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## Symposium Articles

# AI and Data Surveillance: Embedding a Human Rights-based Approach

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**Abstract**

Artificial Intelligence (AI) has the potential to revolutionize public health surveillance by analyzing large datasets to detect outbreaks. However, privacy, consent, and governance issues persist. While the International Health Regulations do not explicitly mention the use of AI in infectious disease surveillance, transparent processes, accountability, and public trust are key for responsibly integrating AI in pandemic preparedness.

**Keywords:** artifical intelligence; public health survillence; data surveillance; International Health Regulations; human rights

## Introduction

Surveillance is a cornerstone of public health,[1] and Artificial Intelligence (AI) holds tremendous potential to revolutionize public health and epidemiological surveillance.[2] In particular, AI can analyze various datasets to detect abnormal events, alerting the world to potential infectious disease outbreaks.[3] Looking to machines with the ability to compute, analyze, reason, learn, and discover patterns, AI holds immense potential for enhancing public and human health.[4] The promise of AI extends beyond international infectious disease surveillance. AI can also promote public health by expediting medical diagnoses, aiding in developing and using new drugs and vaccines, and revolutionizing healthcare.[5]

This article explores the historical development and current trends in infectious disease surveillance, which traditionally has been framed as a security issue. It underscores the need for deeper integration of a rights-based approach to mediate tensions between individual and collective interests,[6] particularly with the growing use of digital disease surveillance and artificial intelligence in international infectious disease control.

Throughout global health history, international cooperation in population-based surveillance has informed evidence-based policy making in public health and infectious disease control. The COVID-19 pandemic accelerated digital disease surveillance, with countries adopting tools like digital tracing applications and digital vaccine passports as part of their response. Some countries have gone further, using AI tools such as facial recognition in public spaces for infectious disease monitoring. The shift from digital disease surveillance to AI surveillance could accentuate legal challenges associated with public health surveillance — for instance, where governments collect information unrelated to risk of infectious diseases. Consequently, this article concludes by underscoring the urgency of adopting a rights-based approach towards AI and data governance under global health law.

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## Evolving Means of Surveillance Under Global Health Law

Surveillance has long been crucial for global health, playing a key role in the early detection, timely response, and management of infectious diseases. It allows for rapid identification of outbreaks, enabling swift containment measures and coordinated responses among health authorities. Central to surveillance, continuous data collection is essential for monitoring disease trends, understanding epidemiological patterns, and identifying high-risk populations.[7] This information guides public health strategies and resource allocation. Predictive modeling based on surveillance data can forecast outbreaks, aiding preventive efforts and public health policy-making. Effective data surveillance underpins global health infrastructures, ensuring preparedness and resilience against infectious diseases.[8]

The contemporary international infectious disease control regime began in the 19th century, prompted by cholera outbreaks in Europe and the Americas that highlighted the need for international cooperation, leading to the first International Sanitary Conference in 1851.[9] Following from a series of International Sanitary Conferences, the establishment of the World Health Organization (WHO) in 1948 marked a significant step toward a coordinated global health response, providing an institutional foundation for the collection and dissemination of health data.[10] The 1969 International Health Regulations (IHR) provided a framework under WHO for preventing the spread of disease while minimizing disruptions to trade and travel. However, the original IHR's focus on specific diseases like cholera, plague, and yellow fever was insufficient to ensure surveillance of rising infectious diseases.[11]

A pivotal moment in the evolution of global health surveillance was the revision of the IHR following the 2003 SARS outbreak, which demonstrated that delayed reporting and lack of transparency could

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exacerbate the spread of infectious diseases.[12] The revised IHR (2005) introduced several key changes to enhance global health security. WHO Member States were required to (1) develop and maintain core capacities for surveillance and response, including the ability to detect, assess, report, and respond to public health emergencies,[13] (2) notify WHO of any events that might constitute a public health emergency of international concern (PHEIC) within 24 hours of assessment,[14] providing a secure platform for sharing information about public health events and coordinating responses.[15]

Importantly, the revised IHR (2005) have emphasized the importance of respecting "the dignity, human rights, and fundamental freedoms of persons."[16] Additional health measures should be implemented in a transparent and non-discriminatory manner.[17] This human rights framing has shifted international infectious disease control discourse away from being seen as a security matter, which focuses narrowly on individual state interests.[18] However, unchecked digital disease surveillance and AI surveillance, as seen in the COVID-19 pandemic, could significantly roll back human rights if left unaddressed.

## The Rapid Development of Digital Surveillance and Rise of AI Surveillance

Public health measures such as contact tracing and disease reporting have been longstanding practices in the prevention, preparedness, and response to disease outbreaks.[19] Yet the non-digital implementation of these measures required, among other things, the deployment of multiple health authorities who would investigate suspected and confirmed infections of a selected disease, manually constructing the chain of transmission. This information would then provide the basis for the ad hoc notification of diseases by healthcare providers to authorities at different levels of government. All of these procedures were time-consuming and had varying degrees of accuracy.[20] As contact tracing and disease reporting are necessary for effective infectious disease control and monitoring, governments began experimenting with digital tools that were easy to adopt and offered real-time surveillance as the COVID-19 pandemic erupted. These digital tools also overcame the constraints imposed by traditional surveillance methods. Some countries have gone even further, adopting facial recognition and language modeling as tools of AI surveillance to detect the potential spread of SARS-CoV-2. As countries embraced technological tools, they sometimes gravely undermined human rights when left unchecked.

### *Digital Disease Surveillance*

Whereas digital disease surveillance already existed, the COVID-19 pandemic led to the gradual replacement of these procedures by new information technologies at an unprecedented pace around the world. This allowed for changes in both the speed of data collection and the depth of such data.

In terms of speed, the use of digital tools for contact tracing and disease reporting allowed authorities and individuals to be informed about the potential risk of exposure to disease. Such information was made available almost in real-time, allowing for a more accurate epidemiological modeling that could help calculate infection rates and trajectories of the spread of the disease.[21] These processes acquired a cross-border dimension during the COVID-19 pandemic, as the use of "vaccine passports"[22] as a requirement for travel meant that border authorities could immediately access information concerning the immunization status of a person even if they received their vaccination in a different country.

The increase in the use of digital disease surveillance tools also led to a change in the depth of the data collected. Individuals could be tracked on a constant basis in order to determine where they were, and when, even in instances not strictly connected to the risk of exposure to COVID-19.[23] This unprecedented scope of digital disease surveillance brought with it unprecedented normative challenges,[24] mainly due to the scale of surveillance of entire populations enabled by the new technologies. In several instances during the pandemic, courts validated the use of digital disease surveillance in light of the emergency the world was facing.[25] Nevertheless, there were reports of national authorities using information gathered through the use of digital tools for purposes other than those strictly related to mitigating the spread of COVID-19, which raises important questions about the need for human rights protections in public health measures. These rights-restricting measures should be assessed against human rights standards of legality, necessity, and proportionality, as public health measures affected a range of human rights: the right to privacy, health, and other social and economic rights, for instance.[26]

### *Moves Toward AI Surveillance*

The use of AI, in turn, risks enhancing these normative pitfalls. During the COVID-19 pandemic, the effective use of digital tools mostly depended upon their active use by individuals — by actively downloading specialized applications on their mobile phones[27] — as well as validation by public health authorities accessing such data. The move towards AI could render such requirements obsolete, as it could allow for both complex tracing of disease trajectories based on language modeling,[28] as well as the automatic notification of infection patterns without needing prior validation by a public health authority. Algorithms may now include wide-ranging sources of personal data, such as health records and social media accounts,[29] alongside the use of facial recognition in public spaces to trace movements and determine risk of exposure to a disease, which would lead to imposing quarantines and isolations.[30] Given these privacy concerns and other major implications of the use of AI in digital disease surveillance, the potential for AI misuse has become a source of concern around the world.

AI and data surveillance thus heighten the tension between individual and collective interests as well as private and commercial interests.[31] Since AI depends on large datasets to make predictions, the absence of data can lead to skewed results.[32] Further, as data becomes a valuable commodity, the benefits and burdens of AI are not often distributed equitably.[33] The increased use of AI in data surveillance thus presents a multitude of regulatory, legal, and ethical challenges that often transcend national boundaries.

Beyond infectious disease surveillance, AI can also pose threats to human health and well-being by influencing how people receive information, exacerbating existing health inequalities through its algorithms.[34] While the societal and regulatory impacts of emerging technologies are not new, AI in the global health context introduces nuanced regulatory and ethical complexities.[35] These include the need for vast datasets to power AI,[36] which can undermine privacy and public trust in jurisdictions that grapple with developing laws to keep pace with AI advancements.[37] The opacity of AI algorithms can reflect bias and discrimination, exacerbating inequalities within and across countries.[38] Furthermore, as AI tools and digital health infrastructure are developed, maintained, and owned by large

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transnational technology corporations, commercial interests can sometimes conflict with and undermine public health.[39]

## Regulating AI and Data Surveillance to Protect Rights and Promote Health

Despite the need for governance over these new technologies, the new amendments of the IHR do not mention or reference the use of AI in international infectious disease surveillance, leaving a regulatory vacuum at the international level.[40] Whether incorporating AI as part of a national surveillance system would be considered a part of disease surveillance core capacity under the IHR remains to be seen. Despite this ambiguity, technical challenges like data interoperability, where different systems and databases cannot easily exchange data, remain a significant barrier to fully capturing the benefits in using AI for disease surveillance — affecting all countries.[41]

Additionally, governance of AI remains a "Collingride dilemma," where early action is necessary before the technology permeates social life to the extent that it then becomes difficult to regulate.[42] While a growing consensus exists that the global governance of AI necessitates a global concerted effort, it is not easily achievable in an increasingly polarized world.

Nonetheless, at the global level, the rapid and unpredictable progress of AI across sectors has prompted numerous global initiatives to provide principled approaches to AI governance.[43] These governance efforts are often fragmented, lagging behind AI advancement and requiring better coordination.

As AI continues to permeate various aspects of social and political life — impacting individual behavior and choices at a micro level and the global risk to society and the political economy of globalization at a macro level — addressing technological determinants of health through a rights-based approach becomes increasingly urgent. A rights-based approach places central importance on transparency, deliberation, and accountability in policymaking. It calls for appropriate legal safeguards and balanced decisions about individual rights in privacy, autonomy, and the rights to health and life and public interests in health security. Reinvigorating a rights-based approach is complicated by the current political and economic structures governing global health, and resistance to expanding obligations through existing normative instruments. These challenges necessitate global health diplomacy to navigate these complexities.

### *Global Governance of AI and Data Surveillance*

The rapid pace of AI development presents a pressing global governance challenge, with policymakers often grappling in keeping up with technological progress through legislation and regulations.[44] With its Constitutional mandate as the coordinating UN agency for public health, the WHO is well-positioned to issue guidelines, recommendations, or policy documents to harmonize or coordinate AI and data surveillance policies at the global level.[45] However, the agency lacks financial resources, public trust, and political support, compounded by the chaotic global health architecture.[46] This discrepancy between the speed of technological advancement and the lag in policy development underscores the urgent need for more agile and forward-thinking governance frameworks that can adapt to rapid technological changes.[47]

In addition to technical and policy-related obstacles, regulatory, ethical, and societal concerns over the use of AI in data surveillance, the use of AI in public health and epidemiological surveillance raises human rights concerns about privacy, consent, potential data misuse, and equitable distribution of AI benefits.[48] With the global reach of AI and the increased use of technology in public health surveillance, discussions about AI deployment need to be more inclusive and transparent, with policy documents from international organizations reflecting inclusive participation and meeting local needs and demands. A rights-based approach to AI and data governance is crucial to mediate the tensions among individual, public, and commercial interests.[49] This approach ensures that data are assessed, stored, and used in accordance with human rights principles while ensuring the availability of high-quality and timely data for public health surveillance.

### *Global Strategy on Digital Health*

The *Global Strategy on Digital Health* (2020–2025) (*Global Strategy*), with a possibility of renewal by WHO Member States,[50] could provide a transformative opportunity for global health. Given AI's potential bias and discriminatory impacts in global health, ensuring AI is developed and deployed in a way that prioritizes public interest and is consistent with human rights is crucial.

If renewed, the *Global Strategy* would rely on the voluntary internalization of the relevant stakeholders rather than the force of binding law. The mobilization of resources at all governance levels to oversee the responsible use of AI in data surveillance will be imperative.[51] Further, in fostering state implementation of this soft law, it will be crucial to ensure the quality of deliberation processes and the openness of public consultations during negotiations. It is equally imperative that negotiations over the renewal of the *Global Strategy* are transparent and inclusive, allowing for the incorporation of a diverse range of perspectives into the renewed *Global Strategy*.

Given the colonial origins and historical injustices in international infectious disease control,[52] the equitable use of AI and data surveillance presents an opportunity to address and rectify these past wrongs under a rights-based approach. The COVID-19 pandemic has underscored the pivotal role of public health surveillance in pandemic preparedness, thereby underscoring the necessity of public deliberation, public trust, and appropriate legal safeguards in shaping the integration of AI into future pandemic preparedness efforts. To meet this necessity, future uses of AI in digital disease surveillance should adopt a rights-based perspective. On the basis of the *Principles and Guidelines on Human Rights in Public Health Emergencies*,[53] public health authorities should ensure that infectious disease surveillance is preceded by a participatory decision-making model. Individuals should be informed whenever their data are being collected, and safeguards should be in place to guarantee that data will be deleted whenever they are no longer necessary to fulfill the public health goals.

## Conclusion

Global health law is critically important in promoting a rights-based approach to AI and data surveillance governance. It ensures that AI and data surveillance align with fundamental human rights principles. By offering a clear normative stance, global health law safeguards individual and public health and fosters international cooperation in the rapidly evolving landscape of AI and data surveillance.

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