Step Change

Taxonomy of citizen science interventions for ID outbreak preparedness

Deliverable 5.2

October 2022

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2.0	20/10/2022	Carla Montesano, Marina Potestà (UNITOV)	Second draft
4.0	31/10/2022	Elena Bužan (UP) Laura Iacolina (UP)	Final version

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Acronyms

Acronym	Description
CS	Citizen Science
CSI(s)	Citizen Science Initiative(s)
ID	Infectious Disease
UTCP Model	UNITOV CS/P Model

Summary

The CSI developed by UNITOV is intended to address this issue by co-designing a citizen science strategy for Italy's epidemic preparedness and response, fostering citizen scientists' role in support of institutions responsible for managing infectious disease outbreaks and research.

The pathway towards the development of this strategy includes different actions, one of them is the development of a taxonomy of CS interventions for epidemic preparedness. The taxonomy aims to identify CS practices that can be usefully applied to the different components of epidemic preparedness based on existing CS approaches and initiatives carried out in Europe or elsewhere. The taxonomy considers the use of CS to fight against any type of ID, even though the great majority of CS experiences tend to concern a quite restricted group of IDs, including COVID-19, Zika, Chikungunya, Ebola, SARS, MERS, and Flu infections.

The work done to develop the taxonomy was a process that included several activities. An initial round of literature review was carried out to screen an extensive literature review and identify both outbreak preparedness and response models of CS activities. Based on the results of the first round of analysis, a new taxonomic structure was developed, named 'UNITOV CS/P model'.

A second round of literature analysis was conducted to identify cases where CS or participatory mechanisms were used in outbreak preparedness. All collected cases were analysed and selected, based on three relevant criteria; this activity resulted in an inventory of 56 cases that were described in a template and classified according to the "UNITOV CS/P Model".

The last activity was the design and drafting of the present document, the deliverable 5.2

This document is aimed at presenting the taxonomy elaborated under the UNITOV CSI. It is organised into three chapters.

Chapter One will present the activities carried out and the model used for developing the structure of the taxonomy.

Chapter Two will report an inventory of 56 cases in which CS has been applied to address different components of epidemic preparedness. The inventory is aimed at getting information about how CS and participatory approaches, strategies, and practices have been concretely applied and with which effects.

Finally, in Chapter Three, some lessons learned will be drawn from the analysis of the cases and the application of the structure of the taxonomy for future activities.

Chapter One

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The taxonomy

Activities

The taxonomy development process included different activities.

Scoping literature review: first round

The first activity has been the screening of a wide literature review.
The review falls into the category of scoping reviews (Arksey & O'Malley, 2005), i.e., an analysis of scientific publications and relevant policy documents geared to determine the volume of literature available on a given topic or set of topics and make an overview of the themes considered (Munn et al. 2018).
The first round of the literature review has been conducted with the aim to:

- identifying models of epidemic preparedness and response
- Identifying models of CS activities.

Three sets of keywords have been used, producing different combinations, as illustrated in the figure below.
This activity started in May and was completed in June 2022.

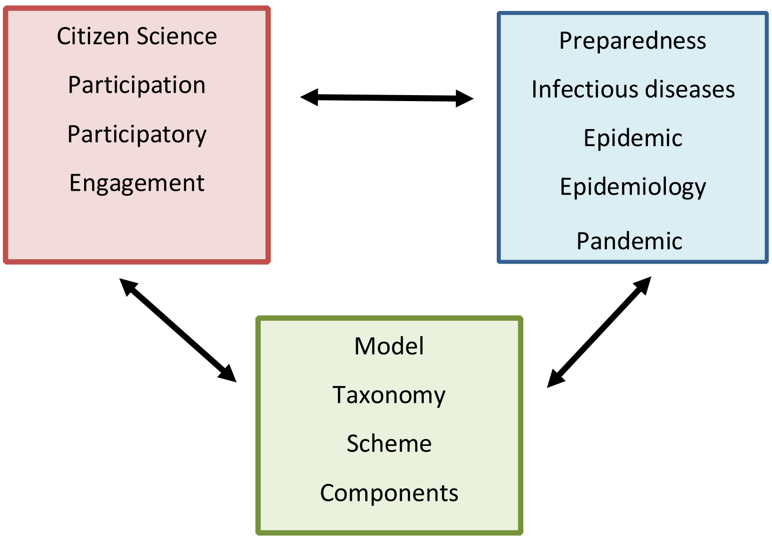

Fig. 1 – Keywords used in the first round of the literature review

Development of the taxonomy structure

Based on the results from the first round of the scoping review, a new taxonomy structure has been elaborated, combining two different models, one referring to epidemic preparedness and one referring to CS activities. The resulting model, for sake of brevity, will be referred to as the "UNITOV CS/P Model" or UTCP Model.

This activity started in half of June and was completed in July 2022.

Scoping literature review: second round

Parallelly, a second round of the literature review was carried out to identify cases in which CS or participatory mechanisms have been used in epidemic preparedness.
Again, three sets of keywords have been used, producing different combinations, as illustrated in the figure below.

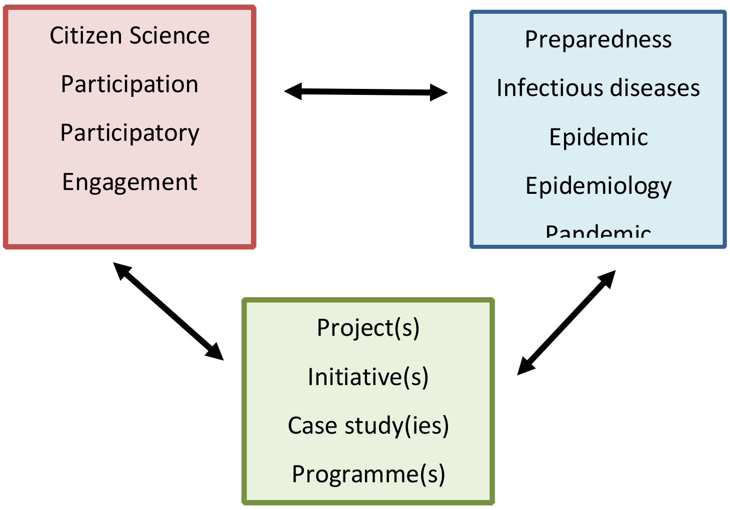

Fig. 2 – Keywords used in the second round of the literature review

The second round of the literature review allowed us to get information about some 90 cases in which CS or participatory mechanisms have been applied in the context of epidemic preparedness.

This activity started in June and was completed in half of August 2022.

Selection process and inventory

All the cases collected have been analysed and selected, based on some criteria:

- The wealth of information provided by the sources (cases for which the information provided was limited in comparison to other cases were excluded)
- The relevance of CS/participatory practices (cases in which the participatory mechanisms had limited relevance were excluded)
- The innovativeness of the CS/participatory practices (cases presenting CS/participatory mechanisms particularly original or advanced have been selected)

This process led to an inventory of 56 cases. Each case is presented using a standardised template and categorized following the UTCP Model (see below).
The CSI team analysed and categorised the cases by involving some universities, high school and middle school students and teachers. The latter participated in a training module in which the CSI was presented and in which they were shown how to apply the UTCP Model.

This activity started in July and was completed in half of September 2022.

Draft of the D5.2

The last activity was the design and drafting of deliverable 5.2. This activity started in September and ended in October 2022.

The structure of the taxonomy

As mentioned above, the structure of the taxonomy is based on a new model – the UTCP Model – developed through the fusion of two existing models, i.e.,

- A model of CS/participatory activities
- A model of the components of epidemic preparedness

As for CS/participatory activities, different models have been considered. Because of its completeness and its focus on epidemiology, the model set up under the CitieS-Health project has been chosen, even though it has been partially modified to better adapt it to the needs of the CSI (Bach, et al., 2017; Dan Broeder, et al., 2018; Chan, et al., 2021; Ciasullo, et al., 2021; Froeling, et al, 2021; Tan, et al., 2022).

As for the model of epidemic preparedness, a group of models have been deepened (Fatiregun, et al., 2017; Bedford, et al., 2019; Oppenheim, et al., 2019; Bardosh, et al., 2020). Finally, the model of Pandemic Preparedness and Response (PPR) developed by WHO and the World Bank (2022), has been selected.

These two models will be described in the next two paragraphs (a. and b.). In paragraph c., the model developed based on them – the UPCM – will be presented.

The CitieS-Health model

The Model developed by the CitieS-Health project of the CS activities is schematised in the following picture.

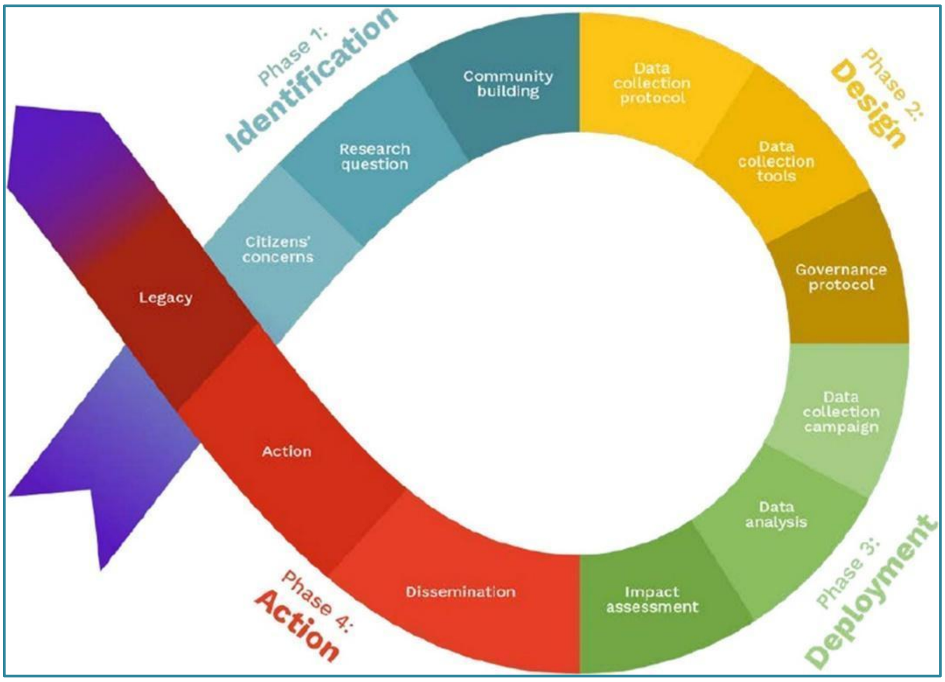

Fig. 3 – The CitieS-Health Model (Froeling, et al. 2021)

The model includes four phases (Identification, Design, Deploy, and Action), each of them made up of three components. The description of the components is given in the table below.

Table 1 – The components of the CitieS-Health Model (Froeling, et al, 2021)

PHASES	Components
PHASE 1 - Identification	**Citizens' concern** Identification of health and environmental issues of more concern to citizens, to gain a deeper understanding of the problems at stake through, e.g., surveys, stakeholder mapping exercises, ethnographic analysis)
	Research questions Translation of the selected concerns into research questions (through, e.g., interviews, public consultations, deliberative mechanisms, literature reviews).
	Building community Identification and contact with communities, organisations, and stakeholders concerned with the issues to investigate
PHASE 2 – Design	**Data collection protocol** Co-design of the data collection protocol, including information on experimental variables, type of data to be collected, methods and tools.
	Data collection tools Preparation of the tools
	Governance protocol

	Identification of roles, rights, and duties of all involved participants
PHASE 3 – Deploy	**Data collection campaign** Campaign to raise awareness about the study and recruitment of more participants, and data collection
	Data analysis Analysis of the collected data, in cooperation with citizen scientists
	Impact assessment Analysis of the impact of the research activities and possible pilots/experimentations at different levels (individuals, environment, policies, etc.)
PHASE 4 – Action	**Dissemination** Dissemination of the results to different targets (civil society, policymakers, the academic community, public authorities, etc.)
	Action Co-creation, planning, and delivering actions generating recognition of the issue explored (through, e.g., public-facing activities to wide awareness and feed dialogue)
	Legacy Planning for lasting impact by favouring other actors to reuse and uptake the results of the CS project (through, e.g., policy recommendations, socio-technical infrastructure, etc.)

However, to favour the involvement of school students and better adapt the UTCP Model to the needs of the CSI, the CitieS-Health Model has been simplified and partially modified.

In particular:

- The phases of identification and design have been considered as part of the same phase
- The phase of deploy has been split into two phases, i.e., data collection and data analysis
- The name of the phase "action" has been modified into "results and action" to include any possible involvement of citizens in the production and management of the research activity
- The distinctions among the components of each phase have been not considered

The phases of the CS Model included in the UTCP Model are presented in the table below.

Table 2 – The components of the CS Model included in the UTCP Model

PHASE 1 – Identification & Design	Any form of participation of citizens and stakeholders in the identification, mapping, deepening and analysis of the issue to deal with through research activities, identification of research questions, mobilisation of other citizens and stakeholders, and design of the research
PHASE 2 – Data collection	Any form of participation of citizens and stakeholders in data collection activities, including the preparation phase, development of the data collection tools, and implementation of the data collection campaign
PHASE 3 – Data Analysis	Any form of participation of citizens and stakeholders in the data analysis of the collected data (including data processing, data interpretation, and impact assessment)
PHASE 4 – Results & action	Any form of participation of citizens and stakeholders in the use of the results of the research activities, including, e.g., dissemination of results to different targets, co-creation, planning, and delivering actions related to such results, and development of policy-related and mobilisation activities.

The WHO/WB (PPR) model

The WHO/WB model of Pandemic Preparedness and Response (PPR) is schematized in the figure below.

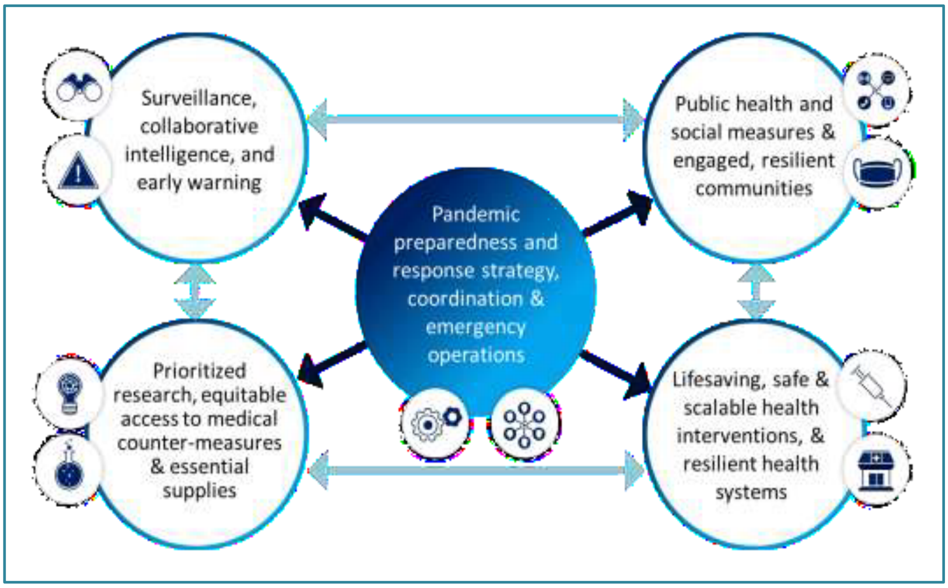

Fig. 4 –The PPR Model (WHO & the World Bank, 2022)

The model includes five different components. They are described in the table below.

Table 3 – The components of the PPR Model (WHO & the World Bank, 2022)

Nickname	Extended name	Content
SURVEILLANCE	Surveillance, collaborative intelligence and early warning	Surveillance data collection and analysis; connection with alert systems; appropriate laboratory capacities; analysis of the intersection between human health, animal health, and the environment
RESEARCH	Prioritized research and equitable access to medical countermeasures and essential supplies	Research into emerging and potential IDs; preclinical and clinical research to develop countermeasures; reinforcing the supply chain;
PUBLIC MEASURES	Public health and social measures and engaged, resilient communities	Development of containment, control, and mitigation measures; involvement of the affected communities; risk communication.
HEALTH MEASURES	Lifesaving, safe and scalable health interventions and resilient health systems	Health system capacities (human resources, infrastructure, material); motivated and skilled workforce;
COORDINATION	PPR strategy, coordination & emergency operations	Marshal and deploy the appropriate resources (knowledge, data, financial, material, operational)

These components can be found at the local, national, and global levels. Therefore, vertical mechanisms of coordination among the levels should be also put in place.

The UNITOV CS/P (UTCP) Model

Building on the two models – the CitieS-Health CS model and the WHO/WB PPR Model – the UTCP Model has been developed.

Its aim is "localising" the different kinds of CS-related and participatory activities (Identification, Design, Deploy, and Action) within the different components of epidemic preparedness (Surveillance, Research, Public measures, Health measures, and Coordination).

In this way, the resulting matrix includes 20 cells, as shown in the table below.

Table 4 – The components of the UTCP Model

CS Model / **Preparedness/Response Model**	PHASE 1 Identification/ Design (I)	PHASE 2 Data Collection (D)	PHASE 3 Data Analysis (Y)	PHASE 4 Results/ Action (A)
SURVEILLANCE (S)	S/I	S/D	S/A	S/R
RESEARCH (R)	R/I	R/D	R/A	R/R
PUBLIC MEASURES (P)	P/I	P/D	P/A	P/R

HEALTH MEASURES (H)	H/I	H/D	H/A	H/R
COORDINATION (C)	C/I	C/D	C/A	C/R

For example, projects in which an app has been used to collect data on COVID-19 symptoms to predict hospital admissions fall into the category S/D since citizens have been involved in a data collection campaign (D) to anticipate the evolution of the COVID-19 pandemic (S).

This matrix has been used to categorize the cases of application of CS initiatives or other forms of participatory projects to epidemic preparedness (see Chapter Two).

Three observations deserve to be done.

First, the typology presented above is of a theoretical nature. In this sense, it should not be considered an anomaly that one or more of the 20 categories included in the scheme is not represented by any case.

Second, the boundaries between different categories of the model are blurred. Therefore, cases might fall into more than one category, since, on the one side, many of them involve citizens and stakeholders in different ways and for pursuing different aims and, on the other side, the same action sometimes may be used for multiple ends.

Finally, it is to highlight that inevitably the attribution of a case or an activity included in the case to a specific category of the UTCP Model has been to a certain extent arbitrary. This also depended on the clarity of the sources. Anyhow, an effort has been made to consistently use the UTCP Model, for example organising meetings with the team members to discuss the cases that were more difficult to categorise.

Chapter Two

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The inventory of cases

Description of the inventory

This chapter includes an inventory of 56 cases of initiatives (projects, programmes, etc.) in which CS or participatory mechanisms have been used in epidemic preparedness.

Each case is described based on a template, including the following information:

- A progressive number
- A descriptive title
- The country or countries in which the initiative was conducted
- The reference to the source
- A short description of the case (Synopsis)
- The CS methods cited by the source
- The classification of the case according to the UTCP Model. The classification process has been carried out based on an interpretation of the information drawn from the source. The classification has been done by individual researchers and citizen scientists (students and teachers) and checked by the CSI team.

The selected cases

1. Investigation of the presence of the virus on surfaces in public settings	
Country(ies)	Spain
Source	Ardura, et al., 2021
Synopsis	Researchers and citizen volunteers found SARS-CoV-2 RNA on frequently touched urban surfaces. A portable, user-friendly machine for SARS-CoV-2 eRNA detection was employed. Training activities have been carried out.
CS Methods	Use of a device to collect samples, after training. Overall, 141 citizens participated, organised in research teams (3 professional scientists and 2/4 citizen scientists).
Classification	Surveillance + Data collection (S/D) Research + Data collection (R/D)

2. Co-immune project	
Country(ies)	France

Source	Masselot, et al., 2021
Synopsis	Over 6 months, the Co-Immune programme gathered 234 participants of diverse backgrounds and 13 partners from the public and private sectors and organized 8 events to facilitate the creation of 20 new projects as well as the continuation of 2 existing projects to address the issues of vaccination hesitancy and access in relation to the COVID-19 pandemic. The projects made their data, code, and solutions publicly available in an open framework.
CS Methods	**CS methods:** A wide range of methods including the use of apps, data mining for analysis and game design.
Classification	Public Measures + Identification/Design (P/I) Public Measures + Data collection (P/D) Public Measures + Data Analysis (P/A) Public Measures + Results/Action (P/R)

3. PublicCo project	
Country(ies)	Switzerland
Source	Spitale, et al., 2021
Synopsis	The project aims to develop a tool that helps tackle the COVID-19 infodemic, with a focus on enabling a nuanced and in-depth understanding of public perception.
CS Methods	The project combines literature and media review and analysis as well as empirical research using mixed methods, including an online survey and diary-based research.
Classification	Public Measures + Identification/Design (P/I) Public Measures + Data collection (P/D)

4. CoronaCare	
Country(ies)	Germany
Source	Paul, et al., 2021
Synopsis	CoronaCare investigates how these socio-political distancing measures related to COVID-19 affect social care, i.e., the forms of care linked with social relationships in daily life. For the collection of voluntary ethnographic data, participants receive an 'ethnographic manual' introducing and describing the different techniques they can use to document their own lives.

CS Methods	A variety of research methods, including interviews, ethnographic materials, and a standardised questionnaire on workload (Copenhagen Psychosocial Questionnaire).
Classification	Public Measures + Data collection (P/D) Public Measures + Data Analysis (P/A)

5. Creation of community-informed pandemic plans	
Country(ies)	Canada
Source	Charania & Tsuji, 2012
Synopsis	The study was aimed to elicit and address First nations community members' suggested modifications to their community-level pandemic plans after the 2009 H1N1 influenza pandemic. The study area included three remote and isolated First Nations communities located in sub-arctic Ontario, Canada.
CS Methods	A community-based participatory approach and community engagement process (i.e., semi-directed interviews (n= 13), unstructured interviews (n= 4), and meetings (n = 27)) were employed. The data subsequently informed the modification of the community-level pandemic plans through an iterative participatory process.
Classification	Public Measures + Results/Action (P/R)

6. Predictors of incident SARS-CoV-2	
Country(ies)	International
Source	Lin, et al., 2021
Synopsis	The study focuses on individual behaviours related to SARS-CoV-2 to identify individual-level factors associated with one's risk of contracting SARS-CoV-2. It comes to be a cohort study with 2.4 million participant-days of data from participants in 99 different countries providing unprecedented geographical diversity for a study analysing individual-level factors associated with the risk of SARS-CoV-2. The study used the COVID-19 Citizen Science Study, an international, community and mobile-based study collecting daily, weekly, and monthly surveys in a prospective and updated manner.
CS Methods	Crowdsourcing using an app.

Classification	Public Measures + Data collection (P/D)

7. Covid Symptom Study	
Country(ies)	Sweden
Source	Kennedy, et al., 2022
Synopsis	The study was aimed at collecting data on COVID-19 symptoms to predict hospital admission. The app-based COVID Symptom Study was launched in Sweden in April 2020 to contribute to real-time COVID-19 surveillance. Overall, 143,531 study participants have been enrolled (≥18 years) who contributed 10.6 million daily symptom reports between April 29, 2020, and February 10, 2021. Data from 19,161 self-reported PCR tests were used to create a symptom-based model to estimate the individual probability of symptomatic COVID-19.
CS Methods	Crowdsourcing using an app.
Classification	Surveillance + Data collection (S/D)

8. Study on the emotional responses to the threat of coronavirus	
Country(ies)	Serbia
Source	Sadiković, et al., 2020
Synopsis	The study examined factors contributing to the emotional responses to the threat of coronavirus infection and isolation due to a pandemic. A custom web application was developed for participants to join the study (1,526 participants). For each participant, a random code was generated which they used to access different surveys and questionnaires. Citizen scientists actively participated in all phases of the research. For example, questions related to substance abuse during a pandemic were suggested by citizen scientists. They actively worked to promote the research, engage the respondents, and motivate them to complete the questionnaires on a daily basis. The results of the survey were regularly available on the research website, social networks and media, and citizen scientists contributed to their dissemination.
CS Methods	Crowdsourcing using a web application.
Classification	Research + Identification/Design (R/I) Research + Data collection (R/D)

	Research + Results/Action (R/R)

9. Study on malaria control	
Country(ies)	Rwanda
Source	Asingizwe, et al., 2019
Synopsis	The study is aimed at increasing surveillance of mosquitoes to control malaria.
CS Methods	Participatory design workshops have been organised through which all stakeholders including users (citizens in this case) that are affected by the upsurge of malaria in their environment, are invited to collectively define the problem that affects them and to set up mechanisms to solve the problem while anticipating their needs. Community members decided on the technical tools for collecting and reporting mosquito species, mosquito nuisance, and confirmed malaria cases. Community members set up a social structure to gather observations by nominating representatives to collect the reports and send them to the researchers.
Classification	Surveillance + Identification/Design (S/I) Surveillance + Data collection (S/D)

10. Study in the oral microbiome in cystic fibrosis	
Country(ies)	Spain
Source	Willis, et al., 2021
Synopsis	The study was aimed at collecting data on the specific composition of the oral microbiome in CF. In collaboration with Cystic fibrosis (CF) associations in Spain, oral rinse samples from 31 CF persons (age range 7-47) have been collected and matched controls, and then performed 16S rRNA metabarcoding and high-throughput sequencing, combined with culture and proteomics-based identification of fungi to survey the bacterial and fungal oral microbiome All donors received clear indications about the sample collection procedure in person, and the collection of the samples was carried out with the assistance of a researcher involved in the project, following a demonstration. All participants responded to a uniform questionnaire (see below), which was adapted for CF in collaboration with CF partner associations. Sample collection was

	coupled with science communication activities with CF individuals and their relatives, aiming to raise awareness about the microbiome, its role in health and disease, and its potential particularities in CF. The SLL2 project questionnaire about health and lifestyle was adapted to CF with the help of CF associations.
CS Methods	Involvement of patients in collecting personal health data through patients' associations.
Classification	Research + Data collection (R/D)

11. Behaviours, and disease occurrence to facilitate the public health response to COVID-19	
Country(ies)	USA
Source	Beatty, et al., 2021a
Synopsis	The objectives of the study are to generate knowledge about participant-reported COVID-19 symptoms, behaviours, and disease occurrence to facilitate the public health response to COVID-19. These methods highlight clinical study innovations and future directions for advancing science using digital clinical study methods. Novel engagement strategies such as participant-proposed questions, and feedback in the form of real-time results to the participants
CS Methods	Eureka Research Platform. digital study participation.
Classification	Surveillance + Identification/Design (S/I) Research + Identification/Design (R/I) Surveillance + Data collection (S/D) Research + Data collection (R/D)

12. Adverse effects after COVID-19 vaccination	
Country(ies)	USA
Source	Beatty, et al., 2021b
Synopsis	The objectives of this study were to describe adverse effects and identify factors associated with adverse effects after COVID-19 vaccination in participants in an online cohort study. In addition, the study sought to identify factors associated with more severe adverse effects. These results may help the public gain a greater understanding of the real-world experience of adverse effects after

	COVID-19 vaccination. We included data collected between March 26, 2020, and May 19, 2021. Participants must be 18 years or older, register for a Eureka Research Platform account, have an iOS or Android smartphone with a cellular phone number.
CS Methods	CCS is hosted on the Eureka Research Platform, a digital platform for clinical research studies including a mobile application (app) and web-based software.
Classification	Surveillance + Identification/Design (S/I) Research + Identification/Design (R/I)

13. The Influenzanet system	
Country(ies)	The Netherlands
Source	Koppeschaar, et al., 2017
Synopsis	The authors describe the Influenzanet system and provide an overview of results from several analyses that have been performed with the collected data, which include participant representativeness analyses, data validation (comparing ILI incidence rates between Influenzanet and sentinel medical practice networks), identification of ILI risk factors, and influenza vaccine effectiveness (VE) studies previously published. Influenzanet comprises country-specific websites where residents can register to become volunteers to support influenza surveillance and have access to influenza-related information. Participants are recruited through different communication channels. Following registration, volunteers submit an intake questionnaire with their postal code and sociodemographic and medical characteristics, after which they are invited to report their symptoms via a weekly electronic newsletter reminder. Several thousands of participants have been engaged yearly in Influenzanet, with over 36,000 volunteers in the 2015-16 season alone.
CS Methods	Web-based intake questionnaires containing various sociodemographic, medical, and behavioural questions.
Classification	Surveillance + Identification/Design (S/I) Research + Identification/Design (R/I) Surveillance + Data collection (S/D) Research + Data collection (R/D)

14. Covid Symptom Study,	
Country(ies)	UK
Source	Murray, et al., 2021
Synopsis	A smartphone-based surveillance study on COVID-19 symptoms in the population is an exemplar of big data citizen science. 4.7 million participants and 189 million unique assessments from March 2020. ExeTera, the software, was designed to address scalability challenges and to enable reproducible research across an international research group for datasets such as the Covid Symptom Study dataset.
CS Methods	ExeTera, an open-source data curation software designed
Classification	Surveillance + Identification/Design (S/I) Surveillance + Data collection (S/D)

15. Participatory Syndromic Surveillance of Influenza in Europe	
Country(ies)	France
Source	Guerrisi, et al., 2016
Synopsis	The use of a participatory system using unconventional means to engage the public in monitoring community health as the syndromic surveillance of influenza-like illness (ILI) in Europe. Through standardised online surveys (Influenzanet), the system collects detailed profile information and self-reported symptoms volunteered by participants resident in the Influenzanet countries. Established in 2009, the experience of 7 influenza seasons illustrates how Influenzanet has become an adjunct to existing ILI surveillance networks, offering coherence across countries, the inclusion of non-medically attended ILI, flexibility in case definition, and facilitating individual-level epidemiological analyses generally not possible in standard systems. Influenzanet was used in Italy for surveillance efforts to monitor cases of Zika virus infection, in France, a food-consumption survey submitted to Influenzanet participants for an outbreak investigation during a Salmonella epidemic in early 2016 provided public health authorities with timely findings to identify the source of the outbreak. Influenzanet can offer a timely tool to measure the epidemiological status, opinion, or behaviour of the general population regarding different indicators and diseases. The

	study shows limits on data collection, data may be incorrect or not ascertained. In any case, the limit does not affect the result
CS Methods	Standardised online surveys
Classification	Surveillance + Data collection (S/D)

16. Local Environmental Observer (LEO) Network	
Country(ies)	USA
Source	Mosites, et al., 2018
Synopsis	The LEO Network can offer advice on One Health issues such as food safety, air quality, and waste disposal. The system can provide indicators of potential community health issues, as well as a means of information dissemination. Although the LEO Network has multiple functions, it is not a surveillance system for health outcomes. In Alaska, health information is collected through reportable disease surveillance, sentinel surveillance, administrative data, and epidemiologic studies. The health information reported through LEO could serve as an indicator of issues requiring follow-up for public health practitioners.
CS Methods	Observatory, development of a mobile application
Classification	Surveillance + Identification/Design (S/I) Surveillance + Data collection (S/D)

17. Predictors of incident viral symptoms ascertained in the era of COVID-19	
Country(ies)	USA
Source	Marcus, et al.,2021
Synopsis	It can be difficult to track individual-level characteristics and behaviours, particularly as they are dynamic and changing over time, as they relate to incident disease. Members of the public may benefit by understanding strategies under their direct control that may influence their own risk of infection and viral transmission. Tracking viral infection is hindered by the absence of universal and repeated testing. In the absence of such testing, recent evidence suggests that symptoms themselves may be useful markers of SARS-CoV-2 infection. In the past, ascertainment of viral symptoms has relied on assessments of those seeking medical care or retrospective surveys that may be prone to recall bias. Given the current near-ubiquity of

	smartphones and the use of related mobile apps, technology is now available to regularly and repeatedly query large numbers of individuals over time, providing access to symptom development as it arises. Although monitoring for viral symptoms may be neither sufficiently sensitive nor specific for SARS-CoV-2 infection, these outcomes are, by their nature, inherently experienced by the individual, potentially providing valuable information that may be best leveraged by modern mobile technology. We conducted a worldwide mobile application-based prospective cohort study available to English-speaking adults with a smartphone. We collected self-reported characteristics, exposures, and behaviours, as well as smartphone-based geolocation data.
CS Methods	Worldwide mobile application
Classification	Surveillance + Data collection (S/D)

18. School Citizen Science Programs in Infectious Disease Surveillance	
Country(ies)	The Netherlands
Source	Abourashed, et al., 2021
Synopsis	Students can collect data that are not always easily accessible to expert researchers, which can give a better picture of the true epidemiological situation of various diseases. This review's objectives are to determine success factors in terms of data quality and students. The authors found 23 projects, none of the projects found focused on infectious disease surveillance, and the majority centred around species biodiversity. Overall, students at different educational levels and disciplines were able to collect usable data that was comparable to expert data and had positive learning experiences. The taxonomy for school CS programs was performed through peer-reviewed literature searched from PubMed, Education Resources Information Center (ERIC), SocINDEX (EBSCO) and PsycINFO. For the search, we used (a variation of) the following terms: (1) "citizen science" and "education" or (2) "citizen science" and "school". For the databases, queries were restricted to titles, abstracts and full texts written only in English.
CS Methods	PubMed, Education Resources Information Center (ERIC), SocINDEX (EBSCO) and PsycINFO
Classification	Coordination + Data collection (C/D)

	Coordination + Data analysis (C/A)

19. Citizen science initiative on BCG and Covid-19	
Country(ies)	Spain and Russia
Source	de la Fuente, et al., 2021
Synopsis	Current results do not provide conclusive evidence on the effect of BCG vaccination on COVID-19 alone or in combination with other factors. To address this limitation, in this study we used a citizen science initiative on the COVID-19 pandemic to collect data worldwide. A questionnaire was conducted from 2 October 2020 to 30 October 2020 containing 10 qualitative questions (sex, blood group, country of residence, BCG vaccination, COVID-19 diagnostic, hospitalization with COVID-19, PCR test, antibody test, symptomatic and consent), two quantitative questions (age, duration of symptoms) and one space for free text (symptoms description) (total of 13 questions) was circulated via e-mail and social networks (i.e., Twitter, LinkedIn). 1,233 individuals were involved in the CS study for analysing the factors and characteristics of affected individuals about BCG vaccination. For the first time, the results of our study suggested that vaccination with BCG may increase the risk for COVID-19 at a certain age, particularly in individuals vaccinated in childhood.
CS Methods	Questionnaires via e-mail and social networks
Classification	Surveillance + Identification/Design (S/I) Surveillance + Data collection (S/D)

20. Oral microbiome	
Country(ies)	Spain
Source	Willis, et al., 2018
Synopsis	Here, the authors used a citizen science approach and 16S profiling to assess the oral microbiome of 1,500 adolescents around Spain and its relationships with lifestyle, diet, hygiene, and socioeconomic and environmental parameters. All participants, and at least one of their parents or legal guardians for those under the age of 18, signed a consent form to use their saliva samples for microbiome research.

	The target population was teenagers in the third course of Spanish secondary compulsory education (ESO), ages 13–15 years old. Additionally, they also collected samples from teachers of the participating schools. Schools were selected among those who volunteered to cover a broad range of Spanish provinces. Samples were collected from February to April 2015. Participants were asked to answer one questionnaire inquiring about aspects relevant to their hygiene and dietary habits. Available at the PhenX toolkit (consensus measures for Phenotypes and eXposures), which provides recommended standard data collection protocols for conducting biomedical research and which has been recommended by the microbiome research community.
CS Methods	Questionnaires
Classification	Surveillance + Data collection (S/D) Research + Data collection (R/D)

21. Test of crowdsourced eligibility in COVID 19	
Country(ies)	UK, Austria, USA
Source	Noel-Storr, et al., 2022
Synopsis	Crowdsourcing platform Cochrane Crowd has engaged a global community of 22,000 people from 170 countries. To test whether a crowd could accurately assess study eligibility for reviews under time constraints the authors created four crowd tasks, corresponding to four Cochrane COVID-19 Rapid Review and the time to produce required training modules, crowd sensitivity, specificity, crowd consensus and time taken to complete was analysed. The authors conducted a crowdsourced screening exercise (uploaded and an interactive training module for each activity) using the sets of search results identified from a convenience sample of four Cochrane Rapid Reviews produced in response to the COVID-19 pandemic. The four reviews were: • Quarantine alone or in combination with other public health measures to control COVID-19; • Barriers and facilitators to healthcare workers' adherence with infection prevention and control; • Universal screening for Severe Acute Respiratory Syndrome Coronavirus 2; • Convalescent plasma or hyperimmune immunoglobulin for people with COVID-19

	Across all four reviews, 14,299 records were screened by 101 crowd contributors. The crowd completed each screening task within 48-h for three reviews and in 52 h for one. Sensitivity ranged f 94% to 100%. Crowdsourcing can play a valuable role in study identification and offers willing contributors the opportunity to help identify COVID-19 research for rapid evidence syntheses.
CS Methods	Crowdsourced, interactive training module
Classification	Surveillance + Identification/Design (S/I) Research + Identification/Design (R/I) Surveillance + Data collection (S/D) Research + Data collection (R/D)

22 Disease-Carrying Insects	
Country(ies)	USA
Source	Munoz, et al., 2018
Synopsis	We propose a system that assists infectious disease experts in the rapid identification of potential outbreaks resulting from arboviruses (mosquitoes, ticks, and other arthropod-borne viruses). The proposed system currently identifies mosquito larvae in images received from citizen scientists. Mosquito-borne viruses, such as the recent outbreak of the Zika virus, can have devastating consequences in affected communities. We describe the first implemented prototype of our system, which includes modules for image collection, training of image classifiers, specimen recognition, and expert validation and analytics. The results of the recognition of specimens in images provided by citizen scientists can be used to generate visualizations of geographical regions of interest where the threat of an arbovirus may be imminent. Our system uses state-of-the-art image classification algorithms and a combination of mobile and desktop applications to ensure that crucial information is shared appropriately and accordingly among its users.
CS Methods	Deep Learning network (CaffeNet) and a specific mobile application for image collection
Classification	Surveillance + Data collection (S/D)

23. Public health emergency preparedness for tick-borne diseases	
Country(ies)	Sweden
Source	De Vries, et al., 2018
Synopsis	This case study project aims to identify enablers and barriers for unity and institutional synergies related to preparedness and control of tick-borne diseases. Specifically, the study aims to: • identify good practices and patterns of cooperation between affected communities and the official institutions mandated to address tick-borne diseases such as TBE and Lyme borreliosis; • identify inter-sectoral collaboration between health and non-health-related sectors about tick-borne diseases, such as TBE; • identify model community engagement activities for other EU countries. A case study research design included the following methodologies: • Official documents and media reports; • Interviews with a range of experts working at national and community levels (n=26); • Two focus group discussions with community representatives (n=9); • Participant observation at the Dutch National Green Lyme Working Groups; • Stakeholder mapping. Fieldwork was conducted during a visit to the Netherlands between 17 November and 5 December 2017. The data were subjected to thematic analysis in Atlas.Ti qualitative software and UCINET social network software.
CS Methods	Media reports, Interviews with experts, focus group discussions, Stakeholder mapping
Classification	Public measures + Identification/Design (P/I) Public measures + Data collection (P/D) Coordination + Identification/Design (C/I) Coordination + Data collection (C/D)

24. Arboviral vector surveillance	
Country(ies)	Solomon Islands
Source	Craig, et al., 2021
Synopsis	The need for a better understanding of the arboviral disease spread through the study of disease-carrying mosquitoes. Traditional surveillance tools are limited by jurisdictional and logistics limits, to overcome these, we undertake a pilot study designed to explore if citizen science provides a feasible strategy for arboviral vector

	surveillance in small developing Pacific Island contexts. The authors recruited, trained, and equipped community volunteers to trap and type mosquitos within their household settings, and to report count data to a central authority via short-message-service. Participants collected data for 78.3% of the study period. The authors analysed the motivation for participation and the barriers to participation. In general, the authors note that the success of citizen science-based surveillance is dependent on the appropriate selection of equipment and participants, and the quality of engagement and support provided.
CS Methods	One-day training, mosquito identification card, SMS
Classification	Surveillance + Data collection (S/D)

25. Learning the language of science	
Country(ies)	USA
Source	Damiani, et al.,2021
Synopsis	The purpose of this study was to explore how citizen scientists describe their role in communication with researchers. In-depth interviews (N = 9) were conducted with citizen scientists at a translational health research centre. The results include that citizen scientists were invested in learning researchers' discipline-specific language and viewed small group sizes as conducive to their active participation. Programs can apply these findings to improve citizen scientists' long-term engagement in research.
CS Methods	In-depth interviews
Classification	Research + Data collection (R/D)

26. Epidemiological survey COVID-19	
Country(ies)	Brazil
Source	Santos de Melo, et al., 2020
Synopsis	This study shows a model epidemiological survey to detect the prevalence of SARS-CoV-2 and to demonstrate a new health technology tool, whose use could be extended to other parts of Brazil. MonitoraSUS application is a technological product developed by our group of researchers. Volunteers have access to the result of their serological and biological tests through this app. It

	also geolocates participants' seroreagent for SARS CoV-2, and, therefore, assists in the development of epidemiological control strategies, about effectively controlling social distance and keeping patients in isolation. The application of this model epidemiological survey can show the actual prevalence of the disease. To do this, our group developed a new technological tool that could be used to record and analyze data on the sociodemographic characteristics, comorbidities, and geolocation of patients with the outcomes. The use of this epidemiological survey model is an effective, and inexpensive strategy to measure the prevalence of confirmed cases of COVID-19 and can contribute to improved outcomes for the population by providing a better understanding of the distribution of the disease and allowing more effective social distancing measures to be put in place.
CS Methods	MonitoraSUS application
Classification	Surveillance + Data collection (S/D)

27. Surveillance and Modelling for Pandemic Preparedness	
Country(ies)	Georgia
Source	Monto, et al., 2006
Synopsis	Pandemic preparedness also involves the application of current surveillance techniques to past pandemics to identify their viruses and patterns, as well as the estimation of the potential burden of future pandemics. The recent development of molecular diagnostics has shed new light on the origin and structure of the viruses responsible for the past 3 pandemics, allowing for comparisons with new viruses identified through ongoing viral surveillance. Models previously used to estimate hospitalizations and mortality associated with past epidemics and pandemics have evolved to estimate the burden and required surge capacity of future pandemics. The CDC provides online modelling tools, FluAid and Flu Surge, based on Meltzer's studies, to help public health planners and policymakers plan and prepare for the next pandemic. These software programs can use state-specific statistics to approximate the impact of a pandemic on a given area. By entering state-specific rates for outpatient visits, hospitalizations, and/or deaths, state

	health officials can calculate the expected number of these events during a pandemic.
CS Methods	FluAid and Flu Surge statistic predicting methods software
Classification	Surveillance + Data collection (S/D)

28. Emerging infectious disease preparedness in private hospitals	
Country(ies)	India
Source	Ambat & Vyas, 2020
Synopsis	Hospital preparedness is a key step in strengthening a country's ability to address any public health emergency. In India, 80% of the healthcare utilization happens in private hospitals, it is important to assess the preparedness level of these hospitals against emerging infectious diseases. The study was a cross-sectional study, conducted between January 2019 and May 2019, 54 hospitals were enrolled in the study. A predesigned, semi-structured, and validated questionnaire was administered to administrative staff and doctors and laboratory personnel, and responses were recorded. It was found that there was a need to enhance the preparedness of the hospitals in response to emerging infectious diseases. The findings were suggestive of a need for preparedness of the hospitals against the upsurge of emerging infectious diseases.
CS Methods	Validated questionnaire
Classification	Surveillance + Data collection (S/D)

29. Smartphone apps test and track infectious diseases	
Country(ies)	USA
Source	Ravindran, 2021
Synopsis	The authors describe the importance of smartphones in citizen science projects. Their diffusion worldwide offers unprecedented opportunities for disease tracking, diagnostics and citizen science. Examples include apps that enable phone users to monitor COVID-19 symptoms, count disease-carrying mosquitoes and detect microscopic pathogens. They could even help the world to prepare for the next pandemic. The authors describe several examples of citizen science projects for tracking diseases such as Zika, Dengue

	and malaria, as well as covid-19 symptoms which use smartphone applications to collect data.
CS Methods	Smartphone app
Classification	Surveillance + Data collection (S/D)

30. Crowdsourced disease surveillance	
Country(ies)	Canada
Source	Lee, et al., 2021
Synopsis	Since 2015, FluWatchers, the program and its more than 12,000 participants, have been helping to improve the quality of public health. Weekly, participants, compile a dataset for the Canadian public health agency for surveillance and detection of ILI (Influenza-like illness). FluWatchers is a participatory syndromic surveillance system that relies on Canadian volunteers reporting cough or fever symptoms to PHAC every week.
CS Methods	Questionnaires organized by Canadian Network for Public Health Intelligence, scientific computer-based platform, Crowdsourced.
Classification	Surveillance + Identification/Design (S/I) Surveillance + Data collection (S/D)

31. OneHealth approach to reduce infection and antimicrobial resistance in children.	
Country(ies)	India, Indonesia, and Chile
Source	Manikam, et al., 2020
Synopsis	The Childhood Infections and Pollution Consortium (CHIP)1 is designed to reduce the rise of childhood infections and AMR, especially in children under 5 in urban slums. CHIP is composed of interdisciplinary academics, health professionals, veterinarians, international and local nongovernmental organizations, veterinarians, international and local non-governmental organizations, current and past policymakers, local artists, and community champions. The CHIP consortium invites collaboration on research, targeted investment, and co-development of slum interventions. Social mapping and 1:1 interview with mothers and key informants in urban slums in India, Indonesia and Chile. Use of a geo-tagged action camera geo-referenced camera to observe potential infection pathways and sociocultural aspects of each

	community. Interviews explored the slum dwellers' understanding of infections and their routes of transmission and provided us with the feasibility of collecting biological (nose, throat, faeces, etc.) and nonbiological (soil, water) data.
CS Methods	Interviews, geo-tagged action camera geo-referenced camera
Classification	Surveillance + Identification/Design (S/I) Surveillance + Data collection (S/D) Surveillance + Data analysis (S/A) Public measures + Identification/Design (P/I) Public measures + Data collection (P/D) Public measures + Data analysis (P/A)

32. Covid-19 Participatory Disease Surveillance	
Country(ies)	India
Source	Garg, et al., 2020
Synopsis	The creation of an "Aarogya Setu" app based on a participatory surveillance mechanism, which complements the current surveillance system, has been useful to identify Covid-19 cases that are not declared to the health system, making data analysis faster, limiting the spread of the pandemic and avoiding overcrowding in health facilities.
CS Methods	It requires the use of an app based on self-reporting of symptoms and using geolocation data and Bluetooth, it was possible to assess proximity to a COVID-19-positive person by consulting government databases of confirmed COVID-19 cases.
Classification	Surveillance + Data collection (S/D) Public measures + Data collection (P/D)

33. "The BBC Four Pandemic": Leveraging citizen science and mobile phones to model the spread of disease	
Country(ies)	UK
Source	Kissler, et al., 2020
Synopsis	In 2018, the (BBC) released the documentary "Contagion! The BBC Four Pandemic" to describe the science behind pandemic preparedness in the UK. The authors of this article were responsible for producing a mathematical simulation for this documentary about

	how a highly contagious respiratory pathogen could spread in the UK. According to the documentary's narrative, "the outbreak" begins in the town of Haslemere, England.
CS Methods	The mathematical simulation is based on real human interaction models. A three-day citizen science experiment was conducted, during which the distance between two people of Haslemere's 469 total volunteers was continuously monitored via an app.
Classification	Surveillance + Data collection (S/D) Coordination + Data collection (C/D)

34. Method for Assessing Human-Pathogen Interactions in the Natural Environment	
Country(ies)	UK
Source	Jones et al., 2017
Synopsis	In this paper, the authors describe a novel method, involving citizen scientists, to sample natural environments in search of bacteria belonging to *Campylobacter* species to study its distribution during seasons, in different kinds of soil and about human presence.
CS methods	Citizen scientists have been asked to wear boot socks over walkers' shoes and then walk over wide areas. Socks have later been analysed in search of the different bacterial species. Citizen scientists have been divided into groups of three walkers and have walked along one of six tracks several times over a span of months in different regions of England.
Classification	Surveillance + Data collection (S/D) Research + Data collection (R/D)

35. Modelling the COVID-19 pandemic in context: an international participatory approach	
Country(ies)	UK
Source	Aguas et al., 2020
Synopsis	In the setting of this citizen science initiative, an international consortium of citizens and public health experts has been created to develop models of infectious disease to submit to institutions for the elaboration of effective strategies to control the COVID-19 pandemic.
CS methods	The mathematical model that has been employed was elaborated by professionals and used by groups of citizens to ask the most important

	questions according to the different cultural, geographical, and social contexts.
Classification	Public Measures + Data collection (P/D) Health Measures + Data collection (H/D) Coordination + Data collection (C/D)

36. CSASR	
Country(ies)	Iran
Source	Vahidi, et al., 2021
Synopsis	In the project, titled COVID-19 Self-Assessment and Self-Reporting System and Application (CSASR), volunteers are required to provide personal data and answer questions about their symptoms and risk factors of COVID-19
CS methods	Digital-based self-assessment questionnaires. Further, the tool provides advice on whether to visit a healthcare centre or not.
Classification	Surveillance + Data collection (S/D)

37. AC19	
Country(ies)	Iran
Source	Vahidi, et al., 2021
Synopsis	Under the project, titled AC19, an app has been used to collect data useful to estimate COVID-19 distribution and the size of the outbreak in the country, which helped raise awareness and convinced citizens to stay at home.
CS methods	Mobile and web app where volunteers provided their telephone number and biometric information. Based on their symptoms and medical history, they receive recommendations on what to do next. The app also gives news and updates about the pandemic and regulations.
Classification	Surveillance + Data collection (S/D) Public Measures + Data collection (P/D)

38. Digital contact tracing (Mask)	
Country(ies)	Iran
Source	Vahidi, et al., 2021

Synopsis	Under the project, citizens were asked to register through an Iranian telephone number and provide information about their health. The app had access to proximity contacts through Bluetooth, GPS, manual pinning of location and scanning of barcodes/QR codes. The app also provided an interactive map of confirmed and suspicious COVID-19 cases across Iran.
CS methods	Both mobile and web apps are used to collect health-related data.
Category	Surveillance + Data collection (S/D) Public Measures + Data collection (P/D)

39. Gharbalgar	
Country(ies)	Iran
Source	Vahidi, et al., 2021
Synopsis	The project was aimed at collecting audio samples to train machine-learning-based predictive models for early screening and diagnosis of suspicious and positive COVID-19 cases.
CS methods	Through a mobile and web app, users were asked to fill in a basic questionnaire and record a few seconds of coughing through the microphone of their device. More than 500 volunteers contributed to the project.
Classification	Surveillance + Data collection (S/D) Research + Data collection (R/D)

40. CHIACD	
Country(ies)	Iran
Source	Vahidi, et al., 2021
Synopsis	When the main resources to fight COVID-19 were only in Chinese, a language instructor had the idea to create this project to transfer China's experience to Iranian health workers. The project gathered several groups of citizens with different expertise: Chinese and Persian language students and scholars, people with a background in medicine and engineering, and Afghan volunteers. This variety of citizens has been divided into several working groups to best put to work their different capabilities. The groups mainly used the messaging app WeChat to communicate and organize the different activities. All

	translations have been reviewed to ensure an appropriate quality of work.
CS methods	Use of citizen scientists' expertise in a health policy.
Classification	Public Measures + Results/Action (P/R) Health Measures + Results/Action (H/R)

41. Global Digital Citizen Science Policy for Pandemics	
Country(ies)	Canada
Source	Katapally, 2020
Synopsis	This article outlines a comprehensive digital citizen science policy that provides the theoretical and methodological basis for the ethical acquisition of big data from citizens to address pandemics such as COVID-19.
CS methods	With more than three billion smartphones in circulation globally, innovative mobile health (mHealth) apps have been brought to life, enabling digital epidemiology to prevent, detect and manage the COVID-19 pandemic, as well as to predict and prepare for subsequent waves. Another app is the SMART Framework.9 which integrates citizen science, community-based participatory research, and systems science through tools for conducting population health research in the digital age.
Classification	Surveillance + Data Collection (S/D)

42. Analysis of Maintaining Engagement of Citizen Scientists in an infectious disease surveillance Project	
Country(ies)	USA
Source	Smith, et al., 2021
Synopsis	In this paper, the effectiveness of the guest user feature has been tested in increasing the number of weekly symptom reports and in improving the frequency of registered user reporting. The old surveillance system has been changed with a new system. The authors compared the implementation of the old system with the new Influence - Flu Near You (FNY) – that collects weekly health reports from its volunteers. High levels of engagement and constant user participation are essential to accurately track the disease and estimate its burden. This paper evaluated the impact of three

	measures implemented by FNY to maintain high levels of CS involvement. The users can register on web site and each week are sent a reminder email with a link to a brief weekly report to evaluate the health status of the user. If a user reports "Not feeling well," the user has the opportunity to select symptoms they experienced during the previous week. The user is then asked follow-up questions about the date of illness onset and whether the user sought a health professional for care.
CS methods	Online website, interviews with the users.
Classification	Surveillance + Data collection (S/D)

43. Student Crowdsourcing and service-learning Strategy for Implementation of Antibiotic Discovery	
Country(ies)	Spain
Source	Maicas. et al., 2020
Synopsis	Finding solutions to antibiotic resistance requires the development of new antimicrobials and new strategies, including increased social awareness of the problem. The Small World Initiative (SWI) and the Tiny Earth (TE) network are citizen science programs that pursue the discovery of new antibiotics from soil samples and the promotion of scientific culture. SWI and TE projects were put into practice in Spain, trained 140 university students to disseminate this initiative into schools, involving teachers and students as researchers. A total of 7,002 bacterial isolates were obtained from 366 soil samples and tested, moreover a specific app for the geolocation of sampling sites was developed. Recruitment used a crowdsourcing strategy and a Service Learning (SL) educational approach, with the intent to encourage students to pursue careers in science and to involve them in the discovery of soil microorganisms producing new antimicrobials.
CS methods	App for geolocation, crowdsourcing strategy, and Service Learning.
Classification	Research + Data collection (R/D)

44. Surveillance of hormonal biomarkers and subjective measures of well-being in COVID-19 pandemic status	
Country(ies)	Germany
Source	Schneider, et al., 2022

Synopsis	In social interactions, the potential neuroendocrine mechanisms that have healthy social effects include the release of oxytocin and its regulation of stress axes. During the first wave of the Covid-19 pandemic in a large cross-sectional online survey anxiety and depression symptoms, loneliness, and attitude towards social touch were measured with the online Social Touch Questionnaire (STQ) online.
CS methods	Online Social Touch Questionnaire.
Category	Research + Data collection (R/D)

45. Pervasive Computing for Disaster Response	
Country(ies)	India and USA
Source	Bunn, 2011
Synopsis	The objective of this project is to develop key components of community-based pervasive systems which will allow citizens to respond to disasters. The research will enable a new generation of community-based cyber-physical systems, in which the community helps to detect, communicate, and respond to rapidly evolving events such as earthquakes, tsunamis, fires, floods and epidemics. The development of sensors and software enables the collection of situational information and the dissemination of alerts. Techniques are also being developed for reliable and timely alerting of communities and individuals; these techniques exploit geographical and societal scale correlations to improve the speed and resilience of the dissemination process.
CS methods	Development of sensors and software which enable the collection of situational information and the dissemination of alerts. Classification or tagging, Data analysis, Geolocation, Identification, Learning, Measurement, Observation.
Classification	Surveillance + Data collection (S/D) Research + Data collection (R/D)

46. Kenai River Baseline Water Quality Monitoring	
Country(ies)	USA
Source	https://www.kenaiwatershed.org/science-in-action/research-information/water-quality/

Synopsis	Water is at the core of everything we do. It not only defines us as an organization, but the waters of the Kenai Peninsula literally and figuratively connect us with our communities and ultimately the resources and people we work for. The Kenai Watershed Forum maintains a comprehensive water research program that revolves around a fundamental understanding – and sustainability – of water quality and water quantity on the Kenai Peninsula and beyond. Kenai enrolled volunteers participate in water quality sampling. Water quality analysis is also aimed at preventing infectious diseases by measuring fluctuations in bacteria levels throughout the summer, including during the public use of these beaches during the high-traffic Kenai River Personal Use Fishery.
CS methods	Online questionnaire for enrolment, the citizen volunteers are directly involved in project activities for data collection.
Classification	Surveillance + Data collection (S/D)

47. Disease Surveillance for Dengue and Chikungunya - PROJECT IN PROGRESS	
Country(ies)	USA and Mexico
Source	https://www.citizenscience.gov/catalog/173/#
Synopsis	CDC's Division of Global Migration and Quarantine, Skoll Global Threats Fund, and the University of Arizona are collaborating to develop a mobile app to allow community members to report symptoms of illness, and day-biting mosquitos, to monitor the potential emergence of Zika, dengue, and chikungunya in the U.S.-Mexico border region, and provide education to participants.
CS methods	App to collect data.
Classification	Surveillance + Data collection (S/D)

48. The Invasive Mosquito Project: A Public Education Tool- PROJECT	
Country(ies)	USA
Source	http://www.citizenscience.us/imp/
Synopsis	One of the main goals of the project is to transform teachers and students into citizen scientists. The Invasive Mosquito Project provides educational materials for teachers and students. As part of data gathering, students collect mosquito eggs around their houses. After a week, upon the presence of eggs, students bring the mosquito

	eggs to class and choose to raise ¼ of the eggs to adults following the protocol and safety measures provided in the lesson plan. The remaining eggs were sent to USDA. Classes have the opportunity to assess local, regional and national mosquito distribution data and to determine if there is an increased risk of particular pathogens in their community based on the presence of certain mosquito vector species. In addition to the public education component, another goal of the IMP project is to monitor invasive mosquito species in the United States
CS methods	Partnered approach to citizen science given each classroom is paired with mosquito and public health professionals that support the lesson plans and data gathering.
Classification	Surveillance + Data collection (S/D)

49. GoViral PROJECT	
Country(ies)	Global
Source	Chunara, 2013
Synopsis	GoViral is a free and real-time online Cold & Flu surveillance system administered by researchers at New York University. Participants will get a Do-It-Yourself flu saliva collection system that they can keep and use at home if they are feeling sick. All samples will be analysed at a central laboratory that checks for 20 different viral infections. GoViral participants will get their laboratory results and, through the aggregate data, be able to see what infections and symptoms are going around near them so they can take appropriate public health measures and understand when something might be abnormal. The data will be used for research purposes only.
CS methods	Saliva collection system self; biological samples collection.
Classification	Research + Data collection (R/D)

50. Predictors of self-reported symptoms and testing for COVID-19	
Country(ies)	Canada
Source	Wu, et al., 2020
Synopsis	Population-based surveys to estimate the prevalence of SARS-CoV2 infection are useful to understand distributions and predictors of the infection. The Angus Reid Institute (ARI) conducted an online survey from April 1–5, 2020, the first-ever nationally representative survey in

	Canada polled 4,240 adults aged 18 years and older about self-reported COVID experience in March, early in the epidemic. The survey questionnaire included questions related to COVID and socio-demographic characteristics among both the respondents and members of their households. Questions related to COVID symptoms included whether the respondent experienced any of a list of symptoms. Self-reported symptoms are, by their nature, subject to limitations and misclassification. However, the trends over time, even with misclassification, are useful for understanding trends in the actual underlying prevalence of infection. In conclusion, COVID surveillance using nationally representative surveys is essential.
CS methods	Online survey.
Classification	Surveillance + Data collection (S/D)

51. Ebola and Marburg virus using quantitative and participatory epidemiology techniques	
Country(ies)	Uganda
Source	Nyakarahuka, et al., 2017
Synopsis	We describe knowledge and attitude towards Ebola and Marburg virus outbreaks in two affected communities in Uganda to inform future outbreak responses and help in the design of health education and communication messages. The study was a community survey done in Luweero, Ibanda and Kamwenge districts that have experienced outbreaks of Ebola and Marburg virus diseases. Quantitative data were collected using a structured questionnaire and triangulated with qualitative participatory epidemiology techniques to gain a communities' knowledge and attitude towards Ebola and Marburg virus disease. The results highlight as the public health sector should enhance the community knowledge and empower them more by supplying educational materials for epidemic preparedness in future using appropriate communication channels as proposed by the communities
CS methods	Structured questionnaires, qualitative participatory epidemiology techniques.
Classification	Surveillance + Data collection (S/D) Research + Data collection (R/D) Public measures + Data collection (P/D)

52. *Experiment and Educational Modules to Improve Coronavirus Safety in Communities and Schools*	
Country(ies)	France and USA
Source	Eichler, et al., 2020
Synopsis	Appropriate communication of health response actions - or lack thereof- can impact both epidemiologic and economic trends, a major educational campaign is needed to build community cooperation toward the wide-scale use of face coverings to increase community resilience to both current and future infectious disease outbreaks such as COVID-19. A citizen science project exercise was presented here to promote discussion and greater awareness of facemask effectiveness by providing an innovative hands-on activity. Based on a validated spray simulation method, community members can observe first-hand how textile barriers stop the dispersal of coloured droplets. The educational module contains four experiments of varying difficulty and is freely available as an archive of the latest versions and community contributions as a website in multiple languages. The visualization of the module on mobile smartphones was through QR-code. The study used an online data submission form where citizen scientists (adults, supervised children, or teachers) can share the results of their experiments with the global community and see the aggregate responses globally.
CS methods	Device for experimental experiences QR code, website
Classification	Public measures + Results/Action (P/R)

53. *A crowd of BashTheBug volunteers reproducibly and accurately measure the minimum inhibitory concentrations of 13 antitubercular drugs from photographs of 96-well broth microdilution plates*	
Country(ies)	UK
Source	Fowler., et al., 2022
Synopsis	This study evaluated Tuberculosis, which is a respiratory disease treatable with antibiotics. Through the “BashTheBug project” hosted on the Zooniverse citizen science platform, a crowd of volunteers can reproducibly and accurately determine the MICs for 13 drugs and

	simply taking the median or mode of 11–17 independent classifications is sufficient.
CS methods	In total, 9,372 volunteers participated in classifying this dataset doing a total of 778,202 classifications. The project has collected a large number (20,637) of clinical TB samples, each having the MICs of a panel of 13 antibiotics measured using a 96-well broth microdilution plate with the majority of samples also undergoing whole genome sequencing. Samples were collected by 14 laboratories based in 11 countries spread across five continents and included all the major lineages and were biased towards drug resistance.
Classification	Research + Data collection (R/D)

54. Citizen science helps predict the risk of emerging infectious disease	
Country(ies)	USA
Source	Meentemeyer., et al., 2015
Synopsis	In this article citizen scientists played a key role in the spatial prediction of an emerging infectious disease. The yearly citizen-science program called “Sudden Oak Death (SOD) Blitz” engages and educates volunteers in detecting the causal pathogen during peak windows of seasonal disease expression. This program improved our understanding of disease dynamics and increased the accuracy of our predictive models.
CS methods	In this article, the citizen is involved in collecting large amounts of ecological data and citizen scientists played a key role in the spatial prediction of an emerging infectious disease. We used these data – many of which were collected from under-sampled urban ecosystems – to develop predictive maps of disease risk and to inform stakeholders on where they should prioritize management efforts.
Classification	Surveillance + Data collection (S/D)

55. The Asian tiger mosquito Aedes albopictus (Skuse) in Kosovo: First record	
Country(ies)	Kosovo
Source	Muja-Bajraktari, et al., 2022

Synopsis	After a citizen reported the presence of the Asian tiger mosquito (*Aedes albopictus*) on social media, the authors decided to investigate the presence of this insect in Kosovo.
CS methods	Volunteers cooperated with the authors by providing information about the mosquito's presence and by permitting to investigate their properties during the fieldwork.
Classification	Surveillance + Data collection (S/D)

56. Deep learning identification for citizen science surveillance of tiger mosquitoes	
Country(ies)	Spain
Source	Pataki, et al., 2021
Synopsis	Traditional mosquito monitoring requires catch and manual inspection by experts, which is very time-consuming to upscale to a global level. This is why new approaches like Mosquito Alert are relying on communities and the Internet.
CS methods	Mosquito Alert is a dedicated mobile app where users can take and upload pictures of mosquitoes. The app automatically attaches a geotag to the picture to have information about the localization of the mosquito.
Classification	Surveillance + Data collection (S/D)

Chapter Three

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Data analysis and orientations

Data analysis

The inventory of cases is not a representative sample of projects using CS and participatory practices in the domain of preparedness and response to infectious diseases. However, it can provide some general information about how such practices are used. In the following sections, a short analysis of the most relevant data is done.

A total of 200 articles was analysed, and of these, only 56 included participatory use of CS in the context of infectious diseases. The literature research was performed using the following scientific databases: Pubmed, GoogleScholar and Scopus.

Year of publication

The first set of data concerns the year of publication of the information sources used to set up the inventory.

The data are given in the figure below.

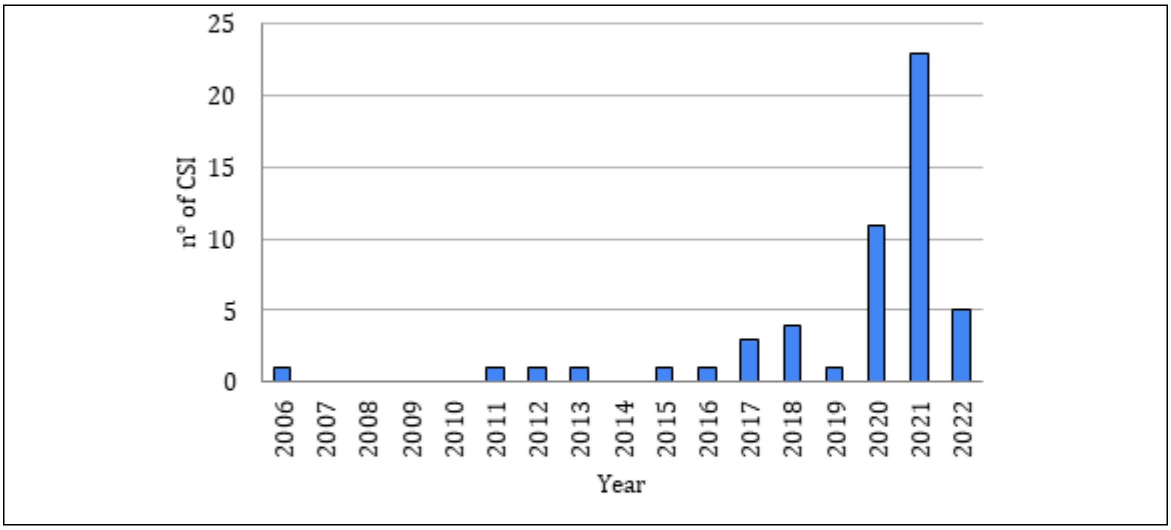

Fig. 5 – Distribution of the sources by year of publication

As it is easy to see, the sources are extremely recent. 39 sources out of 53 (74%) have been published in the last three years.

This trend could be the expression of an increased application of CS practices in research about preparedness and response to infectious diseases. This is likely also linked to the COVID-19 pandemic, which provided a new strong motivation for the development of this kind of study. Overall, 25 cases out of 56 (i.e., 45%) concerned the COVID-19 pandemic.

Probably, this trend also reflects a wider diffusion, during the last two decades, of citizen science as an approach to making science (as maintained by many scholars) as well as an increased interest of social researchers and policymakers towards CS.
Moreover, this growth could be also due to the remarkable rise over the last years in the application of IT technologies (apps, website platforms) to the implementation of wide empirical research programmes based on the involvement of citizens (see below).

Areas of application

The most interesting set of data is likely concerning the areas of application of CS-related practices in the preparedness and response to pandemics.
As explained above, a classification of the cases has been done based on the UTCP Model, combining, and adapting a model of citizen science and a model of the components of epidemic preparedness and response. Overall, 20 areas in which CS can be applied have been identified.
The figure below gives the distribution of cases by application area. The total does not correspond to the number of cases included in the inventory (56) since a group of them covers more than one area.

Table 5 – Distribution of the cases by application area according to the UTCP Model

CS Model **Preparedness/ Response Model**	PHASE 1 Identification/ Design (I)	PHASE 2 Data Collection (D)	PHASE 3 Data Analysis (Y)	PHASE 4 Results/ Action (A)	Total
SURVEILLANCE (S)	S/I	S/D	S/A	S/R	49
	10	38	1	0	
RESEARCH (R)	R/I	R/D	R/A	R/R	22
	5	16	0	1	
PUBLIC MEASURES (P)	P/I	P/D	P/A	P/R	22
	4	11	3	4	
HEALTH MEASURES (H)	H/I	H/D	H/A	H/R	2
	0	1	0	1	
COORDINATION (C)	C/I	C/D	C/A	C/R	6
	1	4	1	0	
Total	20	70	5	6	101

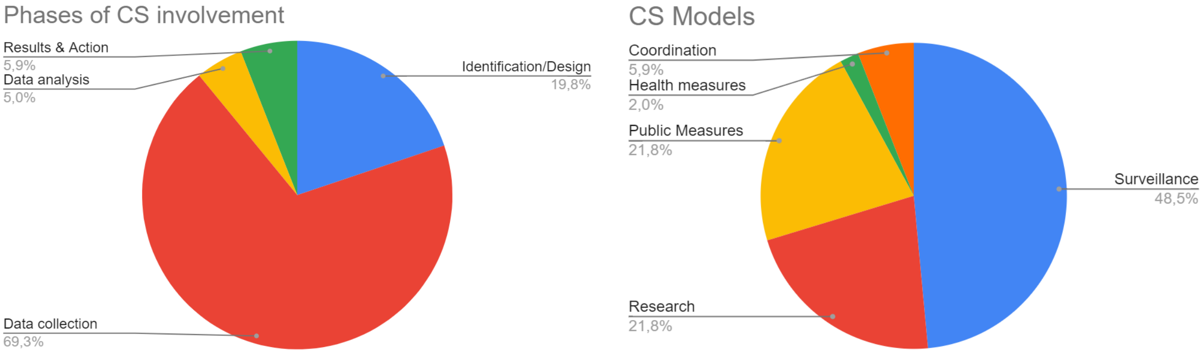

Fig. 6 – Distribution of the sources by application area according to the UTCP Model

The distribution is quite unbalanced. Citizens are primarily involved in data collection for purposes related to surveillance, research and, to a lesser extent, the development of public measures. In 70 out of 101 cases, the occurrences concern data collection. They are more than three times the occurrences falling into the category "identification and design", which is second in the ranking.
Further analysis of phase 1 (identification/design), results (not provided), has shown that only in 4 cases out of 20, citizens have been directly involved in the design activities while in the remaining 16 cases, they have been engaged in identifying health-related or social problems connected with infectious diseases.
This trend is not surprising. Indeed, citizens are more likely to be involved as scientists in activities where the production of fresh knowledge is essential, precisely as surveillance and research. Moreover, it likely mirrors the increasing use of apps and IT tools (see the following section below), allowing the collection of a wealth of data in a short time, with a limited effort by citizens and little cost for research institutions.
The use of IT technologies for involving citizens represented a big opportunity for research institutions and professional scientists, allowing them the implementation of wide research projects otherwise economically unsustainable. This approach does not necessarily entail a modification of the conventional approach to scientific research (which largely remains driven by professional scientists) and sometimes could even hide a sort of exploitation of citizens as a cheap workforce.
However, it is worth noticing that, in most cases, citizens serving as data collectors play an active role (for example, they interact with professional scientists and enjoy a degree of autonomy in data collection) and benefit from participation in terms of, e.g., awareness-

raising, science literacy, and scientific knowledge. Moreover, citizens' involvement in data collecting increases the level of transparency in research activities.

In very few cases the involvement of citizen scientists in the management of results and actions (6 occurrences) and the data analysis (5 occurrences) are reported. This suggests that citizens still have a very limited influence on some of the most intimate aspects of the research process (data interpretation is one of them) and on the social and policy exploitation of research results.

The limited involvement of citizen scientists in the development of health measures (2 cases) and coordination (6 cases) can be explained by the fact that these activities are not continuous (like surveillance) or frequent (like making research projects) but quite episodic, highly regulated, and specialistic. Adopting citizen science-related practices in these areas, for many policymakers and health practitioners, is far from being obvious.

The engagement of citizen scientists is higher in the development of public measures. This is an episodic activity too but, by nature, involves multiple actors, including, e.g., professionals (practitioners), local authorities, schools, welfare operators, NGOs, and volunteers. The participation of citizens is therefore more likely and, to a certain extent, inevitable.

Methods

The analysis of methods used in the CS initiatives is more difficult to do since research tools are many. A quite rough classification is given in the table below. In a few cases, more than one method has been used.

Table 6 – Distribution of the cases by method

Methods	Occurrences
Use of apps or website platforms	31
Survey	14
Interviews	6
Organisation of workshops or meetings	11
Other methods	5

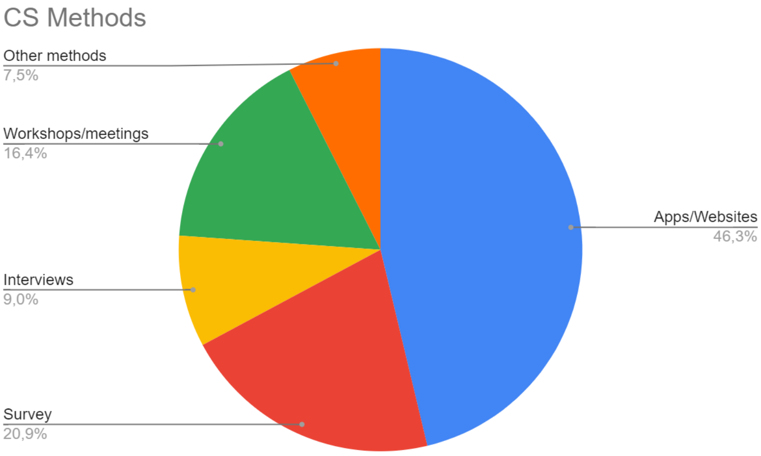

Fig. 7 – Distribution of the cases by method

The distribution of the methods shows how much IT technologies are increasingly playing a key role in Citizen Science. Indeed, apps and website platforms to involve citizen scientists are used in 31 cases out of 56 (55%).

This widespread use of IT technologies has probably an impact on the way citizen science projects are conducted. For example, two-way communication and personal contact are made more difficult because of the large number of citizen scientists involved (the inventory included cases in which more than 10,000 people have been engaged) and the usually large geographical scope of this kind of research (some of the cases of citizen science initiatives included in the inventory cover different countries and, in a couple of cases, they have global scope). However, the use of apps and website platforms is sometimes combined with organisational solutions facilitating interactions and participation (for example, the organisation of groups of data collectors mixing professional scientists and citizen scientists or the implementation of training sessions in person or online involving small groups of participants).

As for the other methods, in 11 cases (25%), surveys are carried out and in 6 cases (10% around) interviews are conducted. Consultation processes (workshops or other forms of meetings) are mentioned in 11 cases (20% around). These methods are likely linked to the involvement of smaller groups of citizen scientists and more intense two-way communication processes.

Geographical distribution

The last topic to consider is the geographical distribution of the cases included in the inventory. This is given in the table below.

Table 7 – Distribution of the cases by country

Countries	Occurrences
USA	15
UK	6
Spain	6
Iran	5
India	4
France	4
Canada	4
Global	2
Germany	2
Uganda	1
Switzerland	1
Sweden	1
Russia	1
Mexico	1
Kosovo	1
Indonesia	1
Chile	1
Austria	1

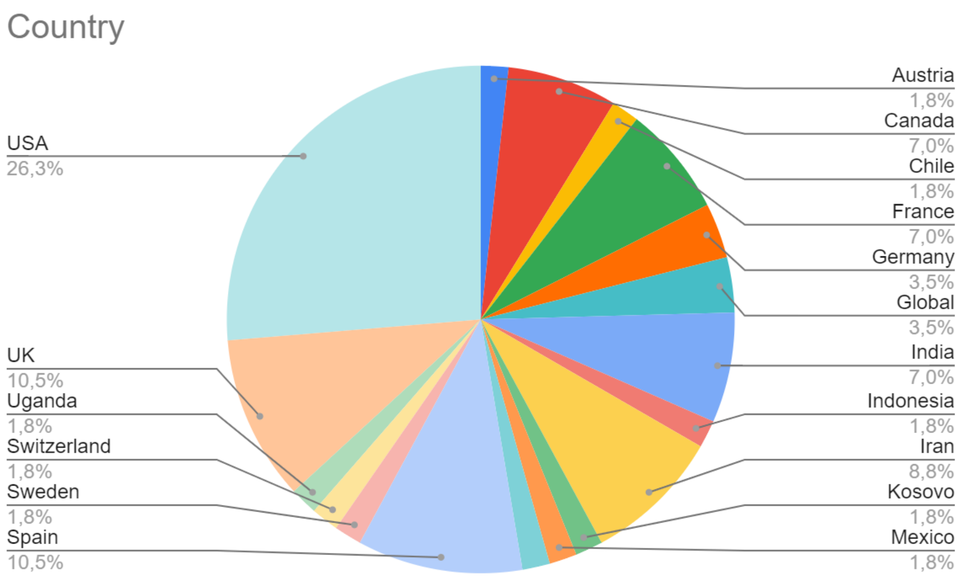

Fig. 8 – Distribution of the cases by country

Since the inventory is not based on a statistically representative sample (also because the size and features of the universe of CS projects in the field of preparedness and response to infectious diseases are unknown), the geographical distribution of cases is mainly useful to see to what extent the inventory is geographically balanced.

The concentration of cases in the USA (15 cases, i.e., more than 1 out of 4), is explainable both by the size of the country and the fact that in this country, the diffusion of citizen science is high.

Seven European countries (UK, Spain, France, Germany, Sweden, Kosovo, and Austria) are represented. Some large countries (for example, Italy and Poland) are not represented as well as some that are particularly advanced in terms of scientific production (for example, the Netherlands and Denmark).

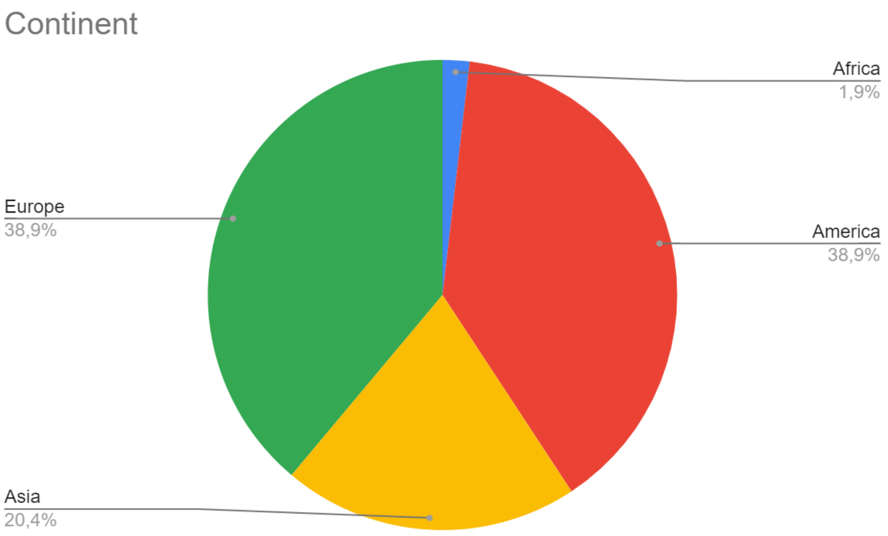

Fig. 9 – Distribution of the cases by continent

In regional terms, the Americas and Europe are equally represented (21 cases each, i.e., 37%), Asia is present with 11 cases and Africa with 1 case only (probably these latter regions are underrepresented). The absence of cases referring to Oceania (especially Australia and New Zealand, which are two small countries in terms of population but scientifically advanced) is to be highlighted.

Overall, the inventory seems to consider a fairly large number of countries (with a concentration in the US and Europe), although some important European countries and some regional areas are poorly or not represented at all.

Orientations

The UNITOV CSI is intended to develop a citizen science strategy for Italy's epidemic preparedness and response. The inventory was therefore aimed at providing an empirical basis, in the form of taxonomy, to allow this strategy to be developed.
The data collected allows identifying some orientations to help guide this process.

Expanding the application scope

The analysis of the cases included in the inventory identifies a limited scope in which citizen science is applied, i.e., data collection and, to a lesser extent, identification and design in relation to surveillance and research.

As noticed above, this trend is due to different reasons, including

- The growing use of apps and IT tools that have made the massive involvement of citizens as data collectors easy and rather cheap (at least in comparison to other approaches to engage citizens or conventional ways to collect data)
- The same nature of surveillance and research which are frequent or even continuous (in the case of surveillance) activities while other activities, like the development of new health or public measures, are more episodic

The engagement of citizens mostly as "data collectors" or "sensors", although beneficial for the same citizens, does not allow for fully exploiting the potential deriving from the use of citizen science. The risk is to develop an "augmented" model of science, i.e., a conventional approach to science whose capacity to collect data is augmented through the engagement of many citizens via IT technologies.
Indeed, the peculiar feature of citizen science resides in its capacity to involve citizens at an epistemic level, combining scientific knowledge with other kinds of knowledge (e.g., political, experiential, activist, traditional knowledge). Mixing different knowledge could prove essential, for example, to develop public measures, health measures and coordination systems, to interpret the data coming from research and surveillance activities and to disseminate, manage and exploit them. In this sense, citizen science can be viewed as a new model of making science and not only as a way to improve the conventional one.
Although the involvement of citizens and stakeholders in these areas is more difficult and requires time and two-way communication channels, an effort should be made under the UNITOV CSI to explore how and under which conditions CS practices can be applied also

in these areas, expanding as far as possible the application scope of citizen science and its potential results in the context of epidemic preparedness and response.

Deepening and articulating the methods

Another orientation, which is connected to the previous one, concerns the methods applied in the involvement of citizen scientists.

The inventory seems to show a strong convergence towards IT-based methods (use of apps, use of website platforms) which allow a massive involvement of citizens.

One of the consequences of such convergence is that the inventory includes a limited number of participatory methods and tools which can be potentially applied to preparedness and response to infectious diseases.

Nevertheless, over the last decades, there has been a huge development of participatory methods, tools, and approaches, many of them conceived for being used online, which could be extremely appropriate for engaging lay people, for example, in interpreting and managing scientific data or designing new public measures.

Thus, the second orientation is to carry out further analysis of the participatory approaches and tools that could adapt to the different areas of the UTCP model, even going beyond those reported in the inventory. This would allow articulation of the many participatory methods and techniques according to the different areas of the model, trying to find the most appropriate ones for each of them.

Verifying the UTCP model in the real world

The UTCP model is theoretical in nature. It is based on the combination and adaptation of two existing models, one referring to citizen science and one referring to preparedness and response to infectious diseases.

Inevitably, the real world is different from and more complex than the model we use to analyse it. To make an example, the boundaries between the different areas (for example, those between surveillance and research or those between data interpretation and results/action) could turn out to be much more blurred and difficult to identify than the model suggests. Moreover, local authorities, health practitioners, and stakeholders could have different models in mind and could use other categories to refer to the different components of preparedness and response activities.

The third orientation that emerges from the inventory is that the CSI should also be aiming to verify the usefulness and reliability of the UTCP model itself, identify its potential and limitations, and, if necessary, develop a more advanced version of the model.

The need for restitution

One of the aspects which emerges from the inventory is the limited involvement of citizens in the management of research results and the development of actions emerging from them.

This fact can be explained in different ways. However, it overall signals the presence of a gap between the production of scientific information and its use. In the context of conventional science, scientific information mainly becomes a matter of scientific publications or publications targeting an expert audience.

When citizen science is concerned, the process requires what can be referred to as "restitution", i.e., the transformation of data into information relevant to and comprehensible by citizen scientists, stakeholders, and the public at large.

This process is not mechanical. It comes to connecting scientific information to what is at stake with the research project and the different standpoints concerned with such a stake. For this reason, restitution requires adopting participatory approaches and two-way communication channels.

The fourth orientation is thus that of including restitution mechanisms in the UNITOV CSI tailored to the different targets (for example, general practitioners, local authorities, and NGOs) to avoid the use of results being limited to the scientific community. This could hamper the exploitation of research data and results in terms of social change and the development of public policies.

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