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## Implementing co-created citizen science in five environmental epidemiological studies in the CiteS-Health project

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## ABSTRACT

**Background and aim:** Scientists and scientific institutions are adopting more extensive participatory models, hoping to revisit the existing relationship between science and society. Though citizen science has become more common in environmental monitoring, it is seldom utilized in environmental epidemiology. In the CiteS-Health project, we co-created epidemiological studies with citizens in five European countries. The aim of this paper is to share our experiences and impart methodological insight into the application of co-created citizen science strategies in environmental epidemiology.

**Methods:** We applied the CiteS-Health framework, involving citizens in all the phases of the studies: identifying research questions, designing research protocols, collecting data, analysing data, interpreting data, formulating conclusions, authoring scientific articles and communicating the results to diverse audiences. These epidemiological studies, conducted in specific areas in Italy, Lithuania, the Netherlands, Slovenia and Spain, covered diverse local environmental issues and health effects ranging from air pollution and mental health to industrial pollution and kidney disease.

**Results:** Together with citizens, we successfully conducted environmental epidemiological studies that generated new scientific knowledge reflecting the concerns and knowledge of citizens. Citizens contributed in all the research activities, including activities beyond formulating the research questions, though the researchers initiated several design discussions and conducted time-consuming and complex tasks (e.g. data analysis, measurement of specific exposures and health outcomes). The challenges we encountered were engaging effectively with citizens throughout the study, harmonizing citizens' knowledge and values with the academics' expertise, managing civic expectations, making complex concepts understandable to citizens and representativeness of participating citizens. The co-created studies were able to empower citizens to address local health concerns by sharing and using scientific knowledge generated from studies.

**Conclusions:** Integration of co-created citizen science in environmental epidemiology is feasible and has the potential to improve the quality of research whilst promoting civic trust in research and results.

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## 1. Introduction

Citizens are being encouraged to become more and more involved in research activities through an array of participatory approaches. These participatory approaches range from participating in data collection (crowd-sourcing) to citizens conducting the entire study themselves (extreme citizen science) (English et al., 2018). Recent experiences show that civic participation in research can create better, context-specific knowledge that can stimulate local policy changes (Den Broeder, et al., 2017; Woolley et al., 2016). In environmental epidemiological studies it is common to include patients or stakeholders in advisory boards (Israel et al., 2005). However, in these settings, citizen contributions are more limited than in citizen science (CS) projects (Froeling et al., 2021).

In projects addressing typically polarized socially relevant research questions, researchers may be faced with distrust from the public regarding scientific methodology and results (Funtowicz and Ravetz, 1993; Saltelli and Funtowicz, 2017). A clear example of this was during crises such as the COVID-19 pandemic, where the lack of civic involvement and increased distrust created barriers for the adoption of preventive measures (Bory et al., 2023; Di Marco et al., 2021; Jennings et al., 2021). This is also the case in research regarding environmental health issues. Trust is necessary for decision making that requires individual or institutional behavioural change (Mousoulidou et al., 2022). Concerned local residents are often the first to identify and respond to environmental issues but unfortunately a notable challenge arises when these individuals attempt to provide policymakers with the data or insights they have gathered (Berti Suman et al., 2023). Unfortunately, the current legal framework restricts the potential of citizen data to effectively address pressing environmental concerns (Berti Suman et al., 2023). For this reason, various groups involving both researchers and citizen alike, are trying to find, adapt and implement more inclusive participatory models to foster close collaboration between citizens and researchers to improve civic trust and generate knowledge that can lead to a visible impact on society (Ashby, 2003; Grazuleviciene et al., 2020a; Irwin, 1995). In these more inclusive participatory approaches it is important that researchers embrace citizens with critical or polarized views, to foster open dialogue and cooperation (Bory et al., 2023). Co-created citizen science represents a significant step forward in this regard as citizen driven data can help empower citizens to influence policy-makers and bridge knowledge gaps (Berti Suman et al., 2022).

In the field of environmental epidemiology, steps need to be made to incorporate explicit contributions from citizens in the design, execution and interpretation of studies. In a previous narrative review, we provided an overview of the existing participatory approaches within environmental health. This review focused on the opportunities co-created CS presents in redefining civic relationships with experts whilst making the local production of knowledge a more inclusive and sustainable process (Froeling et al., 2021). We defined co-created CS as an approach where scientific projects are led by researchers together with citizens who collaborate throughout all stages of the research process (CitieS-Health, 2022; Froeling et al., 2021). This approach supports current initiatives in (environmental health) research field working towards more ethical, responsible, inclusive, open, sustainable and socially relevant research (Chilvers and Kearnes, 2019; Kramer et al., 2012; O'Fallon and Deary, 2002; Weed and McKeown, 2003). The review highlighted the benefits of moving away from the still dominant "productivity view" present in CS projects and traditional environmental epidemiological studies, where citizens are only mobilized in the data collection of research projects to collect large amounts of data (Froeling et al., 2021). Promoting the less mobilized "democratization view" is the key to fostering new insights into the interpretation of problems and results, strengthening the dissemination of findings and ultimately leading to more socially relevant research (Irwin, 1995).

While CS projects may contribute to more socially relevant research,

concerns about CS have also been expressed, including poor data quality, potential biases due to participation of citizens with partisan interests and poor representativeness of involved citizens (Buyx et al., 2017; Froeling et al., 2021; Kocman et al., 2019; Moffatt et al., 2000; Resnik et al., 2015). The challenges associated with working with health data, is the reason why co-created citizen science (CS) approaches are still considered a novelty in environmental epidemiology (Averett, 2017; De Marchi et al., 2020; English et al., 2018; Froeling et al., 2021; Simonova et al., 2019). These challenges include privacy issues, medical ethical guidelines, available monitoring technologies, required expertise in complex study design and addressing analysis issues relative to environmental monitoring. Thus, continued efforts, particularly in the sharing of methodological information, are needed to make co-created citizen science a more accepted approach by environmental epidemiologists.

With this paper, we aim to discuss methodological insights and experiences we have collected from performing co-created environmental epidemiology studies in different settings within the CitieS-Health project. We discuss the benefits and challenges faced throughout the various research phases and conclude with recommendations to assist future co-created CS projects, so that CS may become a more concrete and cohesive approach for environmental epidemiology in the future. Authors would like to acknowledge that the collective "we" used throughout this paper refers to the CitieS-Health research partners who collaborated in writing this paper. This paper thus elaborates on the experiences and findings of academic researchers in conducting a co-created epidemiological project with citizens. However, all of the recommendations and conclusions made in this paper were discussed with citizens participating in the CitieS-Health projects during the CitieS-Health symposium held in Rome in 2022.

## 2. Methods

In this paper, the term "citizen" is only used to distinguish the lay public from professional researchers and does not reflect the citizenship status of people who contribute to research projects. The researchers are aware of ongoing debates regarding the use of the term "citizen" but consider this beyond the scope of this paper.

### 2.1. The CitieS-Health project and framework

CitieS-Health, an EU Horizon 2020 program funded project, started in 2019 with the aim of putting citizens' concerns at the heart of environmental epidemiological research (<https://citieshealth.eu>). This project was one of the first attempts to incorporate co-created CS in environmental epidemiological studies. The CitieS-Health project developed environmental epidemiology studies in five European countries (Table 1). These studies are referred to as the Amsterdam, Barcelona, Kaunas, Ljubljana and Lucca studies. The aim of each of the studies was to include citizens in key decision-making processes throughout all the research phases. Thus, together with citizens, each research partner co-created projects addressing local concerns, which led to the design and implementation of five unique epidemiological studies.

To help homogenize the definition and implementation process of co-created CS in the CitieS-Health projects, all partners made use of the Citizen Science for Urban Environment and Health framework (CitieS-Health, 2022; Toran et al., 2019) (Fig. 1). This framework highlights the key characteristics of co-created CS projects in general epidemiological research, which can be adapted to the individual needs of different environmental epidemiological projects (Toran et al., 2019). Providing researchers and citizens with a practical structure to follow throughout the project. The results section of this paper will be structured using the different phases of the CitieS-Health framework to highlight the main challenges and opportunities identified by the project partners.

2.2. Background on the five CiteS-Health projects

When applying for the Horizon 2020 grant, researchers had already broadly defined the research topics before starting the co-creation process with citizens. Requirements related to the call text were that the project should support CS initiatives, that the activities needed to be clearly defined and should result in the generation of new knowledge. These requirements were very broad and still left a lot of room for citizens to define the research question. To decide on the topics included in the proposal, researchers chose issues of public concern. No formalized methodology was used to define these. In the project grant application, researchers also agreed that each of these studies would study health concerns directly via an epidemiological study. Though the broad research themes were predetermined, citizens played a crucial role in defining the specific research question (see section 3.1).

The Amsterdam study focused on the relationship between wood-burning and respiratory health in four Dutch towns (CHARRED, 2022). In the Barcelona study, partners investigated how air pollution together with noise and green/blue spaces affect mental health (Gignac et al., 2022a, 2022b). The Kaunas team studied the associations between urban environment (built and social) and health outcomes including: obesity, hypertension, stress, physical activity, and gender health risks (Grazuleviciene et al., 2020a, 2020b, 2021a, 2021b, 2022). In Ljubljana the study topic was the link between the quality of the living environment (focusing on noise) and living habits and (mental) health and well-being (Kocman et al., 2020; Kocman et al., 2021). The Lucca team looked into the relationship between chronic kidney disease and the social, historical and environmental characteristics of eight municipalities in the Serchio Valley, focusing on industrial pollution (Biggeri et al., 2021). The selection of diverse environmental issues was a deliberate decision in the design of the project, made by researchers in the preparation of the research proposal for funding by the EU. Table 1 provides a brief overview of each of the study locations, the study period, involved citizens, predetermined themes and actual research questions co-created with citizens.

In the CiteS-Health case studies, citizens were not individually asked about their rationale for choosing a specific research question or why they wanted to help co-create a study. Previous studies show that citizens often engage in scientific studies for a multitude of reasons, each driven by their unique motivations, including a desire for achievement, seeking affiliation with a community, a sense of power or influence, and genuine concern for the issues being studied (Froeling et al., 2021; Van

Brussel and Huyse, 2019; Woolley et al., 2016). Throughout the co-creation process, it became evident to researchers that the civic rationale behind the specific research questions was driven by a combination of factors, primarily citizens' pre-existing concern or interest in the predetermined research themes and their desire to leverage the study's outcomes to instigate positive change in their local environment. This complexity was evident in the humanities and historical research done in the Lucca pilot (Malavasi, 2023).

Although each project partner developed the study locally with their citizens and other stakeholders, the methodology was harmonized across partners. Tools for harmonization included the common framework, the toolkit (see section 3.3.2), specific protocols e.g. for impact assessment and monthly online meetings during which all the study activities were discussed. Many activities were organized by the partners to collaborate and co-create various elements of the studies with citizens. Supplement tables 1-5 provide an overview of the main activities conducted with citizens and the number of citizens involved in the five studies.

Many of the activities done within the CiteS-Health project period were affected by the COVID-19 pandemic and the restrictions in place between March 2020 and February 2022. Though researchers and citizens did their best to think of creative solutions to keep going as planned, the safety of both was the main priority. Thus, not all the teams were able to conduct their studies as originally planned. The experiences described here, though still useful for future research, do reflect studies that were restricted in their face-to-face interactions between researchers and citizens.

We conducted co-created environmental epidemiology studies and this paper shares the experiences we gained during the project. This study is not a social science experiment that treat citizens as study subjects, but trans-disciplinary research. Therefore, we did not consistently ask demographic, socio-economic, or ethnic questions during the identification and design phases of the project. In both the Lucca and Kaunas studies personal data was collected during the identification phase after receiving ethical approval. The remaining studies obtained ethical approval and collected this information for all study participants during the deployment phase of the epidemiological study.

3. Results and discussion

All the studies were successful in including citizens in all the research phases described in the CiteS-Health framework. However, civic

Table 1  
Key characteristics of each study from the CiteS-Health project.

Partner country	Study location	Approximate duration of different phases (months)- phases overlapped.	Citizens	Predetermined theme	Main research question co-created with citizens
Spain	Barcelona	Identification: 10 Design: 7 Deployment: 20 Action: 4	Individual citizens, Organized citizens, Schools for adults	Air pollution and health	How does air pollution together with noise and green/blue spaces affect mental health?
Italy	Barga, Borgo a Mozzano, Coreglia Antelminelli, Fabbriiche di Vergemoli, Fosciandora, Galliciano, Pieve Fosciana, and Molazzana	Identification: 10 Design: 12 Deployment: 27 Action: 2	Individual citizens, Organized citizens, Municipalities, Mayors	Industrial pollution and health	Is the prevalence of chronic kidney diseases (CKD) in the general population of the Serchio Valley associated with industrial pollution?
Lithuania	Kaunas	Identification: 10 Design: 8 Deployment: 12 Action: 6+ (ongoing)	Individual citizens, NGO, stakeholders	Urban environment and health	How do the built and the social environments of neighbourhoods affect health?
Slovenia	Ljubljana	Identification: 14 Design: 11 Deployment: 18 Action: 10+ (ongoing)	Schools, Individual citizens, Organized citizens, Governmental organizations	Noise pollution and health	How does the quality of the living environment (with an emphasis on noise) and living habits affect the (mental) health and well-being of individuals?
Netherlands	Amsterdam, Zutphen, Utrecht, Bergen	Identification: 9 Design: 11 Deployment: 16 Action: 10+ (ongoing)	Individual citizens, organized citizens, Governmental organizations	Biomass burning and health	What are the short-term effects of woodsmoke on respiratory health of adults?

inclusion and participation varied between the different research phases and the different studies. The following sub-sections will highlight different key experiences from the five studies, discuss aspects that led to success or posed challenges, and how citizens impacted the project in the different phases of the CiteS-Health framework. Co-creation with citizens had an influence not only on the research questions but also on design, data collection, interpretation of results and project actionability.

### 3.1. Identification

In the identification phase researchers focused on exploring citizens' concerns, by defining possible research questions and building a community of interested citizens and stakeholders. This is an essential step within the project as the identification phase allows citizens to have an active role in setting current and future research agendas (Rosas et al., 2022). As many of the environmental health issues epidemiologists research are a result of public concern, this phase was the simplest to incorporate co-creation into. To incorporate civic views epidemiologists often discuss possible research questions with relevant stakeholders, including (organized) citizens, before a project is launched. Co-creation, as we interpreted and implemented, goes beyond stakeholder consultation as citizens and researchers equally decided which research questions to address.

#### 3.1.1. Civic concerns

Some decisions were made with regard to the research topic during the grant application but these decisions did not strongly affect citizens' ability to influence the selection of the specific research questions of the studies. A very clear example of citizens' re-defining the research question completely was in the Barcelona study where researchers predetermined that the study would be about air pollution. When

investigating scientific literature and media trends researchers expected that there would be a lot of interest in the effects of air pollution during pregnancy. However, when they organized an event to publicly discuss this, very few citizens showed up, none of whom were pregnant. This meant that a new strategy had to be devised to investigate what citizens were interested in with regard to air pollution. In a recent paper, the Barcelona partners elaborate on their efforts to co-create an epidemiological study with citizens (Gignac et al., 2022a). In short, they organized an online survey from which they deduced what questions were of interest to local residents. They then organized a pop-up event to discuss the various study themes with as many citizens as possible, and check whether these themes reflected societal concerns regarding air pollution. Subsequently, they organized a community meeting where they narrowed down the list of research themes and formulated them in terms of potential research questions. Once they had a list of questions, they created another online survey where citizens were able to vote for the research question they wanted to investigate, which led to the final question "How does air pollution together with noise and green/blue spaces affect mental health?".

The Barcelona and Kaunas teams were the first to complete the identification phase. Their initial experience helped the other CiteS-Health studies tackle this more efficiently. The experience made researchers realize that a combination of several participatory activities were required to give citizens the opportunity to identify and formulate research questions that represent their own concerns, interests and needs. Table 2 presents the activities that were applied in the identification phase, with some observations related to their usefulness. From a scientific perspective, conducting several activities such as (online/paper-based) surveys, pop-up interventions or community meetings, allows researchers to collect both quantitative and qualitative data on civic concerns and interests. In the Amsterdam, Barcelona and Kaunas studies, the combination of face-to-face interviews, online surveys and

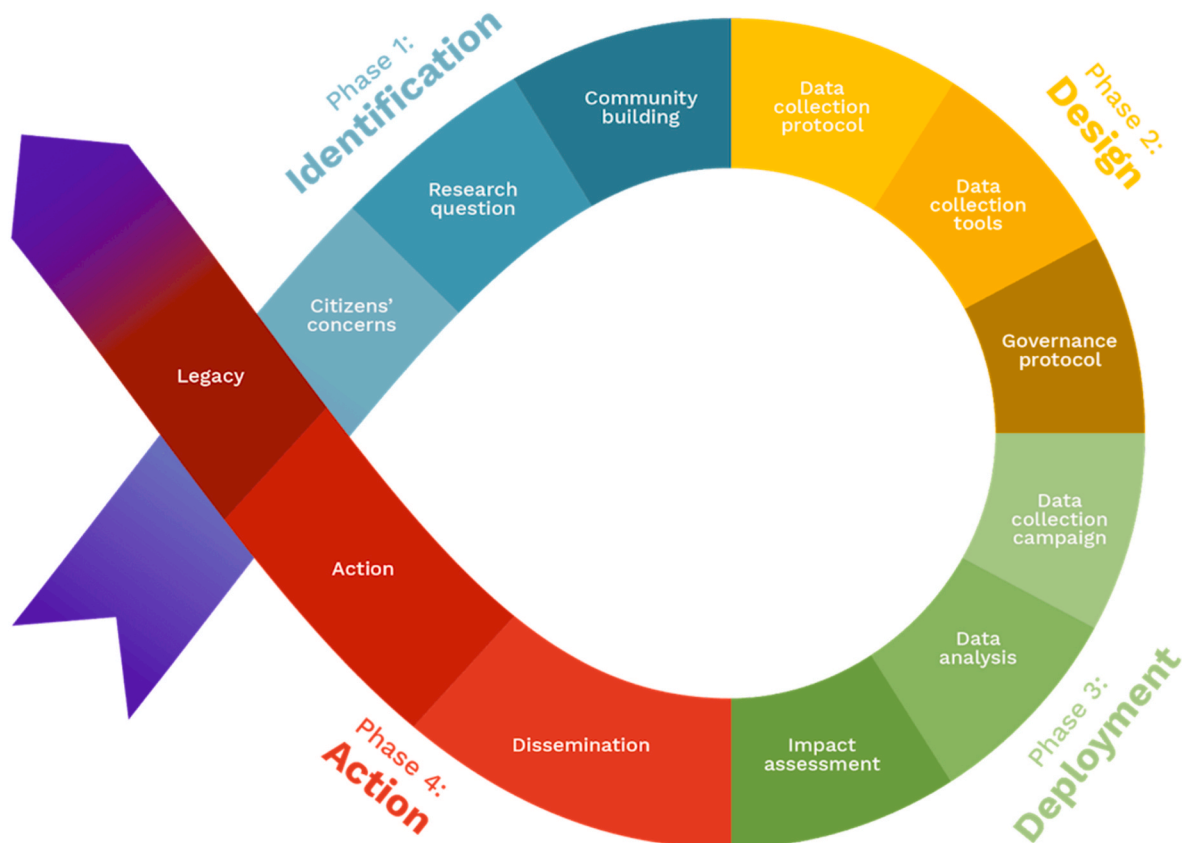


Fig. 1. The different phases of the CiteS-Health framework for co-created Citizen Science in environmental epidemiology (Toran et al., 2019).

**Table 2**  
Illustrates tools used to identify civic concerns and promote co-creation.

Tool	Description	Studies using tool	Observations
Workshops	Meetings where participants play an active role and actively contribute to research phases	All	Useful for discussing different research questions or designing the research protocol. Effective for exchanging information on what is known, what would be novel or what would be difficult to address. Facilitates active participation of citizens and engages them in the research process. More effective with live events using easy and interactive activities.
Face-to-face meeting	Classical meeting style where citizens can have either a passive or active role, but researchers take the lead	All	Allows researchers to disseminate project objectives, study updates and results. Meetings allowed researchers to explain difficult concepts and clarify citizens' environmental and health concerns. Making organizing future activities easier by knowing citizens' personal attitudes, desires, expectations and motivations.
Online meetings	Same as face-to-face meeting, but through videoconferencing to discuss with citizens	All	Online meetings were started during COVID-19 restrictions, but continued to be used after lifting restrictions. The meetings stimulated civic engagement and allowed anonymous participation. Useful for including citizens from a large geographical area (such as the entire Netherlands). The Barcelona and Ljubljana studies showed that having at least one physical meeting with citizens led to higher civic motivation for the studies.
Online qualitative survey	Survey that uses open format questions to elicit questions, experiences and input from citizens	Barcelona, Amsterdam, Kaunas	Useful for the identification of concerns and questions citizens have. This allowed researchers to cluster citizens questions.
Online quantitative survey	Survey that uses closed format questions to determine priority and prevalence of research questions included	Barcelona and Kaunas	Useful for estimating the priority and prevalence of questions.
Pop-up event	An event where researchers distributed strawberry plants to citizens whilst explaining the rationale of the CityS-Health project.	Barcelona	Useful for engaging with citizens and communicating the goal of CityS-Health through an easy and interactive activity. The campaign was successful and got some media coverage. Researchers were able to create a map of air pollution levels in different neighbourhoods of Barcelona using strawberry plants.
Paper-based sociological survey	Anonymous questionnaires that were physically distributed by local associations.	Lucca	Useful for the identification of citizens beliefs and concerns in regard to the topic of interest. It also allowed researchers to understand citizens' knowledge on epidemiological and "official" environmental data. Citizens and associations collaborated in distributing 1025 questionnaires to residents of which 922 were completed (response rate 90%).
Scenario discussions	A round table discussion with relevant stakeholders involved in the co-created study	Lucca and Amsterdam	Useful for discussing various possible scenarios for the results of the study (association between exposure and health yes or no) and related implications in terms of action plans and make commitment to act accordingly. During the Lucca event mayors accepted to co-author a scientific article on the future scenarios and lines of action.
School campaign	Visits to schools, including the organization of Science Days.	Ljubljana	Useful for raising awareness with regard to noise pollution and health. Generated interest to participate in project activities and engage a wide spectrum of participants – pupils, teachers, parents, school staff
Radio interviews	Use of radio interviews to generate awareness of the upcoming research projects and the study results.	Amsterdam and Kaunas	Useful for raising awareness within communities, who listened to the radio, about the upcoming projects. Radios want to cover socially relevant topics and produce insight with regard to the possible societal interest in a project.

face-to-face/online meetings were used. In the Lucca study citizen associations helped distribute 1025 paper-based surveys which resulted in a response rate of 90%. Researchers agreed that the survey data was useful in engaging with citizens during meetings and could be used to help frame possible research questions. The surveys enabled scientists to have clear quantitative answers whereas the meetings helped to contextualize data with personal experiences and stories shared by the citizens. The combination of using multiple participatory activities affected subsequent steps such as community building, participant recruitment, dissemination of results, action, studies legacy and impact assessment.

During the identification phase, citizens sometimes raised questions that were beyond the scope of what epidemiological studies could address. In the Amsterdam study, multiple questions relating to the level of woodsmoke exposure were identified during the online survey and the first physical meetings. The questions included the level of woodsmoke exposure present during a neighbourhood commute, indoor woodsmoke exposures in the homes of people who have a fireplace, and indoor woodsmoke exposure present in the homes of people living near to woodsmoke sources. Citizens thought addressing those questions would be useful for further action. Therefore, these questions were also experimentally addressed in the Dutch pilot in addition to the epidemiological study. In the Lucca study, citizens were concerned with health effect of environmental pollution from heavy metals. In

particular, the causal relationship between human cadmium exposure and chronic kidney disease. Together with citizens researchers developed steps to address this. The first step was an epidemiological survey to assess if there is a health problem regarding chronic kidney disease; the second step would be to measure cadmium contamination in the environment (soil); the third step included the biomonitoring of human cadmium exposure and finally to link their health to cadmium body concentrations. To address citizens' concerns, both researchers and citizens agreed that the Lucca study would focus on renal health by measuring renal disease biomarkers in urine and blood. They also agreed broaden the research frame so that the Lucca study would also store the conferred biological materials in a biobank for future use and obtain approval to conduct heavy metals and cadmium biomonitoring in an upcoming study. Both studies attempted to accommodate civic questions that were considered beyond the scope of the current study or to address these in the future, which not only helped address civic concerns but the interest in citizen driven questions increased engagement in the studies.

### 3.1.2. Community building

Besides identifying civic concerns and formulating research questions, establishing and engaging effectively with a community of citizen scientists is crucial. Prior research has shown that CS initiatives attract a limited number of citizens who only briefly participate in a project



(Geoghegan et al., 2016; Van Brussel and Huyse, 2019). In all studies, we developed a new community around the specific research topics. In the Amsterdam study, some organized anti-woodsmoke groups, but also previously non-organized citizens, contributed to the project. In the Kaunas study, city planners and public health specialists were the most interested in the study outcomes. The CitieS-Health studies had positive experiences with organized civic groups and stakeholders as they were very active, engaging and willing to provide inputs and critiques. Also, through their well-established networks, they were able to mobilize an extended number of citizens and play a key role in the actionability of the studies. However, it is important that projects remain open to including a wide range of citizens beyond the already organized groups to increase the plurality of views. Both the Amsterdam and the Lucca studies focused on building a community around the research topic and addressing public health actions. In the latter case, the participation was pretty stable with a core of about 20–40 people and a citizen association, La Libellula, supporting the whole project. An important moment for promoting civic participation was the setting up of an outpatient clinic, a necessary step to guarantee that blood draws and urine samples could be performed continuously and safely during the pandemic. Tens of citizens mobilized to find an appropriate venue, and volunteered in performing several tasks such as scheduling appointments disseminating flyers with appropriate information, etc.

In the CitieS-Health project, none of the partners chose to have strict rules for participating in the project, meaning that citizens could join or leave the project during different phases, without formal control, depending on their interests and time availability. For all the studies it was important to have a sizable number of citizens providing input throughout the different phases to maintain the co-created nature of the study. Though the CitieS-Health studies purposefully did not document the names of citizens who participated in which phases, they did track the number of those who participated in the various activities (see appendix, Tables 1–5). For all project activities there were a number of citizens who participated, suggesting that co-creation is feasible throughout all of the research phases. For example, the Amsterdam study had about 15 citizens that participated in all the online meetings, from defining the research questions to interpreting the results of the epidemiological study. One expressed concern with CS projects in general, is the limited inclusion of citizens with a low-socio-economic background and from minority ethnic groups (Pandya, 2012; Pateman et al., 2021). Three studies, Amsterdam, Kaunas and Lucca, collected some demographic information during the identification phase and results varied per study. The Amsterdam study, had a diverse group of citizens in terms of age and sex and educational background whereas in the Kaunas and Lucca pilots this was more homogenous. In the Kaunas study slightly more than half of the citizens were women and had a university degree. The most active participants in the Lucca study were essentially middle-aged men and women with 10–15 years of education. Due to the limited demographic information recorded during identification phase, it is difficult to determine whether the CitieS-Health projects sufficiently reached these target groups. However, project partners agreed that researchers should continue their efforts to reach citizens with a low-socio-economic background and from minority ethnic groups. All the partners involved in the project have become more mindful of the specific citizens they are reaching through their initiatives. Researchers from CitieS-Health have taken steps to ensure that the results of their project are communicated and shared through various accessible means. They will also strive to enhance the accessibility of their research to individuals from low-socio-economic backgrounds and minority ethnic groups in future projects.

### 3.1.3. Citizen engagement and motivation

Since the CitieS-Health studies all dealt with locally relevant health concerns, the majority of the participants were willing to invest time and energy in them and remained engaged in the project from start to end. In addition to concern about the potential health effects of their local

environment and the desire to improve the local environment, citizens contributed to the studies for a variety of interests such as curiosity, a sense of achievement or affiliation with a like-minded group. Our assessment of the literature, showed that civic concerns regarding the possible health effects of an environmental factor, and the desire for action to reduce environmental exposures, is a common motivation for participation in CS projects addressing environmental issues (Froeling et al., 2021; Grazuleviciene et al., 2020a). The majority of those interested in the Amsterdam study were people who experienced nuisance from woodsmoke and wanted to see a change in their local environment. Only a minority were people who had a fireplace themselves and, due to the prevalence of the non-woodburning group, it was difficult to keep them involved beyond a few meetings. On the other hand, in the Ljubljana study, where the general theme was noise and health, only a minority of those who participated in the data collection considered themselves to live in a noisy environment or to be bothered by noise. Their main motivation to participate was to help researchers and to gain knowledge about the topic and the research process, respectively.

The level of engagement differed substantially between citizens, both in terms of duration and intensity of engagement. One catalyst for civic-driven engagement, participation and involvement in the Barcelona study was the appointment of ‘community champions’, meaning citizens became representatives of the participating community throughout the duration of the study. These representatives were invited by the researchers, felt passionately about the research topic and were actively involved in the study. To ensure interest in the topic the community champions were appointed after the identification phase. These representatives were useful in helping researchers mobilize the participating community members. The other CitieS-Health partners, though not having appointed community champions, noticed that there were small groups of citizens passionate about the specific studies and that they would rally other citizens into action throughout the different phases of the studies. In the Lucca study many of the citizens were already active in local associations and decided to spontaneously form a committee to encourage dialogue and constant collaboration with local administrators and researchers. The citizens chose an open committee structure, 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 is a clear example of how citizens took the initiative in the study that proved to be quite effective. Whilst the “hard core” group of citizens following all the phases of the study remained stable at some 15–20 people, the number of people contributing to the discussion of key decision processes increased to 50–100.

In summary, researchers found that the identification phase is a phase where citizens can drive the research agenda by helping researchers identify local environmental (health) problems and frame the research questions whilst helping to build an active community of like-minded citizen scientists. The main points researchers need to keep in mind are: firstly they should use a combination of activities or tools to effectively engage with a large group of citizens; secondly they should be able to establish and effectively engage with a network of citizen scientists who are heavily interested in the research topic, and thirdly they should allow for citizen driven initiatives to increase engagement in research activities. These points are crucial for successful co-creation and completion of the project.

### 3.2. Design

This phase focuses on the co-creation of the study design (termed data collection protocol in the framework, Fig. 1), the selection of data collection tools, and governance protocol used in the studies. In all the CitieS-Health studies, citizens contributed to the key decisions in the design phase. All the studies would have been different without the contribution of citizens. Co-creation of the study design (and subsequently data collection, analysis and interpretation) is less common in environmental epidemiological and other scientific studies in general

due to the belief that the objectivity of trained and experienced researchers is necessary. Table 3 presents examples of design inputs suggested by citizens and design options offered to citizens by researchers.

### 3.2.1. Researcher - citizen initiative balance

The design phase was more challenging for citizens than the identification phase, as it required more expertise, time, and effort to develop scientifically sound study designs. As citizens are not full-time researchers, researchers should not expect them to take initiative in all aspects of the project. In our experience, citizens expected scientists to take the lead in proposing sound designs and data collection tools. Researchers thus did so in proposing different design options which were then thoroughly discussed with citizens (see Table 3). On the basis of these discussions, researchers wrote the study protocol as this required expert knowledge and technical jargon, understanding of the structure needed and took a substantial time and effort. For all epidemiological studies (with and without CS), a formal study protocol is needed with additional completed forms to obtain ethical approval for the studies. In order to incorporate civic inputs, the Amsterdam and Barcelona studies sent citizens a copy of the draft study protocol so they were able to provide their feedback either via email, during an (online) meeting or both. In the Amsterdam study, citizens were very active during meetings and were eager to provide feedback. Citizens who were unable to attend meetings were given the opportunity to provide additional feedback via email in both the Amsterdam and Barcelona studies. The latter attempts resulted in little or no additional feedback from citizens. The study protocols for the Kaunas and Lucca studies were also discussed during open citizen meetings. To facilitate this in the Lucca study, researchers organized a public event where four external referees, independently chosen by both citizens and local administrators, were able to critically evaluate the technical aspects of the protocol drafted by the researchers. This resulted in some citizens co-authoring the study protocol.

In the Barcelona and Ljubljana studies, a citizen test group was formed to test the data collection tools. In Barcelona the researchers sent the data collection protocol and NO<sub>2</sub> passive tubes procedures to citizens for feedback to help work out any issues before the tools were disseminated to study participants. Similarly, in the Ljubljana study, researchers organised a focus group to discuss and demonstrate the online application for autonomous data analysis. Researchers also asked participants about their expectations regarding data visualisation and analysis in an online survey beforehand. Based on feedback during the focus group discussions, researchers adapted the web-based application accordingly. This opportunity to test protocols is not unique to CS projects, as it has been applied in epidemiological studies without a CS component. However, due to the closer contact researchers have with citizens in CS projects, it is easier to ask citizens to test tools and receive valuable feedback promptly.

### 3.2.2. Researcher operated measurements versus low-cost sensors

In the academic community, the term CS is often associated with the use of low-cost sensors (see the extensive discussion in a recent review by English et al., 2018). In all the CitieS-Health studies, the researchers proposed to use tools that were already validated by the scientific community as the primary tool to measure exposure and health to ensure credibility and maintain data quality. Citizens agreed with this proposal. The researchers in the studies which also included do-it-yourself (DIY)/low-cost sensors worried about their effectiveness in epidemiological studies. In addition to concerns regarding data quality of measuring exposures via sensors (PM<sub>2.5</sub> in Lucca and Amsterdam), the measured exposures were insufficiently specific to answer the research questions. In the Amsterdam study, all stakeholders agreed to have researchers perform more sophisticated monitoring with limited monitoring by citizens themselves, to ensure the necessary data quality and specificity for the epidemiological study. It was important that woodsmoke particles were measured independently from other (traffic) particles, to achieve this levoglucosan needed to be measured,

**Table 3**

Design options discussed with citizens and examples of adaptations to the design following discussion with citizens.

Study	Design feature proposed by researchers	Civic influence on study design
Amsterdam	<ul style="list-style-type: none"> <li>Study long-term or short-term effects (e.g. cancer or asthma exacerbation)</li> <li>A panel study instead of semi-experimental (intervention).</li> <li>Possible study populations (children/adults; general vs patient population)</li> <li>Health measurements to be taken (lung function tests and daily symptoms diary)</li> <li>Possible study locations: two study locations were proposed by researchers due to collaboration with other relevant stakeholders</li> <li>The use of research-grade air monitors.</li> </ul>	<ul style="list-style-type: none"> <li>Citizens agreed with researchers to do a panel study in adults with and without COPD/asthma.</li> <li>Citizens added relevant symptoms to be added to the symptom diary. Stress was added as outcome of the study, measured via cortisol and self-reported in the diary.</li> <li>Two more study locations were chosen with the help of citizens.</li> <li>Citizens agreed the data to be collected using research grade equipment. But they also wanted to implement a few low-cost sensors at citizens' home addresses.</li> </ul>
Barcelona	<ul style="list-style-type: none"> <li>The pros and cons of three possible types of epidemiological studies including:               <ul style="list-style-type: none"> <li>Observational/panel study</li> <li>Experimental study</li> <li>Cross-sectional study</li> </ul> </li> <li>The mobile application was shared with a small group of "community champions" to gauge the overall user experience.</li> </ul>	<ul style="list-style-type: none"> <li>Citizens preferred an observational panel study, allowing participants to report daily mental and cognitive outcomes in relation to air pollution concentrations.</li> <li>Self-perceived stress and capacity of attention were amongst the most preferred cognitive and mental health outcomes to investigate.</li> <li>Citizens favoured a study design that was convenient and time efficient for participants. They wanted to use a mobile application to collect mental health data through validated cognitive tests (perceived as more objective) and questionnaires.</li> <li>Citizens wanted to receive more personalized results and be able to monitor their personal exposure to air pollution.</li> <li>"Community champions" proposed changes to the mobile application, including displaying the overall score of the STROOP test after completion and allowing the test to be taken in Night-Mode. Some modifications were implemented, while others could not due to technical limitations.</li> </ul>
Lucca	<ul style="list-style-type: none"> <li>A cross-sectional study with biomonitoring.</li> <li>Possible study population (children/adults; general vs patient population).</li> <li>Participants to fill in a food frequency questionnaire and their life styles/occupational history.</li> <li>Make use of do it yourself air sensors for particulate matter (PM<sub>2.5</sub>) monitoring</li> </ul>	<ul style="list-style-type: none"> <li>Citizens agreed with researchers but asked for storing biological samples for futures studies and for biomonitoring cadmium exposure. The study was then designed to store biological samples in a biobank.</li> <li>General agreement to do the study in adults following international protocols.</li> <li>Citizens agreed to provide information on occupation and historical job exposures.</li> </ul>

(continued on next page)

Table 3 (continued)

Study	Design feature proposed by researchers	Civic influence on study design
Kaunas	<ul style="list-style-type: none"> <li>• Across-sectional study design with personal data on health and perception of environmental issues.</li> <li>• The use of GIS for environmental exposure.</li> <li>• International questionnaires for self-rated health and physical activity measurements.</li> <li>• Suggested broader CS initiatives in which citizens could participate.</li> </ul>	<ul style="list-style-type: none"> <li>• Citizens took part in a broader CS initiative on air pollution using low-cost sensors.</li> <li>• Citizens expressed their personal environmental and major health concerns to researchers, which helped formulate the research questions, study aim and protocol.</li> <li>• Citizens suggested using simplified one-sentence questions for subjective self-rated health scoring and physical activity scoring and agreed to use sensors for objective physical activity measurements.</li> <li>• Based on the feedback provided by citizens, their suggestions were included into study protocol.</li> <li>• General agreement to do the study following bioethics requirements, saving anonymously of coded personal data and conduct research by created protocols.</li> <li>• Citizens agreed to take part in the evaluation of environmental epidemiological study outcomes.</li> </ul>
Ljubljana	<ul style="list-style-type: none"> <li>• Various specific research questions were suggested that could be explored related to the exposure to noise, human health and well-being</li> <li>• Demonstration of tools and their potential applications: (low-cost) sensors, portable health devices and gadgets, smartphone apps</li> <li>• A group of participants was asked to provide feedback on beta version of web-based application for data visualisation and analysing.</li> </ul>	<ul style="list-style-type: none"> <li>• Several citizens expressed their belief that topic of noise and health should be placed in the multi-stressors context of the living environment and habits of an individual. This was taken into account when overarching research question was formulated and respective data collection protocol designed.</li> <li>• Based on the feedback provided by participants via focus group, web-based application for autonomous data visualisation and analysing was adapted and its final version created.</li> </ul>

which cannot be done through the use of low-cost particle sensors. In a large Canadian effort, a government agency also elected to prepare measurement kits with research-grade monitors to measure woodsmoke (Wagstaff et al., 2022). These were available for citizens to measure their own environment by themselves.

In the Barcelona study, citizens wore NO<sub>2</sub> passive tubes for the duration of two weeks. These tubes were chosen for their ability to measure personal exposure with low cost and ease of application (no pumps needed). Passive sampling for NO<sub>2</sub> has been used extensively in previous research projects in the past (Cyrus et al., 2012). The analysis of the samplers needed to provide the concentration had to be performed in an external laboratory (Yu et al., 2008). Similarly in the Kaunas study, citizens wore EU-certified sensors Fitbit Alta for 7 days after which citizens could compare their device-gathered data with their reported physical activity data from a previously conducted questionnaire.

In the Lucca study, a network of DIY sensors was established through a CS initiative called *CheAriaTira*, which handled the set-up and calibration of the sensors. This DIY monitoring network collected all the air pollution data which was then compared to the data from the

monitoring network of the Tuscany Environmental Protection Agency (EPA). The Italian team stressed that CS monitoring initiatives can complement official monitoring networks. Though the reliability and completeness of DIY PM<sub>2.5</sub> and PM<sub>10</sub> sensors compared to official monitoring sites did show promise in portraying daily trends or macro-phenomena these devices alone are not able to investigate the impact on local (vulnerable) populations. However, in the Lucca study there was no active EPA monitoring station in the study area. In this case, a DIY monitoring network is better than no monitoring network. In the Ljubljana study, participants measured noise levels using their smartphones with external microphones provided and calibrated by researchers. Due to COVID-19 constraints, citizens were later instructed to calibrate their smartphones themselves using road traffic noise. Researchers emphasized the importance of choosing an easy-to-use noise monitor for daily use to prevent inactivity or drop-out. When using low-cost sensors, partners agree that the responsibility of technically demanding tasks such as sensor calibration should be delegated to researchers.

### 3.2.3. Evidence from single studies and discussing civic expectations

It is important to openly discuss the expectation of citizens, researchers and other stakeholders such as policymakers, as soon as possible and preferably throughout the different phases of the project. At the start of a project, it is important to discuss what citizens expect to achieve by co-creating and conducting a scientific study to address their questions. In the *CitieS-Health* studies many citizens participated in research initiatives with the aspiration that the study will lead to positive changes in their environment or health. However, a key issue is that, in general in environmental epidemiology, conclusions about causal relationships are drawn only after multiple studies are conducted which show consistent associations. In a local study, expectations tend to be that conclusions are drawn from the specific local study. This does not only apply to CS projects, but is also the case for all epidemiological studies on specific local issues, e.g. recent studies on ultrafine particles around Schiphol airport and the steel factory in Taranto, Italy (Lammers et al., 2020; Leogrande et al., 2019). The conclusion is that local settings are crucial for characterizing health effects and potential subsequent action. Thus, citizens (and researchers) also need to be aware of the limited conclusions that can be drawn from single local epidemiological studies: specifically of the possibility that single studies (especially those with small sample sizes) can result in no associations, even when the broader research field indicates that associations between the exposure of interest and health do exist. This was discussed in all pilots throughout the identification phase through open dialogue during meetings or other interactions with citizens and stakeholders. After establishing why citizens want to do a study and determining the research question it is crucial to discuss all the foreseeable study outcomes with citizens to make sure this is in line with their expectations. This was done by conducting an ‘outcome scenario’ meeting with all relevant stakeholders. In an outcome scenario meeting all foreseeable outcomes of a study are described and possible follow up actions are discussed. In the Amsterdam study this was done as follows, “no associations were found”, “partial associations were found”, or “clear associations were found”. Whereas, in the Lucca study, the scenarios were described as “all is well”, “lights and shadows”, “critical”, or “worst-case scenario” (Biggeri et al., 2021). From the *CitieS-Health* projects, we realized that when the research team discusses all the foreseeable outcomes with citizens early on in the research process, the latter are less likely to be disappointed if the results are not in line with their initial expectations. Discussing the various outcomes and also action plans for each one of them could even improve actionability, especially when key policy stakeholders are involved. This was done in the Amsterdam, Lucca and Kaunas studies, but the Lucca study explored these outcome scenarios just after the identification phase, resulting in clearer implications as far as public health actions are concerned. The Italian research team organized a public event to discuss the possible outcomes of their



study. The event included a round table discussion with all relevant stakeholders, including the mayors of the municipalities involved. The goal was to ensure that everyone understood the uncertainties involved in scientific research and to develop lines of action for each possible study outcome to strengthen transparency. As a result, the mayors committed to taking certain actions such as collaborating on further research, acknowledging environmental damage, and discussing possible compensation, depending on the outcomes of the study (Biggeri et al., 2021). By constantly reflecting back on civic and stakeholder expectations and continuing this dialogue throughout the different phases (and at the end of a project) researchers can communicate the study's intended impact more effectively, ultimately enhancing the study's relevance and utility to the community.

### 3.2.4. Governance and ethical approval

The governance of research, particularly with regard to its accessibility and how knowledge is generated, is under scrutiny (Pelacho et al., 2021). The underlying assumption of having good governance protocols is that the groups who share access or usage of a resource manage their actions by agreeing on a set of predetermined guidelines (Madison et al., 2019). The co-creation of research studies implies a co-responsibility of researchers and citizens. Yet, there are no legal rules with regard to assigning and assessing responsibilities of citizens in CS projects, thus questioning who is in charge (Ficorilli et al., 2021). Effective governance discussions are crucial in co-created CS projects as they ensure that the rights and interests of all stakeholders are appropriately addressed. All the *CitieS-Health* studies addressed project governance with citizens via (face-to-face/online) meetings, based on the research ethics requirements. In all of the studies researchers maintained governance over the collected data and citizens performed scientific activities in collaboration with and under the responsibilities of the researchers. Governance also extended to the publication of knowledge generated from projects to ensure the quality of information disseminated during later stages of the project. Thus, access to identifiable participant information was limited to professional researchers. Citizen scientists were not authorized to access this information, but each individual participant could access the data he/she contributed. There was one exception to the latter in the Lucca study, where the people who had access to personalized data and biospecimens were the members who were indicated as authors of the study protocol. This included both the research team and some citizens who signed the study protocol as co-authors. These citizens helped in collecting informed consent forms, administer questionnaires, and collect blood and urine samples as well as in handling some basic associated data. Though citizens may handle some of the personal data, the governance of all the data remains the responsibility of the researchers. A governance strategy to pro-actively modify the usual consent for biobanking to maintain the co-created nature of the project was discussed with citizens and, together with researchers, they developed the *Biobank* proposal (Biggeri and Tallacchini, 2018). This is still in progress, but biospecimens are being collected and stored at the moment following the existing rules of biobanking. Similar reasoning was used during governance discussions for sociological and historical data based on recorded oral interviews in the Lucca study.

Engaging in citizen science research, especially with human subjects, presents an array of ethical challenges which require new ethical considerations to protect and empower citizen scientists. Ficorilli et al. (2021) has extensively covered ethical approval procedures, challenges, and strategies employed in the *CitieS-Health* studies in a separate article. All the *CitieS-Health* partners independently managed the ethical processes for their studies. This included the co-creation of study protocols, information sheets, and obtaining informed consent, while ensuring compliance with their respective countries' medical ethical requirements. Co-creating all of these documents with citizens provides researchers with a unique opportunity to ensure that these documents are easily comprehensible, user-friendly and culturally sensitive.

Throughout the ethical approval process, it is important to clearly identify the dual role of citizens as participants and researchers. In the Amsterdam, Ljubljana and Kaunas studies, this did not result in comments from the (bio)medical ethics review committee, where input from societal partners in research is more accepted. In the Barcelona and Lucca studies, the identification phase was also submitted to an ethics review committee. In the Barcelona study the submission was not evaluated as the medical ethics committee considered that there were no issues that concerned biomedical regulations. In the Lucca study, the research group (citizens and researchers) went through two different ethical approval procedures: one from the University of Florence ethical committee for the sociological survey in the identification phase and one from the medical ethical committee for the epidemiological study with biological samples collection in the design phase. Both of which were successful. There were different opinions in the research consortium on the desirability of submitting the identification and design phase for ethical clearance. Increased bureaucracy, over-formalization of relationships between researchers and society and ethical judgments of colleagues are elements in this discussion. Overall, the co-creative nature of research studies does not seem to be a barrier in receiving ethical clearance as all of the *CitieS-Health* studies received approval from competent ethical committees. However, this may only be true provided that a researcher or a medical doctor is in charge and responsible for the scientific solidity and ethical accountability of the study. In any case, ethical approval procedures are highly dependent on the national laws of each individual country.

In summary, all the partners were able to co-design their research projects with citizens. Though the design phase required researchers to take the lead initially, citizens were able to discuss specific design choices prepared by the researchers. This requires an open attitude from researchers whilst defining and clearly presenting design issues to which citizens contribute. Citizens agreed that the responsibility for data quality maintenance lies primarily with the researchers but steps should be taken in the academic world to improve governance of co-created projects. Ethical challenges faced within co-created studies involving health data are currently complicated by the lack of legal recognition of citizen scientists and variations between ethics committees. Thus, addressing these challenges requires researchers to adapt their approach to the specific context of each study.

### 3.3. Deployment

In the deployment phase, the focus was on collecting data (starting with recruitment of study participants), analysing data and creating an impact assessment tool. This phase could only start after medical ethical clearance was obtained. In this phase there is a distinction between citizens who actively participated as "citizen scientists" in designing and implementing the study, and those who participated more passively as "traditional research participants" by providing biological samples and personal data. All epidemiological studies required a larger number of study participants than the number of citizens participating in design of the study. Some citizens participated both actively and passively as study participants, but this was completely dependent on the inclusion and exclusion criteria of the studies. Citizens who participated in the design of the project also helped with recruitment of participants and other activities in this phase. We used the term "participants" to refer to citizens who only participated in the data collection phase.

#### 3.3.1. Data collection

The data collection for most of the *CitieS-Health* studies took place during the peak of the COVID-19 pandemic restrictions. Researchers had to be creative and limit the amount of physical contact with citizens. An example of this was providing study instructions via online meetings instead of instructions at home. Since the Kaunas study was able to secure biomedical research ethical approval for their study protocol prior to COVID-19 restrictions, this allowed them to conduct some of

their face-to-face interviews as planned. When restrictions were set in place, the face-to-face interviews were replaced with an online survey. In the Amsterdam, Barcelona, Ljubljana and Lucca studies, the entire data collection phase was conducted via *ad hoc* online procedures. In the Amsterdam, Barcelona and Ljubljana studies, study “kits” for citizens were prepared and personal online instruction sessions were planned. Researchers from these studies noted that citizens were keen to discuss and participate in a project when they saw the research kit or a physical device with which they could collect data in their own homes.

In light of the COVID-19 restrictions, the Amsterdam and Lucca studies had to make alternative plans with regard to health data collection, raising the question whether citizens were able to collect their own biological samples. In the Amsterdam study, saliva samples were taken by the citizens to measure inflammation markers instead of the originally planned nasal swabs that require research staff to be present. The tools necessary for this were placed in project data collection packages which were delivered by fieldworkers as a ‘postal package’ to all the participating citizens. Lung function measurements and completion of online symptom diaries were already planned to be self-collected at home. Due to the nature of the biological (urine and blood) samples required by the Lucca study, and country specific ethical rules with regard to the collection of biological samples, this could only be done by medical experts. Thus, collection of biospecimens was deferred and conducted extensively from August 2021 to April 2022 complying with COVID-19 restrictions.

Cities-Health partners agreed that relying on a network of citizens and partnering stakeholders made the data collection campaign process easier, quicker and, most importantly, trusted by all parties involved. Each of the projects conducted scientifically sound studies that maintained data integrity. Citizens agreed that the responsibility of the latter should remain with researchers who have been trained to understand the complex relationships in epidemiological studies. Also, biological sampling in CS studies is feasible as long as methods of collection are trusted and complies with country specific regulations.

### 3.3.2. Data analysis

The data analysis phase was a difficult one for citizens to contribute to. Disentangling and understanding the complex often multifactorial associations between specific environmental exposures and health outcomes can be challenging even for experienced researchers, let alone citizens without the necessary expertise. Epidemiological analyses require sophisticated methods to draw valid conclusions about associations between the exposure of interest and health outcomes. Epidemiological analyses involving health issues are typically more complicated than the analysis of environmental monitoring data. In all studies, researchers made an effort to explain epidemiological concepts to citizens so that they were able to give valuable input. This required time and preparation by the researchers. In addition, the use of descriptive analyses of associations was useful for the communication of results. Data analysis plans of the studies were discussed with citizens before any of the analyses were done. Researchers in the Amsterdam, Barcelona and Lucca studies prepared presentations where the data analysis choices were explained to citizens (e.g., the concept of correlation, covariate adjustment, coding of occupational history, etc.). Researchers then posed explicit questions in areas where researchers anticipated that citizens could actively engage and make valuable contributions. In the Barcelona study, this led to the addition of a confounding variable, sleep quality, that was included in the epidemiological analyses. In the Amsterdam study, citizens suggested an additional relevant exposure period that could be related to health effects based on their personal experience with woodsmoke annoyance (the average exposure between 23:00–07:00). In both cases researchers amended the data analysis plan because of these inputs from citizens. The Kaunas partners organized two conferences (the Human and Nature Safety 2020 and 2021) to discuss the data analyses plan. During these conferences, citizens provided suggestions on how to measure the acquisition of new skills and

knowledge. Researchers explained the process of selecting co-variables included in multivariable analyses models, with the goal of obtaining evidence-based scientific results.

The Barcelona partner developed a Collaborative Correlation data analysis tool, included in the project toolkit (<https://citizensciencetoolkit.eu/>). This tool facilitates collaborative decision-making with citizens by involving them in the process of selecting covariates to be included in the analysis, as well as identifying other questions of interest that can be answered using the collected data, apart from the main research question. Similarly, in the Ljubljana study, an online survey was conducted with the help of a test group, in which participants could express their preferences regarding data visualisation and analysis. This led to a greater emphasis on sleep quality data in the final data evaluation. In most of the studies the main analyses were performed by the researchers, after which participants received a report of their individual data and the results of the full epidemiological analysis. In the Ljubljana study instead, the research team developed a web-based tool that allowed individuals to access and analyse their individual data. The web application, which is also included in the project toolkit, replaced the traditional individualised report for the participating volunteers collecting data, while at the same time allowed three types of functionalities with increased the level of analytical complexity: 1) access to the raw data and basic descriptive statistics, 2) access to pre-treated spatially resolved movement and exposure pattern data, and 3) specific tools for independent data processing (Ftičar et al., 2021). In practice, the number of volunteers who were interested in data analysis, and had the skills to process their own data, was relatively small in all the studies. We further note that the analysis of individual data is not the same as epidemiological analysis of the full study population.

### 3.3.3. Generation of new, co-created, and locally relevant scientific knowledge

All the projects were successful in generating new locally relevant knowledge. In the Amsterdam study, a panel study with forty-six participants was conducted on the short-term effects of woodsmoke on respiratory health between February and May 2021. Daily air pollution exposure data was collected from central monitoring sites in IJburg (Amsterdam), Bergen, Zutphen and De Meern (Utrecht). Participants were recruited from a 2 km radius from the central monitoring sites. The specific woodburning marker levoglucosan was measured on collected PM<sub>2.5</sub> filters. Participants filled in daily symptom diaries, conducted lung function measurements twice a day and collected 3 saliva samples every Saturday to study the stress hormone cortisol. The study documented relevant exposure to woodsmoke at the neighbourhood level, not only from the nearest neighbour (see section 3.3.4). The study found that higher levels of present and previous day levoglucosan exposure were significantly associated with more shortness of breath at rest and extra medication use. Associations were weaker with self-reported woodsmoke. No association was found with lung function or the stress marker cortisol. Results were published in a summary report for the national government, in collaboration with the National Institute for Public Health and the Environment, Municipal Health Service Amsterdam and Netherlands Organization for Applied Scientific Research. A scientific paper is in preparation.

The Barcelona study conducted a panel study to assess the association between short-term NO<sub>2</sub> exposure and cognitive and mental health in adults (Gignac et al., 2022b). The study took place between September 2020 and March 2021. In total, 288 adults in Barcelona were followed for 14 days. Participants performed two tasks through a mobile phone application: the STROOP colour-word test to assess attention performance and a set of 0-to-10 rating scale questions to evaluate perceived stress, well-being, energy and sleep quality. Exposure was measured by 14-day average NO<sub>2</sub> measurements with passive samplers carried by participants, and with hourly concentrations from official monitoring stations and predictive high-resolution maps. The study showed that in the days with higher NO<sub>2</sub>, participants performed worse

in the attention tests and reported more stress. The change in response time (attention score) between a clean and a polluted day was around 5% of the observed individual daily variation in response time.

The Kaunas study conducted a cross-sectional study that included 1086 adults residing in 11 districts of Kaunas. The study used GIS to measure environmental exposures (traffic flow and greenness NDVI) for participant's home address and assessed associations between exposure levels and health issues using multivariate logistic regression. Citizens filled in questionnaires, and were involved in activities of environmental data collection, measuring and rating the neighbourhood environmental quality, and scoring personal health. They also wore sensors (smart-watches) to determine physical activity. The study found that traffic-related health associations were stronger for women than men, and perceived air pollution, lack of green space, and chronic diseases were consistently associated with poor health risks in both genders (Grazuleviciene et al., 2022). The Kaunas partners also found that the environmental quality of the neighbourhood and individual-level characteristics are important determinants of poor health and low physical activity and may promote the development of obesity and hypertension (Grazuleviciene et al., 2020a). The Kaunas study also provided evidence that the social environment and the quality of the built environment had a complex effect on disparities in the risk of hypertension and other chronic cardiovascular health conditions (Grazuleviciene et al., 2020b).

In the Lucca study, a cross-sectional study with biomonitoring was conducted on prevalence of chronic kidney disease between May 2021 and May of 2022. Data collected from 400 citizens, living in one of the eight participating municipalities of the Serchio Valley, aged 17 years and above was included in this study. Participants provided data through telephonically conducted questionnaires, biomonitoring, clinical data, and air pollution exposure data collected from a do-it-yourself sensor network. In this study, diabetes, hypertension, work or residence in the vicinity of a non-ferrous metallurgical industry was found to be the factors most associated with decreased kidney function. The study confirmed an increased risk of CKD for the population living in the Serchio Valley in line with previous literature (Doccio et al., 2023).

The Ljubljana study investigated the links between the quality of the living environment (with an emphasis on noise), mental health and well-being. Adult volunteers who participated in data gathering collected repeated observations of their living environment and mental health, whilst also measuring noise and physical activity parameters. The results revealed associations between well-being of individuals and their activity as well as specifics of the micro-environment. For example, positive feelings were positively correlated with outdoor activities, when people had leisure time, during the weekend, or when they were more rested, while negative mood was associated with work activity and poorer sleep quality. Similar, associations were found between cognitive performance indicators, restfulness and activity of individuals. The results of the momentary measurement of noise levels and perception of the acoustic environment did not show statistically significant correlations with the parameters of well-being and cognitive abilities; however, they clearly indicate that the perception of the acoustic environment depends mostly on the subjective perception of the individual.

### 3.3.4. Interpretation of data analysis results

All the results generated by the CitieS-Health project and preliminary conclusions were discussed between researchers and citizens before the results were made public. In most of the studies the results confirmed civic expectations but citizens did not always agree in the way researchers had formulated the conclusions initially. In the Amsterdam study, the characterization of exposure at a central monitoring site was initially interpreted as a weakness, since emissions from neighbours were not included in the exposure assessment. Citizens argued that the fact that the study was able to find health effects with measurements at a central site affected by woodburning sources in the whole neighbourhood and beyond, indicated that woodburning issue also occurs on a

community level and not just as an issue between neighbours. Citizens were very focused on how the results would be communicated and provided comments that sharpened the typically cautious language of conclusions ("may be associated") researchers used. This also applied to recommendations of the study. Similarly in the Lucca study, some citizens and local administrators were involved in analysing and interpreting the data, were particularly interested in understanding how the findings would affect their local community. They recommended a more cautious approach in communicating project results and policy action. In section 3.4 this is discussed in more detail.

In summary, all the partners were able to conduct an epidemiological study with citizens, that generated new locally relevant scientific knowledge (section 3.3.3). Researchers made an effort to explain complex epidemiological concepts to citizens to ensure they could provide input. Citizens were able to contribute to specific study design elements, which led to valuable adaptations of the study protocol, data analysis plan and how the results were interpreted.

## 3.4. 3.4.Action

The last phase of the CitieS-Health framework involved the dissemination, action and legacy of the project.

### 3.4.1. Dissemination

First, with the help of co-created CS techniques all the CitieS-Health consortium studies were able to generate new (scientific) knowledge that was accepted by fellow scientists, citizens and stakeholders. Results and design of the epidemiological studies have already been published in scientific journals for some of the CitieS-Health studies (Ficorilli et al., 2021; Gignac et al., 2022a; Gignac et al., 2022b; Grazuleviciene et al., 2019; Grazuleviciene et al., 2020a; Grazuleviciene et al., 2020b; Grazuleviciene et al., 2021a; Grazuleviciene et al., 2021b; Grazuleviciene et al., 2022; Kocman et al., 2020). In the Amsterdam study results were included in a National Government letter to Parliament based on a National Institute of Public Health and Environment report (<http://www.rivm.nl/documenten/samenvatting-samenwerking-houtrook-onderzoek>). Table 4 lists key dissemination activities, including primary actors.

The CitieS-Health studies have shown that the combination of civic and scientific expertise can lead to socially actionable study results. A concrete example of this was in the Dutch study where citizens argued that the study documented that woodburning is a problem at the community level and not only an issue between neighbours, the way the problem is often framed. This point ended up being one of the strengths of the study and was identified as an issue by national policymakers. By including citizens in the interpretation and communication of study results they were able to influence dissemination and align it with their interests. These discussions also provided the citizens with the opportunity to ask questions, and get a better understanding of the results. Researchers in turn were questioned on results prior to academic peer review allowing initial critical observations to be addressed. In the Dutch and Italian studies researchers found that involving citizens and stakeholders as co-researchers strengthened civic scientific responsibility. An example of this from the Dutch study is that whilst researchers were discussing preliminary findings, they asked citizens not to publish them until the results were finalized and disseminated as an official report to the national parliament. Even though sharing the information was more beneficial for citizens short-term, the citizens participating in the Dutch study complied with the request.

Besides the publication of results in peer-reviewed journals, the results were also well received by citizens and stakeholders involved in the studies. In the Dutch and Italian studies, partnerships were established early on with stakeholders (Dutch: Municipal Health Service Amsterdam, National Institute for Public Health and Environment and the Dutch research organization TNO; Italy: the mayors of affected municipalities and the Tuscany Health Agency). As researchers have a well-

**Table 4**  
Dissemination of results and design of epidemiological studies.

Activity	Description	Actor
Scientific peer-reviewed articles in international journals (In English)	Ficorilli et al. (2021); De Marchi et al. (2022); Doccioli et al. (2023); Gignac et al., 2022a; Gignac et al., 2022b; Grazuleviciene et al. (2019); Grazuleviciene et al. (2020a); Grazuleviciene et al. (2020b); Grazuleviciene et al. (2021a); Grazuleviciene et al. (2021b); Grazuleviciene et al. (2022); Kocman et al. (2020).	Researchers
Scientific peer-reviewed articles in local languages	Andrusaitytė et al. (2020); Andrusaitytė et al., 2021; Biggeri et al. (2021); Ficorilli (2019); Ficorilli (2022); Malavasi et al. (2023).	Researchers, citizens and other stakeholders
Policy report	Amsterdam study ( <a href="https://www.rivm.nl/documenten/samenvatting-samenwerking-houtrookonderzoek">https://www.rivm.nl/documenten/samenvatting-samenwerking-houtrookonderzoek</a> ).	Researchers, citizens and other stakeholders
Conference proceedings	The final CityS-Health conference held in Rome as well as two articles resulting from other conference proceedings: Kocman et al. (2021); Ftičar et al. (2021).	Researchers, citizens and other relevant stakeholders
Book publication	Historical and sociological research done in the Lucca study based on documents and interviews with local residents. (Malavasi, 2023).	Researchers and citizens
National and local newspapers	The Amsterdam study results were published in various national newspapers a prominent example is the article in the Nederlandse Rotterdamse Courant (NRC). In the Lucca study, all the project phases and the results were published in local newspapers and local pages in national newspapers. The Kaunas project news was published in national newspapers and websites.	Journalists, researchers and citizens
Letter to local government	Letter pressing for action in the Amsterdam study. Citizens wrote a letter to local governmental institutions acting for change.	Citizens
Interviews	Interviews with various media outlets and with relevant stakeholders. In the Amsterdam study, this included a radio interview (NPO1) of one and a half hours to discuss the results of the project. In this interview researchers also engaged with citizens. In the Lucca study various radio/tv interviews. In the Kaunas project, interviews of journalists with researchers including radio interviews were publicized in local newspapers and websites.	Journalists, researchers and citizens
Project Videos	Barcelona ( <a href="https://www.youtube.com/watch?v=RmJNDncDiNY">https://www.youtube.com/watch?v=RmJNDncDiNY</a> ), Kaunas ( <a href="http://citeshealth.vdu.lt/galutin-iai-rezultatai-final-results/">http://citeshealth.vdu.lt/galutin-iai-rezultatai-final-results/</a> ), Ljubljana ( <a href="https://www.citieshealth.eu/2022/09/21/the-ljubljana-cities-health-pilot-final-video/">https://www.citieshealth.eu/2022/09/21/the-ljubljana-cities-health-pilot-final-video/</a> ). Lucca in	Researchers (and citizens in some cases)

**Table 4 (continued)**

Activity	Description	Actor
	collaboration with NoiTV a local TV station ( <a href="https://youtu.be/j1WH2Y2nr6c">https://youtu.be/j1WH2Y2nr6c</a> ).	
Project Website and Social media	Website: <a href="https://www.citieshealth.eu/">https://www.citieshealth.eu/</a> . Twitter: @CitySHealthEU.	Researchers

established scientific network, we believe that they have a responsibility to mobilize these networks to ensure that relevant partnerships are established through which the knowledge generated from projects can quickly be communicated and disseminated to policymakers and/or other relevant parties. These strategies may improve the actionability of knowledge. Though researchers should be responsible for overseeing useful project partnerships, citizens are often in a better position to demand actionability from results. In the Dutch study, citizens agreed that scientists should refrain from strong policy advice (“woodsmoke should be forbidden”), whereas they felt free to use the results of the study to make these demands. Citizens and researchers agreed on the formulation “Reduction of exposure to woodsmoke will very likely result in a reduction of health risk”. Thus, citizens, researchers, policymakers and other relevant stakeholders must keep an ongoing dialogue throughout the project lifespan. Similarly in the Kaunas study, active participants who were also co-authors of published papers strengthened suggestions made to policymakers on how to improve environmental quality, well-being and health of citizens in Kaunas. In addition to publishing the knowledge generated in international journals (typically in English), knowledge dissemination and communication with citizens have been done in the local language. In the Lucca pilot, citizens and local administrators agreed that the conclusions required further epidemiological investigation rather than strong policy actions. These discussions will continue beyond the CityS-Health project lifespan.

**3.4.2. Citizens’ role in promoting local change**

As researchers, we can increase awareness amongst the general public through dissemination activities. We can communicate results to relevant stakeholders that could action change within their respective fields such as doctors, policy makers and local media outlets. However, we believe that the action phase is where citizens can really take the lead. In most of the CityS-Health studies, the close collaboration during the creation of dissemination materials led to citizens’ ability to use these materials to advocate for change on issues of local concerns. To increase actionability of results, all relevant stakeholders should be included as soon as possible and make agreements regarding the necessary action based on the results, as seen in the Kaunas and Lucca studies. For both action and legacy these phases will remain ongoing for longer than the project is still active. In our case, the tools created by the CityS-Health studies contribute to the legacy of the project, particularly through the CS toolkit, an interactive and customizable collection of tools that facilitated the engagement of citizens in different phases of research that worked for the CityS-Health partners. These tools are freely accessible so that anyone can alter or amend them to suit the needs of their projects and inspire further research.

**3.4.3. Impact of co-created projects and policy action**

A common struggle when studying environmental health effects is the delay in uptake of findings into local policy action. In an impact assessment among participating citizens, some studies found that citizens were disappointed that the long process of incorporating their wishes throughout a co-created study did not result in policy actions from the knowledge created. In the Amsterdam study, this sentiment did not prevail, probably because most citizens had already been active in advocating policy change regarding woodburning. In this case, citizens were well aware of the complexities regarding the policy process.



In order to generate future action from a research project, a broad range of stakeholders involved in policies on the topic at stake, should be included and expectations of all partners should be discussed early on in the scientific process. The study topic addressed in Barcelona has been of concern for many citizen groups, resulting in demonstrations or other actions to ask for better air quality, along with several other local research initiatives. Ultimately the city council started implementing measures to reduce air pollution, such as the implementation of a low emission zone. However, it is difficult to disentangle the contribution the Barcelona study results had amongst all the other inputs received by policy makers. In the other cities, we have no evidence of resulting policy actions. In the Dutch pilot, citizens have used results of the project to push for more stringent actions. Policy makers and their advisors at the local and national level were aware of the results. In the Lucca pilot, remediation actions were implemented in July 2023 after environmental measurements documented heavy metal contamination of the soil in the study area. The pilot results served as a catalyst for environmental protection activities.

The impact assessment of the CiteS-Health project also identified the added value of co-created projects in terms of individual progress. For example, the acquisition of new knowledge or skills. Though results may not immediately lead to national policy changes, there is still room for the results to be adopted at a community level through various mechanisms linked to individual decision-making. Future papers assessing the impact of co-created CS in environmental epidemiology would be valuable to generate more interest in this approach within environmental epidemiology. A paper dealing with the results of the impact assessment of the CiteS-Health project is in preparation.

#### 3.4.4. Embracing open science, FAIR principles, and CARE ethics

In the CiteS-Health project, researchers were committed to integrating open science, FAIR (Findable, Accessible, Interoperable, and Reusable) data principles, and CARE (Collective Benefit, Authority to Control, Responsibility, Ethics) ethics. The different studies employed various strategies to enhance findability and accessibility, such as organizing pop-up events, promoting and conducting (online) meetings to involve citizens in research activities, ensuring that results were discussed and accessible to all involved parties before public dissemination and making sure that the communication of results was done on multiple media platforms. The integration of these principles is also evident in the detailed discussion in section 3.2.4 on the governance and ethical considerations of the research endeavours and the earlier publication by Ficoirilli et al. (2021). The commitment to the collective benefit of research was evident in the co-creation of studies, emphasizing co-responsibility between researchers and citizens and enabling trust and efficiency through partnerships. Researchers demonstrated authority over data governance, quality, and research processes, while citizens actively influenced the communication of results, highlighting their authority to control the dissemination and utilization of knowledge. A concrete example that highlights the implementation of the FAIR and CARE principles is the discussions with citizens in the governance process of the Amsterdam study where citizens asked researchers to keep governance over the scientific data to ensure sensitive data is handled correctly to protect participants' privacy. In this case exposure data was made accessible for any of the citizens interested but sensitive health data was only communicated to the individual person and not openly shared. However, before anything was published the results and how this would be communicated needed to be discussed. But these agreements differed between the CiteS-Health studies and researchers tried to adhere to the principles as much as possible if it was possible. For example in the Barcelona study they were able to go a step further and make their datasets (including some non-identifying health parameters) accessible for download and unrestricted use through the open-access file repository Zenodo (Gignac et al., 2020a,b, 2021). But in this case researchers did not share the statistical methodologies. It should be noted that as part of the CiteS-Health legacy the CiteS-Health toolkit

described in section 3.3.2 was developed to improve uptake and reproducibility of the different studies. In this toolkit all of the shared adaptable templates can be used to inspire and enable future projects to engage communities in addressing environmental health issues of common more effectively.

In summary, all the studies were able to generate new scientific knowledge. All CS studies should be assessed on their content, methodology and results. Although citizens were actively involved in all research phases, researchers took the lead in preparing the study design and conducting the main data analysis. Citizens were able to play a much stronger role in advocating change after publication of results. The CiteS-Health partners were committed to implementing the FAIR and CARE principles within their studies. Future studies should assess and apply these principles to meet the requirements of their project.

## 4. Conclusions

In the CiteS-Health project, we performed epidemiological studies using co-created CS in five studies across Europe. The conclusions, with suggestions for future studies are:

1. The co-created CS studies were able to generate new scientific knowledge that was accepted by fellow scientists, citizens and other relevant stakeholders.
2. Co-created CS projects were actionable and locally relevant because the projects were co-created with citizens.
3. Citizens were able to contribute their local knowledge and give valuable input throughout all the phases of research, even though the initiative was more on the researchers' side for specific tasks (detailed study design, data analysis).
4. Citizens do not always have the scientific expertise needed for various steps, nor the required time. Studies should therefore adjust to the time constraints of citizens, and carrying the workload when needed but also by designing activities in a way that always allows interested citizens to participate in making key decisions.
5. Researchers in the CiteS-Health project were motivated to co-create epidemiological studies with citizens. An open attitude (no claim of exclusive expertise) from researchers is crucial for the success of co-created studies.
6. The CiteS-Health project had an open community of citizens contributing to the studies. We had small groups of active citizens participating in all phases.
7. Data quality of co-created projects can be maintained with a primary though not exclusive responsibility for the researchers. CS projects should not be considered synonymous with applying low-cost sensors with often low specificity for the exposure of interest and dubious data quality.
8. Researchers should address civic expectations by discussing all the potential project results and actionable outcomes in the design phase of the study. This includes possible steps with regard to action based on study results.
9. Researchers should incorporate stakeholders and citizens with different fields of expertise, backgrounds and views to improve the project's actionability and legacy.
10. Dissemination of knowledge generated in studies should be done via various media and channels (beyond English-language scientific articles), including local language texts in order to make knowledge generated more easily accessible and actionable.

Despite the opportunities co-created studies present, there are several challenges that need to be addressed such as civic and stakeholder expectations, engaging effectively with citizens, finding a balance in the tasks of researchers and citizens, maintaining data quality, and making complex concepts understandable to citizens involved in projects. The Amsterdam and Barcelona studies focussed on short-term

health effects that occur relatively frequently in the population. The studies are feasible with relatively small study populations. The Lucca and Kaunas partners suggested that the approach extends to long-term exposure epidemiological studies. Future projects should further explore whether other studies focusing on long-term health effects can effectively incorporate co-created CS.

We believe the benefits of CS projects described in this paper outweigh any drawbacks experienced. The Cities-Health studies have shown that the integration of co-created CS methods in environmental epidemiology is feasible and has the potential to improve the quality of research and civic trust in research and results. This, in turn, can contribute to improving public health outcomes and advocating for policy changes. Hopefully the shared experiences, methodology and recommendations assist future co-created CS projects in the field of environmental epidemiology with their co-creation endeavours.

### Authors' contributions

FF, FG, AB, DK, SA, GH, XB - Conceptualization; FF - Writing - Original Draft and Visualisation; GH, RV - Supervision; All authors - Methodology, Investigation and Writing - Review & Editing; RO, GH, XB - Project administration; RT, RO, DK, RV, AB, RG, GH, XB - Funding acquisition.

### Ethics approval and consent to participate

Not applicable.

### Consent for publication

All of the authors have read and approved the paper for publication.

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### Data availability

Some of the data used in the article are available on request.

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### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.envres.2023.117469>.

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