# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Executive Summary</td>
<td>3</td>
</tr>
<tr>
<td>Purpose of the Summit</td>
<td>4</td>
</tr>
<tr>
<td>Health Data Governance Part 1 Review</td>
<td>5</td>
</tr>
<tr>
<td>Improved Data Governance and Collaboration</td>
<td>6</td>
</tr>
<tr>
<td>Keynote Address: Good Data Governance</td>
<td>7</td>
</tr>
<tr>
<td>Expert Panel Insights</td>
<td>8</td>
</tr>
<tr>
<td>Data Research and Stewardship to Promote Greater Impact on the Ground</td>
<td>9</td>
</tr>
<tr>
<td>Identifying Good Data and Research Governance Practices: Breakout Sessions</td>
<td>11</td>
</tr>
<tr>
<td>Institutionalizing Good Practices for Data Governance</td>
<td>13</td>
</tr>
<tr>
<td>Future Directions</td>
<td>14</td>
</tr>
<tr>
<td>Summit Conclusion</td>
<td>15</td>
</tr>
</tbody>
</table>
EXECUTIVE SUMMARY

To promote good quality data governance that results in positive healthcare outcomes, the health data community must apply and sustain health data governance best practices - transforming good ideas to concrete action. In June of 2021, the WHO Health Data Governance Summit convened experts, countries, researchers, users, and international organizations around the world to further the case for data as a global public good. Building on the key takeaways from the first session, the second session of the summit on 30 September 2021 delved deeper into the issues around data governance and infrastructure necessary to make health data as a global public good a reality.

As the COVID-19 pandemic has continued to reveal gaps in the health data value chain, and health system inequities, leaders and partners must seize the opportunity to operationalize good practices that ensure data is effectively used, ethically shared, and equitably distributed. The summit explored consensus across data and research stewardship, best data and research practices, and how to institutionalize those best practices.

The WHO Health Data Governance Summit is aligned with the UN Constitution, the joint statement for data protection and privacy and WHO’s data principles.

The Summit had three objectives:

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

Purpose of the Summit

---

Key Lessons

Health data has overarching legal and ethical challenges that depend on trust, privacy protection, infrastructure, and interoperability of relevant structures.

A common set of principles for health data governance are needed for health data to be a global public good.

Data sharing maximizes positive health outcomes.

Investment, partnerships and strong infrastructure are needed to develop a platform for secure data that is accessible to everyone.

We need to build competencies along all stages of the value chain so that anyone is empowered to derive insights and benefits from data.
The COVID-19 pandemic continues to remind the global health community of the importance of data for timely, reliable decision-making for effective health interventions. Health data gaps globally are impeding health outcomes and preventing the achievement of the Sustainable Development Goals (SDGs) and Triple Billion Targets. In response to these gaps and health inequities exacerbated by the pandemic, WHO is committed to embracing partnership and investing in country health information systems to speed up the accomplishment of these targets.

As the previous year has demonstrated, data sharing is an integral part of making these interventions possible. When health data is a global public good, governments, international health organizations, scientific research, and global populations see positive health outcomes. The sharing of reliable data results in more saved lives. However, due to the nature of health data and the gravity of its potential impact on human lives, health data as a global public good necessitates robust common governance standards and strong infrastructures that protect the privacy and rights of individuals.

With Member States and partners, this summit highlights the need for coordination and focuses on three main topics:

- Research data sharing
- Data sharing of public health and disease surveillance
- Legal and ethical considerations for data sharing policies and practices

“We must be prepared for future health crises by ensuring stable partnerships, trust in data, investments in countries’ health information systems, and political commitment.”

Samira Asma, Assistant Director-General for Data, Analytics and Delivery for Impact, WHO

“We must be prepared for future health crises by ensuring stable partnerships, trust in data, investments in countries’ health information systems, and political commitment.”

Samira Asma, Assistant Director-General for Data, Analytics and Delivery for Impact, WHO
Health data as a global public good maximizes the potential for data to achieve the triple billion targets.

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

These key themes were incorporated into a Summit Statement, which was made available for public comment. The Health Data Governance Statement acts as a statement of intent to build consensus around health data as a global public good and develop good data governance practices for better health outcomes.

SUMMIT STATEMENT CALLS FOR ACTION
- Work together to develop and adopt robust, common data governance practices
- Health data governance stakeholders requires collaboration and dialogue at all levels
- Enabling environment for adoption of a common set of principles
The COVID-19 pandemic emphasized the need for authoritative data sources that the public can trust. Data and statistics have never been more recognized as necessary for human progress. However, the fundamental need for credible data brings a set of governance challenges that the global health community must address collectively. Structures for good data governance must be developed with cross-sector collaboration to enable health data being a global public good.

Health systems are crowded with data and users are overwhelmed with the task of identifying credible sources. How can individuals know what data and sources are authoritative? When the public share their data, they should be able to see the evidence of that data’s impact. In addition, governance structures need to balance the tradeoffs between individual freedoms and collective responsibility. In response to these challenges, the health data community is committed to supporting the public in accessing and interpreting trusted and authoritative data on key global health issues. This task requires coordination across sectors - collaboration which the WHO Health Data Governance Summit promotes. We need a common vision through collective leadership and resources of a multisectoral data and research community.

“At WHO, when we say data as a global public good, we mean that data are being produced for the benefit of all, not just some.”

Steve MacFeely, Director, Department of Data and Analytics, WHO

WORLD HEALTH DATA HUB (WHDH)  
MAKING DATA A GLOBAL PUBLIC GOOD  
The World Heath Data Hub is a platform designed to strengthen data governance from collection to use. In operationalizing data governance, the WHDH reduces data fragmentation, making it a public good and ensuring equitable access globally.
GOOD DATA GOVERNANCE: AN OPPORTUNITY FOR GREATER EFFICIENCY, EXCELLENCE, AND ACCOUNTABILITY

The COVID-19 pandemic revealed society’s dependence on data for effective and resilient health systems. While the benefits of sharing data for health outcomes are increasingly clear, the inherent personal nature of health data makes protecting citizen information crucial. Partnerships, trust, and protecting individual rights are the pillars of health and confidence in health data systems.

The following cases illustrate how standards of practice, partnership, and trust are necessary for health system effectiveness, especially during a crisis.

Essential Data Standards
Early in the pandemic, Statistics Canada was tasked with establishing a cloud-based repository to manage the nation’s PPE supplies. This required fast and effective collaboration to create infrastructure to enable healthcare workers to care for Canadian citizens. It quickly became apparent that the system lacked standardized coding for PPE across regions, making fast coordination extremely difficult. By working on common definitions with partners, the team established the cloud infrastructure in just six weeks. This situation confirmed the necessity of data standards for efficient health care.

Positive Governance Depends on Partnerships
Statistics Canada conducted a national survey to establish prevalence of antibodies across the population. This would usually take 2 years to put in place, but by leveraging existing structures and governance, the program was launched in just 6 months. By collaborating with experts to achieve estimates representative of the country, this outcome was only possible through partnerships.

Trust Enables Health Outcomes
Statistics Canada has a federal mandate to integrate health information from different jurisdictions to benefit citizens lives. The Canadian health information system depends on collaboration for the public good. Timely, relevant statistics are foundational in supporting the wellbeing of citizens. This requires trust between partners and amongst citizens to share data and work together to unite behind common standards and objectives.
INSIGHTS FROM PANEL EXPERTS

The sharing of knowledge, experience, and ideas across geographies and sectors is integral for building systems that foster trust in data governance. The expert panelists represented a range of perspectives from the following organizations and institutions: Government of Canada, South African national Bioinformatics Institute, Gavi, Africa CDC, Center for Supporting Community Development Initiatives (SCDI), Ministry of Health Zimbabwe, Statens Serum Institute, National Statistics Office of Colombia.

The following sections of the report highlight some insights shared by experts.

The panels were organized in line with 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.

The insights presented here also build on research from the Open Data Institute (ODI) research, which has been working with WHO and holding discussions with 23 stakeholders and analyzing 56 documents to derive and communicate the leading perspectives in good health data governance.

Pre- read materials for discussion are publicly available:

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

PANEL THEMES

Data and Research Stewardship to promote greater impact on the ground

Identifying good data research governance practices: breakout sessions

- Research data sharing: Practices and incentives for governing and sharing research results
- Public health and disease surveillance: Data governing data during emergencies & non emergencies
- Ethical and legal considerations of data sharing policies and practices: Data access and sharing and protection and privacy

Institutionalizing good practices for good data governance
DATA AND RESEARCH STEWARDSHIP TO PROMOTE GREATER IMPACT

Panel members
Anuradha Gupta, Deputy Chief Executive Officer, GAVI The Vaccine Alliance
Professor Samba Sow, Director for Center for Vaccine Development, Mali.
Hon. Mercy Mwangangi, Health Chief Secretary, Kenya
Mohsen Asadi-Lari, Director General, International Affairs, MoH and Medical Education, Iran.
Glenda Gray, Perinatal HIV Research Unit, President & CEO South Africa Medical Research Council
Oliver Morgan, Director, WHO Health Emergency Information and Risk Assessment, Health Emergencies Programme, WHO

What good data governance practices need to be promoted to ensure data and research results are used to maximize health benefits?

Promoting equity and fostering trust often starts with the stability of systems for data collection and sharing. Before data and research results can be used to maximize health benefits, data must be systematically collected. This requires infrastructure that is usable and interoperable across all levels of the health system. Building on strong foundational systems, good governance practices foster trust in individuals, communities, and workplaces so data can be shared safely, analyzed, and used to maximize health benefits. Systems that are transparent and protect the individual rights of citizens foster public trust. To build this level of accountability, the global health community must reach consensus on common terms of reference. When governments, international institutions, and health sectors have clear roles and responsibilities, health data can be used effectively, efficiently, and equitably.

“In order to reach our objective of using data for better health outcomes, we need to ensure that all systems for data collection and sharing are built on trust.”

Hon, Mercy Mwangangi, Health Chief Secretary, Kenya
DATA AND RESEARCH STEWARDSHIP TO PROMOTE GREATER IMPACT ON THE GROUND

KEY INSIGHTS

TRUST
Building trust is more than just strengthening the relationship between individuals and institutions that collect and govern health data. International organizations, research institutions, governments, and health systems need to collectively put in place architecture that builds trust to enable entities to prepare for and respond to health crises.

CAPACITY BUILDING
Data governance capabilities begin with building data capacity at all levels of the health system. Two key criteria should be considered in developing data capacity in countries that are data poor:
1. Data collection must be thorough and systematic. For example, every country needs a civil registration system that records all births and deaths.
2. Data sharing must be as straightforward as possible. This requires interoperable digital systems, training, and collaboration between all sectors.

“Data is our greatest asset - that is why we have to protect it and make sure there is integrity in our health data systems.”

Glenda Gray, Perinatal HIV Research Unit, Johannesburg; President & CEO South Africa Medical Research Council

EQUITY
The health data community must accept the principle of equity as foundational in health data governance. Equity is bidirectional, so data collection supports citizens and contributes to health impact, not just supporting the initiatives of the international organizations collecting the data.

STANDARDIZATION
Stakeholders need common terms of reference, clear roles and responsibilities, and interoperable standards to reduce fragmentation caused by development partners.
IDENTIFYING GOOD DATA AND RESEARCH GOVERNANCE PRACTICES: BREAKOUT SESSIONS

1. RESEARCH DATA SHARING: PRACTICES AND INCENTIVES FOR GOVERNING AND SHARING RESEARCH RESULTS

Aliya Naheed, Scientist & Health Systems Specialist, Head, Initiative for Non-Communicable Diseases, International Centre for Diarrhoea Disease Control, Bangladesh (ICDDR,B)
Mahamoud Cherif, Clinical Research Manager, Partnership for Clinical Research, Guinea
Alejandro Lopez, Head of Digital Transformation, Carmelofruit
Vasee Moorthy, Senior Advisor R&D Research for Health, Science Division, WHO
Facilitated by Trudi Lang, Head, The Global Health Network & Senior Research Scientist in Tropical Medicine, Nuffield Department of Medicine, Research Fellow, Green Templeton College, University of Oxford.

When access to data, analysis, and research is extended beyond science to all sectors, outcomes of research data have broader impact potential. Additionally, individuals and diverse sectors are empowered to see the potential of data to increase health outcomes - thereby incentivizing data sharing. To reduce mistrust and incentivize data sharing, it is important that data analysts work with public service providers, managers, and policymakers to demonstrate how data collected and shared can help improve care.

CALLS TO ACTION

1. People who are providing and using data, such as individuals, policy makers, and health managers, must have access to information. The purpose and outcomes of data collection, as well as the underlying data, should be accessible to everyone - not just scientists.

2. Currently, there is a gap between research and progress in healthcare. We need to create opportunities and systems for health care providers to access research in real time so they can apply those insights and improve health service quality.

3. Tools for data collection and analysis should leverage digital solutions. The implementation of digital solutions must be coupled with capacity building and training at all stages of the data value chain so individuals can access and use the data.
2. PUBLIC HEALTH AND DISEASE SURVEILLANCE: DATA GOVERNANCE DURING EMERGENCIES & NONEMERGENCIES

Ilesh Jani, Director General of the National Institute of Health, Mozambique
Alma Tostmann, Hospital epidemiologist & Deputy head of Infection Prevention and Control Unit, Department of Medical Microbiology, Radboud Centre for Infections, Radboud university medical centre, Nijmegen, The Netherlands
Stéphane Hugonnet, Unit Head and Karl Schenkel, Epidemiologist, Field Epidemiology Strengthening Unit, WHO

When disease surveillance data exist in a silo, policymakers and health officials are less enabled to make decisions quickly. To plan health interventions and understand risks, disease surveillance indicators must be supplemented with additional data and information to provide context.

CALLS TO ACTION
1. Combine routine surveillance with data from other sources, from different organizations and sectors, nationally and internationally.
2. Data scientists, immunologists, and microbiologists all need to share data and research during both emergencies and non-emergencies.
3. We need legal frameworks to support data linkage, sharing and data analysis.

3. PRACTICES: DATA ACCESS AND SHARING, PROTECTION AND PRIVACY

Vikas Dwivedi, Senior Health Information Systems adviser, Palladium
Vidya Mahadevan, Senior data governance adviser, USAID
Ian Coltart, Manager Copyright, Licensing & External Publications, Science Division, WHO

Health data face overarching legal and ethical challenges that depend on trust, privacy, protection, and interoperability of relevant structures. Good data governance strikes a balance between supporting governance and policies without compromising data ownership.

CALLS TO ACTION
1. Develop a digital exchange platform that protects personal privacy rights.
2. Share implicit and explicit best practices to promote common standards.
3. Examine and leverage legal framework examples from industries other than the health sector.
4. We need comprehensive laws for data protection, informed consent, and data breaches.
5. We need to build trust, collaborative digital space, equitable and inclusive data collection, and governance of electronic health data, enabling infrastructure, effective information sharing, and pragmatic next steps to mitigate fragmented health systems.
How can we institutionalize and operationalize good practices to facilitate good data governance?

“When we talk about data governance, ask that everyone involved in collecting data get advice from people who are in and really know the community. Community representatives should be involved in bodies making decisions about the data: what it should be used for, where it will be shared, and whether it will be collected.”

Dr. Khuat Thi Hai Oanh, Executive Director, Centre for Support of Community Development Initiatives (SCDI), Hanoi, Viet Nam

Institutionalizing good practices for data governance requires participation and collaboration across sectors and along all stages of the health data value chain. Partners in the health system, development organizations, government, the technology sector, and science must coordinate to ensure that systems are interoperable, and that capacity for data collection and sharing is strong at all administrative levels, and health data results in positive health outcomes. As the push for digital health information systems and health data as a global public good continues across these partners, it is important that local stakeholders are involved in aligning efforts and working to eliminate a fragmentation of data and initiatives. Institutionalizing central health data mechanisms, moving from paper to digital systems, and partner coordination enables health data to result in better health outcomes.
### Institutionalizing Good Practices for Data Governance

<table>
<thead>
<tr>
<th>Institutionlized Practice</th>
<th>Call to Action</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health Data Mechanisms</strong></td>
<td>National health systems need digital mechanisms for data integration, processing, access and use. These systems should have a national health data repository managed at a central level and provide capacity for lower administrative levels to collect and use data efficiently. Administrative data should be managed by the health system.</td>
</tr>
<tr>
<td><strong>From Paper to Digital Systems</strong></td>
<td>Digital capacity building must be a priority of national health systems. Governments have to approve the implementation of new tools, develop interoperability standards, and work to eliminate fragmentation in health data.</td>
</tr>
<tr>
<td><strong>Partner Coordination</strong></td>
<td>Development partner digital projects must be interoperable in order to avoid fragmentation. Partners must also work to eliminate dual requests and harmonize health information standards and policies amongst different sectors.</td>
</tr>
<tr>
<td><strong>Integration of Different Data Types</strong></td>
<td>Combining geo-spatial information and statistical information will operationalize health interventions across sectors. For example, the integration of individual information and population data</td>
</tr>
</tbody>
</table>
FUTURE DIRECTIONS

Recommendations from experts, panel members, and audience participants call on WHO, Member States, and partners to recognize the link between health data and health outcomes and strengthen data governance efforts for epidemic preparedness. Working on key pillars including indicators for concrete programmatic action and better surveillance, WHO is dedicated to improving real time detection, verification, investigation, assessment, and communication of public health data for public health action.

In the context of new technology and innovation, it is becoming increasingly important for people to share their data to enable these advances to be impactful. For example, the sharing of SARS-CoV-2 genetic sequences has allowed science to track bio evolution and variants. This type of big data sharing provides actionable data for both WHO and Member States.

In 2022, WHO will work to promote the sharing of credible and quality data through three main workstreams:

1. WHO is establishing interoperability standards for partners and stakeholders. Just as WHO set standards for vaccination cards so that certificates could maintain validity across borders, interoperability standards will increase global coordination and the efficiency of health information system digitization.

2. The WHO Health Data Governance Summit has shown enthusiasm and agreement amongst stakeholders to develop standards of practice and collaborate on health data governance issues. WHO will continue convening stakeholders to develop these standards and increase the awareness of dataset repositories.

3. WHO is developing a set of tools to support high quality research and guide researchers in data management and sharing.

“Data sharing and data reuse must be maximized in ways that are effective, ethical, and equitable to improve public health.”

Soumya Swaminathan, Chief Scientist, WHO
Science Division
CONCLUSION

As health systems work to recover from COVID-19, the global health community is unifying behind initiatives that solidify health system infrastructure that is more resilient than ever before. Health data is central to this effort. In the context of broader systematic improvements, WHO Health Data Governance Summit participants convene behind the effort to ensure the global population can access, share, and use health data as a global public good. Ultimately, health data is about increasing positive health outcomes for people. Health data as a global public good is one step in harnessing momentum, addressing data gaps and inequalities, and building resilience.

Outcomes from the WHO Health Data Governance Summit Data support governance for data to be effectively used, ethically shared, and equitably distributed. Discussions from the summit offer opportunity to implement better collaboration build on trust and transparency, infrastructure to liberate data, and frameworks to strengthen health information system capacity. Insights on operationalizing and institutionalizing good health data governance practices provide an actionable roadmap for measurable impact moving forward.

ROADMAP AHEAD

With the support of Member States, development partners, and research institutions, WHO remains committed to the following calls to action:

MAKE DATA ACCESSIBLE TO EVERY COUNTRY

FULLY INSTITUTIONALIZE GOOD PRACTICES FOR DATA SHARING AND GOVERNANCE BOTH INTERNALLY AND EXTERNALLY

“We cannot make progress unless we can measure progress.”

Dr. Tedros Adhanom Ghebreyesus, WHO Director-General
Summit Attendance Statistics

Organisations 142
Registrants 800
Countries Broadcasted to 68

Angola • Argentina • Australia • Austria • Bahamas • Bahrain • Bangladesh • Belgium • Brazil • Bulgaria • Burkina Faso • Cameroon • Canada • Chile • China • Colombia • Congo • Denmark • Egypt • Ethiopia • France • Germany • Ghana • Guinea • India • Indonesia • Japan • Kazakhstan • Kenya • Kiribati • Lebanon • Luxembourg • Malaysia • Maldives • Mali • Mexico • Myanmar • Nepal • Netherlands • Nigeria • Pakistan • Peru • Philippines • Poland • Portugal • Qatar • Romania • Russia • Rwanda • Saudi Arabia • Senegal • Singapore • Slovakia • Slovenia • South Africa • Spain • Sri Lanka • Sudan • Switzerland • Tajikistan • Tanzania • Uganda • United Arab Emirates • United Kingdom • United States • Vietnam • Zambia • Zimbabwe