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### ► To cite this version:

Olivier Laurent, Yara Carrejo Gironza, Sophie Ancelet, Olivier Armant, Denis Bard, et al.. Citizen science in environmental health research: A comparison with conventional approaches and creation of a guidance tool issued from the LILAS initiative. *Environmental Research*, 2024, 252, pp.118914. 10.1016/j.envres.2024.118914 . hal-04552658

**HAL Id: hal-04552658**

**<https://ehesp.hal.science/hal-04552658v1>**

Submitted on 22 Apr 2024

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Contents lists available at [ScienceDirect](https://www.sciencedirect.com)

# Environmental Research

journal homepage: [www.elsevier.com/locate/envres](http://www.elsevier.com/locate/envres)

## Citizen science in environmental health research: A comparison with conventional approaches and creation of a guidance tool issued from the LILAS initiative

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### ARTICLE INFO

#### Keywords:

Methods  
Environmental exposures  
Citizen science  
Exposome  
Co-creation

### ABSTRACT

**Context:** Public interest for citizen science (CS) in environmental health is growing. The goals of environmental health research projects are diverse, as are the methods used to reach these goals. Opportunities for greater implication of the civil society and related challenges differ at each step of such projects. These methodological aspects need to be widely shared and understood by all stakeholders. The LILAS initiative (acronym for “application of citizen science approaches such as Living LABs to research on environmental exposures and chronic risks”) aimed to 1) favor a mutual understanding of the main issues and research methods in environmental health, of their stakes for different actors, but also of the requirements, strengths and limitations of these methods and to 2) identify expected benefits and points of attention related to stronger degrees of participation as part of environmental health research projects.

**Methods:** The LILAS initiative gathered institutional researchers, academics and civil society representatives interested in environmental exposures. Five meetings allowed to collectively identify different types of environmental health research studies and reflect about the benefits, limitations, and methodological issues related to the introduction of growing citizen participation as part of such studies. An analytic table matrix summarizing these aspects was co-created and filled by participants, as a tool devoted to help stakeholders with the definition of future CS research projects in environmental health.

**Results:** For different fields of research (e.g.: studies for assessment of environmental exposures, interventions on these exposures, quantitative risk assessment, epidemiological studies), the matrix lists expected benefits for

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<https://doi.org/10.1016/j.envres.2024.118914>

Received 16 February 2024; Received in revised form 2 April 2024; Accepted 9 April 2024

Available online 10 April 2024

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various stakeholders, the fundamental principles of research methods and related practical constraints, but also advantages and limitations related to the use of CS or conventional research approaches.

*Conclusion:* The LILAS initiative allowed to develop a tool which provides consolidated grounds for the co-creation of research projects on environmental exposures involving CS.

## 1. Introduction

In the field of environmental health, some countries such as the United States of America have already cumulated several decades of experience in conducting citizen science (CS) research (Brown, 1992; Morello-Frosch et al., 2009; O'Fallon and Dearry, 2002; Ohayon et al., 2023), thanks notably to regular support by the National Institute of Environmental Health Sciences (Davis and Ramirez-Andreotta, 2021; NIEHS, 2023; O'Fallon and Dearry, 2001). Interest of various stakeholders for CS research projects in environmental health is also rapidly increasing in other countries (Froeling et al., 2024; Gignac et al., 2022; Ngo et al., 2017; OpenRadiation, 2023; Radicchi et al., 2017; Ripoll et al., 2019; Ardrey et al., 2016; Kumar and Mukherjee, 2016; Snik et al., 2014). It is noteworthy that the term "CS" has different definitions (Froeling et al., 2021). One of these definitions by Bonney (1996) refers to top-down approaches in which professional researchers remain the main drivers of research projects and citizen efforts are mainly used to collect a large amount of data at low cost. An alternative definition by Irwin favors citizens' decision at each step of a research project (Irwin, 1995). These two approaches were recently usefully summarized as a "productivity view" versus a "democratization view" (Froeling et al., 2021). Hereafter, we use the term CS in the meaning of Irwin's, that is of the democratization, view.

The aims pursued by environmental health research projects and the methods used to reach them – or attempt to do so – are diverse. This includes for instance research aimed at estimating exposures and identifying their determinants (Goix et al., 2018), research assessing biological, physiological effects and disease risks in humans (Ellickson et al., 2011), in animal and plant species or even ecosystems (Dron et al., 2016), potentially connected to human health in a One Health perspective (Harrison et al., 2019). This also includes research to assess the effectiveness of proposed preventive actions (Galvin et al., 2016), for instance by developing tools and services based on so-called "citizen" (i. e.: low cost) sensors (Trousse et al., 2014). In addition, research methods in environmental health are also rapidly evolving, notably toward the consideration of multiple exposures simultaneously, whereas at the stage of exposure assessment (David et al., 2021; Gilles et al., 2022) or of analysis of biological and health effects (Miller, 2021; Warembourg et al., 2023) These efforts are strongly driven by the growing popularity of the exposome concept (Wild, 2005). Risk assessment methods are also quickly evolving (Marx-Stoelting et al., 2023).

The opportunities for greater involvement of the civil society, expected benefits and related challenges differ at each stage of these different types of environmental health research projects (English et al., 2018; Froeling et al., 2021; Laurent et al., 2022). This needs to be clear for all stakeholders, ideally upstream of the co-design of new research projects. Especially, it is crucial for the development of new CS projects to achieve a good level of mutual understanding between partners: 1) to jointly identify the questions that specific research methods may or may not help to answer in a context of interest, in order to avoid discrepancies between expectations and potential of the proposed studies to meet them, and 2) to be able to justify, as part of a co-design approach, the methodological choices that need to be made.

Houllier et al. (2017) pointed out that "Respect for certain methodological, deontological and ethical principles promotes the quality of production and ensures added value for each stakeholder. Supporting initiatives that strengthen the skills of all the actors involved, researchers and non-scientists-professionals alike, is therefore beneficial" (Houllier et al., 2017). Following this perspective, the LILAS initiative (*Living Labs and*

*other citizen science approaches applied to research on environmental multi-exposures and chronic risks*) aimed, upstream of the development of future citizen science research projects in environmental health, to:

- 1) co-create, between institutional researchers, academics and representatives of the civil society, a shared understanding of the most common questions in environmental health and of research methods that may be used to investigate them, the fundamental principles of these methods (prerequisite for their rigorous application, therefore offering guarantees of scientific validity of the results), their strengths and limitations;
- 2) identify the expected benefits and points of attention related to the introduction of stronger citizen participations as part of research projects using these methods.

A series of meetings focusing on these aspects was therefore organized as part of the LILAS initiative, and an analytic matrix summarizing these aspects was co-created and filled by participants from various backgrounds, as a tool devoted to help stakeholders with the definition of future CS research projects in environmental health. The present paper focuses on the development and results of this matrix.

## 2. Material and methods

The LILAS initiative brought together 33 French institutional researchers (working for government research institutions), academics (working at the university), representatives of major non-governmental organizations (NGOs) interested in different kinds of environmental exposures, which spanned the entire exposome (Wild, 2005). No participant working for any industry was included. Participants had various background (exposure sciences, metrology, analytical chemistry, toxicology, systems biology, medicine, epidemiology, disease prevention and public health, biostatistics, risk assessment, ecotoxicology, ecology, Living Labs, citizen participation engineering, scientific intermediation, sociology and advocacy).

Participants were selected as part of a two-stage process:

1. Twenty-five of them already participated to previous seminars organized by the NGO ALLISS (acronym for "ALLiance between Science and Society", <https://www.alliss.org/>) which gathered people from 40 other NGOs and research institutions to reflect together about prioritizations for joint research studies on environmental exposures and chronic risks. These seminars were called ORRCH (meaning *pluralist orientation of research on chronic risks*). Participants from these seminars interested to develop further on methodological aspects of research studies in these fields were invited to participate to LILAS.
2. In addition, it was felt that expertise from additional fields (e.g.: Living Labs, expology of chemicals or radiation dosimetry, biostatistics) and actors who did not participate to ORRCH (a major environmental NGO and funding agencies in the field of environment or cancer studies) would be needed to help fulfill the objectives of the LILAS initiative. Eight additional participants were therefore invited.

If the full scope of participants is considered, including some who participated only to one meeting, the participation balance was mostly in favor of professional scientists versus other participants (23/10). However when people who actively participated throughout the project (and are therefore co-authors of the present paper) were considered, the

balance was better equilibrated (11/9).

The LILAS coordinators (OL and SC) applied to an internal research call on innovative projects organized by the IRSN called “IRSN2030” and received funding for the LILAS initiative (33,000 euros), which was primarily used for funding a 6-month internship (YCG) and organizing meetings.

Three plenary in-person meetings and two remote online meetings conducted during years 2019–2020 allowed LILAS partners to express their expectations about CS research in environmental health, to collectively identify the main generic questions in environmental health, and methods currently available to investigate them. All LILAS participants were invited to give short oral presentation on these topics and most of them did, in addition to presentations given by the coordinators and by invited experts. Extensive plenary debates involving all participants helped to reflect on the advantages, limitations and methodological precautions related to the introduction of different degrees of citizen participation in using each research method. The discussions were structured and animated by the coordinators in order to answer the project’s main questions, but also allowed for times for expression of all ideas relevant to environmental health issues, including a significant amount of “field testimonies”, that is reporting of real-life experiences. Detailed minutes were written by the coordinators after each meeting and sent to participants for correction and validation. All this material was used during the next steps described below.

During and between the meetings, a prototypic matrix of the types of research studies appropriate to answer various generic questions in environmental health was co-created on the basis of a first proposal issued by the coordinators. This matrix was then improved by the comments from several participants, for instance by adding or modifying header titles, especially during the third meeting. This matrix was then filled by the participants between the third and the fifth meetings, including during the fourth meeting. Content from the validated meeting minutes mentioned above was also used by LILAS coordinators to help fill in some cells of the matrix. The fifth and last meeting allowed participants to agree on the final content of the matrix, on general conclusions, and to propose perspectives.

### 3. Results

The co-created analytic matrix (available as [supplementary Table 1](#)) lists different types of environmental health studies. These study types include: assessments of past and current levels of environmental exposures of humans and identification of their determinants (Miserey and Pellegrini, 2006), test of interventions to improve human exposure levels (Galvin et al., 2016), development of new sensors and applications for monitoring human exposures (Trousse et al., 2014) and their determinants (Goix et al., 2018), development of new models, human health risk assessments (Ellickson et al., 2011) and related approaches called Health Impact Assessments (WHO European Centre for Health Policy, 1999), classical epidemiological studies (either retrospective or prospective, descriptive or analytical) (Goldberg et al., 2017; Richardson et al., 2023), molecular epidemiology studies (Alcolea et al., 2023), experimental studies (Grison et al., 2022), ecosystem health studies (Dron et al., 2016). For each type of study, the matrix details expected benefits for different categories of stakeholders, the fundamental methodological prerequisites and practical constraints related to the implementation these different types of studies, as well as the advantages and limitations of using CS (e.g., *Community Based Participatory research*, *Living Lab*, etc.) or more conventional approaches (i.e., without co-creation) to conduct such studies.

Following the co-creation and filling of the matrix, three groups of research studies in environmental health for which CS approaches can be relevant, but with increasing levels of difficulty, were identified by participants. They are presented below.

**1st group:** The types of studies identified as *most easily feasible in the form of CS research* (regardless of considerations of costs and

authorization times) are as follows:

- Assessment of current human exposure levels (either based on bio-monitoring or monitoring of external exposure, provided that efficient and accessible technological means exist);
- Development of new widely accessible (e.g., *Low Tech*) technological means to assess the order of magnitude of these human exposures – often with increased uncertainty;
- Research on determinants of current human exposure (e.g., sources and habits);
- Test of actions on these determinants to improve human exposure levels and assessment of efficiency - also called “intervention studies”;
- Quantitative assessment of human health and ecological risks (and related approaches called Health Impact Assessments and ecological impact assessments”);
- Epidemiological or molecular epidemiology studies on early effects (e.g., on allergic reactions or asthma attacks occurring shortly after exposures, studies of biomarkers of early effects, etc.);
- Studies on transient changes of environmental exposures and their short-term effects on ecosystems (e.g., observation of impacts over a few days to months following the introduction of a new source of pollutant emissions or its removal);
- Proposal of scenarios of exposure that can be tested in experimental laboratory research (e.g.: on cell cultures or organoids).

These types of studies have maximum potentials for the production of short-term results, the development of preventive action and empowerment of exposed and concerned people. They also allow to manage temporal aspects, or even selection bias, most easily because by definition they focus on current situations, for instance in living people who may generally be reached in some way and participate (although some of them will refuse) or in readily observable ecosystems.

**2nd group:** Other types of studies have been identified as *feasible in the form of CS research but producing most of their results in a long-term perspective*:

- Prospective study of long-term effects of exposure to environmental exposures on ecosystems;
- Prospective epidemiological study on chronic disease risks. This type of design offers a better ability to manage selection and memory bias problems than retrospective studies, and offers maximum potential for data collection or even the development of new study topics (e.g.: coverage of a growing number of pollutants or effects over time) (Goldberg et al., 2017).

It is of course possible to graft into these long-term studies additional specific objectives allowing a shorter-term production, corresponding to the objectives and benefits associated with the 1st group. For example, a prospective epidemiological cohort design can initially integrate the study of short-term effects of environmental exposures (acute health manifestations such as asthma attacks, biomarkers of early effects, including physiological changes, etc.) and then in a second phase focus on long-term effects of chronic exposures. Overall, selection bias in this 2nd group are still manageable but classically tend to increase over time as people tend to relocate out of the study areas and motivation for participation declines, although it may be expected that continuous co-creation would help to maintain higher motivation and retention levels than when conventional approaches are used (Froeling et al., 2021).

**3rd group:** this group includes types of studies *potentially conductible in the form of CS research but requiring more methodological and technical precautions because they are surrounded with stronger constraints*:

- Retrospective assessment of environmental exposures,
- Retrospective epidemiological studies on chronic risks.

The strongest constraints attached to these studies are related to the difficulties in managing the temporal aspects (see [supplementary Table 1](#)), including potentially related selection biases and representativeness issues because people who died or are too sick cannot participate and provide information on past events including exposures. Tracking past environmental exposures is also especially challenging for many types of pollutants or physical stressors, depending on their physicochemical characteristics and of the existence or not of dedicated monitoring systems in the past. The associated action and capacitation potentials are also more limited than in the types of studies mentioned in the first group, since past exposures cannot be changed.

In addition to this general appreciation from LILAS participants, complementarities between CS and more traditional approaches were also identified for different types of research methods, as detailed in the matrix (see [supplementary Table 1](#)).

## 4. Discussion

### 4.1. Added value of the LILAS initiative

LILAS made it possible, through cross-acculturation between institutional researchers, academics and NGO representatives, to lay consolidated grounds for the co-creation of future CS research projects in environmental health. The meetings also provided participants with a better knowledge of CS, and their most promising applications for the study of environmental exposures and related impacts.

Opportunities and points of attention regarding the conduct of CS research projects in environmental health have been identified, and a tool taking the form of an analysis matrix specifying major methodological requirements and practical advices was created to help guide future choices of approaches. The matrix produced will be useful for the co-creation of future CS research projects in environmental health in the context, for example, of participatory workshops involving citizens. It may for instance be displayed as a “sticky note” poster during such workshops. Additionally, it can be provided as a take-home format (either paper or digital), as a basis to favor longer-term reflections and exchanges with people who would not be available for direct participation during workshops.

### 4.2. Limitations

This article reflects the vision of LILAS participants at the end of the project. This vision may further evolve, both individually and collectively, especially since the scientific fields addressed are also evolving rapidly, such as the field of environmental exposure assessment ([David et al., 2021](#); [Miller, 2021](#)) or risk assessment ([Marx-Stoelting et al., 2023](#)). Several participants discovered the vast field of CS research throughout the project, and may continue to do so in the future. While the vision proposed in this report has no universal value, the richness and diversity of the group of participants, both in terms of backgrounds and positions (professional researchers and NGO representatives), made it possible to propose a structured synthesis of current possibilities and to ensure robustness to the proposed conclusions.

Finally, the limited duration of the LILAS initiative and the breadth of methodological aspects to be covered did not allow for specific application of practical examples, which were mainly taken from scientific publications of previous projects and from participants’ personal experiences.

### 4.3. Study constraints and benefits

A number of constraints related to the conduct of various types environmental health studies were identified as part of the matrix. Many of these constraints are common to both CS and conventional research approaches. Some mostly depend on temporal scopes of studies (e.g., retrospective, cross-sectional or prospective but on short-term effects, or

prospective on long-term effects) and were already highlighted in the results section (e.g.: selection biases, increased difficulties to reconstruct past environmental exposures). Other constraints would impact differentially CS and conventional studies, such as for instance the additional resources (time and possibly financial costs) required to conduct CS studies, the generally lower population sizes covered by CS studies (again, considering Irwin’s rather than Bonney’s view of CS) and resulting more limited statistical power ([Froeling et al., 2021](#)). Other constraints related to the need for data quality and standardization, involvement of citizens into very specialized tasks such as sophisticated statistical analysis or analytical chemistry, management of conflicts of interest, data ownership and obtention of ethical agreements, are all potentially more challenging to manage in a CS than in a conventional research ([Froeling et al., 2021](#)). However, this does not mean that they cannot be managed and does not cancel out the benefits of CS research ([English et al., 2018](#)).

### 4.4. Perspectives

Several potential perspectives were proposed by LILAS participants:

- One of them, specific to human health issues, consists in conducting CS research projects within pre-existing, already well established epidemiological cohorts;
- Proposals of specific CS research projects on specific indoor or outdoor pollution issues were evoked, focusing for instance on radon, on pollutants present in nurseries and the homes of childminders, particularly following the use of household cleaning products;
- Several participants discussed the possibilities of broader experiments in areas facing multiple environmental exposures simultaneously (e.g., industrial or industrial-port zones), in an exposome perspective. This perspective will be further explored on the field from the start of year 2024 a part of the ORRCH-IdEeS project in the Dunkerque area (France), thanks to funding by the French Agency for Research. Experience from CS research already conducted in other port zones, for instance in the Los Angeles and Long Beach (USA) ([Garcia et al., 2013](#)) and in the Fos-sur-Mer (France) ([Jeanjean et al., 2023](#)) areas, will be important to examine and take into account as part of this new project.

## 5. Conclusion

The LILAS initiative has made it possible, through cross-acculturation, to lay consolidated foundations for the co-creation of future CS research projects in the field of environmental health. Opportunities and points of vigilance were also identified, and a table matrix specifying methodological prerequisites was co-created as tool to help guide future choices of approaches by stakeholders with various backgrounds.

## Funding

This work was funded by the IRSN, through an internal call for innovative projects entitled “IRSN 2030”. The committee providing funding had no role in the study design the collection, analysis and interpretation of data, in the writing of the report, or in the decision to submit the article for publication.

## CRedit authorship contribution statement

**Olivier Laurent:** Writing – original draft, Validation, Funding acquisition, Conceptualization. **Yara Carrejo Gironza:** Writing – review & editing, Validation, Methodology, Conceptualization. **Sophie Ancelet:** Writing – review & editing, Validation, Methodology, Conceptualization. **Olivier Armant:** Writing – review & editing, Validation, Methodology, Conceptualization. **Denis Bard:** Writing – review &



editing, Validation, Methodology, Conceptualization. **Katia Baumgartner**: Writing – review & editing, Validation, Methodology, Conceptualization. **Sylvie Bortoli**: Writing – review & editing, Validation, Methodology, Conceptualization. **Céline Boudet**: Writing – review & editing, Validation, Methodology, Conceptualization. **Philippe Chamaret**: Writing – review & editing, Validation, Methodology, Conceptualization. **Stéphanie Cormier**: Writing – review & editing, Validation, Methodology, Conceptualization. **Arthur David**: Writing – review & editing, Validation, Methodology, Conceptualization. **Hélène Desqueyroux**: Writing – review & editing, Validation, Methodology, Conceptualization. **Mariette Gerber**: Writing – review & editing, Validation, Methodology, Conceptualization. **Sonia Grimbuhler**: Writing – review & editing, Validation, Methodology, Conceptualization. **Christian Mougin**: Writing – review & editing, Validation, Methodology, Conceptualization. **Laurence Payrastré**: Writing – review & editing, Validation, Methodology, Conceptualization. **Simon Schraub**: Conceptualization, Methodology, Validation, Writing – review & editing. **Brigitte Trousse**: Conceptualization, Methodology, Validation, Writing – review & editing. **Cynthia Reaud**: Validation, Writing – review & editing. **Sylvie Charron**: Writing – review & editing, Validation, Supervision.

### Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

### Data availability

Data will be made available on request.

### Acknowledgements

Our thanks go to the people who brought their perspective, their expertise, or more broadly their support to the project where they agreed to discuss about it. We thank in alphabetical order: Jean-Marc Bertho, Jean-Michel Bonnet, Michel Chartier, Enora Cléro, Christine Fassert, Jacqueline Garnier-Laplace, Jean-Christophe Gariel, Didier Gay, Rodolphe Gilbin, Laurent Guimier, Pierre-Benoît Joly, Lionel Larqué, Dominique Laurier, Charlotte Lepître, Klervi Leuraud, Corinne Mandin, Sylvie Platel, Alain Rannou, Tristan Roué, Sylvie Supervil, Eric Thybaud, Arnaud Vanzenberg, Eric Vial.

### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.envres.2024.118914>.

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