![Health Data Collaborative logo]

EVENT REPORT

18 AND 19 MAY 2023

GENEVA, SWITZERLAND (IN-PERSON AND VIRTUAL)

Better Data for Better Health

INVESTING IN COUNTRY HEALTH INFORMATION SYSTEMS AND HEALTH DATA GOVERNANCE TO ACCELERATE PROGRESS TOWARDS HEALTH-RELATED SDGS
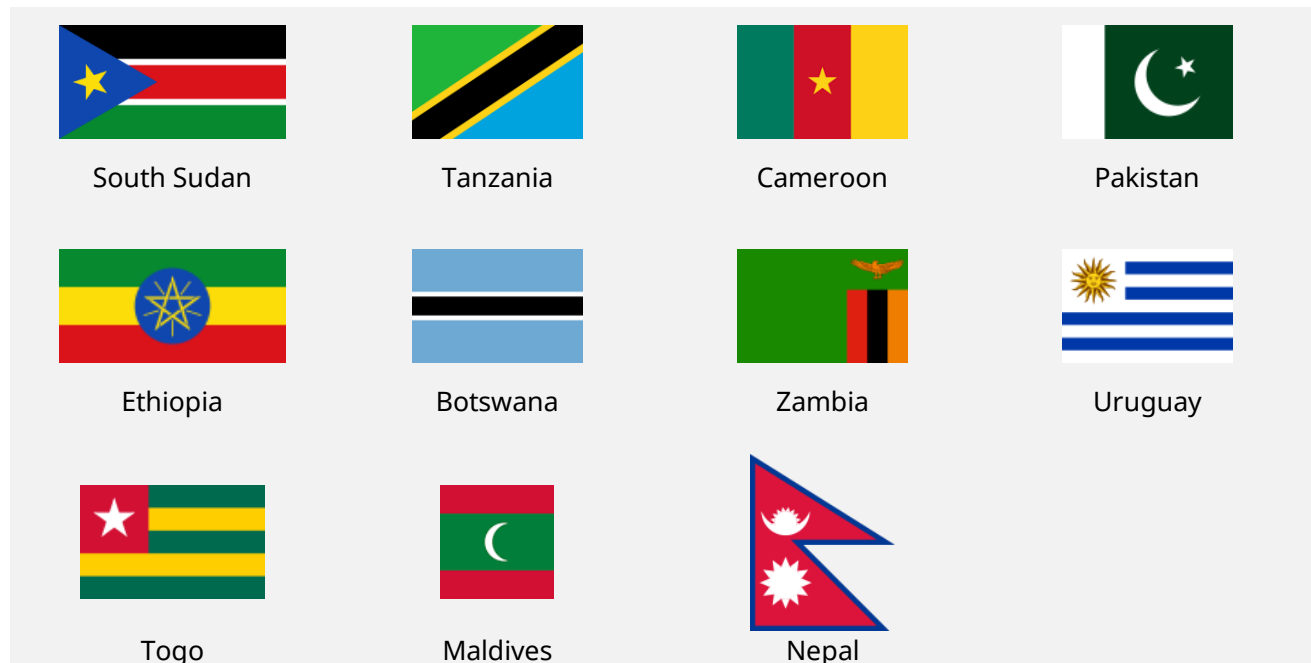
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ACKNOWLEDGEMENTS

The Health Data Collaborative wishes to acknowledge the following partners for their contribution to the planning and execution of this event:

With government representatives from:

South Sudan	Tanzania	Cameroon	Pakistan
Ethiopia	Botswana	Zambia	Uruguay
Togo	Maldives	Nepal	

EXECUTIVE SUMMARY

BACKGROUND

There are significant gaps in data and capacities for tracking progress towards SDG targets and supporting communities left behind. Fragmented approaches to data collection, storage, sharing, analysis and use of data for health outcomes is challenging progress.

Building on the 2021 Health Data Governance Summit and summit statement, the Health Data Collaborative (HDC) partners co-hosted an event on 18 and 19 May 2023 to promote health data as a global good by (a) identifying and promoting good country health data governance practices; and (b) promoting investment in Health Information Systems (HIS), guided by the SCORE for Health Data Technical Package (SCORE) as an approach to investment, especially in Least Developed Countries.

Context-relevant initiatives included i) the World Bank's 2021 Global Development Report making the case for investing in data and ongoing capacity building events for health data governance; ii) the Global Partnership for Sustainable Development Data-led data with purpose and investment case for data (1$ invested in data returning $32 and call for 0.8% of annual spending allocation for data systems); iii) Health Data Collaborative investment case for Routine Health Information Systems (RHIS); iv) the UNSG data strategy; v) WHO data principles; and vi) health data governance principles and advocacy for a global health data governance framework led by Transform Health.

EVENT OBJECTIVES

- Review data governance principles, policies and good practices from countries and partner organisations; and
- Discuss and propose an investment strategy for strengthening country HIS.

EVENT STATISTICS

290 **organisations** represented (in person and virtually);

52 **people in person;**

**319** **people joining virtually** on Day 1; and

229 **people joining virtually** on and Day 2

With government representatives from: Botswana, Cameroon, Ethiopia, Maldives, Nepal, Pakistan, South Sudan, Tanzania, Togo, Uruguay and **Zambia**.

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GEOGRAPHIC BREAKDOWN OF ATTENDEES FROM 91 DIFFERENT COUNTRIES

created with mapchart.net

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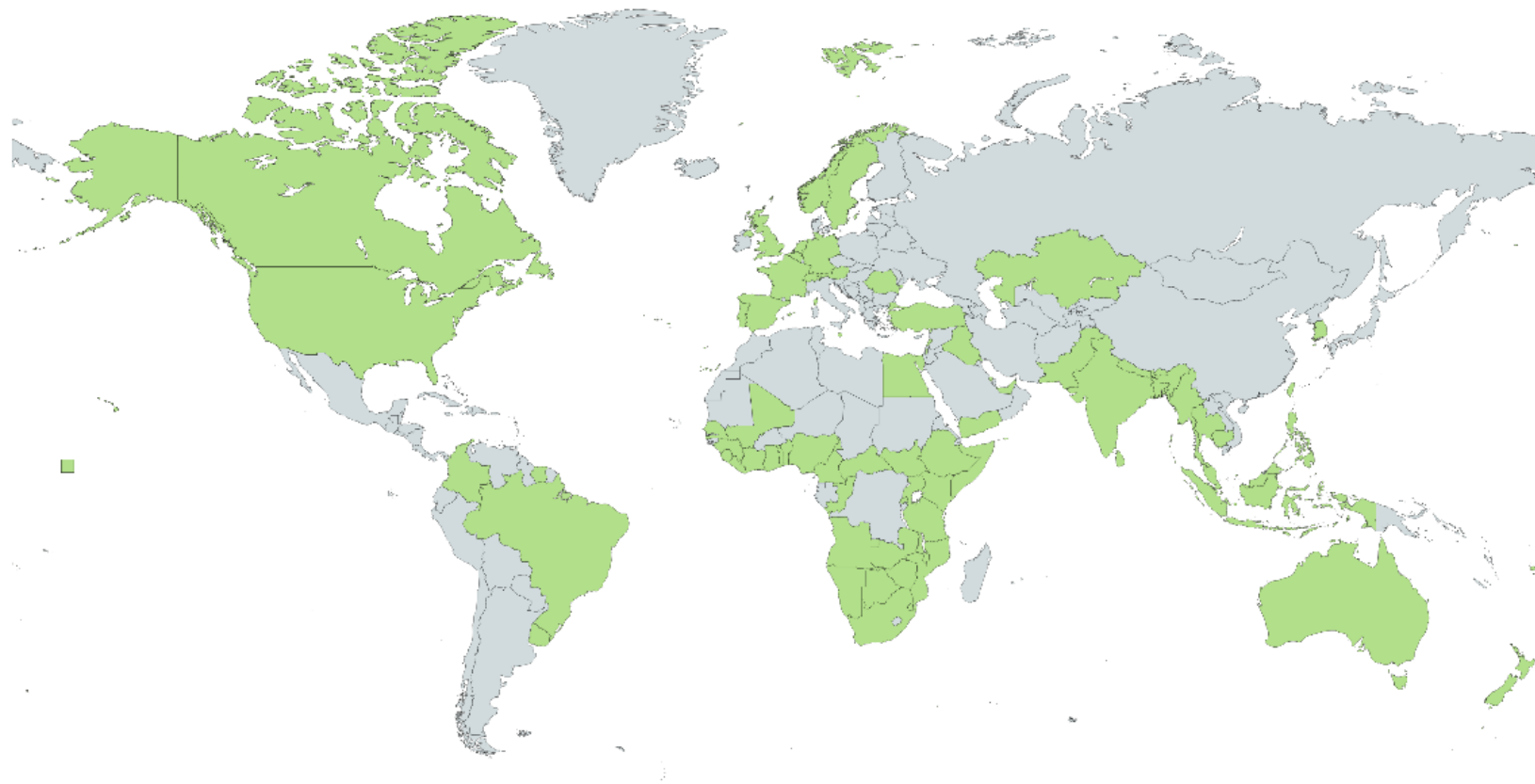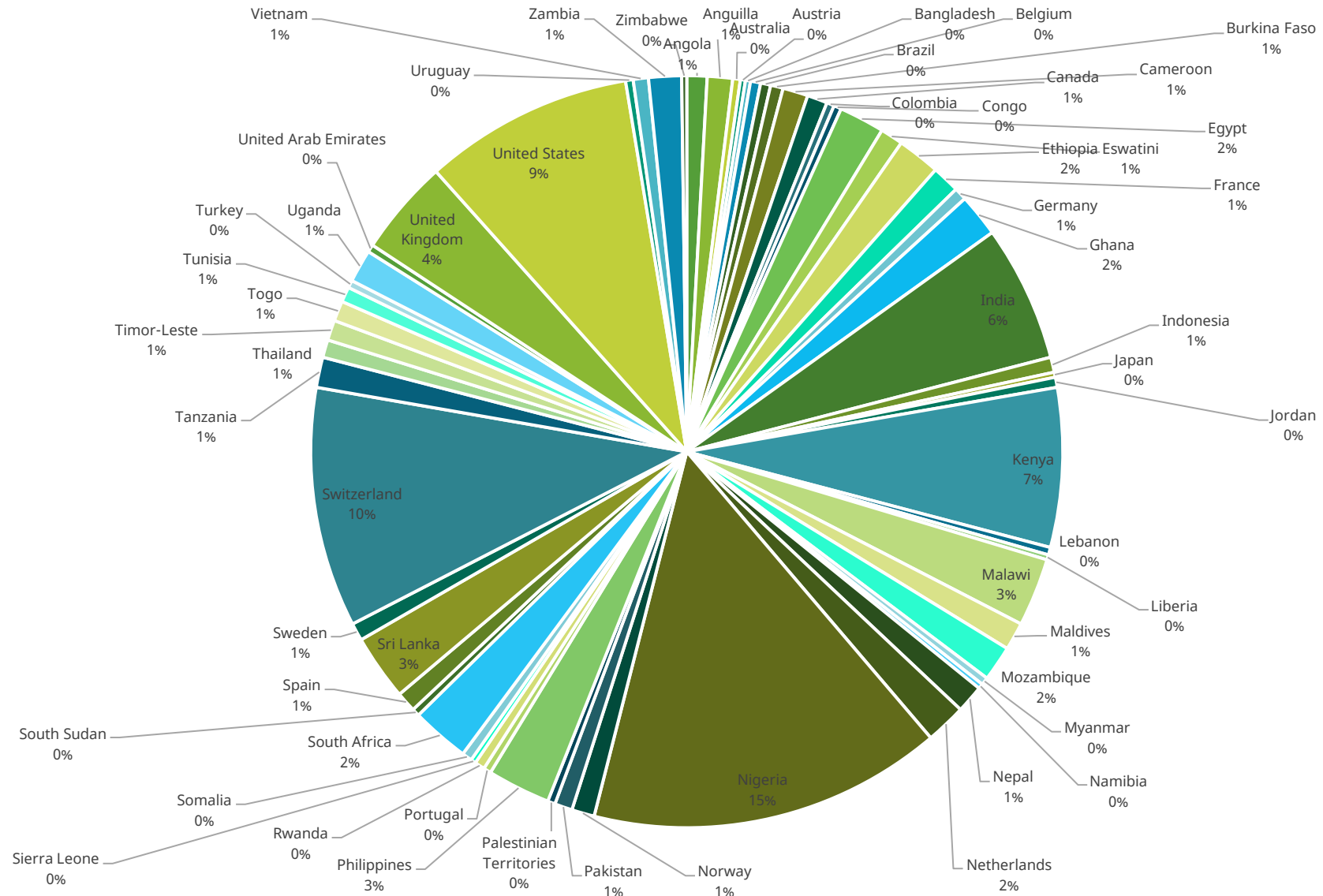
ISSUES ARISING

Session 1 – Part 1: Learning from country experiences

What we heard

Leadership and Governance for data
Many countries have established structures, policies and strategies for HIS/M&E. Challenges remain in legislative frameworks – especially around data sharing across countries and sectors.

HIS Resources-Infrastructure, Systems & Technologies
Many countries use DHIS 2 or have some form of national electronic system, but systems lack interoperability, are fragmented & paper based.

HIS Resources-Human Resource for HIS
Health workers are in short supply and often spend too much time collecting and managing health data, with a lack of data use and analysis skills.

Examples of challenges from country experiences:

Ethiopia: Multiple parallel digital mechanisms operating throughout 20,000 health centres.

Botswana: Launched its HDC in March 2020 after an HIS assessment revealed significant gaps in coordination.

Togo: Poor investment in digital infrastructure, especially in rural areas, have made digitization of data systems a challenge.

Pakistan: Siloed approaches and poor interoperability

Call to partners

1. Align financial and technical support with country priorities identified in national plans and budgets, aligned with budget and planning cycles and one monitoring and evaluation framework.
2. Acknowledge and support country leadership and national governance frameworks.
3. Support national electronic systems and development of comprehensive and integrated systems.
4. Support capacity building at subnational levels for data collection, management, analysis, with a focus on Training of Trainers and skills transfer.

Session 1 – Part 2: Approaches of country and partner collaboration

What we heard

The HDC and SDG3 GAP partners aim to support countries to make better quality data available for use in the right format, to the right person and at the right time. This ensures action can be taken for better health outcomes – better informing policy, budget and programs.

Civil society representation is important to especially consider equity rights issues. Domestic resource mobilization must be emphasized. Common approaches must be scaled up with standards and long-term cross-sector approaches, including the private sector.

Partner commitments

- Investing in data infrastructure, including human resources for health, support country led data coordination mechanisms
- Support country strategies, costed roadmaps and action plans
- Invest in knowledge sharing platforms
- Enhance capacity for countries to develop their own digital innovations and solutions
- Reduce fragmented approach to HIS, including stronger collaboration between private and public sector

- Invest in enabling environment, including development of global health data governance framework which considers a balance between the need to share data with the need to protect the privacy of individuals

Session 2: Data governance: good practices

What we heard

To best contextualize global tools and support country data governance it is important that networking at global level is replicated at the country level. A regional approach is a possible way of addressing siloed approaches to data and funding.

WHO's Data Governance Framework is based on five data principles; (i) Treat data as a public good, (ii) Uphold member states trust in data, (iii) Support MS data and health information systems c capacity, (iv) Be a responsible data manager and steward, (v) Strive to fill data gaps and emerging framework is designed on standards, solutions and structures to support the data journey

World Bank, World Development Report 2021: has as one of its key principles the need for a new social contract for data based on value, trust and equity

US CDC Global Public Health Data Innovation (GPHDI) and Data Modernization Initiative aim to provide government decision makers with more timely, accurate, and comprehensive public health data to better prevent, detect, and respond to public health threats and to create modern, integrated and real time public health data and surveillance that can protect us from any health threats

Country good practices

Maldives
- A national steering committee has been formed, with one of its key roles being to develop the first national digital health blueprint; this blueprint will prevent ad hoc digital health initiatives being implemented

South Sudan
- Developed a Health Sector Policy and Health Sector Strategic Plan (2023-2027) for health information system which provides an overall framework for governance, regulation and HIS programming, which has been lacking

Tanzania
- 97% of health facilities report in a timely manner into DHIS2 with notable improvements in data quality

Uruguay
- Multiple data sources are used for annual health reporting

Session 3: Strategies to strengthen HIS in countries

What we heard

Prioritizing investment in HIS will require a practical approach and collaboration within government, engaging ministries of finance, as well as amongst partners. This must be driven by strong political leadership.

Investment case for data

HDC's RHIS investment case: most comprehensive and needed routine health information systems (RHIS) are inextricable from health care processes, diverts health workers attention from health care, is poorly used, suffers from protracted problems, may cause harm, and receives marginal funding. This situation must be reverted.

Call to action

Multilaterals
Promote RHIS as a "health technology", using Health Technology Assessments (HTA), safeguard link between RHIS and provision of care/UHC, support high quality research and convene partners to adhere to ethical principles of RHIS.

Governments
Demand a regulatory framework for RHIS (e.g., HTA), budget RHIS specifically,

Key findings:

- Government budget for RHIS in some countries is as low as 0.004% of health expenditure, while external support reaches up to 30%.
- In Nigeria, **approximately 43-million-person hours** are spent on RHIS every year.
- If you were to attribute 5% of improvement of healthcare to improved RHIS, this would justify investment of 100x what we are investing now.

Global Partnership for Sustainable Development Data

Investment Case: Multiplying Progress Through Data Ecosystems (led by Dalberg)

- In Bangladesh the UN found that in some of the most recent climate emergencies, having a system in place that delivered early warning data meant that the cost of responding was halved with good data.
- On average a single dollar invested in data systems could deliver USD $32 of economic impact; **this is on par with the value gained from investing in vaccines**.
- Zimbabwe conducted 33 different surveys in 9 years, supported by 10 different donors. The average cost of conducting each survey is around USD 1million, this is not an efficient use of resources.

SCORE for Health Data Technical Package (SCORE): developed by WHO supported by Data for Health Initiative, Bloomberg Philanthropies, and other partners, addresses WHO's commitment to support Member States for the effective collection, analysis, reporting and use of data. It provides a framework for reviewing and investing in HIS that could be useful for countries and partners and could also help countries bring partners together in a coordinated approach.

Francophone countries: Have a unique set of challenges and perspectives. Objectives must be contextualized according to the maturity of each country's system.

In Cameroon, SDGs have been incorporated into national plans, including the Health Information System Strategy 2020-2024.

Togo understands the need for quality, actionable data. Priorities for improvement include harmonization of data systems with a move towards digitization, using DHIS2 for routine health information systems and integration of public health information into routine health information.

Geographic information Systems (GIS) can map, name and ascertain function of health facilities as well as track populations, thereby supporting information to address

factoring contributions, establish funding scenarios.

Technical partners
Stop unduly influencing and fragmenting RHIS, use experts with up-to-date knowledge and expertise on key methods (e.g., human-centred design), adhere to ethical principles of data governance.

Funders
Stop unduly influencing and fragmenting RHIS, acknowledge the radical importance of RHIS to achieve SDG/UHC, factor the RHIS within competing funding needs and fund high quality research.

inequities either as investing at national level or micro planners to reach more households more effectively.

Session 4: Advocacy & action to invest and improve HIS in countries

What we heard

***Global health data governance framework** is suggested to be considered by the 77th World Health Assembly in May 2024 by Transform Health.*

This could be driven by governments who can call on WHO (e.g., at WHA and directly) to lead the process on behalf of, together with, Member States; championing the process to ensure an agenda item is placed on the 77th WHA agenda.

This initiative can strengthen country consensus and alignment on common regulatory standards – for better national legislation/regulation and governing health data sharing across countries (going beyond technical aspects).

The process could be facilitated through the HDC Working Group on Data and Digital Governance and include governments, with the support of partners from multiple sectors.

This process would include a focus on investing in HIS and health data governance to be developed through a transparent, inclusive multi-stakeholder process, with meaningful engagement of civil society and communities.

Kirsten Mathieson (Transform Health) Malarvizhi Veerappan (World Bank) and Xenophon Santas (US CDC), discussing advocacy and action for better health data governance @Mwenya Kasonde/HDC Secretariat

Action steps

Roadmap towards a global framework and to further investment in HIS

May 2023
- Concrete actions and government support to initiate development of a global framework

June to October 2023
- Inclusive process to develop global framework
- Key moments, events, processes, initiatives to advance progress and consult with stakeholders

September 2023
- HLM UHC
- Africa Climate Summit
- SDG SummitG20 Summit

October 2023
- Draft agenda item for consideration of a Framework proposed for consideration by the154th WHO Executive Board

January 2024
- Draft agenda item to be tabled at WHO Executive Board meeting

January to May 2024
- Member States review agenda item reason data governance and investment in HIS for the 77th World Health Assembly in May 2024

Want to read more about these topics? Looking for the slides presented during the event? Looking for the video of the event?

Click here to access the background materials

NEXT STEPS

Health data governance framework

- Build on existing principles and frameworks. Consider broader ongoing UN work but also contextualize and make applicable for country impact to support acceleration to UHC and SDGs.
- May 2023-May 2024: HDC partners (led by data and digital governance working group) support identification of country good practices and publish these. WHO play a convening role and consolidating and contributing to technical inputs, working with others. develop the draft health data governance framework for consideration by partners and WHA 2024.

Country focus

- Support and align partner resources for investing in health data governance and HIS through country led & owned data coordination mechanisms in 26 countries.
- May 2023-December 2025: Using good data governance practices and SCORE as potential frameworks for investment (with priority on human resource capacity building) and HDC / SDG3 GAP partners align with one country plan, one country monitoring & evaluation framework in keeping with national planning and budgeting cycles, in 26 countries* by Dec 2025.

Advocacy and communications

- Build momentum for investing in strong health data governance and health information systems with common messages through:
- Blogs/publications/specific advocacy events 2023-24: CGD hosted event Q3, peer review journal and joint blog Q3, with common messaging for investing in data governance and HIS for better health outcomes
- Make case broader than health: linking to SDG outcomes and socio-economic impact, HDC partners to work with Partnership for Sustainable Development Data, World Bank and others for publications, blogs and events
- Political events and opportunities for joint messaging: UNSG data strategy, G7, G20, HLM UHC, WEF, UNGA, SDG Summit Global Digital compact common agenda all provide partners with opportunities

Capacity building

- Identify national and regional institutes that can build national capacities to analyze and use data. Target audience – health staff at community, district, regional and national levels, with both in person & virtual and in-service / pre-service options.
- May 2023 – Dec 2025: Identify institutes in each region and work in partnership, look to support regional and national institutes to apply and build capacity for data governance and HIS

*Initial countries suggested: South Sudan, Togo, Ethiopia, Tanzania, Uruguay, Cameroon, Botswana, Zambia, Malawi, Pakistan, Maldives, Uganda, Nepal, Kenya, Laos, Burkina Faso, Burundi, Niger, Sri Lanka, Bangladesh, Timor Leste, Bhutan, Rwanda, Congo DR, Indonesia, Paraguay, Sudan, Lesotho, Eswatini, Mozambique, Zimbabwe and Lebanon. Specific GIS requests from South Sudan, Togo and Cameroon.

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OPENING REMARKS

" The global health data gap remains a major barrier to the achievement of the Sustainable Development Goals"

Edwin Dikoloti
Minister of Health & Wellness
Botswana

Key messages

- The Ministry of Health and Wellness of Botswana launched its own Botswana Health Data Collaborative in March 2020, with a mandate to rally all actors in the space of health information systems and monitoring and evaluation **towards a common Monitoring and Evaluation system** to achieve efficiency, transparency, accountability and ultimately lead to a better improved health system
- Through good data governance and investment in **quality, actionable health data** we can improve the way we measure progress and in turn accelerate progress

" For every dollar invested in data systems the average economic return is USD $32 dollars"

Claire Melamed
Chief Executive Officer
Global Partnership for Sustainable Development Data

Key messages

- Effective data governance is fundamental to establishing **public trust**; without the foundations of trust, we cannot unlock the data dividend
- **Data governance frameworks** create enabling environment for more effective and coordinated investment

" The key words are driving measurable impact in countries"

Samira Asma
Assistant Director General - Data, Analytics and Delivery for Impact
World Health Organisation

Key messages

- The **2021 SCORE Global report** highlights the weakest areas of specific country health information systems and is a valuable tool for designing a targeted investment framework, especially as the **World Health Statistics Report** gives mixed news
- Data must be used to bring tailored solutions for countries

SETTING THE STAGE: KEYNOTES

ENTERPRISE ARCHITECTURE: ENABLING THE CONVERGENCE OF DELIVERY AND DATA

Alain Labrique
Director Department of Digital Health & Innovation, World Health Organisation

- Before the Pandemic, many have been advocating for a shift away from discordant vertical pilot projects towards national digital health system transformation, built on solid architectural foundations and driving towards better, more equitable person-centred health

- The "eHealth moratorium" declared by the Uganda Ministry of Health in 2011 was a wake-up call for government to be in the driver's seat of digital transformation

- WHO has been working to enable this digital health transformation over the last decade

- This includes evidence-based guidelines in 2019 to the member-state ratified Global Strategy on Digital Health in 2020, and tools like the Digital Health Investment and Implementation Guide to codify a government-led blueprint for digital transformation

- We have a growing number of examples of countries that have invested in national interoperability standards and a LOCAL enabling environment where a COMMON DATA MODEL **like hl7 FHIR enables a sea of POC solutions, facility health record systems and patient facing applications to interconnect thanks to shared profiles**

- The European Union's InteropEHRate and India's Digital Health Blueprint focus on implementing FHIR-based personal health records and data sharing with providers; New Zealand's Ministry of Health and the United Kingdom's National Health Service provide access to national patient identifier systems using FHIR

- WHO is also leading a process of making all WHO technical and normative content digitally accessible – not just to be read 'online', but to be ingested by digital systems

- Working across WHO technical areas, there is a focus on digitizing the entire PHC continuum into digitally ingestible formats; these are called SMART guidelines: **S**tandards-based, **M**achine Readable, **A**daptive, **R**equirements-based, **T**estable content for digital transformation

- WHO worked with engineers at Google Health, to develop OpenHealthStack, an OPEN, FREE developer environment to facilitate and empower local ecosystems, ESPECIALLY in low-resource settings

- WHO is also launching the WHO Digital Health Clearinghouse – a mechanism to enable Governments to trust in the digitized health and data content, and interoperability functionality of digital solutions, linked to technical assistance and resourcing for common health system requirements

EVERY COUNTRY SHOULD HAVE ROBUST DATA AND HEALTH INFORMATION SYSTEMS: A WISER INVESTMENT FOR ACHIEVING EQUITY AND HEALTH SDGS

Yoon Seok Ko
Executive Principal, National Information Society Agency, Former Leader of Data Department & Data Dam Project, South Korea

- AI has emerged as a technology able to secure large amounts of good data
- Good infrastructure must be established
  - o **Systems** to produce, collect, store and share health data
  - o **Human resources** including data analysis and visualization experts
  - o **Governance** decides how to organize, access, and protect health data
- The Korean government has linked public and private data governance, making it easier to share data
- A pandemic cannot be ended by just one country doing well, all countries must do well
- Health data will be used to developed new AI based services to cure people
- After COVID-19, many countries changed the policy direction from sharing to closing health data
- If we chose isolation instead of opening and sharing, we all lose
- This is a good time to prepare for ***universal health data sharing***

SCORE AS A FRAMEWORK FOR COUNTRY HEALTH INFORMATION SYSTEMS AND IMPROVING ACCESS TO TECHNICAL SOLUTIONS, UNDERSTANDING AND INVESTING IN WHERE THE GAPS ARE

Steve MacFeely
Director Department of Data & Analytics, World Health Organisation and co-chair of the HDC

- HIS refers to multiple systems, often fragmented, stored in different platforms, different formats, using different identifiers with some being digital and others being analogue
- Interoperability and integration should be the starting point
- You can't share data that is not digital
- Many countries struggle with erratic electricity supplies, we need to always think about the infrastructure that supports data architecture and infrastructure
- We must not ignore the importance of legislation, interagency coordination, and local culture
- Developing HIS cannot be done in isolation to the wider public information system, by improving the broader data system, we improve the health data system
- SCORE is an assessment of data systems in counties; this assessment allows for targeted interventions

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EXPERT PANEL SESSIONS

SESSION 1 – PART 1: LEARNING FROM COUNTRY EXPERIENCES

The meeting started with a country roundtable highlighting successes, challenges and opportunities to fast-track progress and investment in Health Information Systems (HIS).

Key messages

- Structures for data governance often exist; these must be supported and not duplicated
- There needs to be increased investment in all elements of data infrastructure, including internet connectivity and human resources for health
- Data security is often compromised by different sources operating without interoperability

Call to partners

- Need a mixture of technical and financial support from partners, aligning with domestic processes and resources
- Use a single government owned national reporting system that meets all stakeholder needs
- Prioritize interoperability of digital tools
- Address prohibitive cost of internet access by working with telecom companies
- Contextualise support for countries, in line with country priorities
- Invest in capacity building for human resources

SUMMARY OF DISCUSSION

	Successes	Challenges
BOTSWANA	• Established structure for M&E coordination with experts from public health, M&E and Health Informatics to support HIS in the country • This structure leads the development of the strategy for e-Health and Digitization • The national data warehouse brings together all sources of data to one place • Botswana will be hosting the WHO AFRO regional committee this year	• Continued disjointed donor support which undermines access to resources • Lack of capacity for effective partner & weak management, structures need to be reinforced • Capacity of leadership for data use
ZAMBIA	• Process started during health reforms • Established Department of M&E at the Ministry of Health in 2016 • The Health Information Strategy guides the development of HIS in Zambia and is aligned with National Health Strategic Plan and National Development Plan • 1st country to use mobile survey data for NCD control	• Multiple reporting for different partners and from different health facilities • Zambia has 3,300 health facilities with multiple different systems being supported by different partners • Hospital HMIS is at its infancy • Weak link between community data and facility data • Data use needs to be institutionalised at the health facility
TOGO	• Has started digitization of health data through DHIS2 since 2013 • Guided by regional strategies to integrate Public Health Intelligence with Routine Health Information Systems to be able to detect diseases that can become epidemic (also through the Transforming African Surveillance Systems (TASS) project) • Accelerated capacity building in data analysis and use during the COVID 19 pandemic • Used a native platform for COVID 19 vaccination tracking, also supported by DHIS 2	• Poor infrastructure, no stable internet connection, even though DHIS2 is in most districts • Need smart phones to support digitization, especially for community health workers • Need for capacity building at all levels for data collection, analysis and use

ETHIOPIA	• Standardised implementation of HIS by aligning all elements starting from the source (the data collection) • Investment in capacity building of healthcare workers, even in remote areas • Ethiopia has 22,000 health centres recording data daily, this previously required 2 months for data to reach the MOH. Now implemented DHIS2, used by 90% of health facilities • Governance structure; standardised strategies, roadmaps and national advisory committees • Data Use partnership by JSI, Bill and Melinda Gates Foundation funded, which offers direct support for HIS at national level which is aligned to MOH plans • One Plan One Budget One Report: no other mantra is accepted • PHC and metrics for blood pressure with supplies of meds – delivery team working with Ethiopia present as an opportunity for DDI	• Poor data quality, completeness and accuracy • Parallel reporting systems and fragmented investments in HIS • Fragmented digitization of HIS • Poor investment in HRH and local capacity building • Limited engagement of private sector and academia • Too much data collection for the purpose of reporting as opposed to improving patient health
NEPAL	• Timely reporting of data and quality of data • Integrating data in DHIS2 • HRH, data analysts, hospital recorders, data entry • Post mission priorities and acceleration scenarios with delivery team	• Approximately 8000 health facilities are not connected to DHIS2 and are operating paperless • Lack of timely and good quality data • Gap in capacity of health workers for data management • Data security is compromised by different sources of data, in different provinces (no interoperability) • Poor national investment in health sector

SESSION 1 – PART 2: APPROACHES OF COUNTRY AND PARTNERS COLLABORATION

After hearing from countries, partners responded with opportunities to align behind and invest for better health data governance and Health Information Systems (HIS).

Key messages

- HDC and SDG3 GAP partners support countries to make better quality data available for use in the right format, for the right person and at the right time
- We need to work better with the private sector and ensure potential solutions are fit for public purpose
- It cannot be called an investment if it doesn't build national capacity; without building national capacity, we only create more dependence
- Digital systems must become embedded in healthcare transformation

Partner commitments

- Invest in data infrastructure including human resources for health
- Support country led data coordination mechanisms
- Support country strategies, costed roadmaps and action plans
- Invest in knowledge sharing platforms, in country as well as regional and global networks
- Enhance capacity for countries to develop their own context specific digital innovations and solutions
- Reduce fragmented approach to HIS, including stronger collaboration between civil society, private and public sectors
- Invest in enabling environment, including development of global health data governance framework which considers a balance between the need to share data with the need to protect the privacy of individuals
- Scale up implementation and move away from pilot projects
- Document evidence of what works and what doesn't

SUMMARY OF DISCUSSION

Collaboration for country support

- The joint HDC missions to Malawi and Nepal are a possible model for partner collaboration

and were led by strong national commitment to UHC and comprehensive Primary Health Care (PHC). Both GIS and CRVS support, together with the SCORE assessment, can

support the resourcing and planning of PHC in those countries.

Leveraging data and digital transformation for better health

Lessons learned from the COVID-19 pandemic

- Real-time data and effective integration of different data and information systems are crucial in guiding an effective, timely and targeted response
- Data was neglected during the pandemic
- WHO also has a data lag which needs to be addressed
- There is inability to effectively use the volume and different types of data available due to various governance issues which were more obvious during COVID pandemic:
  - Lack of health data standards related to the definition, calculation and format of the data
  - Delays in receiving data
  - Lack of integration and interoperability between the different data and health information systems
  - Deficiency of trained people to manage and use these data

Smart investments in HIS

"WHEN TRYING TO DIGITALIZE DATA AND INFORMATION SYSTEMS, DIGITIZING A BROKEN DATA PROCESS, GETS YOU A DIGITIZED, BROKEN DATA PROCESS*"

adapted from @taradmcguinness

David Novillo Ortiz
Unit Head, Data and Digital Health, European Regional Office WHO

- Assessments will guide investments in HIS including the SCORE assessment and the regional support tool to strengthen health information systems
- A plan for investment in HIS must include;
  - A data governance framework
  - Investment in data infrastructure
  - Integration of different data and information systems (including the private sector)
  - Combining of digital solutions and non-traditional data sources

Opportunities to partner and invest for better data governance and Health Information Systems (HIS)

Multilateral and Intergovernmental Organisations

- Data capital, physical capital and better integration around standards must all be brought into data investments
- There are a common set of principles which we can all adopt including;
  1. Scale up, moving away from pilot projects
  2. Taking a standards-based approach: we may not be able to get rid of fragmentation fully, but we must be able to connect the different systems
  3. Investing in frontier technology

Bilateral Donors, Philanthropic Institutions and Regional Funding Entities

- Donors must use platforms such as the HDC to better engage with countries
- Use regional platforms to leverage this engagement

Civil Society

- Encourage focus on investing in enabling environment around the governance of health data, including legislation, frameworks, standards and norms
- Advocate for development of global health data governance framework centred around equity and human rights
- Prioritise inclusive multistakeholder approaches

- Ensure civil society are included in governance structures and ensure meaningful, engaged conversations, including marginalised communities and youth

Global Health Initiatives

- Encourage prioritising infrastructure including human resources and change management
- Coordination mechanisms must be country led and supported
- Data use and data visualisation approaches must also be standardised
- A change in mindset is needed to help improve collaboration

Private Sector

- Needs to be included for better collaboration across all sectors
- Need to leverage on private sector innovation to build stronger HIS
- We need to work around a clear goal which is government led and advocate for shared accountability

Research, Academia and Technical Networks

- Issues of silos and burden of reporting are important on the ground realities
- Improvement of capacity and planning for the future
- Balance is needed to be able to share data while protecting the privacy of individuals

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SESSION 2: DATA GOVERNANCE: GOOD PRACTICES

The session explored the importance of data governance with views from UN and non-UN/civil society. Big data infrastructure and management, and good data governance practices were also discussed.

We also heard good data governance practices from several countries.

Key messages

- A health data governance framework must be underpinned by equity and rights-based principles
- A health data governance framework must be transparent and inclusive, multi-stakeholder process + meaningful engagement of civil society and communities
- Focus on the regulatory environment (going beyond technical aspects)
- Address health-specific governance needs

Call to action

- Digital and data need to work together more and focus on health outcomes
- Embrace citizen engagement with government systems
- Engagement of stakeholders – private sector, civil society, should work with government
- Need to focus on the complete data value chain from collection through to use

SUMMARY OF DISCUSSION

Views from Non-UN and civil society (Transform Health, Centre for Global Development)

- We need stronger data governance to address issues of data privacy, ownership, sharing, and access
- This is also needed to maximise public benefit of health (and health related) data, whilst

managing risks and safeguarding individual rights

- Improved governance of health data will:
  - Reduce fragmentation, duplicative systems and wastage ➜ increased efficiency and performance of public health investments
  - Improve evidence-based decision making ➜ stronger and more equitable health systems
  - Strengthen health emergency response
  - Advance research and innovation
  - Help achieve UHC and SDG goals
  - Build public trust ➜ critical to fostering data use for public good!
  - There is a growing consensus on the need to strengthen health data governance as outlined in:
    - WHO Health Data Governance Summit
    - Lancet FT Report on Governing Health Futures
    - Global Digital Health Strategy
    - Broadband Commission Report
    - G20 Health Working Group
    - Africa CDC Digital Transformation Strategy
    - African Union Digital Transformation Strategy
  - 150+ organisations have signed the Transform Health, Health Data Governance Principles 140+ organisations and governments have endorsed the Transform Health, Health Data Governance Principles
- There is a lack of information on costs for investing in HIS
- Investing in data systems have large joint costs and yet the costs are often measured separately, often by siloed programs
- One of the few studies on the topic showed that is costs **53c per person per year** for HIS
- The is negligent reference to HIS as a key component to pandemic preparedness and response

- The WHO Mosaic Framework and PRET Initiative and proposed pandemic accord are useful but the role of HIS is not as prominent as it could be

Views from UN (World Health Organization, US Centre for Disease Control and Prevention, World Bank)

"GOOD DATA GOVERNANCE IS ABOUT TRUST, RESPONSIBILITY AND ACCOUNTABILITY"

Stephen Mac Feely
Director Data and Analytics
WHO

- **WHO** believes data is shared when there is trust and when the potential benefits are bigger than the risks
- Data governance is about putting in place mechanisms that allow us to build trust and share information with each other.
- Data security and privacy are subsets of data governance
- We now live in a data economy; we are producing and consuming large amounts of data simultaneously
- Data governance had many challenges including the need for data sharing agreements, use and reuse of data, cyber security
- WHO's Data Governance Framework is based on 5 Data Principles
  1. Treat data as a public good
  2. Uphold member states trust in data
  3. Support MS data and health information systems capacity
  4. Be a responsible data manager and steward
  5. Strive to fill data gaps

- There is an opportunity to open the conversation globally across civil society and the private sector for a shared approach to data governance

- The **World Bank** has released the [World Development Report 2021: Data for Better Lives](#)

- This outlines several data governance principles including:
  - We need a new social contract for data based on value, trust and equity
  - Equitable development of the data economy calls for a foundation of infrastructure to ensure that both poor people and poor countries have affordable access to data services
  - The legal and regulatory framework for data entails a balanced development of enablers that support reuse of data for value creations, and safeguards that create trust in the system
  - As more economic activities shift online, a country's data governance choices will have important implications for the real economy, in terms of competition, trade, and taxation
  - Further efforts are needed to support interoperability, data portability and cybersecurity for equitable distributed value
  - Data governance will not get very far without adequate institutions to implement and enforce the rules, and these are often mission

- **US CDC** Global Public Health Data Innovation (GPHDI) and Data Modernization Initiative are opportunities to provide government decision makers with more timely, accurate, and comprehensive public health data to better prevent, detect, and respond to public health threats

- The GPHDI was enabled as part of the ARP that the US congress passed in 2021 that allows the work CDC is doing domestically through the DMI funded through the CARES

act of 2020 to be leveraged for the global health

- The goal of the global public health data innovation is to strengthen global outbreak response, pandemic preparedness, and surveillance through improved data availability and use by modernizing data systems and processes at all levels

- Specific objectives are:
  - To improve national data linkages, the repositories, and the analytics
  - To automate public health data systems, moving data through the country level systems, be it clinical information systems, Lab information systems or logistics information systems
  - To enhance public health situational awareness by integrating data from different data systems in a systematic way through the development of an enterprise architecture

- GPHDI is designed to be easily adaptable to any country in global health setting, however, the program is prioritizing 10 countries (in Africa, Kenya, Sierra Leone, Uganda, and Zambia, in the Americas, Colombia, Honduras and Paraguay an in Asia, Georgia, Indonesia and Thailand)

- Core components include governance and leadership, cloud infrastructure, analytic platforms, data integration, standards, data automation and the workforce.

- All this work is aimed at solving longstanding problems faced by public health:
  - Siloed Information
  - Decades of "panic and neglect" funding cycles have resulted in a plethora of one-off, proprietary systems tracking multiple individual diseases. They keep information siloed and prevent us from seeing the complete picture
  - Outdated skills due to long-standing workforce neglect

- Federal incentives for modernizing healthcare records do not address public health, leaving them outside the data ecosystem

- CDC will engage key players from countries and provide them with coordinated assistance in planning, development and implementation of their digital health policies and governance structures
- The desired state is to have country-led digital health governance structures with the necessary digital health initiatives, policies, and regulations
- Want to get to a state where there are supportive policies and governance established for managing cloud infrastructure, to help build a good sense of security
- The GPHDI will work to empower the public health workforce with the capacity to support the global digital health initiative through coaching, mentoring, and training programs in informatics
- We hope to achieve an environment in the priority countries where the local public health leaders drive coordination
- The data innovation goal here is to setup processes and architectures to support accurate data exchange making sure organizations have access and can compile data from different sources which will be enabled by common data standards and common architectures with the use of core services and repositories like the facility registries, terminologies etc. across the health system
- We want to see a public health system that has adapted international data standards to country context and that enables interoperability

Good Data Governance Practices

gathered and analysed by the HDC Data and Digital Governance Working Group

As preparation for this meeting, the HDC Data and Digital Governance Working Group gathered good practices on data governance from several countries. These were highlighted in this session of the meeting, alongside data governance practices from partner organisations.

Kuwait
- The DGF provided a useful mechanism for shared governance and helped set a clear direction without disturbing the existing workflows or threatening the integrity of intellectual capital

India
- An ecosystem-based approach

Kenya
- Data governance legislation and framework
- Data Protection Act classifies health data as sensitive data and has provisions to safeguard it
- Framework includes data governance principles and structures including issues surrounding privacy, security and confidentiality of health data

Tanzania
- Operationalization of MOH's Data Protection and Sharing Framework led to specific activities focusing on data protection and sharing, improving data security and improving accessibility to data

Indonesia
- Satusehat Platform uses a whole of Government approach, promoting equity and building trust
- With proper training and education for local government officials to interpret and analyze data in order to make informed decisions and allocate resources effectively

Korea
- Use of AI for fraud detection

Country Highlight

GOOD DATA GOVERNANCE PRACTICES IN SOUTH SUDAN

"WE ARE CENTRED ON ADVOCACY FOR THE USE OF '3-ONES' STRATEGY: ONE DATABASE, ONE MONITORING SYSTEM, ONE LEADERSHIP."

John Rumunu
Director General Preventive Health Services
South Sudan Ministry of Health

Contextual challenges

- **Humanitarian pressure:** with 45,890 individuals arriving from several points of entry between April and May 2023, leading to high pressure over the national humanitarian response, particularly over health services
- **Food security:** over 6 million people are estimated to be in serious or urgent need of secure and stable sources of nutrition
- **Security concerns:** resulting in further challenges to health care provision due to vandalization, looting and attacks on health care infrastructure
- **Offer of services:** overcrowding, insufficient water and sanitation facilities, aggravated by recurrent flooding and fragile health systems increases the likelihood of infectious and water-borne diseases

Health Information Systems governance

- The country conducted a Comprehensive Health Information System Landscape Analysis in 2022 that highlighted the key challenges, gaps, best practices and recommendations for improvement.
- Developed a Health Sector Policy and Health Sector Strategic Plan (2023-2027) for health information system which provides an overall framework for governance, regulation and HIS programming which has been lacking
- Developed a roadmap for integration/ interoperability of all parallel and vertical reporting HMIS data bases with the DHIS2, including use of DHIS2 to perform national surveys
- Strengthening of institutional arrangements/structures for HIS governance
  - Coordination structures (HIS steering committee and HIS-TWG established and M&E TWG revitalized) for alignment and harmonization of partners and government efforts for HIS improvement
  - Reconfiguration of existing HIS structures at all levels to become fit for purpose
- When data is being shared, limited access is given to data viewers
- Data quality assurance process is carried out across the country with performance monitoring teams in place to institutionalise data use
- Appreciate and highlights the importance of data disaggregation

COUNTRY PANEL REFLECTING ON TRANSLATING GOOD DATA GOVERNANCE INTO PRACTICE

Pakistan

- Rolling out DHIS2 across the country
- RHIS are collected at district and provincial level
- Primary health data is paper based in the provinces and is translated to DHIS at district level
- SDG3 localisation is used as a monitoring framework integrated into the national vision
- Need to integrate other data sources (climate change, police data) with health data

Cameroon

- Several strategic plans have been established, including for HIS (2020-2024)
- Governance structure in place with members from MOH, police force, Ministry of Finance, Ministry of Defence
- DHIS2 is used as the national HIS, 4000 HCW have been trained in its used and it is used in program monitoring
- Community health strategic plan has recently been developed and feeds into DHIS2
- Interoperability across government ministries is a priority, including established of unique identifier
- Geo localised health facilities
- National Health Observatory hosts the national HDC

Maldives

- MOH is part of the National Statistics Council (NSC) formed 2 years ago
- Key role of NSC is to act as an advisory group for strengthening national data systems – this could be considered a best practice as data systems are harmonised across all SDGs, with inclusion of private sector and civil society
- Steering committee has been formed, with one of its key roles being to develop first national digital health blueprint. This blueprint will prevent ad hoc digital health initiatives being implemented

- Regulatory frameworks and documents have been developed, under Maldives Health Services Act
- Good engagement of private sector for national health data reporting
- Electronic Immunization Registry is an example of a project which was developed in collaboration with partners, avoiding siloed systems being developed by individual agencies

Uruguay

- Several data sources are used for tracking SDGs, including CRVS, health surveillance systems and national electronic medical records (EMR)
- EMR is used to promote and enhance continuity of care for users
- Each institution maintains its own system and feeds into a central registry
- Data sources are used for annual health reporting
- Value generation of data that supports decision making for clinical management and public health purposes
- Sustainable digital health transformation can be used to support the health of the population

Challenges

- Shared governance between different government agencies
- Slow processing of CRVS systems
- Need to enhance data coverage for national EMR and enhance data extraction for use by the Ministry of Health

Tanzania

- 97% of health facilities report in a timely manner into DHIS2 with notable improvements in data quality.
- Data reporting tools are controlled by government.

- Health Information Systems guidelines have been implemented, as well as M&E Frameworks and National Digital Health

Strategy and Digital Health Investment Roadmap

SESSION 3: STRATEGIES TO STRENGTHEN HIS IN COUNTRIES

The meeting was an opportunity to present an investment case for health information systems, developed by the HDC, as well as complementary work making the case for investment in HIS.

Key messages

- 2023 is the year to unlock the potential of data with several political opportunities to support advocacy efforts
- Investment in administrative systems beyond health can pay off in significant ways, including across education and agriculture
- There is a significant data dividend; investments can pay off over time and across sector
- Calculating return on investment is challenging
- Country case studies: what works and what does not is important to document
- Counter argument: 'what if there was no investment in RHIS?'
- Communities left behind: data from CSOs and private sector is needed
- Don't think 'investment case' think > efficient / better investment: financial, technical, political
- Ministries of Finance should be the main target audience, not donors

Health Data Collaborative

Suggested Next Steps from the HDC's *'Making the case for investing in Routine Health Information Systems (RHIS) to achieve the health-related SDGs'*

- We need a paradigm change, using a human centres design based on improving the system and moving away from a technocratic approach or blaming of health workers
- Observational research must be replaced by experimental research
  - **Multilaterals:** Promote RHIS as a "health technology" (HTA), safeguard link between RHIS and provision of care / UHC, support high quality research and convene partners to adhere to ethical principles of RHIS
  - **Governments:** Demand a regulatory framework for RHIS (e.g., HTA), budget RHIS specifically, factoring contributions, establish funding scenarios
  - **Technical partners:** Stop unduly influencing and fragmenting RHIS, use experts with up-to-date knowledge and expertise on key methods (e.g., HCD), adhere to ethical principles of data governance and health care
  - **Funders:** Stop unduly influencing and fragmenting RHIS, acknowledge the radical importance of RHIS to achieve SDG / UHC, factor the RHIS within competing funding needs and fund high quality research

SUMMARY OF DISCUSSION

Panorama of investments in HIS

- The work of the HDC complement's similar work, including the Global Partnership for Sustainable Development Data's Investment Case: Multiplying Progress Through Data Ecosystems (led by Dalberg), outlining benefits of investing in more and better data
- The UN SDG Progress Report shows that there are only 6 of the 17 SDGs for which more than 2/3 of countries have data to report
- The G20 agenda and Africa Climate Summit will bring opportunities for data partnerships
- In Bangladesh the UN found that in some of the most recent climate emergencies, having a system in place that delivered early warning data meant that the cost of responding was halved with good data
- The experiences of the health sector mirror challenges in other sectors
- On average a single dollar invested in data systems will deliver USD $32 of economic impact; this is on par with the value gained from investing in vaccines
- The amount of money going into data over the years has remained static

- Zimbabwe conducted 33 different surveys in 9 years, supported by 10 different donors. The average cost of conducting each survey is around USD 1million, this is not an efficient use of resources
- Working with UN leadership, with the World Bank and different governments to align around specific changes framed around core pillars:
  - Building cutting edge national data partnerships for timely, ethical and efficient data
  - Strengthening data capacities
  - Securing smarter national, bilateral and multilateral financing for data systems

An investment case for HIS

The HDC has developed an investment case with the title "*Making the case for investing in Routine Health Information Systems (RHIS) to achieve the health-related SDGs*". This work was carried out on behalf of the HDC by a consortium formed by the Swiss Tropical and Public Health Institute (Swiss TPH, Allschwil, Basel, Switzerland) and the South African Medical Research Council, under the leadership of Prof. Xavier Bosch-Capblanch

This work was supported by a panel of external experts, including from the RHIS working group of the HDC

One of the components of this work was to carry out case studies in selected countries, to assess the level of investment required to run RHIS and the benefits of such investments. This task does not entail any value judgment about the RHIS in the country, but it rather focuses in understanding how RHIS could be better supported

The study included:

- A scoping review on examples of returns of investments

- Country case studies (National: Colombia, Côte-d'Ivoire, Nigeria, South Africa, South Sudan, Nepal; Sub-national: Cross River State, Nigeria and Western Cape South, Africa)

- Economic analyses

Main findings

- Problems are universal, technology-agnostic, historical

- The Routine Health Information Systems are the largest component of Health Information Systems

  o encompassing the whole health system, from Tertiary University Hospitals up to community health workers – 65 million health workers

  o is permanently active, in every encounter with service users – the whole population

  o has a universal distribution in all countries and territories, even in humanitarian crises – all countries

  o data collection point = data use point – is a process of care

  o carries personal information – data security

- Fragmentation/partners and duplication leading to over-reporting and high workload (Côte-d'Ivoire, Nepal)

- Lack of integration with hospitals information (Côte-d'Ivoire)

- Lack of integration of multiple systems/duplicity (Colombia)

- Lack of integration of HIV programme data (Nigeria)

- Lack of integration with the private sector (Colombia, Nigeria)

- Undifferentiation between health care and data activities (all countries)

- Unequal compliance with data requirements, particularly by community health workers (Nepal)

- Multiplicity of sub-systems

- Government budget for RHIS in some countries is as low as 0.004% of health expenditure, while external support reaches up to 30%

- In Nigeria, approximately 43-million-person hours are spent on RHIS every year

- The highest proportion of costs is for human resources

COVID-19 related issues

- New databases, new procedures and new management (Côte d'Ivoire)

- New digital tools specific to Covid-19; however other health care events ceased to be reported in a timely manner

- Establishment of the Information Management Unit, outsourced to local companies, specific for Covid-19 (Nepal)

- Covid-19 stopped the uptake of the NHMIS 2019 changes: weak reporting through regular mechanisms (Nigeria)

- Multiple adaptations reported, including organisation of health care (South Africa)

The *SCORE for Health Data Technical Package,* supported by Bloomberg Philanthropies Data for Health initiative, comprises five key interventions. These five interventions are represented by the acronym SCORE. Interventions S, C and O focus on improving critical data sources and the availability and quality, while interventions R and E aim to enhance the synthesis, analysis, access and use of health data for action. Indicators and actions are included for each intervention.

The health sector can use SCORE to drive national strategic and operational planning (prioritization of HIS areas). It can also guide countries prioritize

development partners for HIS strengthening- for example, a country with weak CRVS may like to prioritize WHO and UNICEF. On the other hand, it can be used by development partners to not only understand the gaps in the countries, but also to guide allocation of resources. With periodic SCORE assessment, partners and countries can observe trends overtime on different SCORE interventions and elements. Moreover, it can also help prioritize specific HIS areas for deep dives.

Experiences of Francophone countries

French speaking countries, particularly in the African region, have a very distinct set of needs and priorities, which include:

Cameroon does not want to skip steps,
but instead be realistic in their needs:

- The SDGs have been incorporated into national plans, including the Health Information System Strategy 2020-2024.
- National priorities include
  - Focus on governance structures
  - Engage a multisectoral approach
  - Harmonise data systems across government agencies
  - Reinforce legal standards including around cybersecurity and personal data protection

- Enforcing community health data systems, especially for community births and deaths, and linking this with national CRVS and HIS systems
- capacity building with clear linkages to achieving SDGs through improved data systems

Togo understands the need for quality,
actionable data. Priorities for improvement include:

- Reduce duplication and fragmentation of data collection
- Harmonise data systems with a move towards digitization, using DHIS2 for routine health information systems
- Integration of public health information into routine health information systems
- Enabling an in depth understanding of areas that need attention and save resources at the same time

Geographic Information Systems (GIS)
enable micro planners to reach more households more efficiently, sustainably and equitably. Geo-enabled microplanning is the application of geospatial data and technologies to improve last-mile decision-making, ensuring that health services reach every corner of a community.

SESSION 4: ADVOCACY TO INVEST AND IMPROVE HIS IN COUNTRIES

Having heard the evidence presented, the main part of the meeting concluded with advocacy efforts to invest in HIS in countries.

Key messages
- *Need to move from principles and recommendations to action*
- Governments must be in the driver's seat (setting the agenda)
- Partnership and multi-stakeholder collaboration is important
- We must learn from countries and good practices (and from challenges)
- Data governance approaches must be people centred as well as equity and rights based
- Need to focus on sustainable solutions

Health Data Collaborative

Proposed Concrete Next Steps

- Health data governance framework
- Country focus
- Advocacy and communications
- Capacity building

Health data governance framework

- Build on existing principles and frameworks. Consider broader ongoing UN work but also be able to contextualize and make applicable for country impact to support acceleration to UHC and SDGs
- Explore the possibility of leveraging emerging technologies such as Data scorecards which will:
  - o Promote implementation of country strategies
  - o Update organisational strategies
  - o Use effective communication within the country agencies
  - o Improve focus and alignment among divisional or individual goals and the organization's goals and strategies
  - o Align annual or short-term operating plans and performance evaluation measurement with long-term strategies
- Encourage knowledge sharing and best practices by establishing a platform or network where countries can share their successful experiences in health data governance
- May 2023-May 2024: HDC partners (via the Data and Digital Governance Working Group) to support identification of country good practices and publish these; WHO playing convening role and consolidating technical inputs working with others, including Transform Health

Country focus

Support and align partner resources for data governance and HIS through country led & owned data coordination mechanisms in 26 countries

- May 2023-December 2025: Using good data governance practices and SCORE as potential frameworks for investment (with priority on human resource capacity building) and HDC/SDG3 GAP partners, align with one country plan, one country monitoring & evaluation framework in keeping with national planning and budgeting cycles in 26 countries by Dec 2025; developing a robust monitoring and evaluation framework example as scorecard suggested above that enables tracking progress, identifying challenges, and providing continuous support to the countries throughout the implementation process
- Finalise the RHIS investment case and disseminate it widely

Advocacy and communications

Build momentum for investing in strong health data governance and health information systems with common messages through:

- Blogs/publications/specific advocacy events 2023-24: CGD hosted event Q3, peer review journal and joint blog Q3, with common messaging for investing in data governance and HIS for better health outcomes
- Make case broader than health: linking to SDG outcomes and socio-economic impact, HDC

partners to work with Partnership for Sustainable Development Data, World Bank and others for publications, blogs and events

- Engage the private sector, civil society and other relevant stakeholders to build a broader coalition for supporting data governance initiatives and foster multi-sectoral collaboration
- Political events and opportunities for joint messaging include: UNSG data strategy, G7,

G20, HLM UHC, WEF, UNGA, SDG Summit Global Digital compact common agenda

Capacity building

- Identify national and regional institutes building capacity for national capacities to analyse and use data
- Target audience: health staff at community, district, regional levels; attention to the real "data users"

PARTNER ROUND TABLE

To conclude the event, partners shared insights to the following themes:

- Effective partner collaboration: better alignment amongst donors to prioritise investment and promote good data governance practices
- Aligning partner priorities with country priorities
- Strategies to attract investment in country HIS: why is there low or inefficient investment in HIS?
- Operationalising good data governance
- Tracking our collective progress and using HDC platform to leverage comparative advantages

Key messages

- HIS needs a long-time commitment aligned with national planning processes and engage all stakeholders including the private sector and civil society
- Stop activities that create silos and duplication or focus on pilot projects
- Build political will through advocacy
- Call for more collaboration across Accelerators of SDG3 GAP and working groups of HDC

Four-point call to action

- **Health data governance framework:** Build on existing principles and frameworks. Consider broader ongoing UN work but also be able to contextualize and make applicable for country impact to support acceleration to UHC and SDGs
- **Country focus:** Support and align partner resources for data governance and HIS through country led & owned data coordination mechanisms in 26 countries
- **Advocacy and communications:** Build momentum for investing in strong health data governance and health information systems with common messages
- **Capacity building:** Identify national and regional institutes building capacity for national capacities to analyse and use data

SUMMARY OF DISCUSSION

GIZ Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ) GmbH 🖉

- Suggest hosting regional meetings to ensure better and more country participation
- Align regionally with Africa CDC and One Health Data Alliance Africa
- Enhance technical understanding of decision makers to support political will

GAVI, the Vaccine Alliance 🖉

- Supports countries in developing national digital health information for immunization roadmaps that complement existing policies
- Supports data investments that are tailored to country context and maturity levels, specifically to identify and reach marginalized communities

- Recognizes the importance of gender intentional lens
- Encourages building on COVID-19 innovations
- Strengthen collaboration and data sharing between countries, partners and international
- End to end support including investment in HRH, promoting an enabling environment and promoting data governance
- Working with WHO and UNICEF to support joint reporting forms
- Full Portfolio Planning process (FPP) is when applications are designed by countries and submitted for support (41 countries in 2023 are undergoing this process)
- Supports learning and building evidence-based programming

Global Financing Facility 🔗

- Aligns with country priorities, country leadership and a single M&E framework
- Focus on improving HMIS, CRVS, MPDSR and gender equity with support for data reviews and data use
- Support for capacity building and strength training

Global Fund to Fight AIDS, TB and Malaria 🔗

- Leadership, governance and HIS resources (infrastructure and technologies) are a priority
- Capacity development and HRH
- Sustainable, scalable and longer-term plans
- Recognize SCORE as a tool to benchmark donor priorities
- **Value of focused country discussions to complement global discussions**

Norwegian Agency for Development Cooperation (NORAD) 🔗

- Shifting towards health system strengthening and away from disease specific programs
- Focus on Primary Health Care, including civil society
- SCORE can be a useful tool to help identify gaps and a starting place for partners to support country needs

SDG3 Global Acton Plan Secretariat 🔗

- How do we bring support together to one costed national plan?

Transform Health 🔗

- **Would like a resolution on data governance at WHA next year**
- Works across 6 national coalitions and through regional networks

UK Foreign, Commonwealth and Development Office (FCDO) 🔗

- Collectively need to look if we are walking the talk
- **Support need for single M&E framework, a single plan and a single budget**
- Bilateral budgets have declined but support to global health initiatives have been protected
- Need to capitalise from partners in country capacity

UNICEF 🔗

- Effective partner collaboration and leveraging on each comparative advantage is important for maximize impact on the ground
- UNICEF is present in 190 countries
- Data function covers most of the SCORE components and appreciate the package in helping to pinpoint gaps in countries
- Like to translate findings from SCORE to costed improvement plan
- Committed to alignment with national plans and strategies including digital health strategies
- Shift from project-based approach to system strengthening approach
- Important to demonstrate the value of HIS in supporting decision making
- **Need country specific investment case on HIS**

University of Oslo 🔗

- Brains behind DHIS2 technology
- Feeling of local ownership in DHIS2 national implementation, this is important for sustainability

- HISP approach in focused on capacity building (PhD program has graduated 70 students from the global south), including network of locally available expertise
- Focuses on continuous process of HIS strengthening

UNFPA 🔗

- Engagement with HDC is focused on CRVS and GIS
- Hosts global Centre of Excellence for CRVS founded by Govt of Canada
- Emphasize life course approach to CRVS as well as whole of government approach and whole of systems approach, especially in terms of gender equity
- Integrated population data system approach
- SCORE is a critical diagnostic tool to convene around a common set of basic data
- Need for operations research tools to better understand *what* works, *where*, *when* and *how*
- Alignment is closely aligned with 2020 census round
- Alignment of CRVS investment work with GFF investment cases
- Opportunity through timing of voluntary national reviews
- Realize the importance of GIS in health-related SDGs
- Creating use cases for integrated population data with health facility data, in partnership with WHO and UNICEF through HDC and SDG3 GAP

US Centers for Disease Control and Prevention 🔗

- Priorities:
  o Disease surveillance

- o Laboratory systems and infrastructure strengthening
  o Emergency response
  o Workforce improvement
- Data monitorization work
  o Mortality surveillance
  o CRVS
  o Global antimicrobial resistance surveillance
  o Molecular epidemiology including genetic sequencing
  o Support for one health and cross boarder health and refugee
  o Vaccine preventable disease
  o Respiratory
- Call for additional granularity to SCORE
  o Measuring technological improvements such as interoperability, health information exchange, standard exchange and cyber security

The World Bank 🔗

- More intentional approach to embed digital and data in HIS projects
- Focus is informed by country demand and country priorities
- Internal assessment of investment portfolio and better inform systematic thinking and support
- Data governance is an important agenda
- Work in all countries with a focus on LMIC
- Offer support through financing, technical work and capacity building
- **Joint Learning Network has courses in digital health may be a resource to support country needs**

ANNEX

CONCEPT NOTE AND AGENDA

Introduction and background

The world is off track to meet the 2030 health-related SDGs. There are significant data gaps and capacities for tracking progress towards SDG targets and supporting communities left behind. Fragmented approaches to collecting, storing, sharing, analysing and using data for health outcomes is challenging progress. Building on the 2021 Health Data Governance Summit and summit statement, Health Data Collaborative (HDC) partners will co-host an event on 18 and 19 May 2023 to promote health data as a global good by (a) identifying and promoting good country data governance practices; and (b) promoting investment in Health Information Systems (HIS) guided by the SCORE for Health Data Technical Package (SCORE). It will consider SCORE as an overall approach to investment, especially in Least Developed Countries over the next two years. The necessary advocacy steps will be sought to promote good data governance practices and investment in HIS. Urgent attention is needed to promote data as a global public good and sufficient investment in country HIS.

Outlined below are the milestones leading up to this meeting:

1. **Health Data Governance Summit (2021):** WHO hosted a Health Data Governance Summit with a diverse range of stakeholders. This provided an overview of the health data landscape, made the case for data being a global public good and identified aspects of data maturity and good data governance practices. The resulting summit statement emphasized data as a global public good, advocating for i) a global data governance framework with good data principles, and ii) collective leadership and resources from multi stakeholder & multi sector data communities for stronger sustainable systems.
2. **Global Development report and WB work (2021-22):** The 2021 Global Development Report made the case for investing in data. World Bank also hosted capacity building events for health data governance, bringing together stakeholders to identify good health data governance practices and concepts from countries.
3. **Investing in data (2022):** Multiple partners presented at the 2022 UNGA, led by data with purpose and presented an investment case for data. This suggested that for every 1$ invested in data the return is $32, also calling for 0.8% of annual spending allocation for data systems.
4. **Health Data Collaborative investment case for Routine Health Information Systems (RHIS) (2022-23):** partners consistently highlight inefficient investments for HIS. This is a major challenge to provide timely, quality, accurate and complete data for better evidence-based decisions and to monitor progress toward national and global health-related SDGs and UHC. Many health programs and siloed disease specific initiatives have investment cases, providing Ministries of Finance, bilateral donors and global health initiatives guidance on allocating scarce resources effectively and efficiently to maximize health outcomes. There has been no such investment case or systematic review of investing in HIS. The HDC commissioned work through Swiss Tropical and Public Health Institute to support this.
5. **Health Data principles and data governance framework (2021-22):** The UNSG data strategy and WHO both have data principles. A separate set of health data governance principles (endorsed by 140+ organisations, including the HDC) and advocacy for a global health data governance framework is led by Transform Health, with the engagement of wider stakeholders, including the HDC Data and Digital Governance working Group.

Meeting objectives and outcomes

- Review data governance principles, policies and good practices from countries and partner organisations; and
- Discuss and propose an investment strategy for strengthening country HIS.

The expected outcomes of this meeting will include documentation of data governance practices and gaps for health data and opportunities to leverage good practices, and better alignment with partners on proposing strategic investment case for strengthening country HIS.

Meeting format

This is a 2-day hybrid (in-person and virtual) event, joined by approximately 40 in person representatives and stakeholders represented in HDC. There will be an opportunity for partners to discuss on investing in HIS and better aligning with country priorities organized by partners' roundtable. Mixed facilitated panel sessions and materials available beforehand identifying good country health data governance practices and case for better investing in HIS for better quality and more timely, accurate, complete data for UHC and SDG health outcomes. A "Partner round table" on 19 May afternoon gives partners an opportunity to reflect on investing in HIS and better aligning with country priorities.

Organisations co-hosting the meeting

Countries (tbc)	Botswana, Cameroon, Ethiopia, Maldives, South Sudan, Tanzania, Togo, Zambia, Nepal, Pakistan and Uruguay
Multilateral and Intergovernmental Organisations	UNICEF, UNFPA, WHO (Country and Regional Offices) and World Bank
Bilateral Donors, Philanthropic Institutions and Regional Funding Entities	Bloomberg Philanthropies Data for Health Initiative, GIZ and USAID
Global Health Initiatives	GAVI, The Global Fund to Fight AIDS, TB and Malaria and The Global Partnership for Sustainable Development Data
Civil Society & Advocacy	Transform Health
Private Sector	The Palladium Group
Research, Academia and Technical Networks	University of Oslo (WHO collaborating Centre on Innovation and Implementation Research for Health Information Systems Strengthening), Centre for Global Development and US CDC
Health Data Collaborative	Working Group on Data & Digital Governance

Health Data Collaborative

AGENDA	
18 May *Day 1*	

Welcome & Introductions	**09.00 - 09.30**
Video HDC Power of Partnership	
Welcome: facilitated by Samantha Bolton	
Edwin Dikoloti (Minister of Health and Wellness, Botswana)	
Claire Melamed (Chief Executive Officer, Global Partnership for Sustainable Development Data)	
Opening remarks: WHO	
Samira Asma (Assistant Director General, Division of Data Analytics and Delivery for Impact, World Health Organisation)	
Setting the stage: Keynotes	**09.30 - 10.00**
Enterprise architecture: Enabling the convergence of delivery and data	
Alain Labrique (Director Department of Digital Health & Innovation, World Health Organisation)	
Every country should have robust data and health information systems: A wiser investment for achieving equity and health SDGs	
Lia Tadesse Gebremedhin (Minister of Health, Ethiopia) (tbc)	
Yoon Seok Ko (Executive Principal, National Information Society Agency, Former Leader of Data Department & Data Dam Project, South Korea)	
SCORE as a framework for country health information systems and improving access to technical solutions, understanding and investing in where the gaps are	
Steve MacFeely (Director Department of Data & Analytics, World Health Organisation and co-chair of the HDC)	
Session 1 – Part 1: Learning from country experiences	**10.00 - 11.00**
Successes, challenges and gaps in HIS to reach health-related SDGs: Country roundtable highlighting successes, challenges and opportunities to fast-track progress and investment	
*Naod Wendrad (Strategic Affairs Executive Officer, **Ethiopia** Ministry of Health)*	
*Onalenna Seitio-Kgokgwe (Deputy Permanent Secretary Health Policy Monitoring, Evaluation and Quality Assurance, **Botswana** Ministry of Health and Wellness and co-chair of the HDC)*	
*Mwango Mutale (Chief Monitoring and Evaluation Officer (Routine Health Information Systems), **Zambia** Ministry of Health)*	
*Sarbesh Sharma (Director of the Management Division, Department of Health Services, **Nepal** Ministry of Health and Population)*	

*Nassirou Ouro Nile (Chief Information Technology and Communications Division, **Togo** Ministry of Health)*	
Break 11.00 - 11.30 Video on loop [HDC intro and background](#)	
Session 1 – Part 2: Approaches of country and partner collaboration Video [HDC Kenya the Power of Data in the Community](#) Community engagement for Primary Health Care (PHC) and Universal Health Coverage (UHC): what are data challenges and opportunities to overcome (e.g., Geographic Information System (GIS), Civil Registration and Vital Statistics (CRVS)) 1. Importance of community engagement for Primary Health Care (PHC) and Universal Health Coverage (UHC), examples of GIS & CRVS partnership for countries *Malawi and Nepal Government teams* 2. Leveraging data and digital transformation for better health *David Novillo Ortiz (Unit Head, Data and Digital Health, European Regional Office, World Health Organisation)* Opportunities to partner and invest for better data governance and Health Information Systems (HIS) *Panel discussion by:* **Multilateral and Intergovernmental Organisations:** *Malarvizhi Veerappan (Senior Data Manager and Program Manager, World Bank)* **Bilateral Donors, Philanthropic Institutions and Regional Funding Entities**: *Ernesto Lembcke (Advisor, Sector Initiative Global Health, Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ) GmbH)* **Civil Society**: *Kirsten Mathieson (Policy and Advocacy Lead, Transform Health)* **Global Health Initiatives:** *Steve Ollis (Project Director, Country Health Information Systems and Data Use (CHISU) Program, JSI)* **Private Sector:** *Vikas Dwivedi (Senior Health Information Systems Adviser, The Palladium Group)* **Research, Academia and Technical Networks:** *Xen Santas (Global Associate Director Informatics, US CDC)* Q&A facilitated plenary discussion on country partnership	**11.30 - 13.00**
Lunch 13.00 - 14.00 Video on loop [HDC intro and background](#)	
Session 2: Data governance: good practices Importance of data governance: views from UN and non-UN/civil society **Non-UN and civil society:** *Kirsten Mathieson (Policy and Advocacy Lead, Transform Health, and member of the Data & Digital Governance Working Group, HDC) and Victoria Fan (Senior Fellow, Centre for Global Development)* **UN:** *Steve MacFeely (Director Data and Analytics, WHO, and co-chair of the HDC)*	**14.00 - 15.30**

Big data infrastructure and management, and good data governance practices: platforms to safely store, disseminate and use data to improve performance of health care in Primary Health Care (PHC)	
Xen Santas (Global Associate Director Informatics, US CDC)	
Malarvizhi Veerappan (Senior Data Manager and Program Manager, World Bank)	
Q&A on applying data governance and facilitated discussion	

Break 15.30 - 16.00
Video on loop HDC intro and background

Country good data governance practices (from collection to storage, sharing, analysis and use) for health impact: what works	**16.00 - 18.00**
Vikas Dwivedi (Senior Health Information Systems Adviser, The Palladium Group) on behalf of the Health Data Collaborative Data & Digital Governance Working Group	
Data Governance practices in South Sudan	
*John Rumunu (Director General Preventive Health Services, **South Sudan** Ministry of Health) and Kediende Chong (Director General Policy Planning, **South Sudan** Ministry of Health)*	
Country panel reflecting on translating good data governance into practice	
*Naeem Akhtar (Deputy Director, **Pakistan** Ministry of National Health Services, Regulations and Coordination)*	
*Louis Richard Njock (Secretary General, **Cameroon** Ministry of Public Health)*	
*Fathimath Shamah (Director, **Maldives** Ministry of Health)*	
*John Rumunu (Director General Preventive Health Services, **South Sudan** Ministry of Health) and Kediende Chong (Director General Policy Planning, **South Sudan** Ministry of Health)*	
*Ima León (Information Systems Director, **Uruguay** Ministry of Public Health)*	
*Elibahati Akyoo (Data Officer, WHO Office **Tanzania)***	
Building a data governance framework together: Proposal for *"Adapting good data governance practices for countries"*	
Facilitated discussion with countries leading the call	

Reception 18.00 - 20.00

19 May
Day 2

Session 3: Strategies to strengthen HIS in countries	**09.00 - 11.00**
Video HDC Botswana The Power of the Data Journey	
Investing in data for SDGs: Data with purpose and an investment case for data	
Claire Melamed (Chief Executive Officer, The Global Partnership for Sustainable Development Data)	

✓ Routine Health Information Systems (RHIS): investment case
Background literature, stakeholder interviews and country case studies

Xavier Bosch-Capblanch (Project Leader at the Health Systems Support Unit, Swiss Tropical and Public Health Institute) and Christian Auer (Public Health Specialist, Swiss Tropical and Public Health Institute) on behalf of Health Data Collaborative Routine Health Information Systems Working Group

Craig Burgess (HDC Secretariat) on behalf of external experts group

✓ Investing in multiple data sources for optimal decision-making using SCORE:
− Survey Population and Health Risks
− Counting births, deaths and causes of death
− Optimize health service data (RHIS + HHFA)
− Review Progress and Performance
− Enable data use for policy and action (global and country levels)

Jennifer Ellis (Data for Health Initiative for Bloomberg Philanthropies)

Anh Chu (Health Information Systems, DDI, World Health Organization)

Naeem Akhter (Deputy Director, Ministry of national Health Services, Regulations and Coordination, Government of Pakistan)

Francophone: country health information systems and data governance

*Louis Richard Njock (Secretary General, **Cameroon** Ministry of Public Health)*

*Nassirou Ouro Nile (Chief Information Technology and Communications Division, **Togo** Ministry of Health)*

Geographic Information Systems (GIS): why is it an equitable investment for Health Information Systems?

Ravi Santhana Gopala Krishnan (GIS Centre Lead, DDI, World Health Organisation)

Improving Health Information Systems investments for health data in countries: engaging stakeholders

Facilitated plenary discussion with countries and regions

Break 11.00 - 11.30	
Video on loop HDC intro and background	
Session 4: Advocacy & action to invest and improve HIS in countries	**11.30 - 13.00**

Next steps, timeline and initiatives 2023-24

Kirsten Mathieson (Policy and Advocacy Lead, Transform Health, and member of Data & Digital Governance Working Group, HDC) and Victoria Fan (Senior Fellow, Centre for Global Development) representing the HDC Data & Digital Governance Working Group

Craig Burgess (HDC Secretariat)

Facilitated discussion and feedback on next steps by countries and regions highlights on next steps Xen Santas (Global Associate Director Informatics, US CDC) Malarvizhi Veerappan (Senior Data Manager and Program Manager, World Bank)

Lunch 13.00 - 14.00	
Video on loop HDC intro and background	

19 May

Partner Roundtable

Setting the context for Partner Roundtable	14.00 - 16.00

Summary of country needs for investment in HIS and good data governance

*Onalenna Seitio-Kgokgwe (Deputy Permanent Secretary Health Policy Monitoring, Evaluation and Quality Assurance, **Botswana** Ministry of Health and Wellness and co-chair of the HDC)*

SDG3 Global Action Plan: Lessons learned and possible model for supporting countries

*Hendrik Schmitz/Isadora Quick (**SDG3 GAP Secretariat**)*

Better data for better health: possible use of SCORE for health data as a framework for partner alignment and to accelerate progress towards health-related SDGs

1. Comparative advantages of each partner organisation and approaches for better alignment with country priorities
2. Stepping up country capacity from 2018 SCORE assessment to 2024/25 assessment
3. Prioritising support on Least-developed Countries by 2024

Partners share insights to the following themes:
- Effective partner collaboration: better alignment amongst donors to prioritise investment and promote good data governance practices
- Aligning partner priorities with country priorities
- Strategies to attract investment in country HIS: why is there low or inefficient investment in HIS?
- Operationalising good data governance
- Tracking our collective progress and using HDC platform to leverage comparative advantages

Partnering with countries to accelerate progress to SDGs:

Canada: *Marnie Davidson (Senior Health Specialist, Canadian Government)*

Data for Health Initiative, Bloomberg Philanthropies: *Jennifer Ellis (Public Health Team)*

GIZ Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ) GmbH: *Ernesto Lembcke (Advisor, Sector Initiative Global Health) [also representing USAID comments]*

GAVI, the Vaccine Alliance: *Heidi Reynolds (Senior Specialist Evaluation and Learning)*

Global Financing Facility: *Maletela Tuoane (Senior Expert on Civil Registration and Vital Statistics)*

Global Fund to Fight AIDS, TB and Malaria: *Mark Landry (Senior Specialist, Country Digital Health Information Systems)*

Norway: *Tine Larsen (Senior Adviser, Department for Human Development, Section for Global Health)*

SDG3 Global Acton Plan Secretariat: *Hendrik Schmitz and Isadora Quick (SDG3 GAP Secretariat)*

Transform Health: *Kirsten Mathieson (Policy and Advocacy Lead)*

UK FCDO: Desmond Whyms, Health Adviser, UK Foreign, Commonwealth and Development Office

UNICEF: Remy Mwamba (Statistics and Monitoring Specialist)

University of Oslo: Ola Titlestad (DHIS 2 Implementation Coordinator)

UNFPA: Romesh Silva (Technical Specialist, Health & Social Inequalities) & Sainan Zhang (Technical Specialist)

US CDC: Xen Santas (Global Associate Director Informatics)

World Bank: Malarvizhi Veerappan (Senior Data Manager and Program Manager)

Summary and next steps

*Tashi Chozom and Mwenya Kasonde (**HDC Secretariat**)*

Join us!

The HDC is a community of technical experts, political and local leaders, academics, philanthropic organisations, members of civil society, and frontline healthcare workers who can use its platform to support countries, exchange ideas, share views, and scale innovative solutions

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Country would like technical support from our Working Groups?
Want to know more about our partners, how we work and the HDC impact?

*Visit **healthdatacollaborative.org***
or
*Contact us via **HDCsecretariat@who.int***