Societal Impacts 3 (2024) 100058

Contents lists available at ScienceDirect

Societal Impacts

journal homepage: www.journals.elsevier.com/societal-impacts

Social impact: Trusting open science for future pandemic resilience

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ARTICLE INFO

Keywords:
Open science
Epidemiological data
Data quality
Equal access
Transparency
Scientific collaboration

ABSTRACT

In response to the pressing need to improve epidemic preparedness, this paper presents the development and application of EPISOS, a project designed to improve the timeliness, completeness, and accessibility of epidemiological data. Through EPISOS, we have created a dynamic, cross-sectoral collaborative framework that supports the detection, monitoring, and risk assessment of emerging and re-emerging infectious diseases across Europe. This initiative not only addresses the challenges of standardizing data quality and resource availability, but also promotes equity in data access and use. The paper critically analyzes the difficulties encountered in these areas and outlines effective strategies for leveraging open science to strengthen public health responses. Integrating real-world examples, we illustrate the practical impact and potential of EPISOS in promoting scientific collaboration and transparency during health crises.

Subject area	Health Sciences
Category/categories of societal impact	Health
Sustainable Development Goals (SDGS) the research contributes to	*GOAL 4: Quality Education* *GOAL 10: Reduced Inequality* *GOAL 17: Partnerships to achieve the Goal*
Related research article OR Related supporting information Please provide a link to the webpage if relevant	*Project Description* In response to the growing need for a more agile and collaborative approach to public health surveillance, this research project focuses on the development of a pioneering model termed "Crowdsourcing Open-Source Case-Based Data." The primary objective is to establish a resilient framework for the consolidation, standardization, and transparent sharing of epidemiological data. This model aims to harness the collective intelligence of a diverse community of contributors, generating robust evidence to fortify public health decision-making processes. *Webpage available here* – https://tinyurl.com/episorveglianza
Stage of research	***In Progress***

When the world population was small and sparsely distributed, infectious diseases were deadly but local. Globalization and the constant movement of people have turned viruses and bacteria into mass killers. In less than two decades, there have been three major epidemics affecting the human population: SARS in 2003, H1N1 avian influenza in 2009, and Middle East Respiratory Syndrome (MERS) in 2012. And again, Ebola, Zika, HIV/AIDS, West-Nile to severe acute respiratory syndrome Coronavirus-2 (SARS-CoV-2). The best defense against a deadly new pathogen is aggressive suppression of early outbreaks, which requires their rapid detection.

During the COVID-19 pandemic, numerous scientific studies contributed to a better understanding of the virus, its modes of transmission and effective mitigation strategies. However, some of these studies have come under criticism regarding the transparency and reproducibility of results. The pandemic has brought back to the forefront the importance of openness, sharing and use of so-called real data to generate scientific evidence [1] that can enable policy makers to act in an informed manner and adequately consider the trade-off between health consequences and the social and economic effects of measures taken in the short and medium term. This is particularly evident in the field of epidemiological modeling, where accurate understanding of the spread of the virus and the effectiveness of control measures are crucial for guiding health and policy decisions. For example, many studies have used mathematical models to predict the spread of the virus and assess the impact of mitigation measures [2]. Inclusion of the codes used for these models would allow other researchers to examine and validate the methodologies used, thus helping to build confidence in the results and the decisions derived from them. It would also allow rapid adaptability of the models to new information and changes in the epidemiological situation. In addition, in the context of COVID-19 treatment and vaccine research, the inclusion of codes used to analyze clinical data could allow for a more thorough review of results and a better understanding of the effects of treatments or vaccines in different populations. For example, sharing the codes used to analyze COVID-19 vaccine clinical trial data could allow experts to examine in detail the efficacy and safety of vaccines in specific subgroups of patients, such as the elderly or those with pre-existing medical conditions [3].

https://doi.org/10.1016/j.socimp.2024.100058
Received 30 January 2024; Received in revised form 20 April 2024; Accepted 22 April 2024
Available online 23 April 2024

In recent years, the use of open data has been key for: (i) conducting real-time situational analysis, contact tracing, and ensuring prompt and accurate diagnoses to effectively contain the spread of infection; (ii) facilitating coordination and collaboration between national and local governments, enabling swift and cohesive responses to emerging challenges; (iii) enhancing public trust in policymakers by fostering transparency in decision-making processes and data sharing practices; (iv) supporting efficient management of medical supplies and fulfillment of requests for essential medical equipment, thereby optimizing resource allocation and healthcare delivery; (v) identifying and addressing vulnerabilities and specific needs of various population segments through the collection and analysis of disaggregated data; and (vi) combatting misinformation by providing access to reliable and up-to-date information, thus empowering individuals to make informed decisions. The latter point, with the frequent spread of fake news posed a significant challenge during the COVID-19 pandemic, affecting data collection and analysis. False and misleading news undermined public trust in health and government institutions, complicating efforts to contain the epidemic and provide accurate information to the public. In addition, fake news has fueled conspiracy theories and harmful behaviors, such as rejecting preventive measures and spreading unproven or even dangerous remedies. For example, fake news about the origin of the virus, its transmission, and its cure compromised the ability to collect accurate and reliable data to inform health and policy decisions. In addition, the dissemination of misinformation has been able to influence epidemiological models and the results of data analyses, compromising the understanding of the epidemic trend and the assessment of the effectiveness of control measures.

Addressing the problem of fake news during the pandemic required joint efforts by public institutions, the media and civil society. Fact-checking organizations such as Snopes, FactCheck.org, and PolitiFact have worked tirelessly to verify the accuracy of information regarding the virus and the pandemic, publishing articles and reports debunking false claims and providing clarity on the facts. Social platforms such as Facebook, Twitter and YouTube have partnered with fact-checking organizations to report and remove false or misleading content. Governments, health organizations, and other institutions have launched information campaigns to educate the public about the virus and combat misinformation. These campaigns have used various means, such as television ads, social media posts, information brochures, and dedicated websites, to disseminate accurate information and reassure the public. Local and community organizations have played a key role in countering misinformation through education and awareness raising. For example, groups of volunteers have organized virtual events, distributed informational materials, and offered online support to answer community questions and concerns. It has been a collective effort involving a wide range of actors, from the media industry to civil society organizations, in protecting the public from misinformation and promoting the dissemination of accurate and reliable information.

Moving forward, it is imperative to continue these collaborative efforts, strengthen information sharing mechanisms, and empower individuals with the tools and knowledge needed to navigate the complexities of public health crises. By upholding transparency, promoting critical thinking, and fostering a culture of trust and accountability, we can better equip society to address future challenges and protect the well-being of communities worldwide.

Methodology: 3 M-approach for responding to pandemics

The global challenges posed by the coronavirus pandemic have exposed significant weaknesses in the ways countries collect, manage and use information. Outbreak prediction has a questionable track record and its failures have become more evident with COVID-19 [4]. Poor data inputs, faulty modeling assumptions, high sensitivity of estimates, failure to incorporate epidemiological characteristics, poor past evidence on the effects of available interventions, lack of transparency, errors, lack of determinacy, consideration of only one or a few dimensions of the problem at hand, lack of expertise in crucial disciplines, groupthink and bandwagon effects, and selective reporting are some of the causes of these failures. Nevertheless, outbreak prediction is unlikely to be abandoned. Some (but not all) of these problems can be solved. Careful modeling of predictive distributions rather than focusing on point estimates, considering multiple dimensions of impact, and continually reevaluating models based on their validated performance can help. It is important to carefully consider the consequences of decisions based on predictions, especially when it comes to critical decisions such as implementing lockdowns. For instance, in a study comparing the efficacy of nonpharmaceutical interventions (NPIs) for COVID-19 [5], it was revealed that among models developed by Imperial College, those considering the impact of mobility on disease transmission were better supported by data compared to models solely focusing on NPIs or a combination of mobility and NPIs. Furthermore, while some models suggested lockdown as the most effective measure, others indicated minimal or no benefit, especially when introduced at a point when disease transmission rates were already low. These results highlight how critical it is to continually review and validate models based on their actual performance. This process of constant reevaluation allows errors to be corrected, models to be adapted according to new evidence, and predictive ability to be improved over time.

The recent pandemic has provided a valuable opportunity to lay the foundation for more robust measures in the prevention and control of future pandemics. The challenges associated with data analysis affect the entire life cycle of an epidemic. In the early stages, there is a need to gain fundamental knowledge about the epidemiological characteristics of a new infection, from transmission potential to natural history. This requires the use of diagnostic tests and genomic sequencing, as well as rapid clinical impact assessment and open sharing of early results. As outbreaks grow, there is a need to predict disease dynamics, estimate the potential burden, and evaluate the effectiveness of interventions to delay or flatten the epidemic curve. In the next steps, attention turns to estimating vaccine efficacy and monitoring outbreaks and evolutionary dynamics. This may include analysis of a long-term data set, such as cohort studies that can provide insights into epidemic processes over months or even years. The 3 M (Monitoring, Modeling and Management) model has emerged as a strategic framework that not only identifies gaps, but also serves to improve the capacity to respond to infectious disease outbreaks. Monitoring is the cornerstone of the 3 M model, which emphasizes continuous surveillance of the evolution of the epidemic and constant evaluation of the effectiveness of implemented countermeasures. Faced with rapidly evolving situations, real-time data collection and analysis become imperative. A timely view of the progression of the epidemic allows strategies to be adapted quickly, ensuring a more effective response. The Modeling component involves sophisticated analysis and prediction of epidemic spread. Using advanced computational models and data analysis, researchers and policymakers can anticipate potential trajectories, hotspots, and emerging patterns. This proactive approach allows for better resource allocation, strategic planning, and identification of areas requiring greater attention, ultimately contributing to more informed decision making. The Management aspect of the 3 M model involves making timely decisions to effectively manage, mitigate, and suppress infection. This involves a dynamic and adaptive approach to crisis management. Decisions are based on real-time data, predictive models, and a comprehensive understanding of the evolving situation. The goal is to implement rapid and efficient interventions while minimizing the public health impact of the outbreak.

The recent pandemic serves as a catalyst to reevaluate and strengthen the focus on improving the quality, timeliness, and completeness of government-generated health data. Strengthening existing information management practices is critical to improving the preparedness and resilience of health systems around the world. This renewal involves investment in advanced technologies, the promotion of public-private collaboration, and the creation of robust data governance frameworks to ensure the integrity and security of collected information. Effective outbreak management relies on several critical types of data:

- Pathogen genomic data: These data play a critical role in identifying the causative agent, monitoring mutations, and understanding the transmission networks and geographic spread of a disease. Genomic knowledge is invaluable for adapting containment strategies and developing targeted interventions.
- Clinical data: Essential for understanding disease severity, clinical data help develop accurate case definitions and evaluate the outcomes of pharmaceutical interventions. This information is critical for guiding treatment protocols and refining public health responses.
- Serologic data: Characterization of an individual's immunity and antibody responses is critical for assessing population-level immunity, guiding vaccination strategies, and understanding the potential for reinfection.
- Epidemiological data: Epidemiological data, ranging from aggregate case counts to detailed contact tracing information, are critical to characterize key parameters such as reproduction number (R0) and key temporal distributions. These data are essential for shaping public health policies, resource allocation, and the development of targeted interventions.

Results and implications: EPISOS, a one health platform

Based on the principles of the 3 M model, the EPidemic Intelligence System from Open Sources (EPISOS) pilot project [6] plays a key role in addressing the ongoing release and maintenance of quality open data in health sector. The project aims to develop a growing network of practitioners and researchers to address the challenges of data sharing and exploitation in a One Health framework based on cross-sectoral collaboration to support detection, monitoring and risk assessment for emerging and re-emerging infectious diseases in Europe. With minimal graphics, currently the user accessing the platform can explore the different research topics covered by the project and be directed to the corresponding dataset that contains basic information, such as the source of the dataset, a description of the main fields of the dataset, and the code to import the dataset to their device. To ensure a more user-friendly experience, we are developing a graphical section, in collaboration with the "Agenzia per l'Italia Digitale" (AGID), that will allow datasets to be accessed directly on the platform in a more intuitive and visual way. Taking West Nile Virus (WNV) as an example (https://www.dati.gov.it/view-dataset/dataset?id=32a9ef72-ec68-4f47-8df9-ca65c2a0a125), a user previews the files in the dataset and chooses which fields to view with the most suitable graph (line chart, histogram).

Data are gathered from official health monitoring sources (e.g., World Health Organization (WHO), European Centre for Disease Prevention and Control (ECDC), and National Institutes of Health (ISS)) because they adopt standardized methods and rigorous protocols to ensure the validity and reliability of the collected data, which include criteria for case definitions, methods for disease detection and reporting, and procedures for data management. For example, WHO has established detailed protocols for the surveillance and reporting of infectious diseases through the International Health Regulations (IHR) and adheres to international standards for the analysis and presentation of epidemiological data, using standard classifications such as the International Classification of Diseases (ICD) for coding medical diagnoses and the International Classification of Function, Disability and Health (IFC) for assessing health outcomes. It is important to note that despite this, data are often made available through bulletins in PDF format. This format can limit the usability of the data, making it less accessible and difficult to analyze. However, thanks to the efforts of our research team of virologists, epidemiologists, statisticians, software engineers, and molecular biologists who actively collaborate to maximize the value of these data, it is possible to take advantage of the information released by major health monitoring sources and contribute to the knowledge and understanding of infectious diseases. In recent years, this research project has contributed to (i) understanding the origins and transmission dynamics of the recent Ebola outbreaks in Uganda [7] and Avian influenza outbreaks in Italy and around the world [8–10]; (ii) estimating key epidemiological parameters in the early stages of Mpox [11]; and (iii) implementing predictive models to track and predict the spread of COVID-19 [12] and WNV [13] in real time.

In the future, the platform will aim to improve routine activities (epidemic risk monitoring and assessment, adding new data streams, etc.) by directly involving representatives of national public health authorities and creating a feedback loop between expert and user. First, we plan to institute a program of regular upgrades and preventive maintenance to ensure that the platform remains state-of-the-art and responsive to the evolving needs of users. This program will be driven by continuous monitoring of user performance and requests, allowing for early identification of any areas for improvement. In addition, we intend to establish strategic partnerships with academic institutions, research organizations, and national health organizations to ensure access to up-to-date expertise in epidemiological surveillance and information technology. Such collaborations will enable us to stay abreast of the latest developments and integrate new knowledge and resources into the platform. This could include adapting the platform to be interoperable with other existing public health systems and infrastructures, as well as the ability to handle a larger and more diverse volume of data from heterogeneous sources, developing tools for secure data sharing, and facilitating communication and collaboration among platform users.

Currently, the platform relies on GitHub for dataset storage, which has avoided the need to seek external funding. However, we recognize the importance of investing in human resources to ensure the continued development and maintenance of the platform, especially considering the possibility of placing the project in a larger context. Therefore, our future endeavors include hiring staff specialized in taking care of the technical and graphical aspects of the platform. This will allow us to improve the usability and functionality of the platform itself, while ensuring its compatibility with possible broader initiatives in the field of epidemiological surveillance and public health. This approach reflects our commitment to ensuring that the platform remains agile and state-of-the-art, able to adapt to changing needs and emerging challenges in public health.

Conclusions

The severe emergency situation of recent years has increased the sense of cohesion and the perception that others' behaviors end up affecting everyone's life, so a choral effort to achieve shared strategic goals will be essential. There is a need for similar initiatives such as Italy's Statgroup-19 experience [14] for the development of forward-looking policies that enable professionals to work and do analysis on data to try to understand the evolving dynamics of a disease. During the COVID-19 pandemic, researchers in this project faced challenges related to data availability, quality, and management, highlighting the importance of accurate data to support evidence-based policy decisions. In addition, the role of the statistician was highlighted as critical in decision-making and pandemic management, providing statistical and visualization tools to support authorities and inform the public about the progress of the epidemic. The crucial role of effective communication of statistical results to guide decisions and engage the public was emphasized. This allowed them to understand the evolution of the epidemic, assess the effectiveness of intervention measures, and identify significant correlations.

In a public health crisis context such as the COVID-19 pandemic, the EPISOS project aims to be a significant innovation in supporting high-quality data analysis. Here are the main keys about the potential of the EPISOS project:

1. **Real-time situational analysis**: EPISOS aims to provide tools and methodologies for conducting real-time situational analysis during outbreaks. Currently, by aggregating and analyzing diverse datasets and sharing them in a machine-readable format, EPISOS is able to offer insights into the spread of infectious diseases, identify hot spots, and evaluate the effectiveness of containment measures.
2. **Improved contact tracing**: By establishing ad hoc data dictionaries to collect patient information anonymously from unstructured data sources (PDF bulletins, web pages, etc.), EPISOS can improve contact tracing activities, enabling more efficient identification and tracking of individuals potentially exposed to a contagious disease. This capability is critical for containing outbreaks and preventing further transmission.
3. **Improved interoperability and adaptability of data**: EPISOS focuses on ensuring interoperability between different data sources, enabling seamless integration and exchange of information. This interoperability improves the accuracy and completeness of epidemiological data, enabling more comprehensive analysis and decision making. In addition, EPISOS is designed to be adaptable to different contexts and environments. It can be customized to meet the specific needs and challenges of different communities, maximizing its impact on public health.
4. **Continuous improvement and innovation**: EPISOS is committed to continuous improvement and innovation in epidemiological surveillance and data analysis. Through ongoing research, feedback mechanisms, and collaboration with stakeholders, EPISOS evolves to incorporate the latest advancements in technology and methodology, ensuring its relevance and effectiveness in addressing emerging public health threats.

In light of the valuable lessons learned from the EPISOS project and the experience of Statgroup-19, it is clear that harnessing data effectively is critical to preventing the spread of disease. Building on these insights, actionable strategies for harnessing data for disease prevention are described below:

Surveillance and early detection

- Implement a robust surveillance system that collects real-time data on potential disease outbreaks. This can include data from healthcare facilities, laboratories, and even social media platforms.
- Utilize advanced data analytics and artificial intelligence to detect patterns and anomalies in the collected data. Machine learning algorithms can help identify unusual trends or clusters of symptoms that may indicate the emergence of Disease X.

Predictive modeling

- Develop predictive models based on historical data, environmental factors, and population movements. These models can help forecast the potential spread of Disease X and identify high-risk areas.
- Integrate data from various sources, such as climate data, transportation patterns, and demographic information, to enhance the accuracy of predictive models.

Targeted interventions

- Use data-driven insights to tailor interventions to specific populations and regions at higher risk of Disease X. This could involve targeted vaccination campaigns, public health awareness programs, or quarantine measures.
- Implement dynamic intervention strategies that can be adjusted in real-time based on the evolving data. For example, if a new cluster of cases is identified, resources can be quickly redirected to contain the outbreak.

Communication and education

- Develop effective communication strategies based on data-driven insights to disseminate information about Disease X. Tailor messages to different demographic groups and communities.
- Utilize technology and social media platforms to reach a wide audience and provide timely updates. Address misinformation and promote accurate information to ensure public understanding and cooperation.

In terms of epidemic monitoring and response, COVID-19 has shown some promising developments in data integration and analysis, but it has also bequeathed some key challenges.

1. **Standardization**. Capturing epidemiological data from around the world presents significant challenges, mainly because of the diversity of formats by which data are collected, synthesized, and disseminated. Therefore, a key step to facilitate data sharing among different countries is to define a standard format that is common to all the different health reporting systems.
2. **Quality**. Data quality can vary substantially among different information streams, especially in the early stages of an epidemic when they are often less structured. Therefore, while researchers must independently assess the feasibility of specific data to support their study results, it is imperative to have a decentralized model where volunteers and team members from different regions perform information validation, as demonstrated by the COVID Tracking Project. For future outbreaks, it will therefore be important to automate data validation processes through stable funding and flexible approaches, because each outbreak is different from the other. In addition, as all infectious disease outbreaks are likely to become global, a comprehensive global database will be useful to guide coordinated responses.
3. **Sustainability**. The volume and diversity of information generated during the COVID-19 pandemic was unprecedented. To process and analyze these datasets, scientists implemented new tools and updated existing software. However, the health emergency has highlighted the need for a broader view of resource development and maintenance, as successful data and open source software need continuous monitoring to respond quickly to the changing needs of their user communities. In the future, the collaboration of partners as diverse as universities, health organizations, and private sector groups could enable the development of a multidisciplinary, multisectoral network capable of engaging in a "One Health" perspective not only physicians but also the other professionals who can contribute to the prevention, prediction, detection, and response to global health threats.
4. **Equity**. Recent historical events have reminded the world how fragile yet interconnected it is. What threatens a few may soon threaten the entire community. Timely data collection, integration, and dissemination will need to follow guidelines that prevent the use of information to reinforce existing biases or discrimination against specific populations based on gender, age, or location. It is also critical that in the future, data and software code be open source to enable rapid integration among multiple research groups and national governments. A truly open platform can help users overcome existing geographic, organizational, and social barriers to accessing information and enable great accountability and democratization of public health.

Role of the funding source

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Ethical statement

Hereby, I Francesco Branda consciously assure that for the manuscript “Challenges and perspectives of open science for future epidemic preparedness” the following is fulfilled:

This material is the authors’ own original work, which has not been previously published elsewhere.
The paper is not currently being considered for publication elsewhere.
The paper reflects the authors’ own research and analysis in a truthful and complete manner.
The paper properly credits the meaningful contributions of co-authors and co-researchers.
The results are appropriately placed in the context of prior and existing research.
All sources used are properly disclosed (correct citation). Literally copying of text must be indicated as such by using quotation marks and giving proper reference.
All authors have been personally and actively involved in substantial work leading to the paper, and will take public responsibility for its content.

The violation of the Ethical Statement rules may result in severe consequences.

To verify originality, your article may be checked by the originality detection software iThenticate. See also http://www.elsevier.com/editors/plagdetect.

I agree with the above statements and declare that this submission follows the policies of Solid State Ionics as outlined in the Guide for Authors and in the Ethical Statement.

CRediT authorship contribution statement

Francesco Branda: Writing – review & editing, Writing – original draft, Resources, Investigation, Formal analysis, Data curation, Conceptualization.

Declaration of Competing Interest

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

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