Learning Beyond Boundaries:
Linking Global Data to Life-Saving Action in an Era of Pandemics

COVID-19 has already taught us that the greatest public health challenges of our generation will show no respect for national boundaries, will impact the lives and health of people of all nations, and will affect economies and quality of life in unprecedented and unpredictable ways. The collaboration required to address these challenges must be cross-sector, multi-stakeholder, transdisciplinary, and global, in nature. A pandemic is not just a disease; it is a global health emergency which, as such, requires advanced, consistent, and comprehensive tools, data sharing and multi-stakeholder cross-border collaboration.

One of the most explicit obstacles to implementing this collaboration is a lack of comprehensive and standardized ways of structuring data such that it can be rapidly exchanged and accessed. When widely agreed upon and broadly adopted by diverse stakeholders, structured data can enable the rapid sharing of information that is necessary for decisive action to safeguard public health. When the health and well-being of entire populations are at stake, the world must speak one language and must be seamlessly interconnected. Silos of data may work to benefit people who reside in specific regions or who receive their health care through specific organizations, but microbes do not respect these boundaries. When pathogens cross boundaries, the information to manage the disease must see no boundaries.

Addressing both the health and broader societal challenges engendered by a pandemic requires a range of data sources and types that are broader than those required for optimal health care. Included are data from testing, contact tracing, geographical mobility, clinical observations, behavior and research and development; in particular, data related to social determinants of health can help address special needs of highly vulnerable populations. The latter includes historically underserved populations as well as elderly people and nursing home residents. Impactful strategies and solutions will require knowledge-based decisions, informed seamlessly by these data, and actions from public administrations, policymakers, and health system resource managers.

Experience has taught us that most national health information systems have significant limitations in coping with the current pandemic challenge. Clinical and medical data are not integrated among themselves nor are they integrated with social, demographic and mobility data. Furthermore, data are often incomplete, inaccurate, and almost always lack the compatibility required for simple and timely transfers between different sources. Even when the data themselves are suited to their purpose, the processing systems required to transform data into productive and actionable knowledge is often fragmented or non-existent. As a result, it is impossible for decision-makers to reasonably base strategic health care and policy decisions on the observed behavior of the pandemic and to evaluate the effectiveness of those decisions. Without
access to adequate data, the nations of the world are unable to use the powerful analytic technologies and modeling techniques that are now available to surmount the challenges presented by this global health catastrophe. *A pandemic in the digital era should not be fought with analog data and manual procedures of the previous century.* A growing body of literature points to how data gaps and inconsistencies in reporting are undermining responses to the pandemic and needlessly costing hundreds of thousands of lives worldwide, not to mention the resulting incremental economic damage.

To address this situation, we have formed a collaboration among experts from three countries--Spain, Italy, and the United States--all of which have experienced serious challenges during the COVID-19 pandemic. Our mission, as an initiative of the Learning Health Community, is to design and explore a systems-based approach to COVID-19 data management to inform real-time and strategic decisions during a pandemic or other public health emergencies. What we propose together, underpinned by a sense of urgency, is a structured, comprehensive, multi-disciplinary, multi-stakeholder, and multi-national (ideally global) data approach with the following key components:

1. A system linking medical, social, and public administration entities, allowing information to routinely flow to where it is needed to inform optimal decisions.
2. Standardization of all system-relevant data--including clinical, research, social and administrative data--to avoid fragmentation, inconsistencies, and miscommunications.
3. Analytical capabilities to transform raw data into information that will inform decisions.
4. International connection of as many entities as possible to take advantage of much larger data sets and collaborative learning.
5. Full respect for inclusiveness, transparency, and privacy.

*We aim initially to catalyze an international dialogue, culminating in the collaborative realization of such a comprehensive and integrated system.* We believe this solution will be foundational to enabling the type of rapid learning from data that will empower informed decision-making by policymakers, accelerate research into treatments and preventive measures including vaccines, and ultimately save lives and control economic damage. Such a system will not only address the current pandemic but will also empower multiple and diverse stakeholders to take coordinated action to address future emerging pandemics or health catastrophes significantly more rapidly and efficaciously, thus conserving resources and saving lives.

A manuscript detailing this initiative has been published in the Learning Health Systems Journal; [https://onlinelibrary.wiley.com/journal/23796146](https://onlinelibrary.wiley.com/journal/23796146).

Collaborative International Team

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