Health Data Governance Summit

Pre-read: Health Data as a Global Public Good

30 June 2021
"Starkly and powerfully, the COVID-19 pandemic illustrates how critical data use, with a human face, is to protecting lives & livelihoods. The crisis is a wake-up call. We must accelerate a shift in our data and analytics abilities: To respond to COVID-19 and build back better, to drive the Decade of Action for the SDGs, to amplify climate action, to promote gender equality, to protect human rights, to advance peace and security, and to accelerate UN Reform - for greater impact on the ground."

UN Secretary-General

“Despite progress in recent years, high-quality data are not routinely collected in all settings, major health challenges are not adequately monitored, and effective interventions are not directed to the right people, at the right time and at the right place. This impacts policies and programmes and consequently, the health of entire populations. Similarly, in order to meet the shared SDG commitment to “leave no-one behind”, we need disaggregated data to ensure equitable health outcomes. This means we must strengthen comprehensive data systems, collaborate with other sectors, and apply innovative digital technologies to collect, analyse and use data to make informed decisions and deliver impact.”

WHO Director-General
What are global public goods?

“Global public goods are goods... whose benefits cross borders and are global in scope.” - WHO Bulletin 2003

In traditional economic terms, public goods are have two key attributes:

- They are **non-exclusionary**: No one can be excluded from using them.
- They are **non-rivalrous**: One person or entity's use does not prevent anyone else's

In the words from one of our informant interviews:

"Anyone can use them, and anyone can get a benefit from their use".

But this economic definition is unhelpful when considering that some data may be sensitive or private, and therefore should not be open to everyone, but can still be used to bring benefits to everyone.

‘Global public goods (GPGs) provide benefits to people in both rich and poor countries. They play a crucial role in safeguarding the social, economic, and political progress of the past century. They are fundamental to managing global risks such as climate change, infectious diseases, and financial crises that can harm developing countries disproportionately; and in exploiting opportunities, such as new vaccines, that can benefit them especially.”

Birdsall & Diofasi
Center for Global Development

What are global public goods?

The benefits of global public goods should be ‘maximised and felt by the widest range of users’.

Health data as a global public good must:

- **Build public value**: Data informs individuals, benefits communities, and enhances economies
- **Address knowledge gaps**: Data can be used to reduce inequalities and highlight data disparities hidden by aggregation or due to lack of data collection
- **Accelerate progress** towards meeting targets set under the Sustainable Development Goals

### WHO Public Health Goods (WPHG)

WHO Public Health Goods are products and services uniquely delivered by WHO for the benefit of all countries, that are essential to achieve the GPW13 Triple billion targets, with the following three strategic shifts:

1. Leadership functions.
3. Country support.

What are digital public goods?

Endorsed by the ‘United Nations Secretary-General’s Roadmap for Digital Cooperation’, the Digital Public Goods Alliance defines digital public goods as: ‘open source software, open data, open AI models, open standards and open content that adhere to privacy and other applicable laws and best practices, do no harm, and help attain the Sustainable Development Goals.’

For example, UNICEF and WHO are leading a project focused on creating a COVID Digital Centre of Excellence as a digital public good, with ambitions to extend this to become a core digital public good to support implementation of WHO’s Global Strategy on Digital Health 2020-2025 in the future.

Through these initiatives we understand that health data as a public good also includes the data infrastructure that enables data to be high quality, stewarded appropriately, and shared for reuse in responsible ways.

The COVID DICE is a consortium of partners, including the Bill & Melinda Gates Foundation (BMGF), GIZ, the US Centre for Disease Control, the European Commission, The Global Fund, The Foreign, Commonwealth & Development Office (FCDO), the Gavi Alliance, USAID, and the World Bank. It is co-hosted by a UNICEF-WHO virtual secretariat that will be managing day-to-day activities, including coordination with technical partners like Digital Square.

The COVID DICE is currently funded by a donation from the BMGF, and is designed to provide coordinated technical assistance to low- and middle income countries (LMICs) to support sustainable and scalable deployment of carefully chosen mature digital global goods for planning distribution of commodities and vaccines, tracking patients and supplies, surveillance and case detection, monitoring coverage of services, training health workers, and communicating with the general population to generate demand and reduce misinformation.

Learning from others: How official statistics are being recognised as a global public good

Health data stakeholders can look to how the UN and global partners have sought to recognise official statistics as a global public good.

The UN Fundamental Principles of Official Statistics states: ‘Official statistics provide an indispensable element in the information system of a democratic society’.

In the UK, for example, national legislation established an authority with the statutory objective of ‘promoting and safeguarding the production and publication of official statistics that serve the public good’.

The public good is recognised as including:

- informing the public about social and economic matters
- assisting in the development and evaluation of public policy and
- regulating quality and publicly challenging the misuse of statistics.

“Data are the lifeblood of decision-making and the raw material for accountability. Without high-quality data providing the right information on the right things at the right time; designing, monitoring and evaluating effective policies becomes almost impossible. So, too, does the ability of businesses and people to make well-based decisions. As the volumes of available data increase, quality should become the decisive factor when choosing a data source.”

One of the issues raised during the research was what aspects of health data should be considered a public good.

Acknowledging health data as a public good also includes the institutions, technologies and processes (that is, the data governance infrastructure) that ensure that health data management is ethical, equitable, and reusable.
Not all data should be shared or opened. Not all data is non-exclusionary. People’s privacy must be protected.

Sharing health data as a public good requires making data available with the right degree of openness or restriction - at the right points in the data spectrum - to achieve maximum benefit, while reducing any potential for harms.

Deciding which data types to open and share is often an aspect of data governance processes. Opening data doesn’t preclude providing charged-for services over such data as well as making it openly available.

There are already global examples where these economic and political nuances have been successfully navigated:

- Anonymised data for public health surveillance is being opened and made available
- Models like GISAID are successfully encouraging researchers to share data and licensing models to ensure attribution for those contributing data
- Clinical trials data and electronic health record data collected during pandemic and epidemic crises are shared under emergency use arrangements that are time-limited and restricted again, once emergency situations have passed.
The value of health data

An open and trustworthy health data landscape enables value to be generated for individuals, stakeholders and society.

For health data to have a value impact as a global public good, it needs to be available in aggregate. For example, individual genomic sequence data has very limited value. Value can only be realised when global sequencing is made available at scale.

Many smaller clinical trials also have similar limited potential for impact. For example, there are around 10,000 clinical trials focusing on COVID-19 but the overwhelming majority are too small to enable insights for health outcomes or decision-making. Around 1% of all COVID-19 trials are sufficiently large enough to generate decision-making value. If governance and standards were put in place, trial data could be aggregated and enable huge advances in analysis. Studies that provided evidence of the efficacy of using corticosteroids, for example, came from pooling data from multiple clinical trials.

Why is health data important for generating value?

Global movement of populations, the fragmented nature of health service usage and burden of disease data, the often

Unlocking the value of health data generates new types of insights on health that cannot be generated through other means:

- Large datasets that are managed throughout the data journey to create quality, comparative datasets at scale enable analysis.
- Pooled data helps identify opportunities to address specific sub-population group interventions that could reduce health inequalities.
- Timely access to quality, shared data creates opportunities for collaboration and new scientific and community partnerships.

“Open, inclusive, and responsible data can help to improve service delivery, ensure transparency and accountability and drive inclusive and sustainable growth.”

OECD Data for Development Profiles
OECD (2021), ‘Data for Development Profiles Official Development Assistance for Data and Statistical Systems’, https://docs.google.com/presentation/d/1Gsh9xiqZ5H2elpm95k0BDZ3elgi6TkdSKsZ6nSmlp0/edit?pli=1#slide=id.ge04da126ba_0_214
Current conversations in recognising health data as a public good

Informants we interviewed highlighted a number of conversations which must take place if we are to build consensus for recognising health data as a global public good.

These conversations, discussed in the following slides, include:

- How to manage publishing disaggregated data against the risk of re-identifying or stigmatising populations
- How to open data while also supporting commercial opportunities that can spur innovation and industry
- How to set realistic expectations around the impact health data can have on driving action
- How to acknowledge and redress value asymmetries where low- and middle-income countries (LMICs) have been contributing data but the benefits from it (such as professional recognition for researchers) have been predominantly realised by high-income countries
- How to manage the technical aspects of sharing health data as a public good
- How to set boundaries on emergency situations or exceptional circumstances which may warrant making data more readily available for a limited time as a public good

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Digital Square’s *Global Goods Guidebook* describes how global public goods mature. The guidebook highlights the importance of enabling local implementations that adapt global digital public goods and data governance processes to meet cultural, community and legislative values and norms.

How to manage publishing disaggregated data against the risk of re-identifying or stigmatising populations

Informants recognised that to create meaningful value, health data must be disaggregated beyond broad population-level statistics to enable insights into the health equity outcomes facing specific population subgroups.

This disaggregated data must be granular enough to monitor and address inequalities, but not so specific that microdata can re-identify individuals.

Sources: UN (2021), 'Data Revolution for a Sustainable World'
How to open data while also supporting commercial opportunities that can spur innovation and industry

Informants noted three groups of health data:

- Biomedical research
- Health technology data
- Health systems performance data

There was some agreement that health systems performance data could be a global public good. This could also extend to registry data sets such as burden of disease data and civil registry and vital statistics (CRVS) datasets.

However, several informants noted that there is a cost/benefit approach amongst commercial and private entities that collect health data, where health data is seen as a commercial asset and the concept of health data as a global public good could be perceived as a threat to industry.

An agreement that defines health data as a global public good could have global trade implications.
How to set realistic expectations around the impact health data can have on driving action

Some informants noted that the framing of health data as a public good suggests that health data is at the core of decision-making.

Informants noted that while health data is an important factor in evidence-informed decision-making, there are a range of other influences that may have greater impact on decision-making including:

- the political context,
- judgement of peers, and
- the personal and professional experiences of decision makers.
How to acknowledge and redress the traditional value asymmetries where low and middle income countries have been contributing data and value has been extracted for high income country gain

Informant interviews noted that there is still distrust in opening and sharing data between low and middle income countries. There is ‘unfinished business’ following global recognition that an imbalance has occurred when LMICs have made data available and higher-income countries derived benefits from that data.

This asymmetry was noted at multiple levels:

- Researchers felt they had not had their data sharing attributed appropriately, and were not invited to participate in study designs that made use of their data.
- Communities felt data about them was used by their country health systems to deny access to healthcare or to direct resources away from local needs.
- Countries felt that multilateral organisations had made use of their data for global purposes and organisational prestige rather than to aid and assist in strategic planning for the benefit of local citizens.

In addition, data governance models being proposed globally often align with a Global North/westernised view of individual rights that is not the culturally appropriate model in some countries and regions.

“The reason so many labs have provided SARS-CoV-2 genomes to GISAID is precisely because of the data-access agreement that restricts public resharing,”

Sebastian Maurer-Stroh, Singapore

“We really want to share our data, but it is heartbreaking and demotivating when we know we worked so hard to generate data, but we don’t get the credit for it.”

Senjuti Saha, Bangladesh

“Imagine Africans working so hard to contribute to a database that’s used to make or update vaccines, and then we don’t get access to the vaccines. It’s very demoralizing.”

Christian Happi, Nigeria

Some informants noted the challenges of opening health data as a public good if that data had already been collected. In those instances, they felt it was paramount that all stakeholders remain bound by the initial data collection and agreements made between the data stewards and the data subjects, for example, where consent was only provided for individual healthcare purposes. Data governance processes must abide by any agreements made during the collection, storage and use of health data.

When making health data available as a global public good, there will also be the use of health technologies and platforms, and there could be data governance implications in supplier and provider contracts that go beyond what was intended when establishing ethical processes and when initially collecting data from people and communities.
How to set boundaries on emergency situations or exceptional circumstances which may warrant making data more readily available for a limited time as a public good

If agreement is found on what level of access to health data can be considered a public good, there may still be exemptions that apply in emergency health crises. Informants noted that these might be legitimate cases, but ideally need to be articulated in advance, as they might make use of data in ways that are not expected ordinarily when data is used for the global public good.

During the COVID-19 pandemic, decisions were made that reshape our understanding of data sharing. For example, mobile phone data has come to be seen as a crucial dataset for health management, enabling contact tracing, mapping the spread of variants, and identifying ‘hotspots’ for targeted interventions such as testing and treatment services. This data is collected at an aggregate-level and is unable to identify individuals. As such, data protection laws did allow its reuse, but there are limited rules defining appropriate sharing and data governance arrangements. In future, it would be better to have data governance decisions made in advance of new sharing paradigms for unique datasets.

Encouraging new conversations on health data as a public good: A global consensus

“A global consensus would give individuals and enterprises confidence that data relevant to them carry similar protections and obligations no matter where they are collected or used. It would effectively establish a social contract that would strike a balance between the use of data for development and the protection of data in terms of security, privacy, and human rights of the individual. It would also establish ground rules for the exchange of data between commercial use and the public good.”

World Development Report (2021), ‘Spotlight 8.1 The need for a new global consensus on data: A call to action’, https://docs.google.com/presentation/d/1Gsh9xiq25H2elpm9SkoBDZ3eLq67KfduKs26n5lmp0/edit?pli=1#slide=id.ge04da126ba_0_169

“Maintain policies, legal frameworks and programmes which promote research collaboration - among our scientists, research institutions and innovative businesses;

Promote the efficient processing and sharing of research data as openly as possible and as securely as necessary across the G7 and beyond, by improving the availability, sustainability, usability and interoperability of research data, technologies, infrastructure and services. We will work together to address the administrative, legal, and regulatory barriers that hinder our scientific cooperation and slow our ability to respond to crises...”

G7 Communique,
Our Shared Agenda for Global Action to Build Back Better,
https://www.consilium.europa.eu/media/50361/carbis-bay-g7-summit-communique.pdf

Right now, there are multiple global movements advocating for a new global social contract for data sharing. These discussions started as global digital infrastructure increased. The lack of availability of key datasets, and the fragmentation and lack of interoperability of global data systems during the Covid-19 pandemic accentuated the need for new agreements between local communities, countries, regions, multilateral organisations, non-government actors, and private industry.

Recent agreements highlight the need for increased trust in global data flows include:

- G7 Communique 2021
- UN Secretary General’s Roadmap for Digital Cooperation
- World Economic Forum reports on Data-driven economies
- World Health Assembly 2030 Agenda for Sustainable Development

A global consensus

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Why seek to acknowledge health data as a public good?

As global digital infrastructure matures, there is a need to agree on shared principles and create a catalogue of data governance models and processes that can be adapted to meet local contexts and cultural values.

There are four key benefits that informants raised as to why now is the time to encourage global commitment to building trustworthy health data systems:

- Encourage collaboration
- Strengthen strategic focus
- Optimise resource allocation
- Overcome fragmentation

“National Statistical Systems (NSS) in developing countries are often under-resourced and under-staffed, and traditional support to statistical capacity building is often not fit for purpose. While political support to have and use more and better data is essential to realising the full potential of data for development, more effective and better coordinated support will enable country leadership, co-operation, data literacy, and innovation.”

- UN SDG

“While data is the most collected, analyzed, shared, and traded good or service around the world, we know little about how various types of data are governed at the national and international level.”

- Digital Trade & Data Governance Hub, https://datagovhub.elliott.gwu.edu/2021/05/17/the-global-data-governance-mapping-project/
A global agreement on health data as a public good encourages collaboration

This deck has described some of the key issues that need to be resolved with meaningful conversations, for us to move forward with global data governance processes and new commitments to data sharing, within agreed boundaries.

Informants noted that agreements amongst global stakeholders which defined health data as a global public good can encourage new collaborations and partnerships and help them start with clearer foundations. Acknowledging health data as a global public good and setting establishing clear principles helps partners understand and clarify communications and ways of working.
A global agreement on health data as a public good strengthens strategic focus

Informants noted that an agreement on health data as a global public good could help policymakers improve decisions, by creating a global learning community where data can be used to compare policy interventions.

Access to health data "brings into focus what is wanted to be achieved," said one informant. Several others described the power of digital civil registry and vital statistics datasets as instrumental in enabling better decision-making at the community, country and regional levels.
Informants believed that global access to health data would help countries, particularly low- and middle-income economies, to use resources more effectively and efficiently.
A global consensus

A global agreement on health data as a public good overcomes fragmentation

Informants noted that today’s greatest challenges cross sectors and require timely local, disaggregated data to inform policy, service delivery and community engagement.

Data helps drive collaboration and participation amongst governments, civil society, businesses and industry. As can be seen from the use of transport and mobile phone data for healthcare planning, there is also the need for greater joined-up datasets. Establishing health data as a public good can enable new thinking that encourages its use alongside other available high value datasets to generate new insights and analysis across society.
Why now?

Health data needs are growing in urgency, as demonstrated by the impact of the global pandemic. Looking at expected future health challenges facing global populations, from climate crises and extreme weather events, it’s clear that health data can help protect communities, optimise available resources and save lives.

Globally, there is clear recognition of the challenges to data governance systems. There is renewed momentum for creating consensus as we all learn from the challenging experiences over the past year.

“The importance of timely, quality, open and disaggregated data and statistics has never been as clear as during the COVID-19 crisis. Such data are critical in understanding, managing and mitigating the human, social and economic effects of the pandemic. They are also essential for designing short-term responses and accelerated actions to put countries back on track to achieve the SDGs.”

- UN SDG Clinics

Sources: UN (2021), ‘Data Revolution for a Sustainable World’
In Brazil, acknowledging government-held data as a public good enabled community action and generated new insights

Brazil’s laws (LEI Nº 12.527, de 18 de Novembro de 2011) state that public data must be available, as it is a public good (that is, that government collected data must be available at a de-identified, aggregate level, free of charge).

The value of health data

Open data has been essential for:

- **Enabling advocacy and civil society participation in health resources management:** 2016 data showed an increase in infant mortality. Civil society and media were able to use data to advocate for action.

- **Addressing health inequalities:** Data was used to increase resource allocation, bringing more doctors to remote and low-income areas. When maternal mortality was observed during the COVID-19 pandemic, some states used this data to prioritise pregnant women for vaccinations which is now a national policy.

- **Identifying new trends that may have otherwise been missed:** Researchers and academics used health data to identify more granular analysis, beyond the capacity of health department budgets. In this way, scientists helped governments identify microcephaly deaths during the Zika epidemic in 2015 and 2016.

Stakeholders

Opening health data has involved civil society networks, media, research and academia, Ministry of Health, politicians.

Governance processes

**Structural:** National legislation recognising government data as a public good. Presidential committees established to address public health issues identified through health data. Ethical processes are in place when researchers wish to use identifiable data. (For research use of individual data that is non-identifiable, ethics processes are not required.)

**Legal:** Legislation requires researchers using public data via ethics processes to publish findings openly. Processes are in place to delete/restrict data access at the end of research phase.

**Technical:** Standards were developed during H1N1 and an interoperable data surveillance system established which was able to be adapted and extended to meet COVID-19 data collection and sharing needs. De-identification and anonymisation processes are in place. Government has recognised two research hubs where it can share confidential data. Researchers may also request data access and provide details of preferred calculations to be performed on the data. An integration hub is available to share results of the data calculations performed so that data analysis is provided in a timely manner but within privacy and security boundaries. Dashboards have been established by national governments that states and municipalities can clone to create localised data monitoring tools.

Information shared by Fatima Marinho.
Key elements of the Brazil health data landscape
Global data sharing efforts to eliminate malaria continue to improve each year and have resulted in substantial drops in malaria incidence

Several global initiatives have built collaborative networks to enable data sharing to eliminate malaria:

- The World Health Observatory publishes indicators and statistics on malaria incidence.
- The WorldWide Antimalarial Resistance Network (WWARN) has established collaborative platforms and data sharing models to aid researchers and policy makers.
- WHO Western Pacific Region meets annually to strengthen public health surveillance to eliminate malaria.

The value of health data

New health data surveillance has:

- **Supported financing**: Enabling government policymakers to allocate resources to maintain malaria elimination as a public health priority.
- **Reducing incidence**: Across Western Pacific region, there was a 61% decrease of Plasmodium falciparum cases and a 32% decrease of P. vivax cases compared to the same period in 2019.

Stakeholders

Governments, policymakers, research and academia, technology providers, standards bodies.

Governance processes

**Structural**: Global SDG goals include target 3.3 to improve health and wellbeing, and specifically mentions elimination of malaria.

**Legal**: WWARN recently updated its data sharing policies and processes to allow data contributors to select models of data sharing that meets their needs, including through a contributor-controlled access process or through authorising a data access committee to make decisions. These are legally binding agreements made with data contributors.

**Technical**: Global standards are used to ensure data is interoperable and comparative. Technology platforms are used to host and share data, this includes various tools including surveyors that map molecular markers, and tools that ensure quality of literature review evidence.

Sources:
Key elements of global data sharing initiatives to eliminate malaria

- Data Stewards
  - Private
  - Government
  - Civil Society
  - Networks
- Healthcare Industry
- Research & Academia
- NGOs
- Regulators
- Data & ICT Stakeholders
- Civil Society/Advocates
- Standards Bodies

Stakeholders that generate and act on data

Flow of Data

Flow of Value

Flow of Trust

Datasets about
- People
  - Patient Health Records
- Organisations
  - Health care expenditure and allocation
- Society
  - Burden of disease data
  - Malaria incidence data
- Environment
  - Health service facility access and locations

Private profits and professional recognition

Expanded innovation

Optimised health system

Better health outcomes

Reduced inequality
Thank you to all informants and participants for sharing your time and expertise

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