ENDVOC

PREPAREDNESS FOR EPIDEMICS AND PANDEMICS:

Strategic Recommendations for Cohort-Based Research

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Executive summary

The COVID-19 pandemic exposed vulnerabilities in healthcare systems, research infrastructure, and global coordination, while underscoring the critical importance of timely, high-quality data for public health decision-making.

Longitudinal cohort studies, which track individuals over time, have proven invaluable for understanding disease progression, identifying risk factors, and evaluating interventions such as vaccines.

Initiatives like the END-VOC consortium demonstrate the potential of multinational collaborations to generate actionable insights, from the global circulation of SARS-CoV-2 variants to the burden of Long COVID.

However, combining data from diverse cohorts presents challenges in standardization, harmonization, participant engagement, regulatory approvals, and funding alignment. To strengthen future pandemic preparedness, researchers, data protection authorities, and funders must work together to ensure consistent protocols, robust infrastructure, and flexible ethical and funding frameworks.

Researchers should prioritize harmonized data collection, active participant engagement, and cross-site coordination; authorities should provide clear, consistent, and adaptable regulatory guidance; and funders must invest in workforce capacity, standardized platforms, and long-term, flexible resources.

Across all stakeholders, three overarching principles are critical. **Consistency and standardisation** in protocols, coding, and ethical frameworks reduce delays and enhance data comparability.

Preparedness and flexibility, through pre-approved platforms, early agreements, and adaptable funding, enable rapid response to emerging health threats.

Finally, **engagement and coordination** among researchers, authorities, funders, and communities ensure that high-quality, actionable data is generated and effectively utilized. Implementing these recommendations will strengthen the global research ecosystem, accelerate evidence-informed decision-making, and enhance preparedness for future pandemics, ultimately saving lives and improving societal resilience.

1. Introduction

THE COVID-19 PANDEMIC HAS PROFOUNDLY RESHAPED THE WORLD, EXPOSING VULNERABILITIES IN HEALTHCARE SYSTEMS, ECONOMIES, AND SOCIAL STRUCTURES.

Within months, the virus spread across continents, prompting lockdowns, travel restrictions, and urgent public health interventions to halt its advance.

Beyond its immediate health impact, the pandemic highlighted the interconnectedness of global society and the speed with which infectious diseases can disrupt daily life. COVID-19 underscored the importance of preparedness, swift response, and multilevel coordinated action in the face of a highly transmissible pathogen.

Some of the most significant advances in public health have come from cohort research.

While the world continues to recover from COVID-19 effects, including the lasting impact of Long-COVID, experts emphasize that future epidemics and pandemics are not a matter of "if" but "when." Factors such as globalization, climate change, and increased human-animal interactions contribute to the emergence and re-emergence of infectious diseases. The experience of COVID-19 demonstrates that early detection, robust surveillance systems, rapid public health responses, and scientific research are critical to minimizing the spread and impact of novel pathogens. **Proactive preparation, rather than reactive crisis management, will determine how effectively humanity can confront the next global health threat**.

Central to both -responding to current crises and preventing future ones- is scientific research. Researching the biology of pathogens, developing diagnostics, vaccines and therapeutics, and studying societal impacts of mitigation measures are essential for evidence-informed public health strategies. The rapid development of COVID-19 vaccines exemplifies how research can save millions of lives and restore societal stability, while also exposing stark inequities within and between countries. Continued investment in epidemiology, virology, and public health research is therefore not merely an academic pursuit, it is a vital component of global resilience against future epidemics and pandemics.

One of the most important contributions to advancing health research has come from studies that follow cohorts of individuals over time, i.e. longitudinal research.

This type of **cohort research allows scientists to track the progression of diseases, identify risk factors, and evaluate the long-term effects of infections and interventions** such as vaccines. In 2021, a European Horizon call was established to fund research aiming to understand the epidemiology and impact of new COVID-19 variants of concern through cohort analysis.

Among the several projects funded, ENDing COVID-19 Variants Of concern through Cohort studies (END-VOC), with 20 international partners, seeks to elucidate the global circulation of the current and emerging SARS-CoV-2 VOCs and their specific characteristics with the help of **more than 20 international cohorts from Europe, South America, Africa, Middle East and Asia**. Thanks to this type of research, for instance, the burden and risk factors of Long COVID have been investigated across different settings and over time. [1, 2, 3]

Although observational cohort studies offer tremendous opportunities, combining data from diverse cohorts poses several challenges, which have been identified within the consortium. Accordingly, a concept note with strengths and weaknesses reported by END-VOC members was published last June. Following this publication, a workshop was held in July 2025 during the General Assembly in Lisbon, to identify challenges when working with cross-national cohort data and to develop specific recommendations.

This policy brief captures the insights shared by consortium members and presents a **series of recommendations for three key stakeholders involved in pandemic responses: research community, data protection authorities, and funders**.

1/ Thompson EJ, Williams DM, Walker AJ et al. Long COVID burden and risk factors in 10 UK longitudinal studies and electronic health records. *Nat Commun* 13, 3528 (2022).

2/ Kogevinas M, Karachaliou M, Espinosa A et al. Risk, determinants, and persistence of long-COVID in a population-based cohort study in Catalonia. *BMC Med* 23, 140 (2025).

3/ Beale S, Yavlinsky A, Fong WLE, et al. Long-term outcomes of SARS-CoV-2 variants and other respiratory infections: evidence from the Virus Watch prospective cohort in England. *Epidemiology and Infection* 152, e77 (2024).

2. Identified Challenges

WORKING WITH COHORT DATA FROM INTERNATIONAL SITES INVOLVES SEVERAL COMPLEXITIES, INCLUDING DISPARITIES IN CROSS-NATIONAL AND CROSS-INSTITUTIONAL INFRASTRUCTURES, VARIATIONS IN STUDY DESIGN AND DATA COLLECTION METHODS, AND INHERENT CHALLENGES IN DATA SHARING AND HARMONIZATION NEEDED FOR EFFICIENT POOL ANALYSES.

a. Data Collection

A major challenge is data **standardisation and consistency**, so that information is comparable and well-documented across participants, sites, and over time. Identified problems include the lack of a common protocol/questionnaire across different research sites, which leads to variation between datasets that hinders pooled analysis.

Participant engagement and retention within the cohort is another challenge, as maintaining motivation and compliance over time is critical for longitudinal studies.

This became evident as the COVID-19 pandemic evolved from its acute initial phase. This lack of retention reduces participants' contributions to additional data and sample collections, losing some of the benefits of the longitudinal research.

In terms of **logistics and timing**, operational delays -from ethical approval to recruitment to collection- affected the overall timeline and quality of the study. Some partners reported delays of several months in ethical approval. In addition, having many concurrent studies in the same place caused recruitment difficulties for some settings.

b. Data Sharing

Identification of variables is one of the most important challenges. Without clarity on which data should be shared and consistent definition of variables across studies, numerous difficulties arise.

Navigating **ethics and regulatory approval** frameworks for multicohort analysis can be slow and complex, varying across institutions and countries, and often delaying data sharing.

Additionally, there were **protocol and policy issues** that created operational and legal barriers to sharing data, including unclear procedures, restrictions from institutions, or changing legislation.

c. Data Harmonisation

Many problems arose in the process of **variable and data standardisation**. Ensuring consistent variables, definitions, coding, and units are consistent across cohorts is essential for reliable comparing and pooling of data.

Technical and operational harmonisation can be challenging, requiring technical capacity to ensure compatible file formats, structured datasets, and sufficient human resources to process and harmonise the data.

In addition, working with international partners introduces further complexity, as differences in language, study design, and populations complicate data pooling. **Cross-border and linguistic harmonisation** is therefore essential.

According to recent literature, data harmonisation remains one of the biggest challenges in cohort research.[4]

d. Funding

END-VOC consortium members identified two main funding challenges: aligning funding duration with research timelines, and ensuring **realistic planning and resource allocation**.

Funding timelines often do not match the actual pace of research, which can lead to interruptions in longitudinal research. Budgets and schedules also need to account for practical study requirements, including unforeseen delays, variable participant recruitment, and post-pandemic effects.

Many of these challenges have been previously identified and stress the importance of developing strategies to overcome them.[5]

4/ Visentin, A., Nazeri, A., Peñalvo, J.L: et al. Lessons from the European mpox outbreak: strengthening cohort research for future pandemic preparedness, *Clinical Microbiology and Infection,* 2025,ISSN 1198-743X.

5/ Tacconelli E. et al. Challenges of data sharing in European Covid-19 projects: A learning opportunity for advancing pandemic preparedness and response. *Lancet Reg Health Eur.* 2022 Oct;21:100467.

3. Recommendations

EFFECTIVE PANDEMIC RESEARCH REQUIRES COORDINATED EFFORTS ACROSS THE RESEARCH COMMUNITY, DATA PROTECTION AUTHORITIES, AND FUNDERS.

Drawing on lessons from COVID-19, several actionable recommendations emerge to improve data collection, sharing and harmonisation, ensuring readiness for future public health crises.

a. Research Community

Researchers and clinicians play a critical role in ensuring the collection and management of high-quality data. Collaboration and coordination of researchers globally has been called for by the Coalition for Epidemic Preparedness Innovations (CEPI) and the World Health Organization (WHO) as a key principle to be prepared for future pandemics.

To enhance efficiency and reliability of cohort studies, the END-VOC consortium proposes the following recommendations to the research community:

1. Staffing, Training, and Coordination

To streamline collaborative research, studies should **allocate dedicated staff to manage data collection and access**, allowing specialised researchers to focus on analysis and protocol design.

This approach also requires specific training in data collection for those involved.

Early involvement of data managers and statisticians in study design ensures that data collection and management tools are robust.[6]

When multiple studies are initiated, such as during epidemics and pandemics, cross-study coordination, especially with public health agencies, can reduce duplication and optimize recruitment, particularly in multinational cohorts. Clear definitions of partner capabilities will further streamline responsibilities and prevent bottlenecks.

2. Data Collection Tools and Processes

Electronic, coded data entry systems are essential to reduce errors and standardize data.

Pre-designed CRFs or database templates should be readily available, minimizing open-ended questions and supporting tiered datasets for flexibility across different scenarios.

Consistent tracking of time periods and intervals across the different cohorts is necessary to ease the analytical process. **Early provision of harmonised document examples** and well-documented ethical approval processes ensures smoother implementation.

6/ Zaki et al. Factors influencing the statistical planning, design, conduct, analysis and reporting of trials in health care: A systematic review. *Contemp Clin Trials Commun*. 2022 Jan 29;26:100897.

3. Participant Engagement and Retention

Engaging participants throughout the research process is crucial.

Clear communication on study goals and results will foster trust and adherence. In addition, aligning study objectives with local realities and offering incentives could further enhance participation and follow-up compliance, in addition to remote follow-up methods and reminders.

Several of these strategies have been found to be successful in longitudinal studies with more than 200 participants and more than 80% of retention rates over more than 1 year of follow-up [7] and those working with young and vulnerable populations.[8,9]

4. Data Sharing and Harmonisation

Effective data sharing relies on **clear governance and early agreements**. Pre-approved, harmonised data-sharing environments or platforms, combined with swiftly signed agreements, will facilitate collaboration.[10, 11]

Standardized dataset structures and protocols with de-identified variables, flexible consents, and guidance on variables across studies, are essential for smooth integration and interoperability. Similar recommendations have also been highlighted as crucial for investigating Post-Acute Infectious Syndromes, such as Long-COVID. [12]

Importantly, forming consortia before crises, engaging early with ethics committees, and using harmonised templates for data collection could accelerate approvals and data access. This aligns with the recommendation to use similar variables, units, definitions, and coding systems across sites, supported by standardised questionnaires and unified medical ontologies (e.g. ICD-10 and SNOMED-CT) to ensure data is ready for analysis and cross-study comparison.

7/ Abshire M. et al. Participant retention practices in longitudinal clinical research studies with high retention rates. *BMC Med Res Methodol*. 2017 Feb 20;17(1):30.

8/ Henderson, M., Wight, D., Nixon, C. et al. Retaining young people in a longitudinal sexual health survey: a trial of strategies to maintain participation. *BMC Med Res Methodol* 10, 9 (2010).

9/ Nicholson LM. et al. Recruitment and retention strategies in longitudinal clinical studies with low-income populations. Contemp Clin Trials. 2011 May;32(3):353-62.

10/ Logue JK, Chu HY. Challenges and lessons in establishing human immune profiling cohort studies for pandemic response. *Immunol Rev*. 2022; 309(1): 8-1.

11/ Rinaldi, E., Stellmach, C., Rajkumar, N.M.R. et al. Harmonization and standardization of data for a pan-European cohort on SARS- CoV-2 pandemic. npj Digit. *Med*. 5, 75 (2022).

12/ Górska, Anna et al. Learning from post-COVID-19 condition for epidemic preparedness: a variable catalogue for future post-acute infection syndromes. *Clinical Microbiology and Infection, Volume* 31, Issue 3, 380 - 388.

b. Data Protection Authorities

Data protection authorities are central to enabling research while safeguarding participant data.

1. Consistency, Legal Clarity, and Flexibility

Regional and national data protection authorities should enforce **uniform data protection rules across studies**, ensure national and international consistency, and provide legal clarity to support secure data sharing from the outset of protocol development.

Pathogen genomic data should not be unnecessarily classified as sensitive data, as this has shown to be a bottleneck in END-VOC when working with SARS-CoV-2 genomic data. Furthermore, flexible frameworks, such as **pre-approved data access agreements** or laws/hospital policies that allow temporary or crisis-driven exceptions, can remove the legal barriers that often prevent sharing hospital records, particularly during health emergencies. This aligns with the new WHO Pandemic agreement, which calls for the "use of relevant international data standards for interoperability, as appropriate, based on good data governance for preventing, detecting and responding to public health events." [13]

2. Ethics

Well-documented ethical approval processes, with clearly defined national requirements, are crucial. Simplifying approvals for future pandemics without compromising protection standards would accelerate research, such as **allowing fast-track ethics review by national or international committees** by using previously approved templates and checklists. Simultaneously, authorities could provide pre-approved sharing environments while defining partner responsibilities clearly.

c. Funders

Funders are pivotal in ensuring that research systems have the resources and infrastructure to respond effectively to pandemics through longitudinal cohort studies.

1. Infrastructure and Standardisation

Support should extend to establishing **platforms for data collection, storage, and management**, including electronic capture systems, servers, and technical support. Funding should also support the development of common guidelines, standardised dataset structures, pre-designed CRFs, and structured datasets where data is organized into levels or tiers of importance, detail, or accessibility. This allows flexibility depending on the study scope, resources, or regulatory constraints and would facilitate data collection and sharing across studies. These may be done by tying such a type of structures into the funding streams.

2. Workforce, Coordination, and Capacity Building

Investing in **staff training and coordination** across sites enhances data quality and reduces duplication. Funding mechanisms should support personnel dedicated to data harmonisation, cleaning, and analysis. Adequate resources for promoting participant engagement also improve retention and follow-up adherence.

3. Flexibility and Sustainability

Funding must remain **flexible to adapt to evolving crises** and prevent cuts that compromise research capacity. Long-term investment in infrastructure, staffing, and consortium-level preparedness ensures that cohorts and networks are operational when the next pandemic strikes.

13/ Seventy-eighth World Health Assembly. *WHO Pandemic Agreement.* 20 May 2025.

4. Emerging Priorities

WHILE THE RECOMMENDATIONS OUTLINED ABOVE ADDRESS IMMEDIATE LESSONS FROM COVID-19 AND THE END-VOC PROJECT, SEVERAL EMERGING PRIORITIES WILL SHAPE THE FUTURE OF EPIDEMIC AND PANDEMIC PREPAREDNESS.

Anticipating these priorities now will ensure that cohort research remains relevant, equitable, and impactful in the face of evolving global health challenges.

a. Global Governance and Data Stewardship

International cooperation requires **frameworks that extend beyond ad hoc collaborations**. Global data stewardship models such as **data trusts or WHO-endorsed repositories** should balance the principles of open science with the need for national data sovereignty, particularly in low- and middle-income countries (LMICs).

Reciprocal benefit-sharing arrangements must guarantee that all partners, regardless of resource level, gain from participation through capacity strengthening, fair authorship, and equitable access to findings. Establishing such structures in peacetime will allow faster, more trustworthy data sharing during crises.

b. Equity and Inclusion

Pandemic research systems must be explicitly designed to reduce inequities. Funding mechanisms should prioritise **inclusion of resource-constrained settings**, ensuring access to infrastructure and long-term investment in local cohorts.

Cohort protocols should also **integrate perspectives of gender, disability, age, and social vulnerability**, so that research outputs are both representative and actionable. Equity considerations are not only ethical imperatives; they also enhance the scientific validity and policy relevance of findings.

c. Digital Innovation and Artificial Intelligence

Rapid advances in digital health and AI create new opportunities for cohort research. Wearable sensors, smartphone-based tools, and integrated electronic health records can generate high-resolution, real-time data streams. **AI-based harmonisation platforms** can automate the mapping of variables across heterogeneous datasets, reducing delays and technical bottlenecks. In addition, **real-time analytic dashboards** can provide early warning signals to policymakers, turning cohort research into a direct input for outbreak response.

These innovations should be embedded into future funding frameworks and supported by training programs that build digital literacy across research teams.

d. One Health and Climate Change

The increasing frequency of zoonotic spillovers underscores the need for a One Health approach. Cohort platforms should be designed to **interface with veterinary, agricultural, and environmental surveillance systems**, enabling integrated analyses of human, animal, and ecosystem health.

Furthermore, climate change is shifting the distribution of vector-borne and water-borne diseases. Cohorts situated in climate-sensitive settings offer a unique opportunity to study these dynamics, providing vital evidence for anticipatory interventions and resilience planning.

e. Community Trust and Communication

Beyond participant retention, community-level engagement is essential for sustaining cohort research in times of crisis.

Transparent communication of study goals, rapid dissemination of results, and **active countering of misinformation** can build durable public trust. Involving civil society, community leaders, and patient advocacy groups in study governance strengthens legitimacy and improves compliance.

Developing **rapid risk-communication channels** within cohort networks will also allow communities to receive timely, reliable updates during health emergencies.

f. Sustainability between Crises

A recurring lesson from COVID-19 is the difficulty of sustaining research platforms once an acute crisis subsides.

To maintain readiness, funders should consider **dual-track financing models**: baseline support to sustain cohorts and infrastructure during inter-epidemic periods, coupled with surge funding mechanisms that can be rapidly activated during crises.

Establishing **regional centers of excellence**, particularly in LMIC regions, would ensure continuity, reduce reliance on external actors, and foster self-sufficiency.

g. Policy Translation and Uptake

For research to have impact, evidence must flow quickly into policy. Cohort consortia should embed **policy liaison officers or knowledge brokers** who can translate findings into policy briefs, decision dashboards, or real-time guidance for health ministries.

Creating structured **evidence-to-policy pipelines**—including joint workshops with policymakers—will ensure that cohort outputs directly inform resource allocation, public health interventions, and legislative frameworks during crises.

5. Conclusions

THE COVID-19 PANDEMIC HAS HIGHLIGHTED BOTH THE EXTRAORDINARY POTENTIAL AND THE CRITICAL CHALLENGES OF CONDUCTING LARGE-SCALE, LONGITUDINAL, MULTI-SITE RESEARCH UNDER URGENT CIRCUMSTANCES.

Nevertheless, gaps in coordination, standardisation, and regulatory clarity often slowed progress. Across all stakeholders, three principles emerge as critical:

1. Consistency and Standardisation:

Harmonised processes, case report forms and protocols, coding systems, and ethical standards reduce delays and improve comparability.

2. Preparedness and Flexibility

Pre-approved platforms, early agreements, and flexible funding allow rapid response to emerging crises.

3. Engagement and Coordination

Strong collaboration between researchers, authorities, funders, and communities ensures high-quality, actionable data.

Addressing these issues proactively can significantly improve the speed, quality, and usability of cohort research in future health emergencies.

They should be incorporated at the design stage of all studies, in the best possible way, to minimise consequences and avoid delays in usability when necessary. Investing in standardised tools, workforce capacity, and flexible funding, alongside robust participant engagement and international collaboration, will better equip the global research community to respond to the next pandemic.

By implementing these recommendations, stakeholders can build a **resilient, interoperable research ecosystem capable of generating actionable evidence quickly**, supporting effective public health responses, and ultimately saving lives, ensuring that lessons from COVID-19 translate into stronger preparedness for future epidemics and pandemics.

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Strategic Recommendations for Cohort-Based Research

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