

Ebola Data Platform: Secretariat Terms of Reference

Version: 19 March 2019

<p>1. Date Approved and Governing Body</p>	<p>The Steering Committee shall approve these Terms of References (ToR).</p> <p>The Secretariat formally adopted these TORs on the date of their ratification by the Steering Committee.</p>
<p>2. Purpose</p>	<p>The Ebola Data Platform (“Platform”) has been established to develop and promote research and treatment in Ebola Virus Disease. The Platform fulfils three distinct purposes:</p> <ol style="list-style-type: none"> 1. Curation and cleaning of data into a standardised form; 2. De-identification of contributed Ebola data; 3. Management of requests for access to de-identified Ebola datasets. <p>The purpose of the Platform Secretariat is to:</p> <ol style="list-style-type: none"> 1. Oversee and manage the hosting and operation of the Platform; 2. Provide technical and administrative support to the Data Access Committee and Steering Committee; and 3. Manage the agreements with data contributors and researchers. <p>The Secretariat will apply the principles that govern the use of the Platform, in line with the mission and strategic direction set by the Steering Committee.</p> <p>The Secretariat will ensure the highest standards of security and privacy are maintained whilst facilitating the ethical, equitable and rapid access to data.</p>
<p>3. Membership</p>	<p>The Secretariat shall comprise of those individuals that deliver the technical and administrative duties to achieve the Purpose of the Ebola Data Platform described above. This will include institutional representatives from the Infectious Diseases Data Observatory (IDDO) which will coordinate the activities of the Secretariat, and may include but will not be limited to invited data managers, regional/country hubs and representatives from the relevant health authorities for input to specific duties and responsibilities as appropriate. All members will be bound by appropriate contractual obligations of confidentiality and data protection and contractual restrictions against use of the data except as necessary for the purposes of supporting the Secretariat. Membership shall be notified to the Steering Committee and Data Access Committee members.</p> <p>IDDO shall make available the necessary institutional representatives for the performance of its duties and responsibilities. The Secretariat shall perform its duties and responsibilities with due care, skill and judgment in accordance with the highest professional standards.</p>

4. Eligibility	Secretariat staff must agree to abide by the Platform Charter, Ethics Framework and Conflicts of Interest Policy and the rest of the governance framework for the Platform.
5. Revocation	Secretariat staff can be revoked by the Steering Committee from performing any activities relating to the Platform for professional misconduct and/or a breach of the Ethics Framework or Conflicts of Interest Policy or any of the other Platform governance framework.
6. Operation of the Secretariat	<p>The Secretariat may regulate its own procedures subject to the provisions of these ToR.</p> <p>The Secretariat shall organise and manage its members to deliver a functional platform that will deliver on the objectives set out by the Steering Committee.</p> <p>The Secretariat shall process data in accordance with the Terms of Submission and operate as detailed in the Platform’s Security Model.</p> <p>The Secretariat shall transfer data to registered researchers with an approved project under the terms specified by the Data Access Committee, and as per the Data Access Guidelines and the terms of the Data Transfer Agreement which has been ratified by the Steering Committee and which is entered into between the University of Oxford and the researcher.</p>
7. Decision Making	<p>The Secretariat shall make decisions on the operation of the Platform within the parameters of these Terms of Reference, and in alignment with the Platform Charter, Ethics Framework and the rest of the Platform governance framework.</p> <p>Data release will be actioned by the Secretariat under the direction of the Platform Data Access Committee and under the terms of the Data Access Guidelines and the Data Transfer Agreement ratified by the Steering Committee and entered between the University of Oxford and the relevant data recipient.</p>
8. Duties and Responsibility	<p>The Secretariat shall have the following powers and responsibilities:</p> <ul style="list-style-type: none"> • Manage the legal, regulatory, contractual and administrative aspects of the Platform in accordance with the governance framework of the Platform, including: <ul style="list-style-type: none"> ○ support the development and execution of Platform proposals, policy and approvals related to the management of the Platform; ○ fulfil obligations under Terms of Submission and Data Transfer Agreements, including monitoring, where reasonably possible, compliance with signed Data Transfer Agreements and practical enforcement to deal with data breaches under a transparent

	<p>and fair process (with Steering Committee oversight per the Steering Committee’s Terms of Reference);</p> <ul style="list-style-type: none"> ○ ensure operational running of the Platform as per the Data Security Model; ○ manage any contractual agreements that support the operation of the platform; ○ provide technical and administrative support to Platform end users; ○ provide reports as required by the Data Access Committee and the Steering Committee, including security incident reports, risk register, research and stakeholder engagement activity; ○ maintain a risk register and log of mitigating controls that are periodically updated to reflect the changing risk environment; ○ maintain all declarations of interests and register of members; ○ support liaison with country of origin ethics committees for any ethics approvals for the Platform; ○ support liaison with the Platform’s appointed independent ethics board and any expert peer review process; ○ regularly review and update the Platform’s privacy impact assessment, notify the Steering Committee of any material changes and incorporate Steering Committee feedback as necessary; ○ monitor and review the Platform Data Security Model to ensure processing occurs as agreed in the Terms of Submission, and is compliant with all applicable laws, governmental rules, regulations, good practices and guidelines relating to medical confidentiality, medical ethics, privacy, medical research, data protection and data access; ○ all other security tests, audits and reports agreed by the Steering Committee for the Platform. <ul style="list-style-type: none"> ● Provide technical and administrative support to the Data Access Committee and Steering Committee including executing any decisions required, preparing meeting notices, agendas and minutes. ● Receive and check all data request applications are complete, respond to applications and act as the liaison between the data requestor and the Data Access Committee in accordance with the Data Access Guidelines. ● Help to gather and oversee nominations for the Data Access Committee and present these to the Steering Committee; ● Engage and communicate with stakeholders in the Platform and communicate activity to the Steering Committee, in accordance, when available, with the Platform’s stakeholder engagement plan; ● Provide communication support to the Platform (both internal and external) including regularly updating the Platform website with all information and research outputs to be shared publicly. ● Develop, host and maintain the Platform website under suitable safeguards.
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	<ul style="list-style-type: none"> • Develop, host and maintain the Platform Ebola database, including but not limited to: <ul style="list-style-type: none"> - platform technical architecture; - data curation; - data standardization, integration and organisation of disparate data sets into a common data catalogue (in accordance with any minimum standards defined by the Steering Committee); - data quality (of curated data) – making sure data is accessible and useable; - data security and risk management, including establishing administration, legal, technical and physical safeguards for data management and transfer; - maintaining a data inventory. • Assisting with the set up of copies or versions of the Platform in the countries of origin to ensure compliance with the Platform governance framework, including the Data Access Guidelines, security and other standards. • Provide a copy of the curated data to the data contributor. • Ensure that the Ebola data is not linked to any other data held by IDDO outside of this Ebola Data Platform. • Manage Platform funding in line with Oxford University financial management policies and provide the Steering Committee with details of Platform funders and all conditions placed on Platform funding so that there is due opportunity for Steering Committee members to make objections should funding be in contravention of their own institutional financial management policies. • Proactively support research, data access and collaboration between all stakeholders involved in the Platform in line with the Platform’s objectives. • Subject to the approval of data contributors, transfer all Ebola data within the Platform, as well as reasonable instructions and information necessary to assist continuity of management of the data, to a third party chosen by the Steering Committee in accordance with the Steering Committee Terms of Reference if IDDO is no longer to act as the Secretariat for the Platform.
<p>9. Accountability</p>	<p>The Secretariat will monitor the Platform’s compliance with the Platform Charter, the Ethics Framework, the Data Access Guidelines, the rest of the Platform’s governance framework, ethical approvals and all applicable laws, governmental rules, regulations, good practices and guidelines (including without limitation: (i) of the country where the data have been collected or originate from; and (ii) international best standards and rules) relating to medical confidentiality, medical ethics, privacy, medical research, data protection and data access, including without limitation, the duties to not cause harm to individuals or groups, to respect patients’ autonomy, patient confidentiality and the patient’s right to informed consent.</p>

	The Secretariat is accountable to the Steering Committee and may be requested to evidence project compliance/progress to the Steering Committee or to the relevant internal boards. Any issues of strategic importance should be escalated to the Steering Committee as soon as possible.
10. Interests of Secretariat representatives	<p>All representatives of the Secretariat shall abide by the Platform’s Conflict of Interest Policy and declare any interests in advance of joining the Secretariat by using the Declaration of Interests form. This will be reviewed annually or whenever there is a change in circumstances that may affect the Declared Interests.</p> <p>Should any conflict arise, these shall be managed in line with the procedures outlined in the Platform’s Conflict of Interest Policy.</p>
11. Reporting responsibilities	The Secretariat will provide reports to the Data Access Committee and Steering Committee, at a frequency determined by each respective group.
12. Conduct of the Secretariat	<p>The Secretariat shall keep these ToR under review.</p> <p>Any changes to the ToR should be approved by the Steering Committee.</p>