Call for a Global Health Data Sharing Framework for Global Health Emergencies

A Communiqué of the InterAcademy Partnership (IAP)

The ongoing COVID-19 pandemic has highlighted the urgent need for a nimble cross-sectoral global data sharing framework that is standardised, ethical, reliable, and accessible by all countries and governed by a trusted international organisation. This communiqué lays out the need for and role of such a trustworthy framework with recommendations on the governance, operational considerations and skills required for global health data sharing.

1. The urgent need for a global data sharing framework for health emergencies

The devastating effects of the COVID-19 pandemic have highlighted the need for an effective framework for rapidly collecting, managing, storing, analysing and disseminating data for global health emergencies. A critical component is an improved ability for the real-time generation, sharing, and effective use of health data to prepare for, identify, monitor and respond to pandemics. The types of data include routine surveillance, vital statistics, laboratory, clinical, socio-behavioural and public health data, as well as data from the health system. These are needed to simultaneously address several priorities, which include preventing and controlling the spread of disease, providing effective and efficient public health measures, strengthening health systems for the response and provision of regular health services, and providing consistent approaches across all elements of governments (1-3). Pandemics are not restricted by national borders, and the health interdependence of nations means that the availability and access to health data originating from any one location has repercussions on the collective international response. For pandemics and other global health emergencies, these data have a worldwide value and should be considered a global public good.

The Science Academies of the Group of Seven (G7), known as the S7, published a statement in March 2021 calling for the development of an agreement on health data access, urging the G7 to establish an international commission for better 'data readiness' for future health emergencies (4). The proposed mandate of this commission is to agree on a data sharing framework for global collective actions for health. The InterAcademy Partnership (IAP), a global network of merit-based science, medical and engineering academies, convened a group of international experts (see Acknowledgements) to reflect further on global considerations in implementing the S7 statement. In this communiqué, IAP makes five recommendations on health data sharing with a specific focus on health data for effective action guided by scientific evidence (see also Box 1) and the values and principles endorsed by international policy frameworks, such as solidarity, equity, excellence, integrity, and human rights (5-8). This communiqué considers the need for, and the importance of, health data sharing and makes recommendations on the key areas of action identified in the S7 report: governance, operations and skills.

2. Key issues for the generation and sharing of health data globally

Health data emanate from multiple sources and disciplines, being derived from civil registries, surveillance systems, clinical data (including routine health and service use statistics), research data from the biomedical (genetic sequence data being particularly important) and from the social sciences fields, and relevant data generated by other sectors or by other stakeholders, including civil society. Over the last decade, global health organisations and funding bodies have called for greater availability and improved access to good quality data for health, and principles for the collection and use of data

Box 1: Punitive actions for data transparency undermine responses to global health emergencies: the example of SARS-CoV-2 variants of concern and travel bans

Travel bans act as a strong disincentive to share health data, compromising current and future efforts to manage health emergencies. Travel bans and other onerous travel restrictions have been among the most common responses by national governments following the detection of new SARS-CoV-2 variants of concern (9), owing to concerns that more transmissible and more virulent variants, which potentially evade the immunity conferred by vaccines, could lead to a surge in infections and subsequent rises in hospitalisations and deaths. Travel bans have been found to be effective in the early stages of a pandemic, as a measure to "buy time" to advance preparations to respond to the disease, and in geographically isolated locations (10-12). However, travel bans and restrictions have a limited beneficial impact on the establishment of new variants since, by the time of their detection, substantial international spread has already taken place. The identification of variants of concern in places with no direct links to the country that originally reported them also indicates the rapidity with which local transmission in multiple countries is established (13,14).

Further, travel bans contravene basic human rights (15), and go against the recommendations of the WHO*. Travel bans and restrictions also have significant economic repercussions for the countries concerned, and harm the collective response to the pandemic by impacting the delivery of research consumables needed for disease surveillance (14, 16, 17).

* World Health Organization. (2021, November 30). *WHO advice for international traffic in relation to the SARS-CoV-2 Omicron variant (B.1.1.529)*. Available at: https://www.who.int/news-room/articles-detail/who-advice-for-international-traffic-in-relation-to-the-sars-cov-2-omicron-variant

have been proposed (e.g. 18-22). Yet, the ongoing pandemic has brought into focus the lack of progress in establishing a functioning interoperable data sharing agreement. The lack of timely epidemic intelligence from global data sources continues to be associated with huge human and economic loses.

Numerous barriers to health data sharing have been identified. At the most basic level, they include weaknesses in sectors such as health, science and technology, information and communication technologies, commerce, etc. Vital statistics data are needed to establish the demographic changes attributable to disease, and these are provided in many countries by civil registration services, population censuses and clinical data, such as cause of death. Civil registration services also confer legal protection to individuals. In many low-resource countries, there is a lack of comprehensive civil registration services and poor integration between and within sectors, which contribute to poor quality demographic data and exacerbate inefficiencies and global health inequities (23-26). Barriers to data sharing also include the lack of adequate infrastructure and technical capacity in many countries, absence of incentives, and lack of appropriate legal and ethical frameworks, policies and governance bodies (21, 27). A further important barrier to health data sharing is the reluctance of scientists to share unpublished results or the original data that gave rise to the results (21). The implications

of these barriers in dealing with health emergencies were already made evident in 2006 by the hesitancy of some World Health Organization (WHO) Member States to share genetic sequences from humans infected with the highly pathogenic Asian Avian Influenza A (H5N1) virus (1).

A functional data sharing framework and underlying infrastructure require sustained economic resources, and securing long-term financing remains one of the main obstacles (28-30). However, the cost of setting up and maintaining an effective health data sharing framework needs to consider the cost of inaction: aside from the impossibility of assigning a monetary value to the loss of an estimated 5.4 million human lives by the end of the second year of the COVID-19 pandemic[I], the cost to the global economy has been about $2.96 trillion U.S. in 2020 alone[II]. And the pandemic is not yet over. It is important to regard financial allocations for data collection and sharing systems as investments rather than as expenses. Furthermore, these investments should not be made into disparate or siloed systems, but rather should focus on integrated systems that address the priority needs for dealing with epidemics, with particular emphasis on integration with other national and regional digital health investment priorities.

There have been some areas of improvement in data sharing during the COVID-19 pandemic. Notably, the scientific community has embraced Open Access, and to some extent Open Science practices, to share rapidly and transparently the results of research relevant to the pandemic (31). By January 2022, about two years since the first cases were reported, over 21,000 scientific articles on COVID-19 had been shared through the preprint archives bioRxiv and medRxiv[III]. Critically, numerous mainstream medical journals and publishers took the decision to make all COVID-19-related publications freely available to read (31, 32). In addition, several databases of health-related information about COVID-19 have been established, including by WHO[IV]; Our World in Data[V]; the John Hopkins Resource Center[VI]; World Bank[VII]; the UNESCO Institute of Statistics[VIII]; the National Institutes for Health[IX]; and Global Initiative on Sharing Avian Influenza Data (GISAID)[X].

The publication of articles before peer review is not without challenges, especially those related to balancing the speed of publication and the quality and scientific rigor of research, since the outcomes of investigations, including the results of clinical trials, are made available to the media and to policy makers before scientific scrutiny. The balance between speed of publication and rigor is also apparent in the peer-reviewed literature (33). The consequences of poor quality research being disseminated are particularly concerning when the data relate to efficacy and safety of new interventions and treatments and when they contribute to misinformation campaigns related to the pandemic (30, 34).

An international governance framework tasked with coordinating research activities is needed to promote synergies, avoid duplication, and maintain high quality standards by promoting shared master protocols, common statistical frameworks, and agreed reporting requirements. This framework is needed not only in the event of global pandemics but should form part of a regular process of global health surveillance that is fit and ready to scale up operations during health emergencies. Collaboration of a broad and diverse number of stakeholders, including industry, intergovernmental organisations and research teams through research registries to promote open science, is a successful example of how harmonisation and transparency are promoted to build trust and overcome some of the key research challenges in health emergencies (35-37).

A call for improved global leadership and accountability has been made by the Independent Panel for Pandemic Preparedness and Response for the WHO Executive Board (29), proposing the establishment of a new Global Health Threats Council. More recently, the WHO Health Emergencies Programme established a Hub for Pandemic and Epidemic Intelligence[XI], financed by the German government with an initial investment of US$100 million. The Hub will work to enhance access to multiple data sources; develop analytical and modelling methodologies; facilitate decision making by WHO and Member States to address health emergencies; and connect institutions and networks responding to disease outbreaks.

The IAP endorses the creation of a global governance commission on data sharing for health emergencies. To build trust and gain support for its actions, the governance commission must be inclusive. It should be hosted by an international institution under the banner of the United Nations (UN), so that all member nations have shared ownership of, accountability for, and access to health data. The legitimacy, credibility and public trust in the hosting institution is crucial due to the lack of legal mechanisms for enforcing global participation and compliance with any agreed procedures and standards set for the collection, sharing, storage, and use of health data. IAP supports the WHO as an appropriate host institution, and the WHO Hub for Pandemic and Epidemic Intelligence as an appropriate location within the institution. IAP agrees with the S7 statement on the importance of incentives to promote international action towards an effective data sharing framework to deal with public health emergencies.

3. Governance

A coordinated response to future pandemics requires standardised high-quality and timely laboratory, clinical and epidemiological data collected in every country that are made globally available, following One Health principles (38). Incentives to participate in

the framework should be considered. Since participation of individual countries is voluntary, effective governance is essential to encourage broad participation and compliance with existing policy frameworks. A governance commission which represents all WHO member states is strongly supported by the IAP. The host institution supporting the governance commission and its processes must be trustworthy, inclusive and well-respected. The specific goals and objectives of data collection and the intended audiences and users need to be carefully formulated and communicated. The governance commission will have responsibility for setting the parameters for data collection, including the type of data: e.g., surveillance data, clinical data, population data, mental health data, etc., as well as for the integration of different datasets. The responsibilities of different member organisations and of private sector organisations for data collection, sharing, use and preservation must also be clarified. The governance commission must develop the guidelines for standardising and accessing the data, as well as for the provision of feedback to those responsible for collecting and collating them. The governance commission should also have responsibility for establishing nimble mechanisms for updating the ethical, social and legal requirements including informed consent, taking into account differences in cultural values and the balance between individual liberties and collective priorities in different settings. Permissions for data use need to be considered both at the level of organisations providing data and individual patients and citizens whose data are reported.

Principles, values and operational procedures will need to be debated and defined for data collection and sharing. These factors may require the establishment of an ethical review mechanism to consider the scope and types of proposed analyses, and to mitigate potential inappropriate uses of data. Additionally, those sharing will need to agree to possible commercial uses of data, and appropriate protocols and legal processes established to take appropriate steps if these are breached. The WHO ethical guidelines for research during public health emergencies (39) and the ethical guidelines proposed by the Council for International Organizations of Medical Sciences for health-related human research (40), which establish that scientific and social value constitute the fundamental justification for conducting research, should be followed.

Comprehensive cybersecurity measures are required. The role of formal governance vested in authorities, such as those of public health authorities and others with a role in intersectoral action who bear a significant share of the responsibility for data collection and sharing needs to be detailed.

The International Health Regulations (IHR, 41) stipulate that State Parties must notify the WHO within 24 hours of all public health information relevant to a Public Health Emergency of International Concern. However, the IHR do not classify genetic sequence data as public health information, and there is no legal obligation to share this class of data (1), although during the COVID-19 pandemic, it was reported and used to craft recommendations. The sharing of genetic resources and biological samples is governed instead by the UN Convention on Biological Diversity (CBD)[XII] and the CBD Nagoya Protocol on Access to Genetic Resources and the Fair and Equitable Sharing of Benefits Arising from their Utilization[XIII]. Parties to the UN have sovereignty over genetic resources within their borders. There is a need to align the IHR, CBD and Nagoya Protocol to respond better to global health emergencies (1). The World Health Assembly has initiated the negotiation of a global accord aimed at increasing compliance with IHR to better prevent, prepare for and respond to future pandemics through global political coordination.[XIV,XV]

4. Operations

IAP recommends that the proposed data framework builds on existing health databases and existing standards to the extent possible. Agreement is needed on the methodologies used, the interoperability and protection of different data systems, and the formatting and level of aggregation required. Preference should be given to non-proprietary open standards for codifying data to prevent countries being burdened by costs of subscriptions to non-open interoperability standards.

To facilitate the widespread use of data, the FAIR principles, **F**indability, **A**ccessibility, **I**nteroperability, and **R**euse of digital assets, must be followed.[XVI] Databases require data dictionaries, interoperability standards

XII   https://www.cbd.int/doc/legal/cbd-en.pdf
XIII   https://www.cbd.int/abs/doc/protocol/nagoya-protocol-en.pdf
XIV   https://www.who.int/news/item/01-12-2021-world-health-assembly-agrees-to-launch-process-to-develop-historic-global-accord-on-pandemic-prevention-preparedness-and-response
XV   https://blogs.bmj.com/bmj/2021/09/16/what-is-the-missing-ingredient-in-global-pandemic-preparedness-and-response/
XVI   https://www.go-fair.org/fair-principles/

(both semantic and syntactic) and accessible terminology services, utilising existing open standards, such as the Logical Observation Identifiers Names and Codes database (LOINC)[XVII], the International Statistical Classification of Diseases and Related Health Problems (ICD[XVIII]), and the Health Level Seven International Fast Healthcare Interoperability Resources Foundation (FHIR HL7[XIX]).

Data collection efforts must be responsive to the rapid generation of new information such as differential responses to disease related to gender, ethnic and age groups, with consideration for vulnerable populations. This requires applying an equity lens to data collection and analysis and highlights the importance of disaggregated data (42, 43). A framework is also needed for the handling of rapidly changing information, such as data on daily cases and deaths. The data collected must be useful from the moment of registration, which requires compliance to set standards for quality assurance and reporting. As a second stage of priority, real time data for other sectors will be needed for a comprehensive response, considering the implications of a One Health approach, food systems, international mobility and trade, and national security. Consideration must be given to how these datasets from multiple agencies will be able to interact with each other. The collection and sharing of this information must also include participation of the United Nations and its specialised agencies, in addition to the WHO and the United Nations Educational, Scientific and Cultural Organisation (UNESCO).

Effective data collection requires extensive national and international research coordination. As an example, effective genomic surveillance of COVID-19 ideally involves sequencing a random subsample of positive specimens to monitor for mutations and variants of concern (13). At the national level, this entails coordination between different public and private institutions: health services, testing centres, sequencing laboratories, and computational groups with the expertise to analyse large genomic datasets (13). Responsibility for sharing this information can rest on individual researchers, national public health organisations or regional bodies. Regional institutions such as the Africa Centres for Disease Control and Prevention, the Pan American Health Organization (PAHO/WHO), and the European Centre for Disease Prevention and Control could play an important role in a trust network supporting country-level surveillance and ensure standardisation. Genomic surveillance, for example, is not performed in many countries due to the lack of dedicated resources, infrastructure and technical skills and, as noted in the previous section, countries are not legally obliged to share genetic sequence data. The appointment of national centres designated as regional surveillance hubs and coordinated by regional institutions can play an important role in supporting countries that are not able to perform genomic surveillance.

5. Skills

Establishing an effective data sharing framework necessitates that all countries have the required capacity, access to tools, and adequate and reliable funding support to collect, process, maintain, analyse and share the data required, both for public and private sector institutions. The development of human capacity for the collection and analysis of complex data sets and the establishment and maintenance of the enabling technology (e.g., digital technologies, computational capacity, and information communication systems) is a long-term endeavour, while all countries must be ready to share data at the onset of health emergencies. When appropriate, countries and institutions could be enabled to conduct analysis on datasets in a decentralised manner (with the appropriate permissions), including the use of machine-learning approaches (44).

Sustained, long-term funding is one of the critical challenges. Pandemic preparedness cannot be divorced from attaining the intertwined Sustainable Development Goals (SDGs[XX]), including SDG 3[XXI], 'Ensure healthy lives and promote well-being for all at all ages', and SDG 4, 'Inclusive and equitable quality education[XXII]'. Fundamental to these goals, is the need for skilled health care personnel to achieve universal health coverage, quality health care, and reliable health data. The investment in developing the skilled personnel needs to start now and be maintained, so that countries are in a position to generate and share health data when the need arises. The benefits of global health data sharing should accrue to everyone contributing and participating in the process.
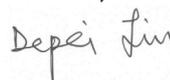
6. Recommendations

1. IAP calls on the WHO to establish a global health data governance commission in 2022, with the mandate to oversee intersectoral collaboration and harmonisation in a comprehensive, international response to data collection, sharing, storage, curation and standardisation using open interoperability standards for utilisation for global health emergencies. The commission should also be tasked with the development of a data bill of rights and responsibilities establishing the relationship between the data providers, custodians and users.

2. IAP endorses the World Health Assembly as the venue for the negotiations for a global accord (i.e., Pandemic Treaty), which will also require the design of a legal instrument to deal with global health emergencies that enables access and benefit sharing in line with the CBD Nagoya Protocol on Access to Genetic Resources and the Fair and Equitable Sharing of Benefits Arising from their Utilization. It is important that the data providers also receive benefits and recognition for their role in contributing to health data as a global good.

3. IAP supports the use of the ethical guidelines proposed by the Council for International Organizations of Medical Sciences for health-related human research, which establish that scientific and social value constitute the fundamental justification for conducting research, and the WHO ethical guidelines for research during public health emergencies. The guidelines underline that every effort be made to provide fair access for all to the benefits derived from research conducted during emergencies. Since health data are a global public good, the use of these data must also be for the global good.

4. IAP calls on the WHO to revise and update the International Health Regulations (IHR) to make them more effective at dealing with global health emergencies, in particular with respect to the expeditious sharing of genetic sequence data and pathogen samples.

5. IAP calls on philanthropies and educational institutions to expand capacity building and training activities to a level that countries have sufficient skilled individuals supporting the global data system across the entire value chain from the sources of data to the reporters of data, including at the national level. This data capacity is essential to generate effective early warning systems and provide useful epidemic intelligence to guide pandemic responses. Strengthening of capacity building programs is essential to achieve global equity in the capacity to collect, share and analyse data for global health emergencies.

Signed by the members of the Steering Committee of the InterAcademy Partnership (IAP) in February 2022

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About the InterAcademy Partnership (IAP)

Under the umbrella of the InterAcademy Partnership (IAP), more than 140 national, regional and global member academies work together to support the vital role of science in seeking evidence-based solutions to the world's most challenging problems. In particular, IAP harnesses the expertise of the world's scientific, medical and engineering leaders to advance sound policies, improve public health, promote excellence in science education, and achieve other critical development goals.

IAP's four regional networks - AASSA, EASAC, IANAS, and NASAC - are responsible for managing and implementing many IAP-funded projects and help make IAP's work relevant around the world. For more information about IAP see www.interacademies.org and follow @IAPartnership on Twitter, on LinkedIn and YouTube.

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This Communiqué can be downloaded at https://www.interacademies.org/publication/call-global-health-data-sharing-framework-global-health-emergencies.

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