

Ebola Data Platform: Platform Charter

Version: 4 December 2017

The signatories of this Charter wish to establish an Ebola Data Platform (the « Platform ») with global reach to become the repository of data related to Ebola (the « Data »), and foster a culture in which promoting access to Data is the expected norm and is conducted in the public interest and the interests of the individuals and communities from which Data originates. This Charter is intended to ensure a common understanding of the mission and remit of the Platform and its Steering Committee in line with the Platform's Ethics Framework. In the future, this Platform may be expanded to encompass additional emerging pathogens.

Background

Despite more than two dozen Ebola outbreaks over the past 40 years, research on the pathogenesis and optimal management of the disease remains limited. This has resulted in delays in outbreak recognition and inadequate options for diagnosis, treatment, prevention and response for Ebola virus disease (« Ebola »).

The 2013-2016 West African Ebola outbreak highlighted the imperative to advance research and development (« R&D ») preparedness and effective collaboration frameworks ahead of any new epidemic. At the same time, it has demonstrated that it is possible to accelerate R&D during emergencies and that it is feasible to safely and effectively implement research interventions in affected countries. The World Health Organisation R&D Blueprint action plan to prevent epidemics may provide inspiration and guidance on how to achieve R&D preparedness and response.

Mission

By enabling ethical, equitable and rapid access to Data and information on Ebola Virus Disease and, in the future, other emergent pathogens, the Platform aims to increase the dissemination of knowledge to improve health. The Platform ultimately seeks to improve patient outcomes, public health preparedness and outbreak response.

The Platform's mission shall thus be to:

- (a) Incentivize and maximize contributions to the Platform of the widest variety of Data and information, whether clinical, epidemiological, laboratory, methodologies or other data of any kind related to Ebola or other emergent pathogens;
- (b) Give the scientific, health, research, and public health communities equitable ability to use such Data through a timely and transparent data access process which has as few restrictions as possible;
- (c) Enable use of the Platform to: strengthen and promote research by researchers in Ebola-affected countries through collaboration, training and capacity strengthening; facilitate and accelerate the research for curative, preventative and diagnostic tools; assist in the identification of new outbreaks; and improve response to epidemics in case of ongoing outbreaks;
- (d) Encourage the rapid dissemination of information in an equitable manner, which respects the interests of those who collect the data;

(e) Ensure adequate and timely access to the outcomes of any research using the Data by all countries in need. The Platform intends to collaborate on measures to facilitate such access, including measures concerning availability and affordability of the research outcomes;

while

(f) Protecting the interests, rights, safety and privacy of the individuals and communities from whom the Data originated and ensuring compliance with ethical requirements and applicable laws and regulations.

This mission will be optimally achieved through collaboration with other organizations.

Founding Members

The founders of the platform, the Guinea Ministry of Health, the Liberia Ministry of Health, the Sierra Leone Ministry of Health and Sanitation, the West African Health Organisation, the West African Task Force for the Control of Emerging and Re-Emerging Infectious Diseases, International Medical Corps, Médecins Sans Frontières, Oxford University and Wellcome Trust, have agreed to form an initial steering committee for the Platform consisting of one institutional representative from each founder (together the “**Steering Committee**”).

The Steering Committee will develop and approve an ethics and governance structure for the platform as outlined in this Charter, the Ethics Framework, the Conflict of Interest Policy, the Terms of Submission, the Data Access Guidelines and the Terms of Reference for the Steering Committee, Data Access Committee and Secretariat.

WHO participates in meetings of the Steering Committee as an observer. The Infectious Diseases Data Observatory acts as the Platform secretariat.

The Steering Committee will be accountable to the mission of the Platform described in this Charter.

Signed for and on behalf of [institution name]:

Name:

Title:

Date: