



HEALTH DATA COLLABORATIVE

Note for the Record – Monthly HDC SRG Meeting		
Location: Zoom		
Date: 21 April 2022, 16:00-17:00 CET		
Meeting Chair: Jennifer Requejo (UNICEF)		
Co-Chairs	Stephen MacFeely (WHO), Jennifer Requejo (UNICEF)	
Participants:	Countries	Judith Nawa (MOHW Botswana)
	Multilateral and Intergovernmental Organisations	Rachel Snow (UNFPA)
	Donors	Ernesto Lembcke (GIZ) Olga Joos (CDC Foundation) Betsy Fuller (Bloomberg Philanthropies)
	GHIs	Emily Bigelow (PHCPI)
	Civil Society	
	Research, Academia and Technical Networks	Pam Dixon (World Privacy Forum) Kathleen Gallagher (US CDC) Debra Jackson (LSHTM) Marie Donaldson (CUNY)
	Private Sector	
	Observers	
Working groups:	<i>Data and Digital Governance</i> Vidya Mahadevan (USAID) Vikas Dwivedi <i>RHIS</i> Jean Pierre de Lamalle (RHINO)	
WHO secretariat:	Craig Burgess, Mwenya Kasonde, Alexandra Laheurte Sloyka	
Objectives:		
<ol style="list-style-type: none"> 1. To present updates from Pakistan and Botswana and follow up steps 2. To present Data & Governance principles for SRG consideration and possible HDC endorsement 3. To present progress update and launch for new HDC website 4. To get feedback on Q4 Global Partners Meeting 5. To get initial ideas for elements required for HDC evaluation 		
Agenda:		
<ol style="list-style-type: none"> 1. Welcome and introductions (chair) (5 mins) 2. Country Updates (15 mins) <ul style="list-style-type: none"> • Update on Botswana HDC activities • Update on Pakistan 3. Working Group Updates (15 mins) <ul style="list-style-type: none"> • Data and Digital Governance: presentation of principles (for consideration and possible endorsement) 	<ol style="list-style-type: none"> 4. Planning for Evaluation (10 mins) <ul style="list-style-type: none"> • Initial ideas for dimensions of evaluation for drafting RFP 5. Comms and events (10 mins) <ul style="list-style-type: none"> • Biannual Global Partners Meeting outcome and action points (for discussion) • Planning for Q4 event, hosted by South Asian institute • Guidance on launch of HDC website 6. Next steps: Chair (5 mins) 	



SUMMARY OF DISCUSSION

Welcome and introductions (chair) (5 mins)

UNICEF-Jennifer Requejo

- Meeting objectives:
 - Present an update on the Botswana HDC.
 - Present the Data & Digital Governance principles for SRG consideration and possible HDC endorsement.
 - Get initial ideas for HDC evaluation.
- Agenda also includes discussion on communication and events, such as a reflection on the Global Partners Meeting, a preview of the Q4 event hosted by a South Asian institute to continue efforts on increasing regional engagement, and the launch of the HDC website.

Country Updates (15 mins)

Update on Botswana HDC activities

Update on Pakistan

MOHW_Botswana-Judith Nawa

- Director of the Department of Monitoring and Evaluation in the Ministry of Health and Wellness in Botswana.
- Botswana Health Data Collaborative (BHDC) was launch in March 2020.
- Work started in 2018/19 with HIS/M&E baseline assessment which identified key progress and some challenges.
- Joint effort by public and private stakeholders in the health sector to develop a BHDC roadmap to:
 - Strengthen national health information and M&E systems.
 - Improve quality of health data.
 - Build capacity to monitor progress made towards SDGs and national health priority goals.
- Implementation arrangements for BHDC
 - Alignment with health sector planning framework is anchored on existing policy and strategic documents, such as the National Health Policy, Integrated Health Sector Plan 2010-2023, MOHW Strategic Plan 2019-2023.
 - BHDC governance and coordination structures include a steering committee, technical working groups, secretariat, and District Health Stakeholders forum.
 - The Steering Committee has not been able to meet regularly due to COVID-19, but Technical Working Groups has been meeting regularly.
 - Advocacy and Communication includes promoting the BHDC agenda, stakeholder engagement and focuses on the health sector.
- BHDC coordination structures with the health sector:



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- Sector Thematic Working Groups – Social Upliftment Thematic Group.
- Health Sector Partnership Forum coordinated by our department within the Ministry.
- BHDC Steering committee.
- 4 Technical Working Groups managed by the Secretariat.
- Digital Health TWG
 - Milestones
 - Establish functional digital standards and regulation for interoperability.
 - Develop and publish a Data Governance Framework for health information.
 - Assess connectivity landscape and identify gaps and communication technologies.
 - Develop and disseminate the coordination guidelines for implementing the eHealth strategy.
 - Achievements
 - Mapped existing digital health systems currently in use and electronic medical records.
 - Implemented a unified national eHealth architecture (for interfacing of data systems, particularly for births and deaths).
 - Developed a web-based master facility list (previously this was a manual document).
 - Working on developing an electronic medical record system that will replace a standalone system that is currently used in health facilities.
 - Phase One is complete. We are in the process of piloting one of the modules.
 - Challenges
 - Poor network connectivity and tendency to revert back to a paper-based system as a result.
 - Low user utilization of digital platforms and EMRs.
 - COVID-19 – Support diverted to COVID-19 activities affected BHDC implementation.
- Data and information Use TWG
 - Milestones
 - Have a national health sector M&E strategy that was aligned to the IHSP that ended in 2019. We are awaiting the review of the IHSP to develop and align the national health sector M&E plan.
 - Align Health Data Management Policy with the Data Protection Act, including developing data management regulations.
 - Develop health sector indicator reference manual.
 - Harmonization of data collection and reporting tools in line with the national indicator reference manual.
 - Establish data management centers at all levels. Each district will have its own data management center.
 - Achievements



- Data analysis training (still ongoing).
- Development of the health sector indicator is still ongoing.
- Draft data regulation to align with the Data Protection Act is in the final stages. It will be submitted to our Legal Office for next steps, such as sharing with stakeholders.
- Data centers currently being established in districts.
- Challenges
 - Under utilization of electronic systems – both manual and electronic system are being used at the same time where there is poor network.
 - Development of the M&E framework awaits development of the new integrated health services plan.
- Civil Registration and Vital Statistics TWG
 - Milestones
 - Main activity was the ICD 11 training.
 - Development of Civil Registration and Vital Statistic Strategic plan 2021-2026.
 - Development of verbal autopsy standards and guidelines and training.
 - Achievements
 - Introduction to ICD 11 conducted.
 - Challenges
 - Lack of funding for ICD 11 training which was planned for December 2021.
 - Have not started training healthcare workers and clinicians. We are working with WHO on how best they can support us.
- Quality Health Care TWG – looks at quality of care at the facility level.
 - Milestones
 - Mortality, morbidity review and clinic audits.
 - Undertake a client and employee satisfaction survey to address challenges and gaps.
 - Development of clinical guidelines and protocols.
 - Review of Botswana quality of care framework.
 - Achievements
 - Trained staff on quality improvement at facility levels.
 - Mortality and morbidity review are being conducted and still ongoing at different levels depending on district.
- Most key intervention areas within the BHDC roadmap have just been started due to refocusing from COVID-19.
- Resource mobilization for BHDC activities is ongoing, and most activities have received a budget allocation from partners of the Ministry.



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Questions

UNICEF-Jennifer Requejo

- How well are partners engaged with your working groups in terms of improvement of partner alignment with your work?

In response

MOHW_Botswana-Judith Nawa

- We worked with them as we were working on the BHDC. In each TWG, the Chair is not from the Ministry. It is the partners and stakeholders, so that they feel part of us and attend the meetings.

Working Group Updates (15 mins)

Data and Digital Governance: presentation of principles (for consideration and possible endorsement)

USAID-Vidya Mahadevan

- The ask for today is to see if anyone has questions or concerns about the HDC principles and see if we can get the HDC to endorse them as we work towards a health data governance framework.
- Approach to the development of the health data governance principles was a bottom-up approach. Civil society played a significant role in terms of leadership, initial regional workshops and through participation and public consultations.
 - Workshops included all of HDC's constituency group.
- Deliverables of the Data and Digital Governance Working Group was the principles and the framework.
- Transform Health provided funding support as well as time and energy into facilitating this process.
- Principles have a lot of diverse inputs and perspectives.
- Goal is to make sure we are targeting country implementation and country-owned programs and applying a human rights and equity perspective.
- Overview of the principles
 - Take a human rights and equity approach. Focus on data solidarity.
 - Supporting more sustainable and resilient public health systems for universal health coverage.
 - Balance public value of health data with individual rights, including potential harms and risks to individuals.
 - Shared vision of equitable health data governance.
 - Strengthening the health data governance ecosystems.
- Link to principles: <https://healthdatapinciples.org/>
 - More detailed advocacy toolkit available on the website, such as template letters, speaking points, presentation and other materials for those wanting to move them forward.



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- 8 equally weighted principles within 3 equally weight objectives of protecting people, promoting health value and prioritizing equity.
- Principles were launched on World Health Day (April 7).
- Over 60 endorsers and are available in English, French and Spanish.
- There has been a lot of communication and social media outreach.
- Next steps to move this forward is getting endorsement and uptake from a broad range of stakeholders, including governments, and socializing the principles in the organizations that have endorsed them.
- The goal for World Health Assembly advocacy is to seek endorsement of the principles and begin discussion at a higher level about the data governance framework, including upcoming events to talk about how different stakeholders would incorporate the principles into their work.
- Webinar planned for May 3.

Questions

GIZ - Ernesto Lembcke

- Do you know of any donors that already endorsed them?

UNFPA-Rachel Snow

- How is this linked or aligned to the overall process within the United Nations (UN) to build up the UN data governance system? The high-level committee on programs under the Secretary General set up a process that is underway right now to create UN data governance principles, etc. Stephen MacFeely is a co-chair of this process.

WHO-Stephen MacFeely

- These aren't WHO principles.
- Most data principles are generic. I'm curious why health principles in particular? The principles could probably be applied to data in general.
- There are UN fundamental principles for official statistic and fair principles. What was missing in those that you felt you had to develop this?
- Too many principles may undermine the need for them.

HDC Secretariat-Craig Burgess

- Building on what Rachel and Stephen said, it would be useful to heard the added value of these principles above and beyond the UN principles, and WHO data principles.
- Also suggest looking at how these principles can be used by and apply to civil society and non-UN entities. There could be an added value for these principles in the non-UN sector.



In response

USAID-Vidya Mahadevan

- I don't think any donors have endorsed these yet. We are having conversations within USAID and moving through the process. It's going well, but it takes time.
- The process was stewarded by the data policy group within Transform Health. We had conversations with them and have similar goals, so we've been involved in the entire process.
- It might be good for us to discuss the ongoing UN efforts as well.
- Agree that a lot of this would apply to any program in the industry, but one of the priorities of health is that there are more vulnerabilities tied to health data.
- WHO has been leading a lot of conversations around public health data.
- Health data breaches and risks associated with health-specific data are more urgent, more dire, and more intrinsically tied to us. For example, DNA registries and platforms.
- Can also pertain to health data and data for health, such as agriculture information, weather patterns, and other things that can be used to inform and are linked to health data.
- The principles are not intended to be used by one type of stakeholder or constituency group. They are intended to be used by everyone, from civil society to private sector groups, ministries of health and other governance counterparts and implementing partners.

Data Governance WG - Vikas

- As much as it was a bottom-up process with the involvement from civil society, different countries and regional groups, the Digital and Data Governance Working Group of the HDC was very much involved at various stages of design and finalization.
 - We reviewed and provided comments to move the process.

LSHTM- Debra Jackson

- I think also that in many health systems, they will not necessarily look to other sectors or broader digital guidelines so would miss these key principles when establishing or updating their systems.

World Privacy Forum-Pam Dixon

- In response to the question on why specific health governance, about 20 years ago, we saw the emergence of general data governance principles which has been added to over the years. There has been a very clear need to further fine tune the governance to sector-specific examples.
- 4 sectors emerged that require specific principles
 - Health – There is a need for addressing some significant variables within the health context that do not exist within the broader principles.
 - Inclusion – I believe the Transform Health principles written from the bottom up captures this.
 - Artificial intelligence and machine learning.
 - Statistical data ecosystems.



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- Also seeing an emphasis on governance for government – how do governments use data? Governments are in the process of revamping their systems so that data use and data protection is much more balanced.
- I believe this is part of the maturity process of data governance.

UNICEF-Jennifer Requejo

- Need more clarity on what is distinct about these principles when compared with existing principles from the WHO and UN process.
- Need further clarity on the specificity of principles for health.
- Would also like to hear how presenters are using the side event to get endorsement from member states. and what is meant by endorsement from the HDC, that is what it implies.
- Let's pick this up at another meeting.

Planning for Evaluation (10 mins)

Initial ideas for dimensions of evaluation for drafting RFP

HDC Secretariat-Craig Burgess

- This is an opportunity to provide feedback on independently contracting an evaluation of the HDC.
- Plan to start implementing around Q4 2022 or Q1 2023.
- RFP to be drafted in the next few months but want to know what dimensions should be in place for the RFP.
- Purpose of this evaluation is because 2023 is the midpoint for the SDGs, to position the HDC as strongly as possible for the remaining years leading up to 2030, and to learn what has worked and what hasn't worked since its inception in 2016.
- Would like written feedback and initial ideas.

LSHTM - Debra Jackson

- I would think it would follow our mission, objectives, our various terms of reference, coordination, communication, working groups, deliverables/global goods developed, and country engagement.
- It would be helpful to see what is happening with all the things we create, endorse or use.
- Framework for effectiveness, efficiency and economics.

US CDC-Kathleen Gallagher

- Anything that can quantify what has been accomplished is beneficial, especially if looking for funding support.



Question

UNICEF-Jennifer Requejo

- What is the objective of the evaluation? Is it to revise the workplan?

In response

HDC Secretariat-Craig Burgess

- Ultimate objective is to have a set of lessons learned, disasters, or good practices since 2016.
- It is also to give recommendations on what is working well, and what needs to be expanded strategically between 2023 and 2030.
- It's not just about the workplan. It's more about the strategic direction for the HDC between 2023 and 2030, based on what happened between 2016-2022.

Comms and events (10 mins)

Biannual Global Partners Meeting outcome and action points (for discussion)

Planning for Q4 event, hosted by South Asian institute

Guidance on launch of HDC website

HDC Secretariat-Mwenya Kasonde

- Key messages and agreed upon action points from the Global Partners Meeting:
 - Had a good discussion on resourcing the HDC workplan.
 - Had separate calls with CDC, donors, and Global Health Initiative constituency – there seems to be some positive progress on getting more support from colleagues. Will have more conversations moving forward.
 - Country-specific follows up – there is a planned joint mission co-led by HDC, SDG GAP, and possibly UNFPA, WHO and others to Malawi, Nepal, and Pakistan to support CRVS and GIS later this year.
 - Will follow up with a group of countries, including Burkina Faso, Niger, and Sudan.
 - Niger is still trying to develop their national health observatory and are looking for support from HDC.
 - Will have an expanded list of focus countries by the end of this year. Goal is 16.
 - Heard from 2 UNICEF contractors on their findings on the states of alignment of partners in different countries. Reports are close to finalization and will be circulated when available.
 - RFP for the RHIS investment case will be released in the next 2 weeks.
 - Received updates from working groups and will reach out to follow up on issues regarding membership – this is an ongoing conversation.
 - Seeing a bit more country engagement.
 - Discussed the added value of different constituencies – We are working on the request for different target numbers for each constituency.



- RFP for the HDC evaluation to be developed and circulated for comments.
- Some action points from the Data Governance Summit.
- Website is being revamped – plan to launch in June or July.
- We look forward to your feedback on the recent Global Partners Meeting.
- Will have a Q4 event and hope to have it hosted by a South Asian institute.
 - Also look forward to feedback on what you would like to see at the Q4 Global Partners Meeting.

LSHTM - Debra Jackson

- We had a long discussion in the CRVS group about the 16-country target, and what it meant for the small Secretariat and for partners. I think this should be discussed at the next meeting.

Next steps: Chair (5 mins)

UNICEF-Jennifer Requejo

- We will flag for further discussion the 16-country target for the next meeting.
- Could also have a longer session about country engagement in general.
- Thank you for participating. We will send out notes and any presentations to continue the discussion next time.

Action Points

Action	Person Responsible	Timeframe
Provide more clarity on why health-specific principles, value add of the principles compared to existing UN or WHO principles, and outline what HDC endorsement would mean and what it looks like.	Data and Digital Governance Working Group	
Put together a straw man for the HDC evaluation RFP and circulate for comments for the next meeting.	Secretariat	
Include an item at the next meeting to discuss what the 16-country target/goal means for HDC partners and the Secretariat.	Secretariat	