

## Deliverable 5.4

*Strategy for Citizen Science in Infections Diseases outbreaks preparedness*



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## Deliverable description

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<b>PU</b>	<b>Public</b>
<b>CO</b>	<b>Confidential, only for members of the consortium and AB (including the Commission Services)</b>
<b>CI</b>	<b>Classified, as referred to in Commission Decision 2001/844/EC</b>

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# Index

Acronyms	6
Overview of WP5	7
Objectives	7
Actions	7
Activities	7
Executive Summary	10
Introduction	11
Objectives	11
Phases	11
1. The rationale for a citizen science Strategy	13
a. The centrality of preparedness	13
b. The use of CS for the preparedness	13
c. The relevance of social mobilisation	14
2. Facilitating factors	15
a. The tendency towards mobilisation cuts across the divide between public and private	16
b. There are well or semi-organised networks of social mobilisation already in place.	16
c. The size of this 'pool' of social mobilisation is certainly significant, yet it is hardly measurable.	16
3. Hindering factors	17
a. The inadequacy of preparedness policies	17
b. The scarce tendency to promote 'multi-actor policies'	17
4. The logic of change	17
5. Strategy stages and activities	18
a. Preparation phase	18



b. Explorative phase	18
c. Demonstration phase	19
d. Institutionalisation phase	19
6. Conclusions	19



## Acronyms

Acronym	Description
ASL	Azienda Sanitaria Locale (public body of the Italian public administration, responsible for the provision of health services in a given territory)
CS	Citizen Science
CSI(s)	Citizen Science Initiative(s)
ID	Infectious Disease
NGO	Non-Governmental Organization
ISS	Istituto Superiore di Sanità (technical-scientific body of the National Health Service in Italy, that conducts research, experimentation, control, consultancy, documentation, and training in public health matters)
T	Task
WP	Work Package



## Overview of WP5

### **Objectives**

- Developing a Taxonomy of existing and potential citizen science interventions for 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.

### **Actions**

The pathway toward the development of this strategy included different actions:

- the development of a taxonomy of CS interventions for ID epidemic preparedness, which represented the objective of Deliverable 5.2. The taxonomy 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.
- the development of a policy brief aimed at raising the policy issue of why and how to apply CS to strengthen preparedness for epidemic events in Italy, while taking into account prior experiences in Europe described in the Taxonomy.

### **Activities**

Based on the results obtained, further activities have been implemented to promote a multi-stakeholder's dialogue aimed at co-designing the strategy indicated by the objective of this Citizen Science Initiative (CSI). Various stakeholders within the quadruple helices (ie.: societal sectors such as academia, civil society, industry, and policy making) have been contacted and asked to participate in two workshops. In total, twenty-four people participated in the workshops including their preparation. Six participants did not participate in person but provided valuable contributions to the implementation of the initiative. The components of the UNITOV team should be added to the above-mentioned participants. Some people who could not participate in the workshops (both or just one of the two) have been met individually and



provided their points of view on the issues discussed. In the exchanges, some UNESCO Chairs members were also involved.

The first workshop was called to discuss an “outline-for-discussion” document that contained the crucial issues that – based on the Policy Brief and the previous CSI phases – had to be dealt with to define a strategy for Citizen Science and Preparedness for epidemic outbreaks. The document was prepared through the consultation of relevant literature (mainly of a grey type) concerning the issues to be discussed (beyond those connected to that of preparedness and citizen science, already consulted in the previous phases, some literature concerning strategy definition was considered too). In the second workshop, a draft of a possible strategic document was discussed. This draft was based on the debate held so far in the process and, particularly, in the first workshop. The participants in the second workshop provided their comments that were considered for the final definition of the Strategic Document that represents the main text of this deliverable.

Thus, after the two workshops (both implemented in hybrid mode i.e. face to face and online), a document titled “Strategy for Citizen Science in Italy Infectious Diseases outbreaks preparedness. The Building Blocks of Strategy” was finalized containing the results of the discussion held and the information collected (also in individual exchanges). It was again circulated among the participants in the meetings and then edited and translated into final version.

The Strategic Document has been written in Italian since it is mainly addressed to the Italian policymakers and stakeholders. Anyhow, it is also based on the results of the preceding steps that considered the experiences of citizen scientists operating in Europe and beyond. In general, the entire Strategic Document has a European breath and can be relevant for being adapted to other contexts.

The strategic document is composed of the following sections:

- Introduction, which provides the background of the strategic document and the STEP CHANGE project.
- 1. “The rationale for a citizen science strategy?” which proposes the reasons at the basis of the document
- 2. “Facilitation factors” which describe the elements that favor the promotion of CS in the framework of preparedness for epidemic outbreaks
- 3. “Hindering factors” which describes the obstacles to be considered to successfully implement CS in the framework of preparedness to epidemic outbreaks





- 4. “The logic of change” in which the principles of the strategy are presented
- 5. “Stages and activities”, in which possible phases of the strategy are presented
- 6. Conclusion.



## Executive Summary

This document outlines 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. It is the result of a Citizen Science Initiative (CSI) that included the production of a “Taxonomy of citizen science interventions for ID outbreak preparedness” ([https://stepchangeproject.eu/wp-content/uploads/2023/09/D5.2\\_Taxonomy-of-citizen-science.pdf](https://stepchangeproject.eu/wp-content/uploads/2023/09/D5.2_Taxonomy-of-citizen-science.pdf)) and a “Policy Brief on Citizen Science role in Infectious Disease (ID) outbreaks in Italy and Europe” (Deliverable 5.3).

This document contains the following sections:

- Introduction, which provides the background of the strategic document and the STEP CHANGE project.
- 1. “The rationale for a citizen science strategy?” which proposes the reasons at the basis of the document.
- 2. “Facilitation factors” which describe the elements that favour the promotion of CS in the framework of preparedness for epidemic outbreaks.
- 3. “Hindering factors which describes the obstacles to be considered to successfully implement CS in the framework of preparedness to epidemic outbreaks.
- 4. “The logic of change” in which the principles of the strategy are presented.
- 5. “Stages and activities”, in which possible phases of the strategy are presented.
- 6 Conclusion.



## Introduction

### **Objectives**

The Department of Biology of the University of Rome 'Tor Vergata' has implemented, within the framework of the European project [STEP CHANGE](#) (see box 1 below), a Citizen Science Initiative (CSI) on infectious disease outbreak preparedness in Italy. The aim of the CSI is **to define the basis for a strategy for the inclusion of citizen science in Italy preparedness** for ID epidemic events.

### **Phases**

The initiative was developed in three main phases.

- In the first phase, an extensive literature review was conducted to understand how and to what extent Citizen Science (CS) has been used in the context of preparedness activities for epidemic events (see Box 2).
- In the second phase, through a consultation of a panel of citizens with different professional backgrounds, a **policy brief** was developed to raise the question of the use of CS in the preparedness for epidemic events.
- In the third phase, in this case through a consultation of a panel of experts, the first elements for a CS promotion strategy in epidemic preparedness were defined. These elements constitute the content of this Note, which should be shared as widely as possible to enable an initial discussion on the subject.

#### BOX 1

##### STEP CHANGE project.

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



refers to any form of individual or organised participation of citizens, i.e. people who are not professional researchers, in research initiatives, on any topic and at any level of involvement.

## BOX 2

### CS initiatives in preparedness

As part of the citizen science initiative promoted by the University of Rome “Tor Vergata”, a literature review was conducted to understand how citizen science was used in the preparation and response to epidemic events. A total of 56 studies were selected and analysed.

Among the examples of citizen involvement in preparedness-related research, we can mention the following:

- 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)

Altogether, the analysis provided some general indications about the use of CS in preparedness:

- There are numerous cases in the world (only a 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 and design questions, while they are hardly involved in the analysis of data and management of results
- The epidemic preparedness and response sectors where they are most involved are surveillance and, albeit to a more limited extent, epidemiological research, and public intervention measures



## 1. The rationale for a citizen science Strategy

The rationale behind the development of a strategy for Italy aimed at promoting citizen science in the preparedness for epidemic events stems from three main considerations.

### ***a. The centrality of preparedness***

The Covid-19 pandemic, and other more recent infectious diseases epidemics, have shown how unprepared most of the countries, including Italy, are to face significant epidemic situations. This concerns both the implementation of effective prevention and response mechanisms to epidemics (starting with the mobilisation and coordination of the many actors involved), and the rapid development of the research activities required for preparedness. We are referring here to biomedical research aimed at identifying pathogenic factors, understanding their impacts, and clinical research to develop effective diagnostic systems and therapies. At the same time, research into other relevant topics that are often less well considered, such as the effects of social and health measures to be adopted or employed to respond to pandemic events, individual and collective behaviour associated with epidemic events, or the quality of response of social and health structures in the face of emergency situations.

### ***b. The use of CS for the preparedness***

A further point to consider is the enormous increase in research conducted over the past decade based on citizen science (for definition see Box 3). This increase, as seen (see Box 2), has also significantly affected the preparedness. The CS may represent an opportunity to promote the detection, as early as possible, of the actual epidemic and health risks faced by specific communities and, on this basis, to promote more prompt and adequate responses, thereby increasing the capacity for prevention. The CS may also be useful for the early detection and study of phenomena related to the very implementation of health policies (e.g. the issue of 'vaccination hesitancy').

#### BOX 3

What is Citizen Science



Citizen Science refers to the involvement of citizens together with professional researchers in scientific activities that produce new knowledge or understanding. Citizens may act as contributors, collaborators, or project leaders and play a significant role in the project.

### ***c. The relevance of social mobilisation***

There is at least one shared trait between these two elements - preparedness and CS. In either case, what we might call 'social mobilisation' plays a central role, as the tendency and ability of a group of citizens or of collective social actors to engage and mobilise other actors to achieve goals of common interest. Indeed, no effective preparedness action can be conducted without the widespread involvement of collective or individual actors (for example, in the case of social distancing), starting with those who are most exposed to epidemic risks or who have or may have roles in fighting epidemics. This involvement takes the form, among other things, of partnerships between public and private actors operating locally in providing health and social care services. However, coordination is essential to relieve hospitals from the almost exclusive burden of intervening in crisis situations (as happened during the COVID-19 pandemic). Similarly, CS is based on the assumption, so far confirmed, that the production of new knowledge represents a powerful driver of social mobilisation, and that CS itself constitutes a form of social mobility that develops around research and innovation.

These three considerations lead to the conclusion that a strategy that integrates CS into preparedness-related research can be useful, for at least four reasons:

- **Sustaining research.** The CS could promote an acceleration of research activities (e.g. those requiring the collection of a large amount of epidemiological data in a short time) and an increase in their quality.
- **Broadening research topics.** The CS could encourage the development of research activities in less studied areas, such as those mentioned above, for which cooperation between biomedical sciences and social sciences and the consideration of the perspectives of a wide range of actors (from health professionals to ordinary citizens) is most needed.
- **CS contribution.** The involvement of citizens and local communities in general can also be used to conduct research projects that have particularly complex objectives, such as



identifying epidemic and health risk situations or determining the influence of social conditions on exposure to these same situations. Within this framework, one can try to make CS part of permanent information gathering systems, thus integrating CS, according to those approaches that gradually prove practicable, part of the epidemic risk prevention system.

- **Collective involvement in the preparedness.** The CS could be an important tool for social mobility on preparedness that could go beyond the research dimension alone, fostering the involvement of social actors and citizens in preparedness policies.

## 2. Facilitating factors

The feasibility of a strategy is measured first and foremost by the presence of facilitating factors, namely non-contingent factors on which the strategy itself can rely to have any hope of success. Both in the preparation phase of the Policy Brief and in the development of the Strategy, the consulted actors recognised, as the main facilitating factor, the widespread presence in Italy of a significant number of social actors equipped with a strong tendency to mobilise on issues of common interest, giving rise to even complex experiences of social and collective action.

The examples given during the meetings are numerous and concern both actors operating in the socio-medical care system (patients' associations, professional associations in the health field, etc.) and actors performing different functions (municipal libraries, schools, citizen organization, religious associations, volunteer organisations, formalised network organisations, etc.); which are often interested in being mobilised on different objectives (multi-purpose organisations). In general, these experiences also involve forms of active collaboration with health institutions. In addition to Citizen Science initiatives, innovative forms of collaboration between actors in the health sector in the promotion of vaccination policies were reported (e.g. the new modalities of vaccination supply managed in agreement with pharmacists).

Upon reflecting on this phenomenon, at least three elements were highlighted that are characteristic of the widespread presence of social mobilisation in an organised form, for some even capillary.



***a. The tendency towards mobilisation cuts across the divide between public and private***

The first element to mark out is that the capacity for social mobilisation cuts across the classic distinction between public and private actors. In other words, strong tendencies to mobilisation can be detected both in public actors (not only ASL or individual social-health services, but also educational institutions, municipal libraries, etc.) and in private actors (non-governmental organisations, private social-health facilities, local community networks, third sector organisations, etc.). Furthermore, it was also noted how numerous public actors - often described as slow to change and affected by bureaucratic lengthiness - proved to be incredibly responsive and flexible (in organisational, financial, communication terms) when it came to adapting to major emergency situations, as in the case of COVID-19. Even among health promotion bodies (hospitals and local health centres) there are those that are strongly active in promoting cooperation with civil society and voluntary actors.

***b. There are well or semi-organised networks of social mobilisation already in place.***

The second element to dwell on is that well-organised or semi-organised networks of social mobilisation already exist in many areas of the territorial area, focusing on specific themes of social commitment. Sometimes they are “pieces” of these networks that cooperate with each other on a continuous basis, involving both public and private actors.

***c. The size of this 'pool' of social mobilisation is certainly significant, yet it is hardly measurable.***

A third characteristic of this social mobilisation pool is that, while it is certainly significant, it cannot be easily measured in its overall extent or in its overall articulation. This is due to the fact that these forms of social mobilisation often tend to appear not as formal and institutionally defined mechanisms, but in a diffuse and unpredictable manner, which can change rapidly over time. This means that the actors active in this mobilisation are not necessarily enrolled in the various rosters of third sector actors open at local or national level, and in contrast those who do, are not necessarily active players.





### 3. Hindering factors

Several potential hindering factors emerged with different weights and relevance. Of these, two are worth mentioning, one more general and the other specific to the issue of preparedness.

#### ***a. The inadequacy of preparedness policies***

The most specific hindering factor is that policies for preparedness appear to be unsubstantial, meaning that beyond the definition of preparedness plans, the organisational, cultural, and operational mechanisms capable of transforming them into real prevention policies have not been activated (at least not sufficiently). This means that any action promoting CS for preparedness would have to fit within a framework (political, regulatory, operational, etc.) that is already weak and underdeveloped, which certainly does not help.

#### ***b. The scarce tendency to promote 'multi-actor policies'***

The second aspect - the most general one - is represented by the still scarce aptitude of public actors to interface with other actors, public or private. In Italy, this has led to a significant and systemic delay in the development of what in Europe is known as 'multi-actor policies' or 'multi-actor governance', i.e. institutional policy measures and actions involving numerous actors, public and private, through the adoption of co-participation and co-responsibility mechanisms. There are exceptions, including in Italy, in certain territorial areas or in certain sectors (see the example of the collaboration with pharmacists or the numerous experiences of mobilisation on HIV). However, the attitude to creating policies based on long-term cooperation systems still appears unsystematic.

### 4. The logic of change

During the meetings, the 'logic of change' to be adopted was discussed at length, which means paths should be defined to make CS more likely to be taken up in preparedness actions in Italy. Two issues emerged clearly:



On one hand, an action aimed at the inclusion of CS in preparedness can only start from actors – both public and private and not necessarily in charge of promoting preparedness - which are already able to promote social mobilisation on social and health issues and who have the potential to bring CS into preparedness.

On the other hand, despite the wealth of actors and experiences, the framework is still excessively fragmented, therefore the actors with the capacity for social mobilisation are often not interacting with each other or are not familiar with each other's experiences.

Hence, the need to **reduce fragmentation** in the first place by fostering the circulation of knowledge, supporting cooperation initiatives, and promoting the idea of CS as a tool for effective social mobilisation.

Only at a later stage, when these elements will be clearly visible as the potential of CS in preparedness, the involvement of the actors institutionally in charge of promoting preparedness could be pursued, even those not particularly efficient.

## 5. Strategy stages and activities

It is possible to attempt on this basis, a first definition of an action programme organised in phases and activities.

### ***a. Preparation phase***

Initially, it is necessary to disseminate the contents of this Note, involving a series of public and private actors potentially interested in sharing its objectives and promoting CS in preparedness. This implies an initial exercise of "stakeholder mapping" aimed at understanding whether the conditions are in place to create a "promoting collective actor" capable of giving continuity to the action.

### ***b. Explorative phase***

Following the preparatory phase, an exploratory phase (which may last from one to three years) should be started with the aim of fostering the creation of an 'ecosystem' in support of CS for preparedness. At this stage, it is necessary to scrutinize more in-depth the social actors (public



as well as private) and networks previously singled out. The focus should be on those that are particularly active in social mobilisation as well as on the experiences of social mobilisation relevant to CS and preparedness. To create this ecosystem, it is essential to promote relations between these actors and existing national and European networks, so that experiences can be known and shared. At this stage, it is also important to explore the possibility of accessing private and public funds and support to enable the entire process to continue.

### ***c. Demonstration phase***

In this phase, which is unlikely to last less than two to four years, the aim is to demonstrate the feasibility and usefulness of systematically incorporating CS to implement and strengthen preparedness research. In this phase, a set of pilot projects should be activated (based above all on the activities conducted during the reconnaissance phase) and a public dialogue should be opened to identify possible models for the use of CS for preparedness; from the simplest to the most articulated ones that require a more relevant involvement of citizens and stakeholders. This phase should also be characterised by a greater connection of Italian experiences with European and international ones, to give them greater visibility and institutional prominence.

### ***d. Institutionalisation phase***

During this phase, the first real involvement of key public actors in the field of preparedness (ISS, Ministry of Health, etc.) should take place with the intention of defining and expanding the implementation process of the CS in preparedness strategy.

## **6. Conclusions**

We have carried out a CSI aimed at investigating a crucial issue, i.e. the role that CS could play in the framework of preparedness for infectious disease preparedness. The entire pathway we followed in the CSI led us to single out the usefulness of CS and the potential obstacles and facilitating factors that, in general, could be met when undertaking it for improving preparedness to infectious disease outbreaks. The first results we reached are presented in two deliverables (D5.2 and D5.3) produced during the CSI. The last step of this pathway consisted of investigating how to promote in practice CS for preparedness to infectious diseases in Italy. Such



results are contained in this Strategic Document and are meant to be taken up by the diverse actors who are entitled to, or interested in, participating in the effort to improve preparedness through a participatory approach that entails the involvement of citizens in research. The strategy outlined was thought for Italy and is based on the results of the research and consultation work that was focused on the Italian case and on the actual difficulties and opportunities connected to such an effort. This is particularly evident in the last two sections concerning the proposed “Logic of change” and possible phases of the strategy proposed.