Ebola Data Platform - Training

A key element of the Ebola Data Platform's mission is to enable use of the Platform to strengthen and promote research and outbreak preparedness in Ebola-affected countries. We deliver on this remit through collaborations, training and capacity strengthening according to the interests of the countries where Platform data originate. We provide training and fellowships in data management, research methods and biostatistical analysis. A selection of activities that have supported the delivery of our mission are outlined here.

Funding has been approved for Dr Kwame Oneill, the Platform's next Fellow supported by the <u>Special Programme for Research and Training in Tropical Diseases</u> (TDR) hosted at WHO. A clinician and District Medical Officer based at the <u>Sierra Leone Ministry of Health and Sanitation</u>, Kwame will join IDDO for a 12-month training program based at the University of Oxford, starting early 2020. The focus will be on developing skills in data management, clinical research, data governance and biostatistical analysis. (JAN 2020)

Dr Sulaiman Jalloh, a clinician from Sierra Leone who recently completed his studies on the <u>Masters in International Health and Tropical Medicine at Oxford University</u>, has a placement as a Research Intern with IDDO until March 2020. Sulaiman is focusing on developing skills in systematic review, data extraction and data analysis to create a core outcome set for Lassa fever clinical trials while supporting the launch of the Ebola Data Platform. Sulaiman is a staff of the <u>Sierra Leone Ministry of Health and Sanitation</u>. (SEP 2019)

In collaboration with the <u>University Gamal Abdel Nassar Conakry</u>, IDDO delivered a <u>1-week training in research methods</u> for 35 of the <u>University's clinical assistants</u>. These assistants are responsible for supervision of research theses by medical students. Funding was provided by the <u>Special Programme for Research and Training in Tropical Diseases</u> (WHO/TDR). (AUG 2019)

Dr Wahdae-mai Harmon, a clinician and researcher from Liberia, undertook a 6-month internship at IDDO following the completion of her <u>Masters in International Health and Tropical Medicine at Oxford University</u>. Wahdae-mai received training on systematic review, reference software and screening tools, and implemented these skills to assemble global evidence on clinical outcomes in Ebola and viral hemorrhagic fevers. (SEP 2018-MAR 2019)

Musa Martin Feika, a data manager and administrative officer in the Directorate of Health Security and Emergencies, Sierra Leone Ministry of Health and Sanitation, completed a 1-month training collaboration with IDDO. During the Oxford-based training, Musa developed skills in data curation, data standards, statistical programming, informatics and data security. He also had the opportunity to participate in local and national events such as 2018 Better Science through Better Data event in London. Musa is now a data team member of the Ebola Data Platform Secretariat. (NOV 2018)

<u>Trokon Omarley Yeabah</u>, a data manager at the <u>National Public Health Institute Liberia</u>, completed a 1-month training collaboration with IDDO. During the Oxford-based training, Trokon developed skills in data curation, data standards, statistical programming, informatics and data security. He also had the opportunity to participate in local and national events such as 2018 Better Science through Better Data event in London. Trokon is now a data team member of the Ebola Data Platform Secretariat. (NOV 2018)

<u>Fayiah Tamba</u>, a lecturer in statistics at the <u>University of Liberia</u> and Researcher at the <u>National Public</u> <u>Health Institute Liberia</u>, completed a 1-month training collaboration with IDDO. During the Oxford-based training, Fayiah developed skills in data curation, data standards, statistical programming, informatics and data security. He also had the opportunity to participate in local and national events such as 2018 Better Science through Better Data event in London. Fayiah is now a data team member of the Ebola Data Platform Secretariat. (NOV 2018)

<u>Dr Mahamoud Sama Cherif</u>, a clinician and clinical researcher at the <u>University Gamal Abdel Nassar Conakry</u>, Guinea, undertook a 12-month <u>Clinical Research and Development Fellowship</u> based at IDDO. This opportunity, funded by the <u>Special Programme for Research and Training in Tropical Diseases</u> (WHO/TDR) included training and mentorship in data management, clinical research and biostatistical analysis (DEC 2017-DEC 2018).

IDDO hosted a workshop on <u>Improving Research Data to Inform Better Treatment of Poverty-Related Infectious Diseases</u> in in Nairobi, Kenya (JAN 2018). The workshop was attended by more than 50 data managers, biostatisticians and researchers, primarily from sub-Saharan Africa. This activity was supported by funding from the British Council and the Newton Fund Researcher Links scheme.

Dr Julius Gilayeneh, a physician from Liberia, undertook his <u>Masters in International Health and Tropical Medicine at Oxford University</u>. Julius' academic supervision was provided by IDDO and he conducted his thesis with the support of IDDO on the use of Ebola evidence to inform the development of treatment guidelines during the 2014-16 West African Ebola outbreak (AUG 2017). Following the completion of his Masters, Julius' undertook a 6-month internship at IDDO to develop research management, ethics and governance skills.

Ebola Data Platform - Collaboration

A key element of the Ebola Data Platform's mission is to enable use of the Platform to strengthen and promote research by researchers in Ebola-affected countries through collaboration, training and capacity strengthening. Newly funded collaborations resulting from the Platform that have supported the delivery of this mission are outlined below.

A collaborative project was developed by the National Public Health Institute Liberia and IDDO to support the integration of research into a new Masters in Public Health program at the University of Liberia. The project, funded by the Global Health Research Challenges scheme of Research England, aims to enrich the education of young researchers and enhance collaboration between the University of Oxford and the University of Liberia. (SEP 2019-JUL 2020)

An award to support the costs of the Data Access Committee has been awarded by Wellcome. IDDO and TDR collaborated on an application for funding to support the travel and sustenance costs of the inaugural DAC meeting, which will be hosted by the Institute Pasteur Cote d'Ivoire on October 30-31, 2019. (SEP-DEC 2019)

Two 12-month Clinical Research Development Fellowships have been awarded by the Special Programme for Research and Training in Tropical Diseases (WHO/TDR) for fellows to be hosted at IDDO. One clinician from Guinea (DEC 2017-DEC 2018) and one clinician from Sierra Leone (DEC 2019-DEC2020) participated. Re-entry funding was also awarded to the fellows, in collaboration with IDDO, to share the research training gained at IDDO with the fellow's home institution.

A collaborative application by the National Public Health Institute Liberia (NPHIL) and IDDO was awarded from the AfOx Initiative travel grant. The funding supported training for 2 NPHIL data managers on infectious disease data curation in Oxford. (MAR 2018)

Ebola Data Platform - Stakeholder Engagement Activities

The Platform seeks to ensure the widest possible engagement of the various communities affected by Ebola in the design and execution of the Platform. The activities below have been undertaken in this interest.

Steering Committee: Regular meetings of this governance committee have taken place since April 2016. <u>Minutes and other documents are available</u>.

Data Access Committee: The Data Access Committee held their inaugural meeting in October 2019. Regular meetings to review applications for data access and improve processes are planned form this date. Minutes and other documents are available.

2019

November & December 2019. Geneva, Switzerland.

Series of meetings to discuss how the Ebola Data Platform can support the objectives of the World Health Organisation Health Emergencies Program.

Stakeholders: WHO Health Emergencies Team, Special Program for Training and Research in Tropical Diseases (TDR), IDDO.

Forum: Closed meetings.

November 2019. Kinshasa, Democratic Republic of Congo.

A Data Access Committee member presented the data access governance framework to conference attendees.

Stakeholders: The global scientific community, with a focus on those conducting research in DRC.

Presentation: Le Comité d'accès aux données de la plateforme de données Ebola : Réduire l'impact des infections émergentes grâce à une réutilisation équitable des données – Esaie Kindombe

Forum: Congrès International de Pathologie Infectieuse et Parasitaire de Institut National de Recherche Biomédicale (INRB, DRC)

September 2019. Oxford, UK.

IDDO presented the Ebola Data Platform for discussion with conference attendees.

Stakeholders: Staff and collaborators of the Oxford University Center for Tropical Medicine and Global Health.

IDDO Presentation: Reducing the impact of emerging infections through responsible data use: lessons

learned from the Ebola Data Platform

Forum: Oxford Tropical Network Conference

August 2019. Conakry, Guinea.

IDDO presented the platform to a group of Professors and clinical assistants to encourage interest in using the platform and requests to access data.

Stakeholders: University of Gamal Abdel Nassar Conakry, IDDO.

IDDO Presentation: Réutiliser les données existantes pour accélérer la science

Forum: Training on clinical research methods at University of Gamal Abdel Nassar Conakry.

August 2019. Conakry, Guinea.

The Director of the Agence Nationale de Sécurité Sanitaire Guinee met with platform representatives to discuss Guinea's signature on the platform charter, and Guinea's involvement in, and benefits from, the platform.

Stakeholders: Agence Nationale de Sécurité Sanitaire Guinee, IDDO.

Forum: Closed meeting

August 2019. Freetown, Sierrra Leone.

A meeting to discuss platform implementation with the Chief Medical Officer.

Stakeholders: Sierra Leone Ministry of Health and Sanitation, IDDO.

Forum: Closed meeting

May 2019. Tokyo, Japan.

A meeting with representatives of major funders with interest in emerging infections to discuss support for data sharing platform as contributions towards better outbreak response.

Stakeholders: GloPID-R members, Wellcome Trust, IDDO.

IDDO presentation: Progress and potential for sharing data during public health emergencies **Forum:** Global Research Collaboration for Infectious Diseases Preparedness (GloPID-R) General Assembly.

2018

October 2018. New Orleans, USA.

Presentation of the Ebola Data Platform via poster.

Stakeholders: Global scientific and policy maker community focused on tropical medicine.

IDDO presentation: Ebola Data Platform: a novel collaboration for training and research in emerging infections – Dr Mahamoud Sama Cherif

Forum: American Society of Tropical Medicine and Hygiene (ASTMH) Annual Meeting

September 2018. Lisbon, Portugal.

Presentation of the Ebola Data Platform via poster and oral presentation.

Stakeholders: Global scientific and policy maker community focused on clinical research in sub-Saharan Africa.

IDDO presentation: Establishing an equitable governance and partnership for the Ebola Data Platform (poster & presentation) – Dr Mahamoud Sama Cherif

Forum: European and Developing Countries Clinical Trials Partnership (EDCTP) Annual Forum

May 2018. Freetown, Sierrra Leone.

A meeting to discuss platform implementation with the data managers, researchers, Steering Committee representative of the Ministry of Health and Sanitation and the Chief Medical Officer.

Stakeholders: Sierra Leone Ministry of Health and Sanitation, IDDO.

Forum: Closed meeting

May 2018. Conakry, Guinea.

The Director of the Agence Nationale de Sécurité Sanitaire Guinee invited platform representatives to meet to discuss Guinea's involvement in the platform.

Stakeholders: Agence Nationale de Sécurité Sanitaire Guinee, MSF, Alima, IDDO.

Forum: Closed meeting

March 2018. Addis Ababa, Ethiopia.

Approaches to respond to emerging infections across Africa were discussed with the academic and public health communities.

Stakeholders: Various African and international academic institutions, various African public health actors, Africa CDC, IDDO.

Forum: International Conference on (Re-)Emerging Infectious Diseases

2017

December 2017. Oxford and London, United Kingdom.

A representative of the Liberia National EC met with ethicists, ethics councils, research ethics committees and IDDO to discuss the best design of relevant aspects of the Ebola Data Platform including consent, ownership, approval and benefits sharing.

Stakeholders: Liberia National EC, Nuffield Council for Bioethics, Oxford Tropical Research EC, Ethox Centre, Wellcome, IDDO.

Forum: Individual meetings at the offices of named stakeholders.

December 2017. Dakar, Senegal.

Representatives of West African national public health agencies discussed the Ebola Data Platform to determine how it could integrate with their outbreak response plans.

Stakeholders: Centre des Opérations d'Urgence Sanitaire Senegal, Sierra Leone Ministry of Health and Sanitation, Liberia National Public Health Institute, Centre des Opérations d'Urgence Sanitaire Côte d'Ivoire, Agence Nationale de Sécurité Sanitaire Guinee, WATER, IDDO.

IDDO Presentation: L'intégration des données et l'accès pour améliorer la préparation et la riposte aux épidémies.

Forum: West African Taskforce for the Control of Emerging and Re-emerging Infections (WATER)
Réunion pour l'elaboration de plans de preparation aux epidémies et urgencies sanitaires en Afrique de l'Ouest.

December 2017. Oxford, United Kingdom.

Faculty of Najala University met with the IDDO team to discuss opportunities for capacity strengthening, community engagement and collaboration.

Stakeholders: Najala University, IDDO.

Forum: Closed meeting.

November 2017. London, United Kingdom.

Representatives of International Science Unions discussed using the Ebola Data Platform as a pilot initiative to develop data integration techniques to inform response to emerging infections.

Stakeholders: International Science Union and representatives from affiliated Science Unions, Committee on Data Science and Technology, Public Health England, IDDO.

IDDO Presentation: Data integration for the tracking and treatment of infectious disease outbreaks. **Forum:** International Council for Science / Committee on Data Science and Technology workshop on data standards and integration.

October 2017. Geneva, Switzerland

World Health Organisation initiative to establish agreed principles and practices on samples, testing and biobanking during public health emergencies.

Stakeholders: Global academic, NGO, funder, government and inter-government institutions.

MSF Presentation: MSF experience on the Ebola Data Platform.

Forum: Biobanking: access to storage and use of samples during a public health emergency, WHO Third Consultation

October 2017. Antwerp, Belgium.

Gaps in the landscape of data repositories for emerging infections data were discussed by researchers, funders, repository managers, public health agencies and policy makers. How the Ebola Data Platform could fill some of these gaps was considered.

Stakeholders: Global academic institutions, funders and public health agencies including Agincourt, INDEPTH, Committee on Data Science and Technology, Bill and Melinda Gates Foundation, Vivli, MSF, Wellcome, WHO, IDDO.

IDDO Presentation: Data sharing in public health emergencies.

MSF Presentation: MSF experience on EVD data platform barriers.

Forum: Wellcome meeting on Best practices in data sharing: incorporating the experiences of researchers from low and middle-income countries.

September 2017. Conakry, Guinea.

A consultation of the West African Ebola research and response community on the topic of leadership and capacity strengthening needs for data analysis and health research including the Ebola Data Platform.

Stakeholders: Ebola survivors, West African researchers, national EC members, Ministries of Health staff, academics, policy makers, national public health agency staff, WATER, IDDO.

Forum: 3rd West African Sub-Regional Conference on Post-Ebola Health Systems Strengthening.

September 2017. Conakry, Guinea.

A discussion with the Minister of Health of Guinea on purpose, design, engagement, and approvals for the Ebola Data Platform.

Stakeholders: Minister of Health of Guinea, MSF, IDDO.

Forum: 3rd West African Sub-Regional Conference on Post-Ebola Health Systems Strengthening.

September 2017. Conakry, Guinea.

A consultation of the West African Ebola research and response community on the topic of data sharing, data governance and the design of the Ebola Data Platform.

Stakeholders: Ebola survivors, West African researchers, national EC members, Ministries of Health

staff, academics, policy makers, national public health agency staff, WATER, IDDO.

Forum: 3rd West African Sub-Regional Conference on Post-Ebola Health Systems Strengthening.

August 2017. Accra, Ghana.

Scientific and policy meeting to discuss emerging infectious diseases and biosecurity.

Stakeholders: Academia, funders, NGOs, patient representatives, MSF.

Forum: 3rd African Conference on Emerging Infectious Diseases and Biosecurity

July 2017. Oxford, United Kingdom.

A consultation of international ethicists on equity, ethics and best practice in data sharing.

Stakeholders: Ethicists from international academic and public health institutions, IDDO.

IDDO Presentation: Journey towards equity in sharing health research data from low and middle-income settings.

Forum: Ethox Centre Seminar Series.

July 2017. Freetown, Sierra Leona

Meeting to establish agreement on principles and process for the sharing of Ebola data and samples.

Stakeholders: Sierra Leone Ministry of Health, South Africa National Bioinformatics Institute, GET consortium, MSF.

Forum: Data and Samples: laboratory management information systems workshop.

July 2017. Oxford, United Kingdom.

Consultation on best practice in data standards for infectious diseases.

Stakeholders: Academic and pharmaceutical data specialists, IDDO.

IDDO Presentation: Better standards for global collaboration in infectious disease research.

Forum: Clinical Data Interchange Standards Consortium (CDISC) UK User's Group Annual Meeting.

July 2017. London, United Kingdom.

Representatives of WHO, national public health agencies, funders, think tanks and academia met to discuss the barriers and solutions to sharing data in public health emergencies, including the application of the Ebola Data Platform.

Stakeholders: Data experts, national public health agencies, funders, think tanks, academia, WHO, Wellcome, IDDO.

IDDO Presentation: Data Sharing for Emergencies: what are the barriers.

Forum: Digital Health 2017: Global public health, personalised medicine, and emergency medicine in the age of big data.

June 2017. London, United Kingdom.

Discussion forum for government, inter-government and non-government organisations to advance ideas, realities and solutions to sharing data during public health emergencies.

Stakeholders: Humanitarian Data Exchange, UK Department for International Development, International Rescue Committee, International Federation of Red Cross and Red Crescent Societies, Action Contre le Faim, Save the Children, Kings College London, IMC, Wellcome, MSF, WHO, IDDO. **IDDO Presentation:** Infectious Diseases Data Observatory, a platform for research and humanitarian communities.

Forum: Wellcome Trust meeting on NGO perspectives on data sharing for research in public health emergencies.

June 2017. Kinshasa, Democratic Republic of Congo.

Meeting to discus the Ebola Data Platform and sample sharing initiatives.

Stakeholders: Institute National de la Recherche Biomédicale RDC, Institut National de Sante Publique RDC, National ethics Committee RDC, Direction de la Lute Contre la Maladie (D4), DRC Ministry of Health, MSF.

Forum: Comité National de Coordination pour la Riposte de l'épidémie de la MVE dans la ZS de Likati / Bas – Uélé, en RDC.

May 2017. Guinea, Conakry.

Meeting with the Ministry of Health Director of Laboratories and the Director of the National Public Health Security Agency to discuss responsibility, design and implementation of the Ebola Data Platform.

Stakeholders: Agence Nationale Sécurité Sanitaire de Guineé, Guinea Ministry of Health, WAHO, IDDO. **Forum:** Closed meetings.

May 2017. Freetown, Sierra Leone.

Meeting with the Deputy Minister of Health and the Director of Hospital and Laboratory Services to discuss responsibility, design and implementation of the Ebola Data Platform.

Stakeholders: Sierra Leone Ministry of Health and Sanitation, WAHO, IDDO.

Forum: Closed meetings.

May 2017. Freetown, Sierra Leone.

Consultation with the Ministry of Health EC on the design, governance, consent process and approval pathways of the Ebola Data Platform.

Stakeholders: EC of the Sierra Leone Ministry of Health and Sanitation, IDDO.

Forum: Closed meeting.

April 2017. London, United Kingdom.

Consultation of data experts and standards developers on best practice in data curation, integration, ontology and format for infectious diseases.

Stakeholders: International data experts from academia, software providers, pharmaceutical industry and standards agencies.

IDDO Presentation: Raising the standard for global collaboration in emerging infections.

Forum: Clinical Data Interchange Standards Consortium (CDISC) European Interchange.

April 2017. Bobo-Dioulasso, Burkina Faso

Meeting to discuss capacity building strategies and the role of the WAHO in the Ebola Data Platform. Stakeholders: WAHO, IDDO.

Forum: Closed meeting.

April 2017. Brussels, Belgium

Meeting to discuss African biobanking collaborations.

Stakeholders: African governments, NGOs, academia, funders, MSF.

MSF Presentation and roundtable: MSF Ebola Data Platform governance experience.

Forum: Biobanking collaboration with Africa: BBMRI-ERIC's contribution to health research capacity building in Africa.

March 2017. Accra, Ghana.

Consultation with national public health agencies and regional health agencies on how the Ebola Data Platform can be integrated into national and regional outbreak response plans.

Stakeholders: West African CDC, National Public Health Agencies and Ministries of Health from 15 West African countries, Connecting Organisation for Regional Diseases Surveillance, Chatham House, WATER, WAHO, IDDO.

IDDO Presentation: Turning data into evidence for action.

Forum: Workshop on the Integrated Regional Platform for Collection and Sharing of Health Information and to Build the Capacity of the West African Network for Infectious Diseases Surveillance (WANIDS).

March 2017, Abidjan, Côte d'Ivoire.

Closed meeting to discuss development of Ebola Platform.

Stakeholders: MSF and West African Health Organization

Forum: Workshop to develop the operating mechanisms proposal for the ECOWAS regional biobank

2016

December 2016. Paris, France.

Consultation with international academics on methodology for pooling individual patient-level data for meta-analysis.

Stakeholders: Clinical researchers from international institutions and networks including Utrecht University, Centre Hospitalier Universitaire Vaudois, University of Toronto, George Institute for International Health, Federal University of São Paulo, International Forum for Acute Care Trialists, IDDO. **IDDO Presentation:** Pooling across trials.

Forum: International Sepsis Forum: Sepsis and the Challenge of Antimicrobial Resistance.

November 2016. London, United Kingdom.

Advocacy and discussion with UK government regarding funding and policy support for data sharing in public health emergencies.

Stakeholders: UK government, Drugs for Neglected Diseases Initiative, London School for Hygiene and Tropical Medicine, IDDO.

IDDO Presentation: How does data-sharing support global health and policy?

Forum: UK All Party Parliamentary Group on Malaria and Neglected Tropical Diseases.

November 2016. Atlanta, USA.

Diverse group of international health, research and policy specialists discussed approaches to governance, security, methods and equity in access to data on tropical diseases, using the example of the Ebola Data Platform.

Stakeholders: International academics, health care providers, staff of non-government organizations and policy makers including Université Cheikh Anta Diop de Dakar, Ministry of Health of Uganda, IMC, IDDO.

IDDO Presentation: Addressing barriers to sharing tropical disease data.

Forum: American Society of Tropical Medicine and Hygiene Annual Meeting.

October 2016. Oxford, United Kingdom.

Ethics and equity of sharing data from public health emergencies and the West African Ebola outbreak were debated by conference attendees.

Stakeholders: Medical students, academics, the public, IDDO.

IDDO Presentation: Ethical perspectives on emerging infection response.

Forum: Richard Doll Society Annual Conference on Tackling the emerging giants of infectious disease.

October 2016. Dakar, Senegal.

Focus group discussion between representatives of national public health agencies and ministries of health on how data can and should be effectively shared to support surveillance and outbreak response.

Stakeholders: WAHO, West African CDC, Connecting Organisation for Regional Disease Surveillance, Ministries of Health and National Public Health Agencies from 15 West African Countries, IDDO. **IDDO Presentation:** Improving Outbreak Response: Lessons Learned from Sharing Research Data. **Forum:** WAHO Workshop on the West African Network for Infectious Disease Surveillance operation manual.

September 2016. London, United Kingdom.

Roundtable discussion on best practice for sharing data to improve public health.

Stakeholders: Many international public health, policy and funding agencies including West African CDC, West African Network for Infectious Disease Surveillance, Mekong Basin Disease Surveillance (MBDS) network, Save the Children, Chatham House, Bill and Melinda Gates Foundation, Wellcome, WHO, IDDO.

Forum: Chatham House Final Strategic Roundtable on Strengthening Data Sharing for Public Health.

July 2016. Lagos, Nigeria

Closed meeting to discuss delivery of Ebola data Platform.

Stakeholders: MSF representation closed meetings with Sierra Leona, Guinea and Liberia Ministry of Health and Ethics Review Board representatives

Forum: 2nd African Voices and Leadership Conference on Emerging Infectious Diseases and Biosecurity (Get Consortium)

May 2016. Freetown, Sierra Leone.

Presentation followed by discussion with the Ebola research, treatment and survivor communities on the design, governance and purpose of the Ebola Data Platform.

Stakeholders: WAHO, Sierra Leone Ministry of Health and Sanitation, Liberia Ministry of Health, Guinea Ministry of Health, Guinea National EC, Liberia National EC, West African academics and health care workers, international researchers, Ebola survivor communities from Sierra Leone, Guinea and Liberia, IDDO.

IDDO Presentation: Sharing data to optimize knowledge on Ebola.

Forum: West African Sub-Regional Collaboration Group Sub-Regional Collaborative Conference on EVD Vaccine & Therapeutic Trials.

May 2016. Freetown, Sierra Leone.

Meeting with the Minister of Health to discuss responsibility, design and implementation of the Ebola Data Platform.

Stakeholders: Sierra Leone Ministry of Health and Sanitation, MSF, IDDO.

Forum: Closed meeting.

May 2016. Freetown, Sierra Leone.

Focus group of key stakeholders to determine the process for designing, approving and establishing the Ebola Data Platform.

Stakeholders: Sierra Leone Ministry of Health and Sanitation, Liberia Ministry of Health, Guinea Ministry of Health, Guinea National EC, Liberia National EC, College of Medicine and Allied Health Sciences, IDDO. **Forum:** West African Sub-Regional Collaboration Group Sub-Regional Collaborative Conference on EVD

Vaccine & Therapeutic Trials.

April 2016. Oxford, United Kingdom.

A representative of the West African Taskforce for the Control of Emerging and Re-emerging Infections (WATER) met with the IDDO team to understand how best to design the platform technical framework and capacity strengthening strategy to integrate West African scientists and data managers.

Stakeholders: WATER, IDDO.

Forum: Closed meeting.

April 2016. London, United Kingdom.

A consultation of West African and international Ebola outbreak responders on the optimal design and implementation of the Ebola Data Platform to inform emergency response.

Stakeholders: West African Ministries of Health, academics, international non-government organisations, IDDO.

IDDO Presentation: Ebola Research and Data Management: Key challenges, new priorities, and how to prepare for future outbreaks.

Forum: GOAL Global Conference on Ebola: Lessons Learned.

April 2016. Bissau, Guinea-Bissau.

A proposal for the Ebola Data Platform was presented to the West African Ministers of Health for feedback.

Stakeholders: Ministers of Health from 15 West African Countries, WAHO, MSF, IDDO.

IDDO Presentation: Optimizing Knowledge from Ebola Clinical Management & Research: The Ebola Data

Platform Initiative

Forum: WAHO Health Minister's Meeting.

March 2016. Monrovia, Liberia.

Consultative engagement of Liberian and regional academics, health care providers and Ministry of Health staff on the design, ethics and implementation of the Ebola Data Platform.

Stakeholders: Liberia Ministry of Health, Liberia National EC, Global Emerging Pathogens Treatment Consortium, Liberia Institute for Biomedical Research, WHO, IDDO.

IDDO Presentation: Optimizing knowledge from Ebola clinical management and research.

Forum: Liberia Institute for Biomedical Research Consultative Engagement workshop on Biobanking in Liberia.

March 2016. Monrovia, Liberia.

Meeting with the Deputy Minister of Planning Research and Development to discuss design and implementation of the Ebola Data Platform.

Stakeholders: Liberia Ministry of Planning, Research and Development, MSF, IDDO.

Forum: Closed meeting.

March 2016. Monrovia, Liberia.

Meeting with the Minister of Health to discuss responsibility, design and implementation of the Ebola Data Platform.

Stakeholders: Liberia Ministry of Health, MSF, IDDO.

Forum: Closed meeting.

March 2016. Conakry, Guinea.

Consultative engagement of Guinean and regional academics, health care providers and Ministry of Health staff on the design, ethics and implementation of the Ebola Data Platform.

Stakeholders: Guinea Ministry of Health, Guinea National EC, Global Emerging Pathogens Treatment Consortium, WAHO, IDDO.

IDDO Presentation: Optimisation des connaissances issues de la recherche et de la gestion clinique de la maladie à virus Ebola.

Forum: Ministre de la Santé de Guinée Atelier de Réflexion: BioSécurité, BioSûreté et Biobanques.

March 2016. Conakry, Guinea.

Consultation with WHO Regional Office on data governance and access for the Ebola Data Platform.

Stakeholders: WHO, IDDO.

Forum: Closed meeting.

February 2016. London, United Kingdom.

Representatives of national public health agencies, funders, think tanks and academia met to discuss opportunities and challenges for data-driven health security in emergencies, including the application of the Ebola Data Platform.

Stakeholders: Data experts, national public health agencies, funders, think tanks, academia, IDDO.

Forum: University College London Festival for Digital Health.

February 2016. London, United Kingdom.

Consultation on the current and potential role of funders in supporting data sharing in public health emergencies.

Stakeholders: Fondation Merieux, Glopid-R members, European Commission, Wellcome, IDDO.

IDDO Presentation: Data solutions for emerging infections.

Forum: Secretariat Meeting of the Global Research Collaboration for Infectious Disease Preparedness (GloPID-R).

2015

December 2015. Venice, Italy.

Consultation of national public health agencies and academics on how to access and use data on public health emergencies.

Stakeholders: International representatives of national public health agencies, academic institutions, WHO, IDDO.

IDDO Presentation: Delivering rapid data for a clinical research response to emerging infections.

Forum: World Health Organization Emerging Diseases Clinical Assessment and Response Network Meeting.

December 2015. London, United Kingdom.

Consultation on the design and application of data sharing platforms for emerging infection outbreaks.

Stakeholders: International academia, research funders, public health agency representatives, research network members, WATER, IDDO.

IDDO Presentation: Building data sharing platforms to enable rapid research response to emerging infections.

Forum: International Severe Acute Respiratory and Emerging Infections Consortia (ISARIC) Stakeholder meeting.

November 2015. Oxford, United Kingdom.

Public questioning and consultation on the UK response to the West African Ebola outbreak and solutions for the future.

Stakeholders: UK Government, public, UK Ebola response organisations, IDDO.

IDDO Presentation: Use of data in outbreak response and the Ebola Data Platform.

Forum: UK House of Commons Science & Technology Committee on Science in emergencies: UK lessons from Ebola.

September 2015. Geneva, Switzerland.

Stakeholders: European Commission, international academics, research funders, medical journal editors, WHO, IDDO.

IDDO Presentation: Data Sharing Platforms for Emerging Infections.

Forum: World Health Organization Consultation on Data and Results Sharing During Public Health Emergencies.

June 2015. Washington, United States.

A discussion with regulators and pharma to understand their role in data harmonisation and sharing during public health emergencies.

Stakeholders: Representatives from pharmaceutical industry, medicine regulators and academic institutions, IDDO.

IDDO Presentation: Ebola virus disease case study: Global harmonisation to increase power and accelerate outcomes in clinical research data.

Forum: Develop Innovate Advance Annual Meeting.

April 2015. Rome, Italy.

Meeting of global experts to improve Ebola characterisation and treatment guidelines, including what data to collect, and what to do with it.

Stakeholders: European Commission, US National Institutes of Health, international academics, Institute Pasteur Dakar, Emergency, West African public health and ministry of health representatives, WHO MSF, IDDO.

IDDO Presentation: Motivations and means for responsible data sharing in Ebola virus disease.

Forum: World Health Organization meeting on Clinical Aspects of Ebola virus Disease. Advancing Standards of Clinical Care.

January 2015. Geneva, Switzerland.

Meeting of global experts to discuss an update on Ebola treatment guidelines, including what data to collect and what to do with it.

Stakeholders: European Commission, US National Institutes of Health, international academics, Institute Pasteur Dakar, West African public health and Ministry of Health representatives, MSF, WHO, IDDO.

IDDO Presentation: Patient record systems and database management platform.

Forum: World Health Organization Meeting on Clinical Aspects of Ebola Virus Disease and Advancing Clinical Care.

2014

December 2014 onwards. Global.

Regular teleconference consultation of organisations collecting data on the possibility of designing and developing a data sharing platform.

Stakeholders: Organisations involved in Ebola response including US CDC, International Rescue Committee, International Federation of Red Cross and Red Crescent Societies, GOAL, Save the Children, Kings College London, IMC, Wellcome, MSF, WHO, IDDO.

Forum: Numerous individual and group conference calls.

November 2014. Geneva, Switzerland.

Meeting of global experts to discuss and agree a strategy for Ebola research. First public proposal of a data sharing platform for Ebola.

Stakeholders: European Commission, US Food and Drug Administration, US National Institutes of Health, international academics, Institute Pasteur Dakar, West African Public Health and Ministry of Health representatives, MSF, WHO, IDDO.

IDDO Presentation: Open collaboration and data for Ebola virus disease.

Forum: World Health Organization Scientific and Technical Advisory Committee for Ebola Research.

Acronyms:

CDC: Centre for Disease Control

EC: Ethics Committee

IDDO: Infectious Diseases Data Observatory

IMC: International Medical Corps MSF: Médecins Sans Frontières

WAHO: West African Health Organisation

WATER: West African Taskforce for the Control of Emerging and Re-emerging Infections

WHO: World Health Organization