological investigation*

To implement an epidemiological investigation with a strong community engagement, researchers and citizens must perform a

<sup>2</sup> The factory, the most important one in the area, has been in operation for about a century and presently counts some 580 employees locally (Malavasi, 2021).

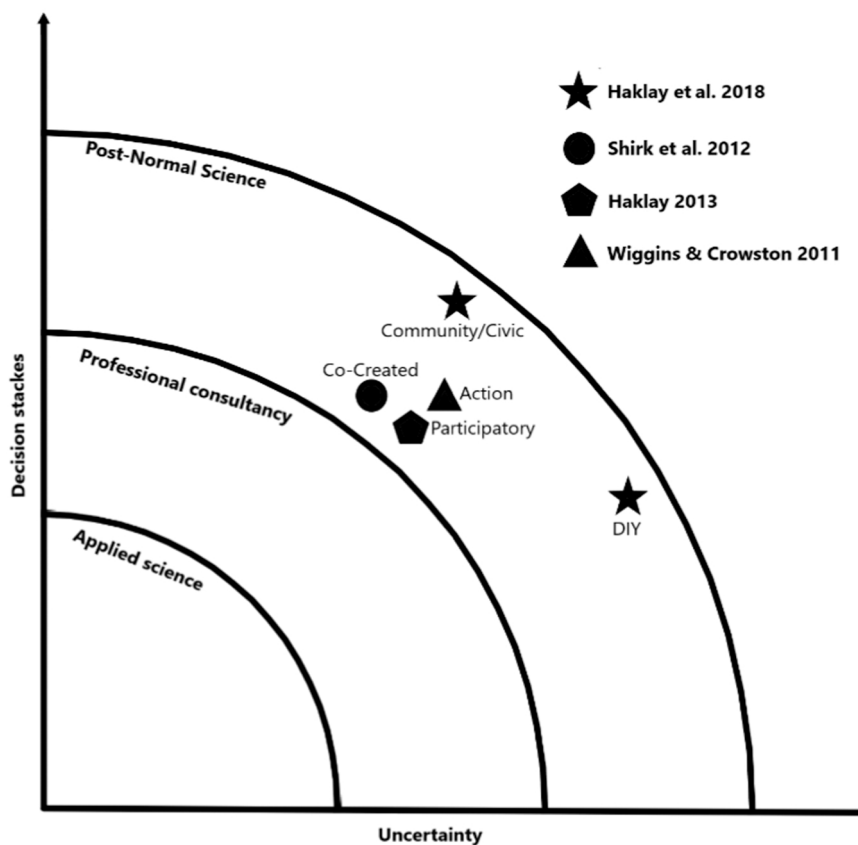


Fig. 1. Based on Funtowicz & Ravetz (1993/2020) and integrated by Haklay (2020, 2022).

number of tasks together: select and define the research questions, write the study protocol, validate such protocol, discuss the interpretations and public health implications of the possible alternative results of the study. The actual carrying out, analysis and interpretation of the final results are less problematic once the preceding steps have been successfully concluded.

At time of writing (May 2021), the CS project “Aria di Ricerca in Valle del Serchio” was starting to enrol the first subjects for the epidemiological biomonitoring study.<sup>3</sup>

As described in the previous section, the agreement concerning the research question was reached at the end of the first year of the project. The prevalence of chronic kidney diseases among the local population emerged as the main question to be answered for the following reasons: 1) preliminary data based on routine health statistics showed a significantly higher incidence than the regional average; 2) environmental pollution caused by heavy metals and specifically cadmium is plausible, based on previous knowledge; 3) a causal relationship between exposure to environmental cadmium and chronic kidney diseases has been long established in the toxicological and epidemiological literature (see for example Johri, Jacquillet, & Unwin, 2010).

The epidemiological study protocol was drafted in collaboration with the CC over the course of several meetings. The task was particularly difficult because the Covid-19 containment measures required multiple revisions of the procedures for enrolment, attainment of consensus, collection of interviews, etc. (see Section 5).

An important decision was to acknowledge the contribution of the citizen scientists to the protocol as well as other research activities and several options were taken into consideration. The choice of a collective name was discarded as it would create discrimination in favour of the members of the research team, individually named in the documents produced. Moreover, in the case of the protocol, it would not satisfy the conditions for its submission to the Medical Ethics Committee, which state that all proponents are personally identified and held accountable. This also prevented the choice of a second alternative, i.e. the adoption of a collective name designating the professional research team and the citizen scientists together. Finally, we opted for a list of individual names of both researchers and citizen scientists.

It is a common experience with epidemiological investigations regarding contested issues of health and environment that the

<sup>3</sup> As we detail in Section 5, in order to comply with the Covid-19 restrictions, it was necessary to open a dedicated out-patient clinic, which was inaugurated on August 7, 2021 in Barga. As of the end of November 2021, progress was as follows: about 300 people had signed the informed consensus, some 280 had completed an interview about their occupation, diet, and lifestyles and some 230 had already conferred their biological samples.

community exposed or the local administrators are dissatisfied, sceptical or suspicious of the results and ask for a further independent evaluation. To prevent this potentially disruptive outcome, the researchers themselves suggested an independent assessment of the study and moreover that this take place before the closing phase (i.e. the presentation of results) during the phase when the study protocol is finalized, i.e. immediately after submission to the Medical Ethics Committee. Ideally, this evaluation of the protocol should be performed by at least three independent reviewers, one chosen by the community, one by the researchers and one by the local institutions (e.g. Mayors or municipal council administrators). The protocol could then be amended according to their suggestions and re-submitted to the Medical Ethics Committee.

Based on the idea of extended peer communities (Funtowicz & Ravetz, 1993/2020), this practice aims to introduce a modification to the traditional peer review process in order to achieve a public validation of the study protocol, consolidate agreement on the research objectives, and strengthen confidence that the selected procedures will be applied correctly and honestly. In our case, we expect that this may prevent (or help resolve) any disputes concerning the final results, as well as any conflicts concerning their health policy implications (De Marchi et al., 2017).

At the time of writing (May 2021), the protocol had just been approved by the Medical Ethics Committee and the local stakeholders were selecting their experts for the independent validation of the protocol.<sup>4</sup>

The protocol specifically refers to a cross-sectional epidemiological survey regarding the prevalence of chronic kidney disease in a representative sample of the resident population 18 + yrs old. The target is to enrol 2000 subjects, half resident in the municipality of Barga, half in the remaining seven neighbouring municipalities. Chronic kidney diseases are operationally defined on the basis of the glomerular filtration rate by means of serum creatinine concentration taken from a blood sample. This procedure is based on an international protocol regarding chronic kidney diseases. All the assumptions underlying these definitions were discussed with the citizens. With regard to the environmental problems and the remediation policies, delimiting the aim of the epidemiological investigation to the assessment of the severity of the average glomerular filtration rate could appear insufficient. Two important points should be made here: 1) it is essential to disclose the limitations of any epidemiological study, which in practice reduces a complex problem to a simpler one; 2) it is important to stress that the goals pursued by those exposed to health risks go well beyond those that can be achieved by a single epidemiological study. Indeed, epidemiological data may be useful as a first input in a step-by-step solution to a health problem, e.g. as a way to strengthen the request for deeper investigations and/or public health actions, environmental remediation activities, etc.

In this perspective, it was agreed to store a quota of the blood specimens for future use, an operation which requires abiding by the rules concerning biobanking human samples. Therefore, the protocol includes the description of the procedures for setting up an outpatient clinic for the collection of blood samples and a clinical lab to process and store them at a temperature of  $-80^{\circ}\text{C}$  in a dedicated freezer. All the necessary professional staff is being recruited locally. Some ideas for possible future studies were anticipated, outside the scope of the current project and budget. Of particular relevance, given the local context, was the possible measurement of serum heavy metal concentrations.

Another issue which we consider appropriate to address a priori, i.e. before the study is completed, is the interpretation of the study results and their policy implications.

We organized a series of meetings and a public event and published a paper in a scientific journal (Biggeri et al., 2021) describing the potential study results and the public health actions and implications for each of them. The researchers, the citizens and the local administrators were all involved.

We sketched four scenarios, which are reported in Table 1.

These scenarios and their implications were assessed and subscribed by the local institutions, namely the eight Mayors of the municipalities of the area under study. Naturally, they do not encompass the whole range of possible results and at the end of the study, some surprises may emerge. They were conceived as a baseline for a clear commitment from the part of the local administrators, a commitment they took in person during a public meeting and by co-signing a paper published in a scientific journal (Biggeri et al., 2021).

The public discussion of the scenarios aims to enhance trust between local institutions and the community of citizens, who are often suspicious that the former will attempt to distort the interpretation of the study results to back predefined policy choices (Michaels, 2020). Their concerns are justified due to the inevitable constraints of epidemiological investigations conducted in an environmentally contaminated area. These are affected by great uncertainty and potentially subject to biases and confounding (for a non-technical discussion see Fagin, 2013). Also, the ambiguity of study findings, with potentially opposite interpretations can be due to the low statistical power of studies with small samples, which is frequently the case of environmental studies in highly polluted areas.

#### 4. Ethics and Citizen Science

Ethical issues concerning participatory CS studies have only recently become the subject of attention (Patrick-Lake & Goldsack, 2019; Rasmussen & Cooper, 2019; Rasmussen, 2019; Tauginiené, Hummer, Albert, Cigarini, & Vohlan, 2021; Wiggins & Wilbanks, 2019). The current debate is ongoing, and institutional guidelines and rules have yet to be established. A framework for the ethical

<sup>4</sup> Four independent experts - an epidemiologist, an environmental physicist, an occupational health physician and a bioethicist - made some observations regarding the research protocol in a public event held in Barga on October 27, 2021. In the same occasion, the historian of the team presented her research in progress on the main industrial plant operating in the Serchio Valley and its connections with the local community (see note 2).

**Table 1**

Plausible scenarios of the research end-results. Prevalence of chronic kidney disease with regard to the Tuscany regional average, interpretation in terms of level of evidence, public health implications.

Prevalence of chronic kidney disease	Interpretation (Epidemiological)	Implications (Public Health Actions)
No change	Study design weaknesses; selection or information bias; confounding.	Environmental characterization.
Inconclusive	Large statistical uncertainty; lack of evidence vs evidence of absence.	Further epidemiological studies; environmental characterization.
Higher than expected	Criteria for causal evaluation in epidemiology; alternative explanations; exposure assessment; previous knowledge needed.	Individual/subgroup studies; environmental characterization/exposure assessment.
Conclusive	Evidence of renal damage; clinically relevant results.	Treatment strategies for the sick; characterization of population subgroups; residential cohort study; environmental characterization and remediation.

approval process has been envisioned as part of the CiteS-Health project, which aims to address this emerging issue (Ficorilli et al., 2021). Below we will illustrate some considerations concerning the CiteS-Health ethical framework and will provide information regarding the first lessons learned from the Italian pilot study.

#### 4.1. Emerging ethical issues and challenges

As repeatedly mentioned, in co-created CS projects such as ours, the full participation of citizens implies taking into consideration their active role in all stages of the investigations performed. Hence, the rise of two different roles of citizens enrolled in this type of projects: a new role as citizen scientists (active participants) and a traditional role as research subjects (passive participants).

From an ethical point of view, the active participation of citizens means that the principles and values of current research ethics must become a shared and respected common legacy of rules. Thus, the duty of researchers to act according to ethical standards of good science practice also extends to citizens. For instance, this means respecting the dignity, autonomy and privacy of individuals who provide their personal data and biological samples, ensuring scientific rigor, research integrity and competent management in collecting, storing, analysing, sharing, and using environmental data as well as personal data and biospecimens. A number of challenges may thus emerge regarding, e.g. research integrity and information asymmetry and possible conflicts between citizens' and researchers' points of view in designing and implementing the study with regard to research questions, data sharing and re-use, etc. Moreover, citizens already involved in the co-design phase may also be enrolled in the co-implementation phase. If this is the case, special attention should be paid to issues such as possible conflicts of interest, bias, and robustness of the studies. Furthermore, the sharing of responsibilities between professional researchers and citizen scientists should be recognised as a fundamental theoretical assumption to be implemented during the project.

The active participation of citizens also poses challenges regarding ethical clearance, especially when it is mandatory and binding. The Italian CS study belongs to the type of projects in environmental epidemiology that gather personal data, including health parameters and human biospecimens, and adopt the principle of pseudonymisation. Precisely because it involves the collection, storage, processing and use of identifiable human biospecimens, based on the current European and national provisions and guidelines, the study falls in the category of clinical research (European Parliament and the Council, 2016). This implies that our co-designed study protocol, the related information sheet, and informed consent form (from now on referred to as study protocol and related documents) have to receive a mandatory and binding approval from a competent Medical Ethics Committee.

Challenges emerge, however, considering that current legal rules and ethical requirements focus on protecting the rights and welfare of individuals involved in research projects in their passive role of research subjects and do not address issues concerning their active role as involved citizen scientists. In this case, ethics involves taking into consideration domains such as study design, data quality, data sharing and intellectual property, the reporting of misconduct, authorship, and publication (Resnik, 2019; Resnik, Elliot, & Miller, 2015). In addition, public entities may require ethical clearance to fund scientific participatory projects. Nonetheless, the nature of CS research, built around co-design and co-creation, leads to situations where the specific methods and techniques employed emerge from an ongoing collaborative process, rather than being fixed prior to the beginning of the study. While ethical approval is usually granted once a clear methodological plan for the overall research has been established, this becomes almost impossible in the context of CS, where research design and protocols are not fixed a priori, and the work of the mixed teams of researchers and citizen scientists tend to be open-ended and flexible. Hence, the key question arises regarding how to harmonize the new role of citizens in co-created projects with the current procedures of ethical approval designed for traditional research projects.

#### 4.2. Ethical clearance and open questions: the Lucca pilot study experience

At the beginning of CiteS-Health project, we contacted the competent Medical Ethics Committee for information on how to submit the CiteS-Health protocol and the Lucca pilot study with regard to ethical clearance. They responded that the subject does not fall under the Medical Ethics Committee's authority.

Therefore, we submitted the CiteS-Health protocol, which also contains details on the Lucca pilot study with regard to citizen

**Table 2**

New elements introduced in the epidemiological protocol and related documents submitted to the Medical Ethics Committee.

Co-proponents of the study	Together with those of the researchers, we indicated the names of one local general practitioner, some citizens and some local health professionals who co-designed the study protocol and related documents, as co-proponents (see Section 3.2). As in previous occasions, the choice of names was made together by all those involved (De Marchi et al., 2017). In any case, in accordance with Italian law, the principal investigator – a local general practitioner in our case – continues to be the person in charge, held responsible for the scientific solidity and ethical accountability of the investigation. Instead, the co-responsibility of researchers and citizen scientists is not legally contemplated, despite their joint involvement in all phases of the research.
Co-design process	We described all the practices envisioned and implemented to engage more and more residents in debating, co-designing, and assessing the study protocol and related documents (public meetings and events, independent validation of the study protocol, etc.). (See Section 3.2).
Training for active participants	We provided information on specific training for citizens enrolled as active participants. Namely, the standard training of staff in any epidemiological study plus specific training in bioethics.
Additional new criterion for recruitment	We introduced a new participatory criterion besides those traditionally applied to recruiting research participants, i.e. we kept participation open to all those citizens who might be interested in the study and affected or empowered by it. In practice, whilst a minimum and essential threshold of enrolment was defined according to scientific criteria for inclusion, the research remains open to all volunteers. We judge such criterion to be appropriate for CS research.
Conflicts of interest of co-proponents of the study	We required disclosure of financial and/or non-financial conflicts of interest by citizens who appear as co-proponents of the study (Resnik et al., 2015).
Returning individual medical results	We are committed to returning individual medical results to each participant who expresses this will in the informed consent form, with the utmost respect for his/her privacy. Those who present clinical results outside the standard laboratory range will be guaranteed the possibility to contact their general practitioner and, if deemed necessary, also the reference specialist in nephrology of the epidemiological study.
Participatory governance for possible future use of data and biospecimens	We took a commitment to explore the theoretical aspects and the practical feasibility of a participatory approach to give citizens full control of possible future uses of their personal data and biospecimens collected during the study. We envisage following the model implemented in the case of the civic project <i>Fondazione Bioteca di Sarroch</i> (Sarroch Bio-Library Foundation) (Biggeri & Tallacchini, 2015). The statute of the Foundation aims to create a participatory governance model, which guarantees that the storage and management of human biospecimens and associated data for future research uses are under the full control of the people who provided their materials and data, through the statutory bodies of the Foundation itself <sup>a</sup> . A similar proposal of participatory governance can be found in Buyx, Del Savio, Prainsack, & Völzke, 2017.
Co-authoring documents/articles	We introduced some innovative aspects in the publication policy, based on the belief that the joint work undertaken in the project must be recognised also in its outputs. Therefore, the names of individual contributors, be they professional researchers or citizen scientists, will appear in articles and other documents prepared together. Moreover, the collective name “Aria di Ricerca in Valle del Serchio” will be used/added whenever deemed appropriate.

<sup>a</sup> The development of a participatory governance model for CS projects in the field of environmental epidemiology is also a deliverable of the *CitieS-Health* project.

engagement and the sociological survey, to the Commission for Research Ethics of the University of Florence. The Commission provided approval, with the recommendation that individual data be accessible only to researchers and not to lay people, who instead are granted access only to aggregate data. It is important to note that the names of some citizens were included in the list of authors of the survey questionnaire and related documents concerning procedures for submission.

Overall, feedback from this Lucca pilot experience highlighted four key issues: 1) the Medical Ethics Committee was not the appropriate ethical authority to be contacted regarding the ethical aspects of research conducted in the citizens engagement phase of the study; 2) there are no legal rules regarding how to assign and assess responsibility in CS projects, thus leaving the question open of which authority is in charge; 3) the confirmation that in our case the Ethics Committee to be addressed for the citizen engagement phase is the Commission for Research Ethics of the University of Florence; and 4) the type, number, and competencies of Ethics Committees in the five countries involved in the *CitieS-Health* project are quite diverse. For the Italian pilot, this implied more complicated procedures and longer times to obtain clearance.

At the end of the citizen engagement phase, we finalized the research questions and drafted the epidemiological protocol also regarding the collection of biological specimens. We submitted the epidemiological protocol and related documents to the Medical Ethics Committee with the introduction of several new elements reported in Table 2 below.

The epidemiological protocol and related documents received ethical clearance from the Regional Ethics Committee for Clinical Trials of the Tuscany Region. Full approval was given, and no recommendations were provided. This is an important result, and we are confident that it will become a point of reference for other epidemiological studies based on a participatory approach. At the same time, we would like to highlight some difficulties that we met in submitting the documentation.

First, epidemiologists conducting etiologic research feel uncomfortable in meeting the requirements of a Medical Ethics Committee (Claudot et al., 2009; de Lange et al., 2019). Generally speaking, a reason for such dissatisfaction is that Medical Ethics Committees are designed to evaluate clinical research - mainly clinical trials.



In our case, one important additional difficulty regards the absence, in Italian legislation, of a specific frame for the ethical approval of epidemiological observational studies which do not involve drugs or interventions on patients.<sup>5</sup> Consequently, we felt imprisoned in a sort of Procrustes's paradox, because we had to try and consider the healthy subjects enrolled in our epidemiological investigation as patients that have been assigned a treatment in an experimental trial. Indeed, under the current norms, biomonitoring and the storage of biological specimens are treated as a "medical intervention", which once again improperly equates the act of obtaining a biological sample to the act of administering a treatment. Among other problems, this improperly assigned equivalence implies higher insurance costs, which reverberate on the overall research budget.

A further difficulty is that in Italy, the Medical Ethics Committees are accustomed to evaluating two types of submissions: 1) for-profit clinical trials; and 2) non-profit clinical research conducted by the regional health service. Epidemiological (non-clinical) investigations are therefore in a grey zone and, whenever biological material is collected, they are considered as clinical research. Moreover, in the authorization procedures, it is assumed that a public health service or a public health agency is involved as principal investigator when a protocol is submitted for ethical clearance. This is not the case of the Lucca epidemiological study, which is coordinated by Epidemiologia & Prevenzione, a non-profit SME, and is part of a CS project funded under the Horizon 2020 European Research Programme. In a long negotiation with the Medical Ethics Committee to find a solution to the problem, it was agreed that the promoter of the study is the non-profit social enterprise Epidemiologia & Prevenzione and a local general practitioner is the principal investigator.

The difficulties described above, together with the previously obtained feedback regarding the legal and ethical responsibility for the study, which continues to be only under the Principal Investigator (doctor/researcher) in charge, point to a further issue to be addressed: how is it possible to envisage and implement a legally binding participatory governance scheme. In other words, how one can move from the idea of participatory governance illustrated in the literature (see in particular Buyx, Del Savio, Prainsack, & Völzke, 2017) to its full practical implementation in the field, as the Italian and the other Cities-Health pilot studies are trying to achieve. This is a key and urgent question, also considering the progressive shift of European and global research towards a form of data-centric research (Leonelli, 2019) which depends on digital infrastructures and databases such as the European open science cloud (European Commission, 2021).

## 5. The Covid-19 crisis and project resilience

Due to the Covid-19 pandemic, and the restrictions put in place by the national governments in March 2020, the activities of the Cities-Health project have been disrupted in all five countries. Face to face interactions (meetings, interviews, focus groups, workshops, etc.) were no longer possible, and a lot of energy and resources had to be invested in devising alternative research strategies. Thus, a CS project strongly relying on close interactions between professionals and lay citizens had to revise its implementation plans to make it possible for such interactions to occur mainly online. In the two studies which foresee the collection of biological specimens (the NL and Italy), the challenge was even greater. Here we will concentrate again on the Italian pilot and recall the strategies adopted in response to the new and totally unforeseen conditions which severely hindered or delayed the possibility of collaboration on the territory: the pandemic itself and the consequential lockdowns and strict "defensive measures", including the closure of universities and the suspension of authorized missions for researchers.

In March 2020, we started to organize open meetings using an online platform, so that citizens could still play a central role in the activities envisaged or already under way, such as the preparation of the epidemiological research protocol and the sketching of the scenarios (see Section 3.2). Regarding the data collection, it was agreed to split the study into two steps: 1) a questionnaire survey on lifestyles and food consumption habits to be performed remotely, via ICT (information and communication technology) supported telephone interviews; and 2) a campaign for the collection of blood and urine samples to be taken, processed and stored in an out-patient clinic and a laboratory set-up specifically for that purpose.

To be on the safe side, we decided to follow the guidelines of the Ethics Committee of *Istituto nazionale per le malattie infettive Lazzaro Spallanzani* (IRCCS) regarding how to provide information and receive informed consent via recorded telephone calls. The IRCCS was indicated in a recent Government Decree as the unique national committee for the evaluation of clinical experimentation of medicines and medical devices for patients affected by Covid-19 (Decreto legge, 2020, art. 17). Confirmation by written consent will be delayed to step 2, when biological specimens are collected, of course leaving open the possibility of withdrawal from the study for those subjects that in the meantime may have changed their mind.

Somewhat paradoxically, the research team's travel constraints favoured a deeper involvement of the citizen scientists, who played a central role in managing practical and organizational problems of all kinds. The researchers' concern that the local residents' contribution, so important to date, might be slowed down or diminished, proved unjustified as the new contingency actually strengthened and accelerated their engagement. The CC proved very efficient in setting up an out-patient clinic, including finding the appropriate premises and transferring the necessary equipment (e.g., refrigerators). Indeed, the pandemic restrictions were determinant in the decision to abandon the option of using an existing clinical facility to take, store and process biospecimens in favour of the setting up of a full out-patient clinic dedicated to the epidemiological study, with its own clinical lab and refrigerators and totally independent from any other structure.

A related decision was to rely on local personnel to a larger extent than originally planned and again the input of the CC proved

<sup>5</sup> Italian legislation currently regulates only observational studies on medical products. There is instead a legal void concerning studies such as ours, where no drug or treatment are involved (Agenzia Italiana del Farmaco, 2008).

essential in identifying and recruiting local doctors, nurses, interviewers, and other research staff.

One can confidently state that, due to the pandemic, the original CS format of the project was strengthened further, and the idea of an extended peer community was almost fully implemented, with a radical transformation of the traditional relationship between professional investigators and research subjects, and a joint ownership of the whole research endeavour.

## 6. Conclusion

Even before beginning the research work, and since the time we wrote the project proposal, we have been aware of the many difficulties concerning the planning and running of a CS project in environmental epidemiology.

Not only did we intend to put the citizens' concerns at the heart of our research agenda by asking them to explicitly express their interests, but we also wanted them to fully participate in the creation of the research agenda in all its phases, from the framing of the problem, the definition of the specific research questions, the research design, the collection and analysis of data, the dissemination of results, and the drafting of policy recommendations.

On the basis of previous experiences (De Marchi et al., 2017), we envisaged a number of strategies to favour the engagement of local residents and administrators, discarding the choice of a rigid blueprint, and leaving open the possibility of making changes and adapting to emerging needs/interests and/or unforeseen contingencies. This approach proved to be very useful in the first phase of the project when local associations significantly contributed to the organisation of a survey on health and environmental concerns, and to the retrieval of historical records, documents, and testimonies, in particular with regard to the industrial development of the Valley.

In the second and ongoing phase of the project – which foresees the collection of biological specimens - flexibility proved not only necessary but essential to perform the required tasks under the restrictions imposed by the Covid-19 pandemic. The radical reorganisation was made possible thanks to an increased, rather than diminished, involvement of the local community and many creative solutions were imagined and implemented together with the research team. This testifies a relationship of mutual trust built on the sharing of the research objectives and the collective discussion of the plausible scenarios that may emerge from the research results and their policy implications.

Ethical clearance of the project also posed many challenges, which we had only partially anticipated. A significant and still unaddressed novelty of CS projects concerns the double role of citizens as both research subjects and scientists. Citizen scientists are bound to the same ethical principles, rules, and guidelines as professional researchers, but there are no rules or procedures regarding this aspect.

A connected problem we had not anticipated was that our study was treated as belonging to the category of clinical studies which involve drugs or interventions on patients. This is because of a void in Italian legislation concerning the ethical approval of epidemiological observational studies which do not involve such types of treatments.

Ethical clearance required a strong investment in time and considerable creativity to overcome the many bureaucratic hurdles. We were finally successful thanks to a number of innovative elements that we introduced in our protocol and research planning in order to maintain the co-created nature of our project.

## Declaration of Competing Interest

The authors declare that they have no competing interests.

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