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EXECUTIVE SUMMARY

Quality data governance is necessary for coordinating the steps from data collection to use for evidence-based interventions for positive health outcomes. To build on global momentum for international coordination for data governance, on 30 June 2021, the WHO Health Data Governance Summit made the case for data as a global public good, discussed what data governance changes are needed at the country level, and highlighted possible solutions to complex data governance issues.

In responding to the urgent need for global coordination amidst the COVID-19 pandemic, WHO and the global health community have an unmatched opportunity to strengthen good data governance, leading to better outcomes. These initiatives must include responsive policy and programs, reduction in reporting burdens, and community engagement at all stages of the data value chain. In promoting health data as a global public good, valuing local context as foundational to all data discussions, and sharing data governance best practices, WHO strives to support members states and partners towards the norms and standards for data driven approaches for the 2030 SDG Agenda and an equitable recovery from COVID-19.

The Summit united behind three shared objectives:

1. Review the current landscape of global health data
2. Share good practices in governing health data
3. Encourage consensus for health data being a global public good and good practices for health data governance

KEY LESSONS

Health data as a global public good maximizes the potential for data to be used for health outcomes, achieving the 2030 Sustainable Development Goals (SDGs) and the triple billion targets – ensuring that no one is left behind.

The COVID-19 pandemic revealed the need for stronger coordination to fill data gaps, increase data sharing, and building strong data governance.

Equity is at the center of good data governance principles and practices to ensure no one is left behind.

Good data governance supports each stage in the health data value chain to ensure that data contributors are the beneficiaries of positive change made possible by data sharing.

Trust is the foundation upon which good data governance is made possible.
The Health Data Governance Summit convened experts in global and public health, health data, policy, technology, science, and research across private, public, and academic sectors to discuss solutions for governance issues.

800 Participants, 126 Countries, 400+ Organizations

“Reliable data is the most urgent priority of our time.”
Zsuzsanna Jakab, WHO Deputy Director-General
For more than a decade, the global health community has been working to embrace the data revolution. Lessons learned and strides toward innovation have revealed that data sharing is central to achieving the 2030 Sustainable Development Goals. The foundational availability of data is possible when each part of the data ecosystem encourages the data revolution in their regional and sectoral context.

While there has been a mobilization of efforts and data, the COVID-19 pandemic has revealed how weak governance and ultimate use of data can lead to less evidence-based decision making, resulting in inefficiencies, increased mortality and morbidity and greater inequities. In response to the urgent need for global solidarity, the global health data community needs to take responsibility by thinking about data governance and accountability.

What are the steps to becoming responsible and accountable? The international health community must reach consensus on how to support an environment where data is a sustainable global public good. To be good stewards of this public good, the global community needs a social contract for data. This social contract designs data governance that can be trusted – it incentivizes people to do the right thing with public data and mitigates risks of usage by bad actors. For the global health community, good data governance is about creating a virtuous data cycle that generates investments in data infrastructure, and in turn encourages more use of data and more trust in it.

Next, the global health community needs to support each stage in the data value chain, especially in the most disadvantaged communities. Individuals must see the benefits of data and trust the systems that collect and store it. Governments must be good stewards of data and create systems that generate fast, detailed insights into the health of their populations. Data gaps, made glaringly evident during the COVID-19 pandemic, must be filled. The data-sharing culture must shift so that countries and institutions see that when data is shared, everyone benefits. There is a recognized need for WHO and the global community to convene experts across all sectors and geographies to foster dialogue that will actualize these shifts.

“It’s up to you to learn the lessons of the COVID-19 pandemic, it’s up to you to create a new consensus on health data governance, and it’s up to you to make health data a global public good.”

John Pullinger, President, International Association for Official Statistics

It’s not just about data governance – it’s about good data governance.

The topic of data governance touches every sector of society globally. It does not start and stop with privacy protections, but has dimensions that include ethical, legal, societal, political, financial, and technical implications. When data governance is done well, the results are visible. It is possible to deliver fast interventions at scale and respond strongly to future pandemics. Discussions around data governance are rooted in saving lives and providing better health for all.

To foster trust in the data for health community, WHO has established five data principles to continually reaffirm trust in WHO’s data governance:

1. **Treat data as a public good**
2. **Uphold Member States’ trust in data**
3. **Support Member States’ data and health information systems capacity**
4. **Be a responsible data manager and steward**
5. **Strive to fill public health data gaps**

WHO has also established policies for data sharing in and outside the context of public health emergencies. Insights from this convening and future collaborations will inform how WHO operationalizes these policies and principles to effectively respond to requests for support from Member States.

The **SCORE for Health Data Technical Package** strengthens country health data systems by encouraging stakeholders to invest in areas that have the greatest impact on the quality, availability, analysis, use and accessibility of data in countries.

The **World Health Data Hub (WHDH)** is a partnership between WHO, Microsoft, and Avanade. It facilitates health data as a public good - findable, browsable, and usable. The WHDH will have a country portal for Member States and central data repository to streamline the data value chain - ensuring that all constituents engaging with data for their local context can trust it and use it to advance health outcomes.
INSIGHTS FROM EXPERTS IN THREE PANELS

Our collective knowledge and passionate participation are important assets in moving our conversations on trust in governance forward. The expert panelists selected for the summit brought that knowledge and passion to discuss key topics and to share their field-tested practices that keep their organizations on the forefront of learning and developing new approaches. Many challenges we face in production, handling, and distribution of health data are common as evidenced in the discussions as well as the pre-summit question submissions.

The panelists also represented a range of perspectives from the following organizations and institutions: Oxford University, OECD, UNCTAD, PharmAccess, World Bank, UN Global Pulse, South Africa Medical Research Council, Zambia Statistics Agency, Health Policy Program Foundation, UNAIDS, Malawi National Statistics Office, Indian Council of Medical Research, CERN, European Commission, University of Costa Rica, World Economic Forum and UNITAR.

The following sections of the report will highlight the panels, the experts, and the insights they shared during the event.

The panels united under summit objectives to review the current landscape of global health data, identify and share good practices in governing health data, and encourage consensus for health data being a global public good and good practices for health data governance.

Insights build on Open Data Institute (ODI) research, which has been working with WHO in May and June, holding discussions with 23 stakeholders and analyzing 56 documents.

Pre-read materials for discussions are publicly available:

- The Health Data Landscape
- Health Data as a Global Public Good
- Data Governance Maturity and Best Practices

PANEL THEMES

Health Data as a Global Public Good

Country Perspectives

Health Data Governance Best Practices
The panel on “Health Data as a Global Public Good” reminded us that advocacy for data as a public good is not new but builds on great promise for impact through learnings across the international data community. Success in this area means sustaining the trust of Member States to participate in the data lifecycle, working with donors to better fund access to the wealth of data assets, and increasing coordination for better health outcomes. These outcomes are sustained by quality governance that will reinforce systems of incentives for participants, ensure progress towards equity, help design for interoperability, and maintain community health as a core function.

Open access health data offers unprecedented opportunity for universal health outcomes. When health data is a global public good, stakeholders along the health care value chain benefit from enhanced access to data, knowledge, and coordination.

Open Data impacts health by creating equal opportunities, solving health issues, improving evidence-based decision making, and empowering citizens.

“Collaboration, transparency, trust, respect, and reward are absolutely key to successful health research and data sharing.”

Sarah Lewington, Professor of Epidemiology and Medical Statistics, Nuffield Department of Population Health, Oxford University
What can health data as a global public good accomplish?

Efficiency
Open Data enables the global health community to leverage optimized value from data, resources, and investments. When stakeholders are contributing to and using the same datasets, data quality improves, collaboration increases, and knowledge gaps close.

Resilience
When data is a global public good, institutions have the tools to respond to health emergencies. Open Data hastens global health interventions and ensures that essential resources will be deployed effectively in emergency situations.

Equity
Health data is a key driver for health equity. Open access health data reduces inequalities by enabling targeted interventions and insights for vulnerable populations globally.

Accountability
Open Data is critical for exposing and preventing mismanagement and corruption. Health data as a public good ensures critical review, enables monitoring and evaluation, and reveals inequalities in the health care value chain.

Acceleration
By removing barriers to knowledge, stakeholders along the healthcare value chain progress towards meeting SDGs together. Health data is a global public good enables new industry opportunities and innovations while simultaneously maximizing investments.

How do we get there?

TRUST
Good data governance increases trust in systems so data contributors will share data and researchers, analysts, policymakers, and health professionals will use that data.

INTEROPERABILITY
Data cannot just be available; it must also be useable. Systems to enable interoperability will ensure that the advantages of Open Data are fully realized.

“Free access to data and information in the context of global public health is of central importance. How can we expect to control the spread of disease, or manage and improve health systems, without sharing and analyzing data? How do we combat vaccine hesitancy without presenting facts?”

Steve MacFeely, Chief Statistician at UNCTAD; Co-chair of the Committee of Chief Statisticians of the UN System
COUNTRY PERSPECTIVES

South Africa
Glenda Gray
Non-Executive Director, Perinatal HIV Research Unit, Johannesburg; President and CEO South Africa Medical Research Council

Zambia
Mulenga Musepa
Interim Statistician General, Zambia Statistics Agency

Thailand
Suwit Wibulpolprasert
Ministry of Health, Vice Chair, Intl. Health Policy Program Foundation; Health Intervention and Technology Assessment Foundation, Intl. Health Policy Program

Kenya
Allan Maleche
Executive Director Kenya Legal and Ethical Issues Network on HIV and AIDS; co-chair UNAIDS Human Rights Reference Group

Malawi
Mercy Kanyuka
Commissioner of Statistics, Malawi National Statistical Office

THE REALITY OF FRONTLINE DATA COLLECTION

In many countries, frontline healthcare workers who see patients are also responsible for recording and confirming data. For frontline workers who are already overworked, this is a taxing process that results in lower-quality data.

Strong data governance and investments in digital technology can reduce this burden on frontline workers. It makes data collection faster and easier for frontline workers, real-time updated data available, and resource allocation for disease response effective.

Insights and expertise from WHO Member States are foundational to building systems and principles that foster good health data governance through trust and collaboration. As the global health community looks to build consensus on health data as a global public good and discuss best data governance practices, it must consider realities on the ground. Representatives from South Africa, Zambia, Thailand, Kenya, Malawi, and India provided perspectives on data governance lessons learned, problems to solve, and principles to consider.

The panel addressing country needs for health data governance highlighted the importance of local context as a primary informer for country empowerment through data.

“Communities and people data is collected from are often seen as after thoughts. It is high time we prioritize and put people first at the start of any health data project we take forward and how we collect their data, if we are to address their needs.”

Allan Maleche, Executive Director Kenya Legal and Ethical Issues Network on HIV and AIDS; co-chair UNAIDS Human Rights Reference Group
WHAT NEEDS TO CHANGE?

CURRENT CHALLENGE | PANEL SOLUTION
--- | ---
Policymakers must ensure that data contributors benefit from data collection and analysis. This is made possible when policies are responsive to data analysis, governments and institutions root decisions in data, and data governance has consensus across the data lifecycle. | Quality data and good data governance must be at the center of development. Countries need to strengthen the entire data lifecycle, rather than focus solely on data collection.

The global health data community must focus on reducing reporting burdens for countries, statisticians and frontline health workers. | Resources need to be allocated for data collection, sharing, storage, analysis and use in all health. More sharing and support for those collecting data and aligning efforts to country and community needs could reduce reporting burdens.

Transparency needs to increase through good data governance in health systems to hold institutions and policymakers accountable. | Countries need to have power and ownership over their data. Stakeholders need to understand local context and how good data governance is rooted in local contexts.

Data collection and analysis must be inclusive of all communities. When data is not considered from all communities, it is impossible to get lifesaving services for people who are frequently left out. This is imperative to ensure no one is left behind. | Communities should be involved from the onset, from the collection of data to the use of data. Those providing the data must be at the core of the benefits from that data.

“Data governance is based on trust. Trust takes time to build, a second to break, and a lifetime to rebuild. Start building trust now for the foundation of good data governance.”

Suwit Wilbulpol, Vice Chair, International Health Policy Program Foundation; Vice Chair, Health Intervention and Technology Assessment Foundation, International Health Policy Program
HEALTH DATA GOVERNANCE
BEST PRACTICES

HEALTH DATA GOVERNANCE PRACTICES THAT WILL MAXIMIZE HEALTH OUTCOMES

- Develop systems of incentives for sharing data
- Adopt the FAIR principle: making data fair, accessible, interoperable, and reusable
- Design governance structures with human centricity at the center
- Consistently practice basic data hygiene for how data is stored and tagged
- Use maximum transparency to build trust
- Respect the rights of data submitters and empower them to make good use of the data
- Prepare for the future - the global health community should create a global repository of health facility location

“Rules are not enough, it’s passion and conviction and commitment that really make the difference... We all need capacity to make good decisions around governing data.”

Mark Hereward, Associate Director for Data and Analytics, UNICEF
One size doesn’t fit all. We must remain flexible and work together.

Citizens are not consulted on the use and reuse of their data.

Much data is biased, often skewed in favour of views from high income countries and not necessarily reflective of the world’s diverse population.

There is not enough consideration from stakeholders to resonate with local contexts.

Data colonialism, where developing countries are supplying data but not benefitting from the analysis or use of that data.

Governance ensures these data systems are trustworthy from the perspectives of citizens.

“Good practice is bringing the people and stakeholders together to talk about their challenges.”

Alvin Marcelo, Executive Director, Asia eHealth Information Network
GOOD PRACTICES FROM THE LEADING INSTITUTIONS

Global momentum for international coordination around data requires expert guidance on creating health data governance principles and practices. The panel on Good Practices in Health Data Governance provided insight on health data governance best practices in ethical, legal, private sector, and health care frameworks. Panel members discussed interoperability, data sharing, data storage, privacy, and geospatial data in these contexts. The experts built on the theme of trust as a necessary element for success and underscored that collaborative guidance on creating health data governance principles and practices is foundational to building trust.

CERN
A model for data governance and collaboration in research
One size does not fit all. The global community must be creative in Big Data management collaboration to shape cohesive strategies together.

European Commission
Open data policies: Lessons from COVID-19
Open Science Policy: Where would we be if the COVID-19 genome wasn’t deposited on day one? Good data governance needs to incentivize people to share data that can be used by others. Data as open public good must be:
- **FAIR**: findable, accessible, interoperable, reusable.
- As open as possible and as closed as necessary.
- Delivered through trusted infrastructures. The governance of those infrastructures should be transparent, accountable, and participative.

“Equity is possible when health workers, ministries, and researchers who collect data and the communities from whom data are collected, are part of the benefits of sharing and using the data.”

Laura Merson, Associate Director, IDDO

World Economic Forum
Ethical and legal frameworks for data sharing and private sector engagement
Good data governance is possible with public and private cooperation through technology, investment, and multistakeholder collaborative governance.

“On a day-to-day basis, the basics of privacy, security, and remembering that we are ultimately dealing with people is going to be the key to success.”

Anne Josephine Flanagan, Data Policy and Governance Lead, World Economic Forum
Health data do not stand by themselves. They are part of a much bigger statistical and data ecosystem containing demographic, social, economic information, and all of them have to be connected and integrated.

Stefan Schweinfest, Director, United Nations Statistics Division

WHO Digital Health Technical Advisory Group
Data and digital interoperability: Legal and ethical frameworks
Enough technical interoperability standards exist, but the uptake of those standards must be a systematic requirement in all public procurements. Good data governance fosters trust in the quality of data and trust in systems for citizens to share their data.

University of Costa Rica
Data and research for improving and scaling Primary Health Care: Lessons from Costa Rica and its applications internationally
Digitalization will optimize health care. Data must be usable at every stage of the value chain, so data submitters see the benefits of that data.

“Digital transformation won’t just have a positive impact on health alone but will change the lives of people.”
Rocio Saenz, Former Minister of Health; Professor, Health Promotion, University of Costa Rica; Executive President of the Costa Rican Social Security Fund and Coordinator of the Social Council, Costa Rica

“Health data do not stand by themselves. They are part of a much bigger statistical and data ecosystem containing demographic, social, economic information, and all of them have to be connected and integrated.”
Stefan Schweinfest, Director, United Nations Statistics Division

GISAID
Partnership model: Data storage and sharing
Contributors must know that when they share data, their rights are protected. The three main factors for this are trust, quality, and usefulness. Quality data is collected through close interaction with submitters that are then able to use the data with accessible tools.

United Nations Institute for Training and Research
Good practices for Geospatial Information Systems (GIS) data storage and access
Service to countries should be the focus of every program. Countries must also be foundational partners with access to data and the opportunity to provide feedback on services.
CONCLUSION

LOOKING AHEAD
JOIN US FOR THE SECOND HALF OF THE SUMMIT IN LAST WEEK OF SEPTEMBER

Building on momentum for health data governance collaboration, the second half of the Summit will take place in late September. Guided by inputs from the first half of the Summit, the forum will focus more on good data governance practices by exploring emerging consensus on specific technical areas, implementation, and capacity building.

The COVID-19 pandemic has revealed the urgency with which the global community must embrace the data revolution. Working together builds trust transparently, and trust lies at the heart of making data governance work.

The Health Data Summit welcomes you support this journey and be champions for change.

The WHO-hosted Health Data Governance summit joined the global momentum for stronger health data governance building on the 74th World Health Assembly, G7 Communique, UNSG Data Strategy, World Bank Development report, and the 52nd ECOSOC meeting, among other initiatives.

The forum emphasized the need for coordinated principles based on equity, systematic filling of data gaps with interoperable digital systems, and trust at all stages of the health system value chain. These practices in good data governance will lead to better health outcomes where it counts the most -- for vulnerable communities that are frequently overlooked.

We invite input and public comments on the summit to inform the Health Data Governance Summit Statement, available on https://www.who.int/data/events/health-data-governance-summit/introduction. These comments will guide the next half of the Health Data Governance Summit on September 30th, 2021.

“Data governance should cover all parts of the Data Value Chain, from collection to dissemination and use. As connected parts, each element needs equal governance attention. Only then can we expect to truly derive value out of data.”

Shaida Badiee, Managing Director, Open Data Watch