

Policy Brief on Citizen Science role in Infectious Disease (ID) outbreaks in Italy and Europe

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Acronyms

Acronym	Description
CS	Citizen Science
CSI(s)	Citizen Science Initiative(s)
ID	Infectious Disease



Summary

This Document contains Deliverable 5.3 (D5.3) titled “Policy Brief on Citizen Science role in ID outbreaks in Italy and Europe”. This Policy Brief is one of the products of the activities of Work Package 5 (WP5) of the STEP CHANGE project. WP5 is dedicated to implementing a Citizens Science Initiative (CSI) on “CSI on infectious disease outbreak in Italy”.

D5.3 is composed of an Introduction, presenting the pathway followed to arrive at the Policy Brief, and a section containing the Policy Brief.



Introduction



Introduction

Deliverable 5.3 (D5.3), titled “Policy Brief on Citizen Science role in ID outbreaks in Italy and Europe”, is one of the products of Work Package 5 (WP5) on “CSI on infectious disease outbreak in Italy”. The objectives of WP5 were:

- Developing a Taxonomy of existing and potential citizen science interventions for several infectious diseases and epidemiological behaviours
- Co-designing a citizen science strategy for infectious diseases preparedness for Italy and fostering citizen scientists' role in support of institutions responsible for managing infectious disease outbreaks and research.

The pathway toward the development of this strategy includes different actions. The first of them was the development of a taxonomy of CS interventions for epidemic preparedness. The taxonomy, representing the objective of Deliverable 5.2, was aimed at identifying CS practices that can be usefully applied to different components of epidemic preparedness based on existing CS approaches and initiatives carried out in Europe or elsewhere.

Based on the work done to develop the taxonomy, a further step was implemented dedicated to “problem setting” i.e. developing a policy brief aimed at raising the policy issue of why and how to apply CS to strengthen preparedness for epidemic events in Italy, also considering previous experiences in Europe identified in the Taxonomy.

To develop the Policy Brief, a group of citizen scientists from different backgrounds and with various professional backgrounds was recruited and involved in a three-step process, each focused on a co-creation meeting carried out online. Different means were used for recruiting citizen scientists, including communication activities conducted in the previous phases of the CSI, contacts with specific health institutions and CSOs, and networking activities. Overall, the meetings were aimed at interpreting results of the Taxonomy and defining how to foster preparedness through Citizen Science, considering constraints and obstacles, as well as facilitating factors.



People who participated in the co-creation meetings were both scientists, somehow concerned with the issue of preparedness, and various types of lay people, i.e., people who do not practice science professionally (e.g., students, members of civil society associations, teachers, physicians, members of public agencies promoting health services at the grassroots level, experts in communication). Three meetings were held between 9 February and 11 May 2023, with more than 25 participants overall and averagely about 15 people in each meeting.

In the first meeting, a document presenting the problem of preparedness and citizen science and the results of the Taxonomy was discussed. It was provided to citizen scientists some days before the meeting.

The main outcome of the meeting was the development of a common framework for discussing the proposed issues.

The second meeting was aimed at analyzing in-depth the issues that emerged in the first discussion. It was based on a brief report circulated before the participants meet again. . Thus, the participants were able to have a systematic presentation of the issues and it was possible to reach a consensus and specify some open issues.

The third meeting was dedicated to developing the content and structure of the Policy Brief. A draft version, incorporating the suggestions given by citizen scientists in the second meeting, was circulated before the meeting and then discussed.

The information and points of view collected through the three meetings were complemented by those that emerged from four interviews carried out by a group of three citizen scientists (university students actively engaged in grassroots organizations). They interviewed people who did not participate in the meetings for various reasons but who were eligible to do so (the interviewees were a couple of leaders of civil society organizations, a schoolteacher and a parish priest).

After the meetings, and also considering the results of the interviews, the Policy Brief was finalized containing the results of the discussion held and the information collected. It was again



circulated among the participants in the meetings and then edited and translated into its final version.

The Policy Brief has been written in Italian since it is mainly addressed to Italian policymakers and stakeholders. Anyhow, it is based on the results of the preceding step (the Taxonomy, D5.2), which was focused on the experiences of citizen scientists operating in Europe and all over the world. Furthermore, the same taxonomy upon which the policy brief is hinged is in turn based on theoretical approaches developed in the international context. Therefore, the entire Policy Brief has a European breath and can be relevant and adapted to other contexts.

The Policy Brief is titled “Citizen Science: a resource to be prepared against epidemic crises”. It contains the following sections:

- “Why this Policy brief?”, containing a presentation of the reasons for producing the policy brief.
- “The STEP CHANGE project”, containing a brief presentation of the project.
- “Introduction”, containing a definition of Citizen Science, the description of the objectives of the Policy Brief, the context, and the possible effects of using an approach based on putting together CS and preparedness
- “Analysis”, in which the work done in the preceding step of the CSI is briefly summarized
- “Obstacles and facilitating factors” singled out concerning the possible CS practices to foster preparedness
- “Lines of action”
- “Key messages”.



The Policy Brief



CITIZEN SCIENCE: A RESOURCE TO PREPARE FOR EPIDEMIC CRISES

Why this policy brief

This policy brief is the result of a process of consultation and co-creation that focused on the following questions:

- Can citizen science be used to support improved preparedness for possible epidemic crises in Italy?
- If so, under what conditions?
- What are the obstacles to overcome?

To carry out the consultation and co-creation process, a panel of 25 people from different professional and voluntary backgrounds was created and 4 other people were consulted to gather their opinions. The initiative is promoted by the Department of Biology of the University of Rome Tor Vergata in the framework of the STEP CHANGE project.

The STEP CHANGE project

STEP CHANGE is a Project funded by the European Commission in the framework of Horizon 2020. Launched in March 2021, the project aims to implement five citizen science initiatives (CSIs) in four European countries (Germany, Italy, United Kingdom, and Slovenia) and one African country (Uganda). Through the five CSIs, the project intends to investigate how citizen science can increase the quality of research and become more deeply rooted in research and society.

INTRODUCTION

Aim

- The recent COVID-19 pandemic has shown how central, in Italy as in other countries, is the role of scientific and technological research, not only to understand in advance, as much as possible, the origin and characteristics of epidemic events, but also, for example, to predict the possible economic, social, and cultural consequences of such events, to identify the most effective health and public health measures, and to analyse the impacts of such measures.
- One characteristic of research dealing with epidemic events is that it needs to be done as quickly as possible. To do this research in a short time, however, the involvement of many people is necessary. Moreover, such involvement should be prepared and activated before pandemic events occur, in the so-called health emergency preparedness phase.
- In this sense, the use of Citizen Science can be an essential element as it can:



- speed up research processes.
 - allow capturing aspects that conventional research methods may not detect.
 - facilitate the transition from research to the definition of possible solutions.
 - inform public policies with the gathered evidence.
 - support public acceptance of the measures taken.
- The low involvement of citizens in preparedness and, more specifically, in research represents a missed opportunity and a waste of resources.

What is Citizen Science

Citizen Science refers to the involvement of citizens alongside professional researchers in scientific activities that generate new knowledge or understanding. Citizens can act as contributors, collaborators, or project managers and play a significant role in the

Context

- The COVID-19 pandemic has revealed a certain degree of unpreparedness Italy in dealing with epidemic events. This appears even more serious considering that other epidemic events are highly likely to re-occur with some regularity in the near future.
- For this reason, the issue of strengthening the country's preparedness for epidemic situations is becoming an essential element of preventive health; and research is an essential component of it, since prevention inevitably involves poorly known situations and risks.
- At the same time, preparedness increasingly requires the involvement and collaboration of citizens and stakeholders in a social context that appears more and more fragmented.
- However, health and research institutions, whether public or private, are poorly prepared to cooperate with each other and interact with citizens in a systematic way.
- In general, despite the efforts made in recent decades, the level of coordination among institutions appears very low, the commitment to public communication remains insufficient, and the few experiences of co-involving citizens and civil society actors in choices affecting health and research are in an embryonic state.
- In addition, the Italian healthcare system is still "physician-centric" and has few professional profiles not directly related to medical activity. Moreover, it is a system under continuous stress (due to many factors, such as the lack of human and material resources or the increase in costs related to health care activity). All this limits its ability to interact with external stakeholders.
- Research institutions also have problems: the world of research is increasingly competitive and access to resources is more difficult. In this framework, citizen science experiences are still few and poorly supported at the institutional level. The area of Third Mission, which could be an important ground for interaction between research institutions and society, in many cases is scarcely, discontinuously, and marginally exploited so that, in the end, it does not influence the way research is carried out.



The effects

- In the short term, the main effect of this situation is that the research needed for preparedness is poorly practiced and many of the aspects that can only be known through citizen involvement (e.g., those related to lifestyles, behavioural patterns, risk perception, expectations towards healthcare services provisions) are not studied, or poorly so.
- In the mid-term, a disconnection between health institutions, research institutions, and citizens/stakeholders is an even more critical effect. Cooperation is, indeed, crucial in dealing with epidemics. Mechanisms for cooperation must be activated beforehand to avoid serious consequences .

ANALYSIS

- As part of the citizen science initiative fostered by the University of Rome Tor Vergata, a literature search was conducted to understand how citizen science was used in preparing for and responding to epidemic events. Fifty-six citizen science projects/experiences in the field of epidemic preparedness and response were selected.
- They were analysed through a taxonomy based on the intersection of the phases of research activity (the identification of issues to be addressed and design; data collection; data analysis; management of the results and actions that may result from the research) and the areas of preparedness (surveillance; research on epidemic factors; public intervention measures; health intervention measures; and coordination between the actors involved in the management of epidemic events)¹

Examples of citizen involvement in research on epidemic events

- Collection and analysis of ethnographic data on the impact of distancing practices adopted during the coronavirus pandemic on healthcare (Germany)
- Identification and design of research to understand citizens' hesitation to vaccinate against coronavirus (France)
- Mass data collection via a specific Covid-19 symptom information app (Sweden)
- Collection through a specific handheld instrument of biological samples on surfaces in public places to identify the presence of SARS-CoV-2 RNA (Spain)
- Mass data collection (15,000 subjects) via Covid-19 predictive symptom app (USA)
- Creation of a consortium including researchers, managers of relevant institutions, doctors, and citizens to implement research projects to reduce infections and antimicrobial resistance in children (India, Indonesia and Chile)

¹ To realize the taxonomy, reference was made to Froeling, et al. (2021). Narrative review of citizen science in environmental epidemiology: Setting the stage for co-created research projects in environmental epidemiology. *Environment International*, 152, 106470; WHO and World Bank. (2022). *Analysis of pandemic preparedness and response (PPR) architecture and funding needs and gaps*. (<https://g20.org/wp-content/uploads/2022/02/G20-FHTF-Financing-Gaps-for-PPR-WHOWB-Feb-10-Final.pdf>)



In the following table, the project/experiences identified have been inventoried, by looking at the occurrence of the categories of the taxonomy.

Where citizens are most involved in citizen science initiatives on epidemic preparedness and response

CS Model Preparedness/ Response Model	PHASE 1 Identification / Design	PHASE 2 Data Collection	PHASE 3 Data Analysis	PHASE 4 Results / Action	Total
SURVEILLANCE	10	38	1	0	49
RESEARCH	5	16	0	1	22
PUBLIC MEASURES	4	11	3	4	22
HEALTH MEASURES	0	1	0	1	2
COORDINATION	1	4	1	0	6
Total	20	70	5	6	101

N.B. The total does not correspond to the number of cases analysed because, in many of them, citizen involvement concerned more than one stage of citizen science or more than one component of preparedness.

- The analysis of the literature provides some valuable insights.
 - There are numerous cases around the world (but few in Italy) of the use of citizen science for epidemic preparedness and response.
 - Citizens are mainly involved in the data collection phase and, to a lesser extent, in the identification of research questions and design, while they are little involved in data analysis and management of results.
 - The areas of epidemic preparedness and response where they are most involved are surveillance and, albeit to a more limited extent, epidemiological research, and public intervention measures.
- The data reported overall suggest that significant experiences already exist that can be leveraged to engage citizens in research on issues related to epidemic preparedness and response. However, there is a need to broaden the space for participation, not by limiting it to specific stages of research or specific areas of preparedness.

OBSTACLES AND FACILITATING FACTORS

What are the major obstacles that should be addressed in Italy to promote citizen science in the field of pandemic preparedness and response? And what facilitating factors could be relied upon? The consultation track allowed us to highlight some of them.

Obstacles



- **Communication Obstacles.** • Lack of a common language that enables citizens and institutions to communicate easily • Lack of a favourable information and media environment • Health and research institutions face serious problems in coordination and public communication, as they very often do not have offices and solid tools and procedures to be able to dialogue with each other and with citizens.
- **Cultural obstacles.** • There is a tendency for citizens and institutions not to take an interest in epidemics when they are not yet evident • There is a widespread orientation in Italy toward fatalism • There is a lack of knowledge about the functioning of the national health system and a lack of sensitivity on the issue of the right to health as well as on environmental issues that favour the spread of epidemics.
- **Social obstacles.** • "Intermediary" actors, such as voluntary associations or trade unions, face increasing difficulties in engaging citizens and connecting them with institutions (although they manage to make important contributions in some situations). • There are many territorial differences (for example, between regions or city areas) regarding, for example, the level of vitality of civil society or the degree of trust in institutions, making it difficult to find solutions that apply to the whole country.
- **Technical obstacles.** • Researchers are not equipped with the skills needed to carry out citizen science projects. Institutions manifest a low level of organizational learning • There is a lack of resources, to foster collaboration with citizens • It is not easy to identify, among the "stakeholders" to be mobilized, those who truly have an interest and orientation to be mobilized as opposed to those, sometimes even more important (because of the institutional roles assigned to them), who tend to be passive.
- **Privacy-related obstacles.** • The collection, use, and transfer of data even in the field of epidemiological research are bound by relevant European and national regulations that must be respected but at the same time can complicate citizen involvement. Several needs may conflict: collecting, processing, and making data available, ensuring privacy, and avoiding the spread of unfounded alarmist interpretations.

Facilitating factors

- **Technology.** A fair amount of citizen science activities can be done from a distance, often using specific apps to collect data or samples, to interact with other researchers and citizen scientists, or to access public documents and resources.
- **Motivations.** Individuals or collective entities can act for very different reasons. Understanding and interpreting their motivations to leverage exponentially favours their engagement. The experience of mobilization during the pandemic indicates that a general solidarity orientation can be a driver, both for promoting preparedness and for implementing forms of Citizen Science (e.g., systematic information gathering on the socio-economic conditions of specific population groups). Standard one-size-fits-all solutions do not exist.



- **Social networks.** It is important to consider citizens not as isolated subjects but as part of familial, friendship, professional or broader social networks. This also applies to associative entities. Leveraging this helps broaden the possibilities for mobilization on a larger scale.
- **Networks of institutional actors on the ground.** The promotion of preparedness and citizen science can make use of various institutional networks of actors active on the ground, such as general practitioners, emergency rooms, universities, schools, municipal libraries, etc. Such actors often mobilize to promote preparedness and to practice citizen science.
- **Roles.** To mobilize, individuals and associational entities need to understand what their roles can be. This also allows them to understand, for example, how much they must commit and what this entails. Clarity and transparency regarding individual roles and responsibilities are essential to promoting citizen science.
- **Areas and steps.** It may be important to understand which engagement tools are most effective, depending on the areas of preparedness or phases of research, to facilitate citizen and association engagement.

LINES OF ACTION

- During the consultation, there were also inquiries about the best approach to take and some possible courses of action to achieve it.
- The starting point was the observation that, in Italy, preparedness for pandemic events is not at all as developed as it should be and that there is still a confused and underdeveloped organizational and regulatory framework. Thus, there is an underlying problem to be addressed, namely that of strengthening preparedness tools in general.
- CS can be an important tool to do this. However, although CS has been increasingly used in many areas over the past decade, it remains a fundamentally new practice, both for health and research institutions and for citizens and civil society entities. This prevents the adoption of already defined measures or very articulate and mature policies to promote it in the preparedness sector.
- This means that, to introduce CS in the field of preparedness for epidemic events, a progressive, "light", continuous, and locally focused approach is needed:
 - **progressive**, because it is necessary to proceed in small steps, allowing stakeholders to learn from experience, to have the time to create a culture of citizen science, and to identify the strategies and tools best suited to the Italian context.
 - **"light"**, in that institutional and non-institutional, public, and private stakeholders already face serious technical, organizational, and economic problems, are under great stress. They cannot be burdened with additional demands that would prevent them from seizing CS as an opportunity to save time and resources and to obtain more reliable and useful data.
 - **continuous**, because it takes time and some stubbornness to create the conditions for CS to be incorporated into preparedness for epidemic events



- which could be facilitated with favourable public policies in the medium to long term.
- **locally focused**, because health services are in the domain of the regional authorities and are articulated in the local dimension. Furthermore, Italy is a very differentiated country, socially, culturally, and economically. For these reasons, the pathways leading to the introduction of CS in preparedness cannot be the same everywhere.
 - Within this general framework, some lines of action can be identified which might allow the use of citizen science in preparedness.

Creating a core group of institutional actors to promote CS

- The first problem is to create collaboration among key institutions to enable CS. For example:
 - on the **research** side, citizen science could be included in the collaborative relationships between the National Institute of Health (ISS) and the research institutions of interest.
 - the involvement of **health institutions** (the ASLs, in Italian “Aziende Sanitarie Locali”, i.e., Local Health Authorities) and especially those sectors that are most closely related to citizens (e.g., general practitioners) is equally necessary.
- Creating a core group of institutional actors is necessary because, to begin with:
 - it is necessary to have a package of organizational, physical (e.g., infrastructure, meeting, and exchange places) and financial **resources**, even limited, but reliable.
 - it is necessary to create virtual or physical "**institutional spaces**" to contact citizens and civil society members easier and faster, and to make possible an equal relationship between the actors involved even when it comes to deliberating on the research to be carried out or the use of its results.
 - there is a need to show that **public actors are committed to CS**, take it seriously, and intend to promote it with commitment.

Engaging actors who already have mobilization capacity

- The second point is to identify the civil society actors who are most active and interested in being involved in the promotion and implementation of CS initiatives.
- However, it is not easy to figure out who the "active" actors are, and it is even more difficult to define exactly what the "activism" of an association or network means or how it can be measured. The picture also can significantly vary depending on the local dimension.
- From the considerations made during the consultation, however, it emerges that, at the local level, there are almost always actors that have a certain visibility by virtue of their dynamism and a strong orientation toward action, cooperation, and social responsibility, even regardless of the field of engagement. These could also be actors as diverse as, for example, schools, municipal libraries, parishes, religious



communities (such as the Sikh community) or other forms of associationism. Many of these entities already have active networks, are present in national or international networks, and sometimes already have a high organizational capacity.

Identifying stakeholders

- Then there is the area of stakeholders, i.e., those who are most interested and involved—often for institutional reasons—in preparedness, such as nursing homes, health care institutions, research centres, organizations that provide services or represent vulnerable people, or volunteer social and health care charities. The fact that they are stakeholders does not mean that they are easier to mobilize.
- Again, careful stakeholder analysis (stakeholder mapping) should be done to identify those most likely to mobilize and capable of mobilizing others. It is then necessary to contact them, understand their specific motivations, find appropriate incentives, and establish simple but ongoing communication procedures to keep them together and understand what roles they may play in the development of CS projects concerning preparedness.

Deploying CS tools and technologies

- As mentioned above, a large part of citizen science activities can be realized through information technologies, including virtual platforms for interacting and especially apps for carrying out research activity by involving a wide range of actors. Thus, there is a third line of action to work on, namely engagement through communication via social media or existing CS platforms. This implies a minimum of financial investment for those promoting citizen science projects, however it allows them to reach many more people, lowering costs.

Building on what is already in place

- There are multiple tools available online on most aspects of citizen science (starting with the EU-Citizen Science platform). The inventory of cases made during the STEP CHANGE project also offers many opportunities and information to understand what tools, methods, approaches, and practices may be best suited to promote citizen science in Italy.
- There are Italian experiences to build on, also in medical research, including the field of infectious diseases. They are essential departure points, although initially learning from what already exists may require a specific effort.



Launching pilot projects

- Often, the best starting point is to initiate pilot projects, which are not expensive and confined in space and time, to learn from experience and to better understand what the best way forward might be. This also allows us to demonstrate how feasible and useful citizen science ultimately is in supporting an epidemic preparedness agenda in our country.
- For this reason, it is also important that pilot projects have important components of awareness raising and cultural change that lead all stakeholders to consider CS as an important tool for the prevention and management of epidemic events and not as a secondary option, to be used only in the absence of more effective tools.

KEY MESSAGES

1.

Preparedness should be considered as an area of action adjacent to prevention. The enhancement of preparedness, therefore, should be seen as a way for pursuing healthcare systems effectiveness and efficiency and therefore one of their institutional tasks.

2.

Citizen science can be an important component in enhancing preparedness in Italy. It can make research processes faster, allow capturing aspects that conventional research methods may not detect, facilitate the transition from research to possible solutions, and support public consensus towards the measures employed.

3.

Citizen science is a choral process involving cooperation between actors who may be very different from each other. To be effective, it requires a progressive, "light", continuous, and locally focused approach, capable of triggering involvement processes of the most active, experienced, and capable social actors.



4.

Citizen science is unlikely to fit into preparedness if it is not promoted and supported over time by a core of public actors committed to public health research and promotion. This is important to ensure essential resources to promote CS, to create institutional spaces of interaction among the players involved, and to show the commitment of public actors to support CS.

5.

To make citizen science possible, it may be useful to start with pilot projects, learn from the vast amount of knowledge and experience that already exists, leverage civil society realities already oriented to mobilize, make the best use of information technology, and be open enough to learn and understand which solutions are the most appropriate for the reality of Italy. Pilot projects must also include "soft" aspects aimed at raising public awareness.

This Policy Brief is the result of collective work. Participating in its definition and drafting were, among others: Paola Coppola, Luciano d'Andrea, Andrea Declich, Olimpia D'Emilio, Nicola del Duce, Nabil El Degwy, Carlo Di Manzano, Daniela Di Placido, Agnieszka Kinga Guzikowska Caterina Lorenzi, Matteo Martini, Alessandra Minchella, Carla Montesano, Blasco Morozzo Della Rocca, Damiano Orru, Lorenzo Paglione, Pamela Pergolini, Luisa Portieri, Marina Potestà, Laura Reali, Valentina Roglia, Elisabetta Russo, Gianluca Russo, Andrea Simone, Silvia Vendetti.