

EBOLA DATA PLATFORM

STEERING COMMITTEE MEETING MINUTES

PLATEFORME DE DONNÉES EBOLA

PROCÈS-VERBAL DES RÉUNIONS DU COMITÉ PILOTAGE

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EBOLA DATA PLATFORM STEERING COMMITTEE MEETING MINUTES

Teleconference - 11 November 2019, 11:00-12:30 (GMT) - English
Teleconference - 13 November 2019, 12:00-14:30 (GMT) - French

MEETING SUMMARY NOTES

TELECONFERENCE ATTENDEES

SC members and observers	IDDO
Prof Issiaka Sombié (11/13NOV19)	Laura Merson (11/13NOV19)
Dr Moses Badio (11NOV19)	Matthew Brack (11/13NOV19)
Dr Moumié Barry (13NOV19)	
Prof Philippe Guérin (13NOV19)	
Dr Georgina Humphreys (11NOV19)	
Dr Adam Levine (11NOV19)	
Dr Chinwe Ochu (11NOV19)	
Dr Javier Gabaldon Santos (13NOV19)	
Robert Terry (11NOV19)	

Apologies: Dr John Amuasi, Dr Mosoka Fallah, Dr Alie Wurie

STEERING COMMITTEE MEETING COMBINED MINUTES

Agenda item 1 – Report from the Data Access Committee Meeting in Abidjan 30-31 October

[11 NOV] An update was provided by Robert Terry, Chair of the Ebola Data Platform Data Access Committee (DAC). All DAC members were in attendance save for Prof Akin Abayomi. The role of the DAC was discussed at the meeting as primarily addressing data access proposals in relation to criteria for data access, with ethics approval and alignment with the Research Agenda identified as priority criteria.

The DAC reviewed a range of documents, and applied amendments to the Data Access Guidelines and Terms of Reference. The Secretariat have produced minutes of the meeting but are waiting for the DAC to sign these off and then they will be shared. The meeting focused on discussing the details these documents as a group. The meeting agenda was completed successfully and all governance documentation has been agreed by DAC.

[13 NOV] Laura Merson communicated Robert Terry's update to SC members joining the call in French.

[11 NOV] In response to questions, it was noted that responsibility for the Research Agenda rests with the SC, as described in their Terms of Reference. In terms of data feasibility and definition, the Secretariat have produced an inventory of the total Ebola repository. The DAC can consider if there are sufficient volumes of data available to answer a research question; if these data are held on the platform and ensure that the data requested are the minimal data required to answer the research question. The IDDO statistician is available to support the DAC's understanding of data volumes and feasibility of research.

Clarification was provided on DAC membership and eligibility: an individual cannot represent more than one institution, and one institution cannot have more than one member on the DAC. This is to encourage a diversity of expertise. There is the possibility of a shift of countries affected by Ebola over time, in this case the EDP would look to expand membership across those countries.

A position has been taken by the SC to not introduce any financial requirements (barriers) for researchers to access or for contributors to submit data. This features in the EDP Ethics Framework.

No researcher will be given access to the EDP database in its entirety. Applications to the DAC should feature selected data sets. After the Data Transfer Agreement has been signed, the Secretariat will prepare the data by extracting data from the repository and transfer by secure portal.

There is a time limit set on access to data and the Data Requestor must indicate the length of this period in their application (access can be for up to 18 months). The data can only be used for the questions approved by the DAC and must be destroyed on completion of this analysis.

An application for access may be approved pending confirmation of funding or anything else that may be pending, at the discretion of the DAC.

Agenda Item 2 - Review and approve Data Access Committee amendments to Data Access Guidelines and DAC Terms of Reference

[13 NOV] No changes were requested for the DAC Terms of Reference. Regarding the independent external ethical review, it was agreed by the SC that every time the DAC requests external ethical expertise, then the Secretariat will inform the SC. This will be included in the Secretariat Standard Operating Procedures. **[ACTION – IDDO to incorporate process for external ethics expertise into EDP Data Access SOP]**

Following a review of the contents, the SC were requested to approve the amendments made by the DAC to the Data Access Guidelines and DAC Terms of Reference. All SC members on both calls gave their approval.

Agenda Item 3 – Discuss capacity building strategy

[11 NOV] Matthew Brack gave an overview of the training and engagement proposal shared with the DAC and SC, noting its importance in bringing benefits to countries of data origin. There are different mechanisms for delivery of capacity: from IDDO directly, through partnership with other agencies, and via the data access process and Data Recipients.

Proposals include continuation of existing activities, but also look ahead towards building sustainable frameworks to bridge public health and research response to outbreaks, developing pathways from evidence production to policy application, and contributing to technical systems and standards for better data management.

While the purpose of capacity building is not included in the DAC Terms of Reference, the original creation of the SC was based around the Charter and Ethics Framework, where equity is a focus. Through that initial process capacity building has come to the forefront, and EDP policies have been designed to support this. Capacity building has been the mechanism to deliver benefits, rather than a purpose.

There has been a consistent steer from the countries of data origin is that this is a big part of their motivation to be involved. The Data Access Guidelines refer to capacity building under the criteria for data access. The Terms of Reference are technical and procedural, so for this reason the Terms of Reference have focused on the technical aspects of the data access process. The inclusion of capacity building in the Terms of Reference can be kept under review.

Under the guidance of the SC, the DAC and Secretariat should iteratively refine the approach to ensuring that capacity building is a part of every data access application. Currently, Data Requestors are asked to outline their capacity building plans on their application for access. From the initial applications, a view of different approaches and possibilities will be available to consider how to maximise the impact.

One option is to use funding calls to draw attention to a source of data and a route to access. This can also specify where the applicants must be based. Previously, the Gates Foundation have purposely targeted low- and middle-income countries (LMICs) to fund data reuse. There could be specific drives for meta-analyses on certain research questions, specifying criteria for access. Additional facilitation of mentorship programs and partnerships should be considered. [ACTION – IDDO to explore possibilities for supporting LMIC researchers]

The training and engagement plan has been developed to create a clear plan to monitor and evaluate this work, funnelling as much strength and support as possible for capacity building in the region. This is the type of document that will develop over time, and the Secretariat will send it back to the SC for update and feedback. The Secretariat is currently engaging with NIH Fogarty through a DAC member, and with DELTAS leaders to source funding and training opportunities for researchers from countries of EDP data origin.

[13 NOV] Laura Merson shared an overview of the training and engagement proposal shared with the DAC and SC. Through the process of data applications and DAC review, answers will develop with regards to what Data Requestors should do to show capacity building in a data access application. Rather than being prescriptive, asking for a plan, but looking to provide guidance on what such a plan might improve.

The SC proposed that capacity building in ethics could be included in the plan. WAHO has an effort to coordinate national ethics committees, to which the EDP could link. Mentoring was also encouraged as a key component of capacity building. The Secretariat will share the call for TDR fellowships when it opens again next year. [ACTION – IDDO to share TDR fellowship applications]

Agenda Item 4 – Discuss plans for new funding – IDDO & TDR

[11/13 NOV] Initial funding for the EDP was three years, and is now completed. Wellcome funding has been extended to February 2020. To line up support during 2020, the EDP is pursuing several approaches:

1. MRC funding of 600-700,000 GBP over three years, which has invited researchers from countries to participate in call and make collaborative funding applications, and will address the EDP's top three research questions:
 - a. Define the evolution of Ebola patient symptoms, clinical signs and biomarkers over time, including the earliest signs of infection, frequency of presentation, their relationship to viral factors, and any variance over time or location.
 - b. Determine which host factors are associated with increased mortality risk at particular time point of death (e.g. age, pregnancy, co-infections, co-morbidities, clinical signs, viral load, biological signs, time of symptom onset, health worker status, health metrics such as qSOFA and SIRS, etc.)
 - c. Use clinical and outbreak data to revise and risk stratify the case definition for Ebola.

The award will be announced in June 2020. [IDDO – Complete MRC application in collaboration with countries of data origin]

2. The EDP was invited by Wellcome to submit an application for funding. This will happen after the MRC application. The application will go to the SC before it is submitted. It is a discretionary award for pushing science and also expanding the EDP to other countries, data, diseases – both as a capacity building tool and to improve public health response. [IDDO – Develop application to Wellcome in collaboration with countries of data origin]
3. TDR are currently looking at what they could support in terms of a grant.

[13 NOV] TDR fellows are an important component of EDP grants, which cost 60,000 USD for one year. WAHO funds scholarships in Africa at 10-15,000 USD per year. These fellows stay in Africa, and are seconded to another role or country.

[11/13 NOV] TDR fellowships are integrated into the MRC application to bring them to Oxford provide training and mentorship through partners. Investigators and statisticians will be nominated by Ebola-affected countries.

[11 NOV] Wellcome is increasingly endorsing FAIR Data Principles (Findable, Accessible, Interoperable, Re-usable) in terms of infrastructure. For example, requiring that DOIs (digital object identifiers) are generated for data as minimum so that Wellcome can track use and sharing. Alignment with FAIR Data Principles should therefore be considered when applying for funding from Wellcome.

Agenda Item 5 – Agree timeline and next steps for the launch the Ebola Data Platform

EDP has so far received over 10,000 individual patient data from organisations and the Secretariat continue to be in touch with contributors. We acknowledge the enormous efforts of many to secure access to these data e.g. Dr Chinwe on Nigeria ethics application, Javier Gabaldon from MSF.

The documents the SC has just approved are the last building block on the EDP to be in place. The Secretariat invited input from the SC on when data access should be launched. At the DAC meeting, there was support for hosting the launch around a meeting next year.

[11 NOV] The EDP will be a living platform, so the launch should not wait for a complete product. The launch should be as soon as possible, communicating the understanding that the EDP will continue to add data from the West African and other epidemics going forward.

From the point of view of two applications to MRC and Wellcome, these would be strengthened by having the EDP already launched, to show proof of principle, to allow the DAC to get a feel for what is coming in through applications. Prove that it works rather than waiting for more data puts the EDP in a stronger position for funding. The only reason to delay would be if a funding prize could be lined up to support data access for research.

There is an important need to sensitise the people who the EDP want to be aware of this platform. Nigeria is a critical stakeholder, but knowledge of the platform outside the NCDC is low. Sensitisation needs to happen and plans to reach out directly to stakeholders are needed. A first draft of a Communications Plan on who to reach out to will be circulated with SC to get input.

[13 NOV] There is a need to try to support the current outbreak in DRC, and to not delay data access launch. There is an Assembly of West African ministers at end of March or beginning of April. It would be possible for the EDP to feature on the agenda and be presented there. The next WAC meeting is in Q3 2020, so very far off. [ACTION – Secretariat share draft Launch Plan (Communications Plan) with SC]

[ACTION – Secretariat will follow up with Mosoka Fallah, Alie Wurie and John Amuasi regarding launch plans]

[ACTION – Secretariat will arrange next call with SC once a launch date is decided]

Agenda Item 6 – Any Other Business

Observer status: Clarification of SC Observer status was requested. The difference between a SC observer and member is only voting status. Otherwise everything is the same in terms of communication and valued opinion. In three years, there has never been a vote – decisions have all been taken by consensus. All members are asked to sign up to the Charter. [ACTION – Secretariat share Charter with minutes of the call]

In addition, the SC Terms of Reference limit membership to 10 individuals. Many of the decisions needed are unanimous, so this is practical consideration for a manageable number. Currently, NCDC, WAC and WHO are observers. SC membership can be discussed at the next face-to-face meeting.

APPROVALS

SUMMARY OF COMMUNICATIONS WITH STEERING COMMITTEE MEMBERS FOR APPROVAL

DAC governance documentation:

Email from Adam Levine 11DEC19 with approval of the DAC Terms of Reference and Data Access Guidelines. Agreement that the Secretariat can send out letters as described in the launch plan on behalf of the SC.

Email from Philippe Guérin 11DEC19 with approval of the DAC Terms of Reference and Data Access Guidelines. Agreement that the Secretariat can send out letters as described in the launch plan on behalf of the SC.

Email from Rob Terry 11DEC19 with approval of the DAC Terms of Reference and Data Access Guidelines. Agreement that the Secretariat can send out letters as described in the launch plan on behalf of the SC.

Email from Javier Gabaldón 11DEC19 with approval of the DAC Terms of Reference and Data Access Guidelines. Agreement that the Secretariat can send out letters as described in the launch plan on behalf of the SC.

Email from John Amuasi 11DEC19 with approval of the DAC Terms of Reference and Data Access Guidelines.

Email from Georgina Humphreys 11DEC19 with approval of the DAC Terms of Reference and Data Access Guidelines.

Email from Chinwe Ochu 12DEC19 with approval of the DAC Terms of Reference and Data Access Guidelines.

Email from Issiaka Sombié 12DEC19 with approval of the DAC Terms of Reference and Data Access Guidelines. Agreement that the Secretariat can send out letters as described in the launch plan on behalf of the SC.

As of 14JAN20, Approvals from Drs Wurie, Fallah and Moumié are pending and will be updated in subsequent revisions of these minutes.

**PLATEFORME DE DONNÉES EBOLA
PROCÈS-VERBAL DE LA RÉUNION DU COMITÉ PILOTAGE
(traduit par Google translate)**

Téléconférence - 11 novembre 2019, 11: 00-12: 30 (GMT) - Anglais

Téléconférence - 13 novembre 2019, 12: 00-14: 30 (GMT) - Français

PARTICIPANTS À LA TÉLÉCONFÉRENCE

Membres du SC :

Prof Issiaka Sombié (11 / 13NOV19)

Dr Moses Badio (11NOV19) Dr Moumié Barry (13NOV19)

Prof Philippe Guérin (13NOV19)

Dr Georgina Humphreys (11NOV19)

Dr Adam Levine (11NOV19)

Dr Chinwe Ochu (11NOV19)

Dr Javier Gabaldon Santos (13NOV19)

Robert Terry (11NOV19)

IDDO : Laura Merson (11 / 13NOV19), Matthew Brack (11 / 13NOV19)

Excuses: Dr John Amuasi, Dr Mosoka Fallah, Dr Alie Wurie

RÉUNION DU COMITÉ DE PILOTAGE PROCÈS-VERBAL COMBINÉ

Point 1 de l'ordre du jour - Rapport de la réunion du Comité d'accès aux données à Abidjan les 30 et 31 octobre

[11 NOV] Une mise à jour a été fournie par Robert Terry, président du Comité d'accès aux données (CAD) d'Ebola. Tous les membres du CAD étaient présents sauf le professeur Akin Abayomi. Le rôle du CAD a été discuté lors de la réunion, car il traitait principalement des propositions d'accès aux données par rapport aux critères d'accès aux données, l'approbation éthique et l'alignement sur le programme de recherche étant identifiés comme critères prioritaires.

Le CAD a examiné une série de documents et a appliqué des modifications aux lignes directrices sur l'accès aux données et au mandat. Le Secrétariat a produit un compte rendu de la réunion mais attend que le CAD le signe et ensuite il sera partagé. La réunion s'est concentrée sur la discussion des détails de ces documents en groupe. L'ordre du jour de la réunion a été achevé avec succès et toute la documentation sur la gouvernance a été approuvée par le CAD.

[13 NOV] Laura Merson a communiqué la mise à jour de Robert Terry aux membres du CP qui se sont joints à l'appel en français.

[11 NOV] En réponse aux questions, il a été noté que la responsabilité du programme de recherche incombe au CS, comme décrit dans son mandat. En termes de faisabilité et de définition des données, le Secrétariat a produit un inventaire du référentiel Ebola total. Le CAD peut déterminer s'il y a suffisamment de données disponibles pour répondre à une question de recherche; si ces données sont conservées sur la plateforme et assurez-vous que les données demandées sont les données

minimales requises pour répondre à la question de recherche. Le statisticien IDDO est disponible pour aider le CAD à comprendre les volumes de données et la faisabilité de la recherche.

Des éclaircissements ont été fournis sur l'adhésion et l'admissibilité au CAD: un individu ne peut pas représenter plus d'un établissement et un établissement ne peut avoir plus d'un membre au sein du CAD. Il s'agit d'encourager une diversité d'expertise. Il y a la possibilité d'un changement de pays touchés par Ebola au fil du temps, dans ce cas, l'EDP chercherait à élargir l'adhésion à travers ces pays.

Le CS a pris position de ne pas introduire d'obligations financières (barrières) pour que les chercheurs accèdent ou que les contributeurs soumettent des données. Cela figure dans le cadre éthique d'EDP.

Aucun chercheur n'aura accès à la base de données EDP dans son intégralité. Les candidatures au CAD doivent comporter des ensembles de données sélectionnés. Une fois l'accord de transfert de données signé, le Secrétariat préparera les données en extrayant les données du référentiel et en les transférant par portail sécurisé.

Un délai est fixé pour l'accès aux données et le demandeur de données doit indiquer la durée de cette période dans sa demande (l'accès peut aller jusqu'à 18 mois). Les données ne peuvent être utilisées que pour les questions approuvées par le CAD et doivent être détruites à l'issue de cette analyse.

Une demande d'accès peut être approuvée en attendant la confirmation du financement ou toute autre chose qui peut être en attente, à la discrétion du CAD.

Point 2 de l'ordre du jour - Examiner et approuver les modifications du Comité d'accès aux données aux lignes directrices sur l'accès aux données et au mandat du CAD

[13 NOV] Aucun changement n'a été demandé pour le mandat du CAD. En ce qui concerne l'examen éthique externe indépendant, le SC a convenu que chaque fois que le CAD demandait une expertise éthique externe, le Secrétariat en informerait le SC. Cela sera inclus dans les procédures opérationnelles normalisées du Secrétariat. [ACTION - IDDO va incorporer un processus d'expertise externe en éthique dans le SOP d'accès aux données EDP]

Après un examen du contenu, le SC a été invité à approuver les modifications apportées par le CAD aux lignes directrices sur l'accès aux données et au mandat du CAD. Tous les membres du CP aux deux appels ont donné leur approbation.

Point 3 de l'ordre du jour - Discuter de la stratégie de renforcement des capacités

[11 NOV] Matthew Brack a donné un aperçu de la proposition de formation et d'engagement partagée avec le CAD et le SC, notant son importance pour apporter des avantages aux pays d'origine des données. Il existe différents mécanismes pour la fourniture de capacités: directement de l'IDDO, via le partenariat avec d'autres agences, et via le processus d'accès aux données et les destinataires des données.

Les propositions incluent la poursuite des activités existantes, mais également la perspective de construire des cadres durables pour relier la santé publique et la réponse de la recherche aux épidémies, développer des voies de la production de preuves à l'application des politiques et contribuer aux systèmes et normes techniques pour une meilleure gestion des données. Bien que le but du renforcement des capacités ne soit pas inclus dans le mandat du CAD, la création

originale du CP était basée sur la charte et le cadre éthique, où l'équité est au centre. Grâce à ce processus initial, le renforcement des capacités est venu au premier plan, et les politiques de PDE ont été conçues pour soutenir cela. Le renforcement des capacités a été le mécanisme pour fournir des avantages, plutôt qu'un objectif.

Les pays d'origine des données ont constamment indiqué que c'était une grande partie de leur motivation à participer. Les lignes directrices sur l'accès aux données font référence au renforcement des capacités selon les critères d'accès aux données. Les termes de référence sont techniques et procéduraux, c'est pourquoi les termes de référence se sont concentrés sur les aspects techniques du processus d'accès aux données. L'inclusion du renforcement des capacités dans les termes de référence peut être maintenue à l'étude.

Sous la direction du SC, le CAD et le Secrétariat devraient affiner de manière itérative l'approche visant à garantir que le renforcement des capacités fait partie de chaque application d'accès aux données. Actuellement, les demandeurs de données sont invités à décrire leurs plans de renforcement des capacités sur leur demande d'accès. À partir des applications initiales, une vue des différentes approches et possibilités sera disponible pour examiner comment maximiser l'impact.

Une option consiste à utiliser les appels de fonds pour attirer l'attention sur une source de données et une voie d'accès. Cela peut également spécifier où les candidats doivent être basés. Auparavant, la Fondation Gates a délibérément ciblé les pays à revenu faible ou intermédiaire pour financer la réutilisation des données. Il pourrait y avoir des pulsions spécifiques pour des méta-analyses sur certaines questions de recherche, spécifiant des critères d'accès. Il faudrait envisager de faciliter davantage les programmes de mentorat et les partenariats. [ACTION - IDDO pour explorer les possibilités de soutenir les chercheurs des pays cibles]

Le plan de formation et d'engagement a été élaboré pour créer un plan clair de suivi et d'évaluation de ce travail, canalisant autant de force et de soutien que possible pour le renforcement des capacités dans la région. C'est le type de document qui se développera au fil du temps, et le Secrétariat le renverra au SC pour mise à jour et retour d'information. Le Secrétariat collabore actuellement avec NIH Fogarty par le biais d'un membre du CAD et avec les dirigeants de DELTAS pour trouver des opportunités de financement et de formation pour les chercheurs des pays d'origine des données EDP.

[13 NOV.] Laura Merson a partagé un aperçu de la proposition de formation et d'engagement partagée avec le CAD et le SC. Grâce au processus des applications de données et à l'examen du CAD, les réponses se développeront quant à ce que les demandeurs de données devraient faire pour montrer le renforcement des capacités dans une application d'accès aux données. Plutôt que d'être normatif, demander un plan, mais chercher à fournir des conseils sur ce qu'un tel plan pourrait améliorer.

Le CS a proposé que le renforcement des capacités en matière d'éthique soit inclus dans le plan. L'OOAS s'efforce de coordonner les comités nationaux d'éthique auxquels le PDE pourrait se lier. Le mentorat a également été encouragé comme élément clé du renforcement des capacités. Le Secrétariat partagera l'appel à bourses TDR lors de sa réouverture l'année prochaine. [ACTION - IDDO pour partager les demandes de bourses TDR]

Point 4 de l'ordre du jour - Discuter des plans de nouveaux financements - IDDO & TDR

[13/11 NOV] Le financement initial du PDE était de trois ans et est maintenant terminé. Le financement Wellcome a été prolongé jusqu'en février 2020. Pour aligner le soutien en 2020, l'EDP poursuit plusieurs approches:

1. Financement du MRC de 600 à 700 000 GBP sur trois ans, qui a invité des chercheurs de pays à participer à l'appel et à faire des demandes de financement collaboratif, et abordera les trois principales questions de recherche du PDE:

a. Définissez l'évolution des symptômes, des signes cliniques et des biomarqueurs du patient Ebola au fil du temps, y compris les premiers signes d'infection, la fréquence de la présentation, leur relation avec les facteurs viraux et tout écart dans le temps ou l'emplacement.

b. Déterminer quels facteurs de l'hôte sont associés à un risque accru de mortalité à un moment donné du décès (p. Ex. Âge, grossesse, co-infections, comorbidités, signes cliniques, charge virale, signes biologiques, heure d'apparition des symptômes, statut de l'agent de santé, paramètres de santé tels que qSOFA et SIRS, etc.)

c. Utilisez les données cliniques et épidémiologiques pour réviser et stratifier les risques de la définition de cas d'Ebola.

Le prix sera annoncé en juin 2020. [IDDO - Application MRC complète en collaboration avec les pays d'origine des données]

2. Le PDE a été invité par Wellcome à soumettre une demande de financement. Cela se produira après l'application MRC. La demande sera envoyée au CS avant d'être soumise. Il s'agit d'un prix discrétionnaire pour avoir poussé la science et élargi également la PDE à d'autres pays, données, maladies - à la fois comme outil de renforcement des capacités et pour améliorer la réponse de santé publique. [IDDO - Développer une application pour Wellcome en collaboration avec les pays d'origine des données]

3. Le TDR examine actuellement ce qu'il pourrait soutenir en termes de subvention.

[13 NOV] Les boursiers TDR sont une composante importante des subventions EDP, qui ont coûté 60 000 USD pour un an. L'OOAS finance des bourses en Afrique de 10 à 15 000 USD par an. Ces boursiers restent en Afrique et sont détachés dans un autre rôle ou pays.

[11/13 NOV] Les bourses TDR sont intégrées dans l'application MRC pour les amener à Oxford fournir une formation et du mentorat par le biais de partenaires. Les enquêteurs et statisticiens seront nommés par les pays touchés par Ebola.

[11 NOV] Wellcome approuve de plus en plus les principes de données FAIR (trouvables, accessibles, interopérables, réutilisables) en termes d'infrastructure. Par exemple, exiger que des DOI (identifiants d'objets numériques) soient générés pour les données au minimum afin que Wellcome puisse suivre l'utilisation et le partage. L'alignement sur les principes FAIR Data doit donc être pris en compte lors de la demande de financement auprès de Wellcome.

Point 5 de l'ordre du jour - Convenir du calendrier et des prochaines étapes pour le lancement de la plateforme de données Ebola

EDP a jusqu'à présent reçu plus de 10 000 données individuelles sur les patients d'organisations et le

Secrétariat continue d'être en contact avec les contributeurs. Nous reconnaissons les efforts énormes de nombreuses personnes pour sécuriser l'accès à ces données, par exemple Dr Chinwe sur l'application de l'éthique au Nigeria, Javier Gabaldon de MSF.

Les documents que le SC vient d'approuver sont le dernier élément constitutif de la PDE à être en place. Le Secrétariat a invité le SC à indiquer quand l'accès aux données devrait être lancé. Lors de la réunion du CAD, il y a eu un soutien pour accueillir le lancement autour d'une réunion l'année prochaine.

[11 NOV] L'EDP sera une plateforme vivante, donc le lancement ne devrait pas attendre un produit complet. Le lancement devrait avoir lieu dès que possible, faisant comprendre que l'EDP continuera à ajouter des données sur les épidémies ouest-africaines et autres à l'avenir.

Du point de vue de deux candidatures à MRC et à Wellcome, celles-ci seraient renforcées en ayant déjà lancé l'EDP, pour faire preuve de principe, afin de permettre au CAD de se faire une idée de ce qui se présente via les candidatures. Prouver que cela fonctionne plutôt que d'attendre plus de données place l'EDP dans une position plus solide pour le financement. La seule raison de retard serait si un prix de financement pouvait être aligné pour soutenir l'accès aux données pour la recherche.

Il y a un besoin important de sensibiliser les personnes que l'EDP veut connaître cette plateforme. Le Nigéria est un acteur essentiel, mais la connaissance de la plateforme en dehors du NCDC est faible. La sensibilisation doit avoir lieu et des plans pour atteindre directement les parties prenantes sont nécessaires. Une première ébauche d'un plan de communication sur les personnes à contacter sera diffusée avec SC pour obtenir des commentaires.

[13 NOV] Il est nécessaire d'essayer de soutenir l'épidémie actuelle en RDC et de ne pas retarder le lancement de l'accès aux données. Il y a une Assemblée des ministres ouest-africains fin mars ou début avril. Il serait possible que le PDE figure à l'ordre du jour et y soit présenté. La prochaine réunion du WAC aura lieu au troisième trimestre 2020, donc très loin. [ACTION - Le Secrétariat partage le projet de plan de lancement (plan de communication) avec SC]

[ACTION - Le Secrétariat assurera le suivi avec Mosoka Fallah, Alie Wurie et John Amuasi concernant les plans de lancement]

[ACTION - Le Secrétariat organisera le prochain appel avec SC une fois la date de lancement fixée]

Point 6 de l'ordre du jour - Questions diverses

Statut d'observateur: Une clarification du statut d'observateur du SC a été demandée. La différence entre un observateur SC et un membre est uniquement le statut de vote. Sinon, tout est le même en termes de communication et d'opinion valorisée. En trois ans, il n'y a jamais eu de vote - les décisions ont toutes été prises par consensus. Tous les membres sont invités à adhérer à la Charte. [ACTION - Le Secrétariat partage la charte avec le procès-verbal de l'appel]

De plus, le mandat du SC limite l'adhésion à 10 personnes. Bon nombre des décisions nécessaires sont unanimes, c'est donc une considération pratique pour un nombre gérable. Actuellement, le NCDC, le WAC et l'OMS sont des observateurs. L'adhésion au CP peut être discutée lors de la prochaine réunion en personne.

APPROBATIONS

RÉSUMÉ DES COMMUNICATIONS AVEC LES MEMBRES DU COMITÉ DIRECTEUR POUR APPROBATION

Documentation sur la gouvernance du CAD:

Courriel d'Adam Levine 11DEC19 avec approbation du mandat du CAD et des directives d'accès aux données. Accord que le Secrétariat peut envoyer des lettres comme décrit dans le plan de lancement au nom du SC.

Courriel de Philippe Guérin 11DEC19 avec approbation du mandat du CAD et des directives d'accès aux données. Accord que le Secrétariat peut envoyer des lettres comme décrit dans le plan de lancement au nom du SC.

Courriel de Rob Terry 11DEC19 avec l'approbation du mandat du CAD et des directives d'accès aux données. Accord que le Secrétariat peut envoyer des lettres comme décrit dans le plan de lancement au nom du SC.

Courriel de Javier Gabaldón 11DEC19 avec approbation du mandat du CAD et des directives d'accès aux données. Accord que le Secrétariat peut envoyer des lettres comme décrit dans le plan de lancement au nom du SC.

Courriel de John Amuasi 11DEC19 avec l'approbation du mandat du CAD et des directives d'accès aux données.

Courriel de Georgina Humphreys 11DEC19 avec l'approbation du mandat du CAD et des directives d'accès aux données.

Courriel de Chinwe Ochu 12DEC19 avec approbation du mandat du CAD et des directives d'accès aux données.

Courriel d'Issiaka Sombié 12DEC19 avec approbation du mandat du CAD et des directives d'accès aux données. Accord que le Secrétariat peut envoyer des lettres comme décrit dans le plan de lancement au nom du SC.

Depuis le 14 janvier 20, les approbations des Drs Wurie, Fallah et Moumié sont en attente et seront mises à jour dans les révisions ultérieures de ce procès-verbal.

EBOLA DATA PLATFORM

STEERING COMMITTEE MEETING MINUTES

Teleconference - 29 March 2019, 12:00-14:30 (GMT)

MEETING SUMMARY NOTES

TELECONFERENCE ATTENDEES

SC members	IDDO
Dr Moumié Barry (12:00-13:00)	Laura Merson (12:00-14:00)
Dr Abdourahmane Sow (12:00-13:00)	Matthew Brack (12:00-14:00)
Dr Javier Gabaldon Santos (12:00-14:00)	
Dr John Amuasi (13:00-14:00)	
Robert Terry (13:00-14:00)	
Prof Philippe Guérin (13:00-14:00)	
Dr Adam Levine (13:00-14:00)	

Apologies: Dr Mosoka Fallah, Dr Alie Wurie, Nicola Perrin

STEERING COMMITTEE MEETING (FRENCH) – 12:00-13:00 GMT

Agenda item 1 – Suggestion from the Liberian National Research Ethics Board to invite the West African Consortium to sit on the Steering Committee

- a. The Steering Committee (SC) members attending the call in French were asked how to respond to the LNREB's suggestion to invite a member of the West African Consortium (WAC) to join the SC.
- b. The SC were in agreement, and suggested that the WAC member be invited as an observer in order to retain the current governance structure. They further specified that the invitation should not have an impact on any decisions already taken by the SC.

Agenda item 2 – Language regarding appeals for data applications

- c. The SC members were asked how they would like to align language on appeals to DAC decisions within the governance documents to ensure consistency between the DAC Terms of Reference and the Ethics Framework
- d. The SC agreed that language regarding an 'appeals' process for data requests should be included in both the DAC ToR and the Ethics Framework.

Agenda item 3 – Approval of governance documents

- e. The SC members considered the governance documents circulated in advance of the meeting, which include all changes suggested by the SC at the 27FEB19 meeting in Paris, and have been reviewed and agreed by legal teams at MSF, WAHO and the University of Oxford.
- f. The SC unanimously approved the following governance documents:
 - I. EDP Governance 19MAR19 (including Ethics Framework, Conflict of Interest Policy, SC ToR, DAC ToR and Secretariat ToR)
 - II. EDP Data Access Guidelines 19MAR19 (with language regarding DAC appeals as above)

- III. EDP Data Transfer Agreement 19MAR19.
- g. IDDO was requested to provide a summary of the governance framework development process, including the role of WAHO, for the Guinea National Ethics Committee. (ACTION – IDDO)

Any Other Business – Ebola Data Platform tagline

- h. The SC members attending the call were asked to comment on proposed taglines for the Ebola Data Platform. There was agreement that it was acceptable to use a tagline that incorporated the word 'sharing' and that other committee members could determine the final language.

AOB – Chair nominations for Steering Committee

- i. WAHO volunteered a self-nomination for the position of SC Chair. The nomination was accepted by other SC members for later consideration by other members not on the call.

STEERING COMMITTEE MEETING IN ENGLISH – 13:00-14:00 GMT

Agenda item 1 – Suggestion from the Liberian National Research Ethics Board to invite the West African Consortium to sit on the Steering Committee

- a. The SC were informed about the recommendation from the Liberia NERB to invite a member of the WAC to join the SC.
- b. The SC agreed that it was important to follow this recommendation and accepted the suggestion.
- c. The SC agreed that the policy on institutional membership means that the WAC are the member, and that the appointed representative should represent the WAC and not any particular country.
- d. The SC agreed that the WAC should join the SC with observer status.
- e. The SC recommended that the invitation be made once all governance documents have been adopted, and the governance framework is confirmed and activated.

Agenda item 2 – Language regarding appeals for data applications

- f. The SC members were asked how they would like to align language on appeals to DAC decisions within the governance documents to ensure consistency between the DAC ToR and the Ethics Framework.
- g. The data access request process was clarified:
- Applications come to the Data Access Committee (DAC)
 - DAC reviews and provides a decision.
 - If the DAC are unable to decide on an application, or would like SC support to make a decision, they may refer the application to the SC for final decision.
- h. The SC agreed that this should not be called an 'appeals' process, but rather that language be crafted to demonstrate a clear process where the DAC can delegate authority to the SC to make decisions (ACTION – IDDO).

Agenda item 3 – Approving governance documents

- i. The SC considered the governance documents dated 19 March and sent to the SC on 26 March. These had been edited to include all decisions of the SC, and reviewed and approved by lawyers at WAHO, MSF and the University of Oxford.

- j. The SC unanimously approved the following governance documents:
 - a. EDP Governance 19MAR19 (including Ethics Framework, Conflict of Interest Policy, SC ToR, DAC ToR and Secretariat ToR)
 - b. EDP Data Access Guidelines 19MAR19 (with language regarding DAC appeals as above)
 - c. EDP Data Transfer Agreement 19MAR19.

AOB – Launching the governance process in advance of obtaining all Charter signatures

- k. Clarity was sought regarding the membership status of Guinea and WAHO in order to confirm that they were able to be included in the unanimous decision to approve the governance documents.
- l. It was agreed that legal advice regarding the advancement of the governance framework without Charter signatures from all members is needed.
- m. The Secretariat will seek legal advice from the University of Oxford regarding the need for all SC members to sign the Charter in order to agree the governance documents (**ACTION – IDDO**).
- n. The SC agreed that while awaiting legal advice, the next phase of Ebola Data Platform development could proceed based on the current approval of the governance documents.
- o. The SC agreed that with the current SC approvals, the University of Oxford may sign bilateral Terms of Submission with a data contributor.

AOB – Chair nominations for Steering Committee

- p. The SC were reminded about the need to nominate a Chair for the SC. The SC were informed that WAHO had volunteered a self-nomination.
- q. The SC supported WAHO's nomination and agreed that this position could be confirmed only after WAHO has signed the Charter (**ACTION – WAHO**).

AOB – Shared folder on Google Drive

- r. The SC requested additional documentation on ethics applications be provided, including the protocol and other documents sent to the ethics committees (**ACTION – IDDO**).

AOB – Ebola Data Platform tagline

- s. The SC considered various proposed taglines for the Ebola Data Platform.
- t. The SC agreed on the following two taglines that can be used as appropriate:
 - *Reducing the impact of Ebola through the responsible use of shared data.*
 - *Strengthening knowledge and capacity across the health, research and humanitarian communities to reduce the impact of Ebola through responsible data use.*

ADDITIONAL APPROVALS

SUMMARY OF COMMUNICATIONS WITH STEERING COMMITTEE MEMBERS WHO COULD NOT PARTICIPATE IN THE CALL AND FURTHER FOLLOW-UP

Governance documents:

Email from Nicola Perrin 28MAR19 with her approval of EDP Data Transfer Agreement, Terms of Submission, Data Access Guidelines and Governance, all dated 19MAR19. Also included agreement for SC to have a role in final data access decisions where needed, with the provision of justification for any decision.

Email approval of EDP Data Transfer Agreement, Terms of Submission, Data Access Guidelines and Governance, all dated 19MAR19 received from Mosoka Fallah 22MAY19

Approval of EDP Data Transfer Agreement, Terms of Submission, Data Access Guidelines and Governance, all dated 19MAR19 received from Alie Wurie 9JUN19

WAHO as Chair of SC

Phone call with Alie Wurie confirmed his acceptance of WAHO as Chair of SC 16JUN19.

Email from Mosoka Fallah confirmed his acceptance of WAHO as Chair of SC 17JUN19.

Email from Nicola Perrin confirmed her acceptance of WAHO as Chair of SC 24JUN19.

Legal advice regarding the recognition of SC member approvals on governance documents was received 9APR19 from Oxford University Legal Services as below. This confirms that the unanimous approval of the EDP governance documentation by the 9 current SC voting members is valid to activate the governance framework.

“... signature of the Charter is not a fundamental requirement of membership of the Steering Committee. The ToR for the Steering Committee merely require that members *comply with* the Charter, which is an ongoing obligation, but not stated as a membership pre-condition: a slight but important arguable distinction.

There is nothing in the ToR which provides for what steps/criteria need to be fulfilled before membership is confirmed. I would suggest that a minuted decision acknowledging a party's participation in the Steering Committee as a member would be sufficient.”

“Provided that all 9 members, including WAHO and Guinea MoH, are (1) recognized as participating members in some way, and (2) have given their unanimous ratification of the ToR in some way, then the ToR apply, and the provisions around unanimous decisions apply too.

If both of (1) and (2) are true, then, in my opinion, unanimous decisions can be taken with the agreement of all 9 members, regardless of the status of their signature of the Charter.

[The relevant obligation for membership is “Members 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.”. It would obviously be preferable for this to be fulfilled by way of signature of the Charter by WAHO and Guinea MoH, but I think it's arguable that this is not a necessary condition.]”

EBOLA DATA PLATFORM

STEERING COMMITTEE MEETING MINUTES

Epicentre, 55 rue Crozatier, Paris, France - 27 February 2019, 10:00-18:00 (GMT +1)

SUMMARY OF ACTION ITEMS (updated 26MAR19)

ACTIVITY	RESPONSIBLE	TIMELINE	STATUS
A → COMPLETE GOVERNANCE DOCUMENTS			
1. Send revised governance documents that incorporate SC feedback: - Secretariat ToR - Data Access Guideline - Data Transfer Agreement - Terms of Submission (first draft)	IDDO	8 MAR	Complete
2. Provide written feedback on documents	A.Sow, WAHO / Oxford / MSF legal and all SC members	15 MAR	Complete
3. Circulate documents to SC for final discussion	IDDO	22 MAR	Complete
4. Teleconference to action final content	All SC	29 MAR	Confirmed
B → INVITATIONS FOR DATA CONTRIBUTION			
1. Draft letters to invite data contributions	IDDO	1 MAR	Complete
2. Discuss letters with ministries/authorities	A.Wurie – SL M.Barry – Gui M.Fallah – Lib (tbd)	8 MAR	In progress
3. Send letters to data holders	EDP (IDDO / MoH)	15 MAR	For action
C → CHARTER			
Send Charter for discussion/signature by Guinea	M.Barry	29 MAR	In progress
Send Charter for discussion/signature by WAHO	A.Sow	29 MAR	In progress
D → APPOINT DATA ACCESS COMMITTEE			
1. Send letters of invitation to selected nominees	IDDO / R.Terry	9 MAR	Complete
2. Send notification of reserve list / non-appointment to other nominees	IDDO / R.Terry	25 MAR	In progress
3. Announce DAC	IDDO / R.Terry	28 APR	Awaiting DAC documents
E → RECORD KEEPING			
Circulate meeting minutes	IDDO	8 MAR	Complete
Create SC folder for document access	IDDO	23 MAR	Complete
Follow-up on Liberia ethics review	IDDO / M.Fallah	15 MAR	In progress
Draft long-term capacity building plan	IDDO, TDR, WAHO, Wellcome	15 APR	For action
F → GOVERNANCE DOCUMENT SURVEY			

Survey of governance documents used across the West Africa region	A.Sow and WAHO (supported by SC / Secretariat)	15 APR	In progress
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PRE-MEETING, 26 FEBRUARY

PRE-MEETING SUMMARY AND OUTCOMES

A pre-meeting was held on 26FEB19 to provide additional opportunity to review and discuss ongoing and planned platform activities. Attendees included Moumié Barry, Philippe Guérin, Javier Gabaldon, Abdourahmane Sow, Alie Wurie (SC); and Matthew Brack, Laura Merson (IDDO). Outcomes were agreed as:

- The platform needs to find a balance in our messaging on an Ebola-focused platform and an Emerging Infections-focused platform. The continued sensitivities around Ebola mean that an EI focus is more accepted in some contexts. This must be balanced against the need to deliver the gold standard Ebola data platform that launched this initiative. Attendees agreed that the original vision of an Ebola platform, that will lay the ground work to develop into an EI platform, remains true and agree that different messages can be used as appropriate.
- A number of training activities have already been delivered in advance of platform launch. All partners should work to continue and expand these opportunities as a key output of the platform.
- Different data holders will require different approaches when issuing invitations to contribute data to the platform. IDDO will work with the country representatives of Guinea, Liberia and Sierra Leone to identify which institutions should be issued an invitation from the platform Steering Committee/Secretariat and which should be issued an invitation from the responsible Ministry.
- The platform Charter confers a mandate to IDDO to execute actions, such as inviting data contribution, on behalf of the Steering Committee.

MEETING SUMMARY NOTES, 27 FEBURARY

MEETING ATTENDEES

SC members	IDDO
Dr John Amuasi	Laura Merson
Dr Moumié Barry	Matthew Brack
Dr Javier Gabaldon Santos	
Dr Abdourahmane Sow	
Dr Alie Wurie	Invited speakers
Robert Terry	Prof Akin Abayomi – GET Africa (online)
Prof Philippe Guérin	
Dr Adam Levine (online)	
Nicola Perrin (online)	

Apologies: Dr Mosoka Fallah

1. CONFLICT OF INTEREST REVIEW AND FORMS

- a. Confidentiality and Declaration of Interests Forms signed by all attending SC members present and submitted to IDDO.
- b. Adam Levine has received funding through National Institute of Allergy and Infectious Diseases Grant # R03AI132801: Evaluation of Management Strategies for Maximizing Supportive Care for Patients with Ebola Virus Disease. Adam is a member of the Global Trial Board and Protocol Development Team for the ongoing PALM study.

2. PROGRESS AND MILESTONES

A summary of activities completed since the previous SC call (May 2018) was provided by IDDO. Discussion followed to confirm the following:

Training and Collaboration

- a. **Sama Cherif**, Guinean clinical scientist, completed his 12-month internship at IDDO. Returned to Guinea with refined research and statistical skills.
- b. **Mosoka Fallah**, Ebola SC member, received collaborative grant funding with IDDO from the Af-Ox Initiative to support data management training.
- c. **Trokon Yeabah** and **Tamba Fayiah** from NPHI Liberia, and **Musa Feika** from Sierra Leone MoH&S completed a 1-month data management training at IDDO. Returned to their institutions with new skills in data security and curation, prepared to support Ebola data curation in collaboration with IDDO.
- d. **Wahdae-Mai Harmon**, Liberian clinician, will soon complete a 6-month internship with IDDO. She returns to Liberia following training and participation in a systematic review of viral haemorrhagic fevers.
- e. Plans are underway for a 6-month internship at IDDO by **Sulaiman Jalloh**, Sierra Leonean clinician, to begin summer 2019.
- f. Requests for applications for the 12-month **TDR Clinical Research Development Fellowship** have been promoted to colleagues in Sierra Leone, Liberia and Guinea. IDDO will support applications where requested (**ACTION – IDDO**).

Communications

- a. Ebola Data Platform website updated and stories added.
- b. **Sama Cherif** presented the Ebola Data Platform equitable governance model at the EDCTP Forum in Lisbon, September 2018.
- c. **Sama Cherif** presented the concept of the Ebola Data Platform at ASTMH, November 2018.

Science

- a. We've begun a systematic review of all data-driven Ebola publications to create an inventory of literature as a resource for researchers

Governance

- a. Call for DAC nominations released. Nominations received and detailed for SC decision.
- b. Invitations to join DAC issued to three national REBs. Two accepted, Liberia pending (**ACTION – NPHIL**).
- c. Governance documents further developed. Terms of Submission pending (**ACTION – IDDO**).

Ethics committee submissions

- a. Approval of the Ebola Data Platform protocol and governance framework was given by the Guinea National research Ethics Committee and the Sierra Leone Ethical and Scientific Review Committee.
- b. Submission of the protocol and governance framework was made to the Liberia National Research ethics Committee. Response is expected soon.
- c. What was submitted to the ethics committees was the current version of all governance documents. Two new documents have been produced: the Data Transfer Agreement and Data Access Guidelines. The ethics committees have approved the governance process that control those, and the SC have the autonomy to approve these and subsequent documents.
- d. The SC were reminded that all documents validated by email by the SC back in August 2018, before submission to the ethics committees. Today the SC will consider approval for minuting.
- e. It was noted that the Secretariat has a responsibility to update each ethics committee annually with any changes to the project documentation (ACTION – IDDO).
- f. It was suggested that a survey of governance frameworks and data access policies across the Africa region would inform SC thinking on issues for the platform. The SC agreed that WAHO was in the best position to manage such a process (ACTION – WAHO).

Presenting the Ebola Data Platform

- a. The Secretariat will look to put systems in place so that SC members are aware of presentations, trainings or publications made by members of their respective countries and institutions (ACTION – IDDO).
- b. The SC agreed that different approaches to data contribution invitations can be made to different partners. IDDO will work with the country representatives of Guinea, Liberia and Sierra Leone to identify which institutions should be issued an invitation from the platform Steering Committee/Secretariat and which should be issued an invitation from the responsible Ministry (ACTION – IDDO).
- c. IDDO will draft letters to invite data contribution and send to the representatives of NPHIL, MoH&S and ANSS for consideration, editing and dissemination to appropriate partners (ACTION – IDDO).

Guinea's status within the Ebola Data Platform

- a. It was noted that Guinea has not yet signed the charter and remains an observer on the SC.
- b. It was explained that when all governance documentation is signed and agreed, it will be presented again to the ethics committee, then to the Minister to quickly show that everything is complete and ready to go. The Minister will then be invited to accept Guinea as a member of the SC (ACTION – ANSS).
- c. The SC requested a timeline for Guinea signing the Charter and expressed concern that Guinea's membership was delayed. Other SC members stressed the importance of Guinea being fully participatory to ensure equal representation.
- d. As there is recently a new Minister of Health in Guinea, discussions with the new minister are needed.

WAHO's status within the Ebola Data Platform

- a. The SC were told that WAHO has a new Director General, who was still coming up to speed with the Platform, and were reminded that WAHO's participation is dependent on certain conditions (ACTION – WAHO).
- b. It was confirmed that the three conditions were capacity building, benefits sharing, and a mirrored platform hosted by WAHO, noting that an action plan was required for the last condition to ensure that WAHO were tasked with the design implementation. The first two conditions had been well met (ACTION – WAHO).
- c. It was explained that one can be a founding member without signing all documents. Being a founding member is agreeing to be around the table and part of the discussion.
- d. It was pointed out that almost the same scenario is seen in all three countries: new governments, new ministers, new administrative structures. The SC proposed a mission in support of Guinea, inviting the Secretariat to prepare and brief the Ministry with a presentation. It was also felt this would be of benefit in Liberia (ACTION – IDDO).

Relationship between Ethics Committees, Secretariat and MoH

- a. The SC requested that the submissions to the ethics committees to all three countries be shared with SC members (ACTION – IDDO).
- b. It was noted that the host sends a copy of the data back to the contributor and MoH, and that MoH staff participate in the Secretariat.
- c. It was confirmed that the Secretariat includes members from the ministries and national public health agencies in Guinea, Sierra Leone and Liberia. Members are listed on the platform website.
- d. The role of platform host was discussed. SC members agreed that all parties who are hosting platform data act as hosts, including the ministries of health / public health agencies who will host a copy of data collected in their country, WAHO who will host a mirror platform and IDDO who will host a copy of data.
- e. The SC discussed the important benefits that could be derived from holding data on servers based in the ministries of health/public health agencies of data origin, to strengthen data management in these countries, but acknowledged that this was for future planning and that it could not be immediate.
- f. The SC were advised that when data is submitted to the platform, each country will receive a copy of the curated data collected in their country. It was agreed that the benefits of the platform come in steps: having data shared by all actors; documenting what the data means so people can understand it; starting to answer questions from the Research Agenda.
- g. It was further agreed that when a researcher requests access to the data, it will be enforced that collaboration must be established with researchers from the country of data origin, and that this is a means of capacity building.

3. GOVERNANCE DOCUMENTATION

Consideration of Data Governance Documents 1JUN18

- a. Approval of the following governance documents was tabled for decision:
 - i. Ethics Framework 1JUN18
 - ii. Conflict of Interest Policy 1JUN18
 - iii. Steering Committee Terms of Reference 1JUN18

- iv. Secretariat Terms of Reference 1JUN18
- v. Data Access Committee Terms of Reference 1JUN18
- b. The SC were reminded that these documents had previously been agreed by SC members by email and phone; the documents were also discussed at the SC meeting last year and legal expertise at MOH and WAHO were asked to review. WAHO and MSF legal have given their input and comment on these documents.
- c. The governance framework includes: Platform Charter, Ethics Framework, Steering Committee Terms of Reference, Data Access Committee Terms of Reference, Secretariat Terms of Reference, Conflict of Interest Policy, Data Access Guidelines, Template Terms of Submission and Template Data Transfer Agreement.
- d. The Charter has already been signed by the majority of the parties.
- e. With respect to all the other documentation already shared in a draft version and approved in the past, the final form documents will be circulated after this meeting, to be approved unanimously and signed by all the members of the Steering Committee.
- f.
- g. All documents were approved unanimously by the SC members present. The Secretariat Terms of Reference was approved pending edits to the definition of Secretariat members. Approval will be sought from Dr Mosoka Fallah, who could not attend the meeting (**ACTION – IDDO**).
- h.
- i. It was agreed to amend the definition of the Secretariat (document **iv**) to reflect the functional role of its many members, including the members in the ministries of health and national public health agencies. It was agreed that the Secretariat would provide wording to the SC after the meeting via email for approval.
- j. The SC agreed that the Secretariat has an operational role, while the governance and decisions regarding the platform are made by the SC which has government representation of each founding member.

4. EBOLA DATA LANDSCAPE

PHE-MOHS Ebola Biobank

- a. Matthew Brack presented a slide on the PHE-Sierra Leone MOHS Biobank.
- b. It is noted that PHE subsequently contacted the Secretariat and sent the document 'PHS-MOHS Biobank Collaborations', which will be shared with the SC. PHE also stressed their concern that this resource be used widely for the benefit of the people of Sierra Leone, and requested any suggestions on how to make it more widely known.

GET Africa-Sierra Leone Ebola Biobank

- a. Slides were presented by Prof Akin Abayomi, PI of GET Africa on efforts to address the shortage of biobanking and data capacity in Sierra Leone following the Ebola outbreak.
- b. GET Africa collaborate with the Government of Sierra Leone and have been tasked with securing data and samples from the 2013-2016 Ebola outbreak. GET, the Government of Sierra Leone and MSF have made a complete inventory, search, rescue and pedigree of EVD samples and Data associated collected during the last EVD outbreak. Support from the Government of Canada providing a BSL2/3 hybrid infrastructure in a secure location outside of Freetown. Construction is expected to be completed this summer.

- c. Part of the next objective is to link the samples with the data reference numbers held by GET and the Government of Sierra Leone. After that they will look to source/link the clinical data. The project will also try to identify which samples are in country and out of country to link samples outside of Sierra Leone in a virtual biobank network.
- d. The SC were told that there are a number of consortia generating a lot of samples and data, with the most advanced being H3Africa, supported by NIH and Wellcome Trust. The SC were reminded that the African Academy of Sciences is looking at actors on the continent to see how we can develop a standardised approach relating to samples and data.

WAHO Regional Biobank

- a. Abdourahmane Sow presented developments on WAHO's vision of a regional biobank to strengthen capacity in West African countries to store and manage samples, and to promote scientific collaboration between countries.
- b. Le Centre de Ressources Biologique (CeReB), at Institut Pasteur Cote d'Ivoire, was given as an example of work to date. It was also noted that governance systems are largely already in place.
- c. The SC discussed possible actions to ensure synergies between the EDP and other regional initiatives. The SC felt it important that governance documents between all initiatives be harmonised as much as possible. They also noted the importance of WAHO's support to establish the EDP due to providing a forum for engagement with Ministers in the region on governance issues.
- d. It was pointed out that this work could facilitate research alignment within the region, and the SC were informed of work by the African Academy of Sciences to standardise data sharing efforts across the continent.
- e. The SC agreed that WAHO were appropriately placed to do a landscaping of policies in the region (**ACTION – WAHO**).

5. DAC SELECTION AND GOVERNANCE DOCUMENTS

DAC selection

- a. The DAC selection process and the summary of rankings were described.
- b. The SC agreed that the DAC should consist of nine members, plus a non-voting Chair.
- c. The SC felt it important to address gender balance, Francophone-Anglophone balance and a distribution of country representation on the DAC.
- d. The SC approved the DAC selection.
- e. The SC were reminded that all of these nominations can be invited for the next round as DAC members operated on three-year terms.

Comments on the Data Access Guidelines version 1DEC18 (**ACTION – IDDO**)

- a. It was agreed that a flow chart would be added as an Annex to the Data Access Guidelines to clarify roles and the process.
- b. It was explained that the ethics committee have approved research analyses listed on the Research Agenda. Therefore, if an application for data access addresses a question on the Research Agenda, it already has Ethics Committee approval. If not, separate approval from all countries of data origin would be required.
- c. It was agreed that DAC Terms of Reference should state that all DAC members must receive a copy of all applications and have the opportunity to provide feedback on all applications in advance of a DAC decision.

- d. It was agreed that the role of the DAC is to focus on the ethical aspects of data access applications, not scientific aspects, but that the DAC should ensure that applications are scientifically valid. It was accepted that research questions included on the Research Agenda have been agreed by the SC as scientifically valid. Applications for analysis not included on the Research Agenda should have evidence of a positive peer review submitted with the application to support assurance of scientific validity.
- e. The DAC's role in the review of the volume of data requested was discussed. It was agreed that this could be judged as appropriate (or not) by the DAC and that the DAC would determine how much data should be released for a given request.
- f. It was agreed that the Oxford Tropical Research Ethics Committee (OxTREC) will act as the Independent Ethics Review Board until any alternate solution is justified. It was further agreed that the DAC would seek input from the Independent Ethics Review Board if the DAC felt that the application for access carried a potential risk of harm, or if the DAC felt that an independent review would be useful to inform their decision. The response from the Independent Ethics Review Board would be considered in the final DAC decision.
- g. It was agreed that the DAC would refer requests, and decisions regarding their approval, to the Steering Committee if the DAC disagreed with the recommendation of the Independent Ethics Review Board or if the DAC could not make a decision.
- h. The appeals process was clarified: there would not be an appeals process. Decisions of the DAC (or the SC in the case of the DAC referring to the SC) are final. Data Requestors will be welcome to resubmit an application if the comments (and reasons for rejection) of the DAC are addressed in the subsequent application.
- i. The SC requested clarification to facilitate this process, replacing any mention of appeal with: The DAC will provide written feedback on all rejected applications.
- j. The SC agreed that other documents could emphasise capacity building more, including a stand-alone document on capacity building planning.
- k. The SC requested that the name of the Data Transfer Agreement be made consistent across documents.
- l. The SC agreed that IDDO would make the changes noted above and revert with a new version for approval.

Comments on the Data Transfer Agreement 20DEC18 (ACTION - IDDO)

- a. The SC commented that Oxford appears prominently in the Agreement and asked if this could be adjusted.
- b. It was agreed that University of Oxford Legal Services would be consulted to discover whether the 'Background' section could be moved to the top, and if 'Oxford' and 'IDDO' could exchange places in the text.
- c. The SC also requested that 'third parties' be defined in the 'Definition'.
- d. The SC were told that the document would be translated to French, but that the English version must be signed as the legally-binding copy.
- e. The SC requested a legal commentary on the Agreement in plain English/French (ACTION – IDDO to request from other SC members with legal resources).
- f. The SC requested a copy of the Material Transfer Agreement for the WAHO Regional Biobank. WAHO agreed to share a draft with the SC (ACTION – WAHO).
- g. The SC agreed that MSF can choose which name they are named/under on the Agreement.
- h. The SC requested that the definition of EDP be clarified regarding third parties.

- i. The SC requested removal of article 8.2 or rewriting to remove reference to the UK law.
- j. The SC agreed that one high-level internet link, used once at the top of the Agreement, was sufficient to provide access to the supporting governance documentation.
- k. SC agreed that the DAC cannot have responsibility for actions in the DTA as the DAC is independent, is not a legal entity, and the responsibilities within the DTA are not the role of the DAC. IDDO must retain the responsibilities as originally drafted, including the changing of timelines with the Data Requestor.
- l. The SC requested that articles 4.4 and 4.5 be simplified.
- m. The SC agreed to combine articles 5.1 and 5.2 to cover this publication issue in one sentence.
- n. The SC agreed that no publications will be reviewed prior to publication.
- o. The SC agreed to remove clause 5.3 as IDDO should not be responsible to monitor the use of logos by Data Requestors.
- p. The SC agreed to remove article 5.4.

6. NOMINATION OF NEW EBOLA DATA PLATFORM STEERING COMMITTEE CHAIR

- a. The SC will consider and return nominations at the next discussion.

7. FUTURE OF THE EMERGING INFECTIOUS DISEASES DATA PLATFORM

- a. The SC heard that funding from MSF and Wellcome Trust ends in 2019 and that further funding has not been secured. MSF made clear that they would not be providing any additional funding after.
- b. The SC discussed the importance of moving the EDP forward, even with imperfect governance documents, in order to start demonstrating the value of the EDP.
- c. The SC agreed that an approach to the Wellcome Trust to support the Ebola platform and its evolution into other emerging infectious diseases should be discussed with Wellcome.
- d. Going forward, the SC agreed that comments on governance documents should be made and discussed in an open forum for transparency, rather than only sending them to Secretariat.
- e. The SC agreed that since corrections have now been made in the documents, they accept them, and can move forward with them as working documents once the corrections are made.
- f. The SC agreed that the current phase needed to be completed as soon as possible, agreeing that the governance documents were the main block. The following priority actions were requested:
 - i. Guinea to sign the Charter
 - ii. Liberia to confirm ethical approval
 - iii. WAHO to give quick input to these governance documents
 - iv. Moving forward with letters for MoH and data contributors.
- g. The SC requested that IDDO circulate a list of high-level actions for action by all parties as soon as possible (**ACTION – IDDO**).

Ebola Steering Committee Meeting

3 May 2018

Participants: Moumié Barry; Mosoka Fallah; Javier Gabaldon; Philippe Guerin; Adam Levine Katherine Littler; El Hadji Mamadou Mbaye; Piero Olliaro; Laura Skrip; Robert Terry.

Apologies: John Amuasi; Abdourahmane Sow; Alie Wurie.

Secretariat: Alice Hawryszkiewicz; Brittany Maguire; Laura Merson.

ACTIONS

IDDO: Circulate Research Agenda project protocol to Steering Committee. May 2018.

WATER: Share the platform protocol with eboDAC and discuss areas of synergy. Feedback to SC June 2018.

IDDO: Invite TDR to Chair the Data Access Committee. May 2018.

IDDO & TDR: Create list of potential Data Access Committee membership criteria to circulate to SC. June 2018.

IDDO & TDR: Agree language regarding funding and cost recovery for the governance documents. Circulate to SC June 2018.

IDDO: Include discussion of the tagline on the agenda of the next in-person meeting.

MINUTES

Updates since December 2017 meeting:

The list of actions from the December meeting was circulated with annotations on status. A copy is available at the bottom of these minutes. The following topics were highlighted during the call:

- g. The **research agenda project** was submitted for ethics review in Guinea. The English version will be finished soon and circulated to SC member for comments.
- h. WAHO has reviewed **governance documents** and given their comments and suggestions. IDDO has requested a call with WAHO to clarify the comments.
- i. The **Platform Charter** has been signed by seven of the nine voting Steering Committee members. WAHO and the Guinea Ministry of Health remain outstanding.
- j. **Data curation and management training** will take place in Oxford this June. The training will be for one month on data curation, mapping, Stata, privacy and security. Two participants from Liberia and two from Sierra Leone have been nominated by the respective Ministries of Health.
- k. A **definition of 'stakeholders'** was proposed and discussed. For the purpose of developing a Stakeholder Engagement Plan, the following definition was agreed by the Steering Committee, *Stakeholder: "An individual, group or organization who share values and common objectives with the platform"*.

Dr Moumié provided an update on the challenges of launching the platform in Guinea. A recent meeting in Conakry with IDDO, Alima, MSF and the Agence Nationale de Sécurité

Sanitaire confirmed the support of the ANSS Director for the platform. A letter to the Minister of Health has been sent to request formal appointment of the ANSS Director to the platform Steering Committee.

Laura M. reported that Dr Wurie hosted a meeting with IDDO in Freetown. Data managers have been selected to be trained on platform curation and researchers have been identified to roll-out the research agenda project. The platform protocol is under review in advance of submission to the Ethics Committee.

Dr Fallah reported on the successful AfOx grant funding application which will fund training for 2 NPHIL data managers. Submission to the Liberia National Research Ethics Board is planned soon.

Follow-up:

Dr Mbaye suggested that the eboDAC collaboration could support community engagement in the project. Dr Mbaye will share the platform protocol with eboDAC and discuss areas of synergy.

Data Access Committee:

The need to appoint a Chair of the Data Access Committee (DAC) was discussed. Based on excellent experience and outputs of TDR/WHO as the Chair of the WorldWide Antimalarial Research Network (WWARN) DAC, IDDO suggested inviting TDR to Chair the Ebola Data Platform DAC. The proposal was discussed and agreed by consensus amongst the Steering Committee members. IDDO will write the Director of TDR to invite TDR to Chair the DAC.

The SC were reminded of the decision made at the December 2017 SC meeting to invite one member from each of the national ethics committees of Liberia, Guinea and Sierra Leone.

Methods of nominating additional DAC members were discussed. As chair of the WWARN DAC, TDR made an open call for nominations to the community of malaria researchers who had contributed data to the WWARN platform. All communications, information and criteria were published on the WWARN website for transparency. Nominations were considered against published membership criteria including geographic representation, equal fe/male split and expertise. It was suggested that experience of decision making committees would be a valuable skill set.

The SC discussed the definition of 'open call' and made clear that there should be a well-defined list of requirements and criteria published online. Clear profile, nationality and expertise area criteria should be decided.

It was suggested that the DAC composition of H3Africa and TDR-chaired DACs should be considered in the definition of criteria. IDDO and TDR will make a first draft of the DAC membership criteria and send to the SC for comments and suggestions in June.

Governance Outstanding Issues:

Most SC members have confirmed their agreement to the governance documents circulated following the December meeting (versioned 8DEC17). Outstanding comments/edits requiring decisions were discussed as below.

Use of a tagline to be used in platform communications to clarify the aims of the project was discussed. ***The Steering Committee agreed that a tagline should be agreed for this purpose. It was agreed that the suggested line: “Sharing data responsibly for knowledge and capacity strengthening” should be amended.*** The consensus was that the tag line should incorporate concepts such as ‘health’ and ‘impact’. In addition, it is also important that the tagline be translatable into French and other relevant languages. IDDO will include this discussion on the agenda of the next in-person meeting.

Regarding public communication materials, the current draft Steering Committee Terms of Reference states that the SC “having a right of veto over their publication”. It was felt that ‘veto’ was too harsh, and that it could instead be amended to ‘and agreeing’. ***The Steering Committee agreed to this change.***

The need for transparency in the platform ‘business model’ was considered. Governance documents do not currently make clear a commitment to cost-free access, the possibility of a cost recovery model, nor whether applicants from countries of data origin have preferential access (e.g. tiered pricing). It was acknowledged that clarity on the conditions of access should be a part of the governance documents and the wider discussions on equity. It was suggested that we may not have to be specific about cost-recovery at this stage, provided it is clear that there are no barriers to access. Some members of the SC felt that additional transparency was needed and that clarity on platform financing, funders and sources should be provided. ***It was agreed that TDR and IDDO should talk offline and agree a term for the governance documents,*** which will be circulated to SC for review.

It was acknowledged by the SC that this is a key topic and decision which should be addressed in the future. However, at this time the platform will remain committed to free access for all. The platform should consider the funders ideas as ‘return on investment’ is a difficult strategy to implement in this landscape. ***The Steering Committee agreed that the Platform will have no-cost access until further consideration is made and agreed.***

Follow-up on actions from the 4DEC17 meeting. Not included in the call, but for information.

Agreed actions from 4DEC17 meeting:

- To promote transparency and integrity, this activity should move forward as a research study, pending approval of the local ethics committees (regional study coordinators). **Done**
- Copies of the study documents and plans will be sent to the SC and further feedback on methodology will be welcomed (regional study coordinators). **Expected next week. Final drafts near complete.**
- Leverage the experience and links of SC members based in West Africa as well as WHO (regional study coordinators). **Ongoing.**
- Move forward with the study in parallel with other platform initiation activities such that the launch of the platform is not delayed (regional study coordinators). **Done**
- Incorporate data security training into the planned IDDO-West Africa data management training (IDDO). **Done**
- Source other capacity strengthening activities to benefit those who can make use of the platform across West Africa (all SC members). **SC to report.**
- Send IDDO information on TDR training opportunities and ideas on how external funding can be sourced (PO). **Ongoing.**
- Collate links and information on training already provided (IDDO). **Done. Available at IDDO.org/ebola/engagement-activities**
- Collate links and information on training opportunities available for research and platform delivery activities on the platform website. Supplement with activities sent by SC members (IDDO, with input from SC members). **Incomplete.**
- Request legal review of governance documents from WAHO (IDDO). **Done**
- Share all draft governance documents as well as a summary of the platform objectives, design and history to facilitate discussions with Ministries of Health (IDDO). **Done**
- Produce and circulate revised version of charter (IDDO). **Done**
- Execute platform charter (all SC members). **7/9 are signed. Pending Guinea and WAHO.**
- Liaise with institutions that will host data in West Africa to understand the technical, software, hardware and human resource needs of hosting platform data (IDDO). **Planned for June Data Manager Training in Oxford.**
- Produce a data security model which incorporates regional datasets (IDDO). **Done**
- Compile a list of all stakeholder meetings held to date on the Ebola Data Platform (IDDO). **Done. Available at IDDO.org/ebola/engagement-activities**
- Draft a definition of stakeholders (IDDO). **Done. For the purpose of developing a Stakeholder Engagement Plan, we propose the following definition: An individual, group or organization who share values and common objectives (whether competitive or complimentary) with the platform. Justification is attached.**
- Identify and engage with stakeholders. Inform the secretariat for the recording of such activities (all SC members). **?**
- Assemble estimated running costs in advance of next discussion on sustainability. **Planned for next face-to-face meeting.**
- Distribute the Q&A for SC input, feedback and use. **Done.**
- Share the Q&A with your communications teams for comment (SC members with institutional communications teams). **Done. Available at IDDO.org/Ebola/mediaQA**
- Send a short (max 300 word) biography and high-resolution photo for use on the SC member page of the website. **Done (AL, PG). Not done (RT, JA, JG, KL, BM, MF, AW, AS)**
- Summarise what and how WHO communications will flow from the SC to other departments, country offices and regional offices, and ensure the flow is actioned (PO).
- Define how WHO and WAHO will communicate regarding the platform (PO & AS).

- Link Piero to AFRO office contacts who are aware of the platform (IDDO & JA).

Task	Target Date	Status
Revised charter shared for execution	5 Dec 2017	Complete
Draft governance documents shared	8 Dec 2017	Complete
Nominate Sierra Leone coordinator	20 Dec 2017	Complete
WAHO legal review of governance documents	30 Dec 2017	Complete
Summary of stakeholder meetings produced	30 Dec 2017	Complete
SC member meetings with key government and ethics stakeholders	10 Jan 2018	Complete
Charter signed by all members	15 Jan 2018	7/9 – Pending Guinea & WAHO
Comments on governance documents from SC members	15 Jan 2018	Complete
Research agenda input	Ongoing	Submitted to ethics in Guinea. Final draft for Liberia and Sierra Leone ready MAY18
Communications strategy	Ongoing	Incomplete.
Ethics submission in Liberia, Sierra Leone, Guinea	30 Jan 2018	Prepared, awaiting signatures for submission
Invite external data for curation	30 Jan 2018	
Accept government held data for curation	30 Jan 2018	
Curate data	Ongoing	
Data Manager training	Spring 2018	Grant funding received for Liberia. Planned for June 18 for Liberia and Sierra Leone.
Build WAHO Platform	Spring 2018	
Steering Committee governance documents approval	Mar 2018	Following 3MAY18 call
Ethics approval	May 2018	Oxford complete. Others pending.
Nominate Data Access Committee	Jun 2018	
Nominate Steering Committee Chair	Jun 2018	
Launch of Platform for access	Jul 2018	
Data analysis	Sep 2018	

Ebola Data Platform Steering Committee Meeting

4 December 2017

Minutes

Attendees:

*John Amuasi (West African Taskforce for the Control of Emerging and Re-emerging Infections),
Moumié Barry (Guinea Ministry of Health and Public Hygiene),
Mosoka Fallah (via teleconference during section 2) and Laura Skrip (Liberia Ministry of Health),
Alie Wuire (Sierra Leone Ministry of Health and Sanitation),
Philippe Guérin (University of Oxford),
Adam Levine (International Medical Corps),
Katherine Littler (Wellcome),
Piero Olliaro (via teleconference during section 1) (World Health Organisation)
Javier Gabaldón Santos and Alice Proby (Médecins Sans Frontières).*

Secretariat and chair: Laura Merson and Alice Hawryszkiewicz (Infectious Diseases Data Observatory)

Apologies: Abdourhamane Sow (West African Health Organisation)

The meeting began with a welcome to new committee member and introductions of each member.

The Secretariat reported that all actions from the Steering Committee call of 20SEP17 were complete or amended and that these would be reported on during the course of the meeting.

1. Collaboration, Capacity Strengthening & Engagement

Objectives: Communicate current activities. Identify gaps.

Delivery of capacity strengthening activities has been an iterative effort to date on the basis of resource identification and attainment. A formal prospective plan has not yet been developed and will await input from the West African Steering Committee members as well as identification of funding, resource, and training opportunities either from Steering Committee members or externally.

A **survey of West African research and health communities** is in planning, to be delivered by the regional platform coordinators (currently Julius Gilayeneh in Liberia, Mahamoud Sama Cherif in Guinea and Sierra Leone to be identified). This activity will include questions regarding preferences for topics and delivery mechanisms for training, and should include research and academic organisations as well as Ministries of Health. It is recognised that different groups or regions may have differing priorities, none of which should be mutually exclusive. The output of the study will feed into the current draft of the research agenda. It is acknowledged that the research agenda is an iterative document which is expected to change with wide ongoing input and additionally driven by the hypotheses detailed on the data access requests submitted. Prioritisation of the research agenda may be decided by the Steering Committee if necessary and is expected to focus on research which improves patient outcomes.

Agreed actions:

- To promote transparency and integrity, this activity should move forward as a research study, pending approval of the local ethics committees (regional study coordinators).
- Copies of the study documents and plans will be sent to the SC and further feedback on methodology will be welcomed (regional study coordinators).

- Leverage the experience and links of SC members based in West Africa as well as WHO (regional study coordinators).
- Move forward with the study in parallel with other platform initiation activities such that the launch of the platform is not delayed (regional study coordinators).

Capacity strengthening activities to date include:

- A funding application is in preparation by SC members for the Africa-Oxford initiative to support the training of data managers from Liberia, Sierra Leone, Guinea and WAHO in data curation and data security.
- A funding application has been prepared by the secretariat in collaboration with the Liberia National Ethics Committee to support empirical research in perceptions, barriers and interests in equitable data sharing.
- Julius Gilayeneh, a Liberian physician, has recently completed his thesis in collaboration with the secretariat on the role of evidence in the development of treatment guidelines during the West African Ebola outbreak, as a part of the Oxford Masters in International Health and Tropical Medicine. Julius will support the coordination of the platform launch for Liberia over the coming months.
- Mahamoud (Sama) Cherif has recently joined IDDO on a 12-month TDR Fellowship in Oxford to develop skills in clinical research, data management and the use of data platforms to support equitable, collaborative science. Sama will support the coordination of the platform launch for Guinea.
- The secretariat is currently discussing the next opportunity for a Liberian clinician and Oxford Masters in International Health and Tropical Medicine candidate to undertake a research project identifying capacity strengthening opportunities in Liberia.

With regard to focus for **future activities**, members agreed that data management, data security and statistical analysis capacities are critical to develop. Training on legal aspects of data sharing can also be considered. Skills in prospective research and public health emergency response should also be included. Various existing opportunities were discussed and will be included in a curated resource including: TDR opportunities for LMIC researcher training within their fellowship program (IDDO currently hosts 1-4 TDR fellows on an annual basis), IMC NIH funding for database analysis, ALERRT EDCTP grant, TDR CREDO training, GET Workshops, etc. Discussions on how academic credit can be issued from West African or other universities should be pursued. Training may be linked to the FTP programs in West Africa.

It was acknowledged that the breadth of capacity strengthening required cannot fit within the platform's remit, nor be delivered solely by IDDO. The WHO R&D blue print should serve as the overarching framework for delivery of capacity strengthening. Feedback and lessons learned from platform activities can inform the R&D Blueprint evolution via SC members and may serve to identify gaps and best practice. No capacity strengthening activities should delay actions to launch the platform.

Agreed actions:

- Incorporate data security training into the planned IDDO-West Africa data management training (IDDO).
- Source other capacity strengthening activities to benefit those who can make use of the platform across West Africa (all SC members).
- Send IDDO information on TDR training opportunities and ideas on how external funding can be sourced (PO).
- Collate links and information on training already provided (IDDO).

- Collate links and information on training opportunities available for research and platform delivery activities on the platform website. Supplement with activities sent by SC members (IDDO, with input from SC members).

2. Governance

Objectives: Summarise draft documentation. Receive feedback from members. Consider Platform Charter.

Much progress has been made in the development of a robust forward-looking **governance framework and documentation**. Terms of reference for the platform committees, a platform charter, a platform ethics framework and a conflict of interest policy have all been drafted. The next steps are to finalise the charter for execution and engage with all levels of government in the SC member countries to ensure communication of platform objectives and direction. Full government support is imperative to the success of the initiative; therefore, these communications should be prioritised. Following discussion, there was agreement that current drafts of governance documents should be shared immediately and that comments of SC members were welcomed in advance of submission to the national ethics committees mid-January. There was recognition that the governance documents need to be dynamic and will evolve throughout the evolution of the platform. Therefore, that delays should not be imposed due to multiple layers of institutional delays to refine intricacies of the framework. They should be seen as working documents and not hold progress or submissions for ethics approval. Effort not to over complicate the structures and requirements is important.

Revisions to the circulated **governance diagrams** were discussed. Revised versions are attached to these minutes.

The need to have West African legal review was discussed, as were the limitations of such resources within the participating Ministries of Health. The SC agreed to request support from WAHO for legal review of the governance framework.

Agreed actions:

- Request legal review of governance documents from WAHO (IDDO).
- Share all draft governance documents as well as a summary of the platform objectives, design and history to facilitate discussions with Ministries of Health (IDDO).

The draft **platform charter** was reviewed by the SC. Edits to the circulated draft were agreed including:

- The name of the platform will be the Ebola Data Platform. This omits the word “sharing” due to negative perceptions and misunderstandings which have been communicated by partners in Ebola affected regions.
- Minor semantics such as the addition of patient “interests”, renaming of the Ethics Framework (to remove “Principles”), stating that governance documents will be “develop[ed] and approve[d]”, etc.

Following these edits, it was agreed that the resulting version of the charter would be signed by all members. The signing of the charter does not denote an acceptance of other platform governance documentation.

Agreed actions:

- Produce and circulate revised version of charter (IDDO).
- Execute platform charter (all SC members).

In line with the agreement that the **platform name** would not include “sharing”, it was agreed that the platform would adopt a tag line which explains the key purposes of the platform, for use in selected communications. Key words suggested include: knowledge sharing, capacity strengthening,

responsible data sharing. One proposal put forward was: *Sharing data responsibly for knowledge and capacity strengthening*.

There was a detailed discussion on the role and structure of the **Data Access Committee**. It was acknowledged that there are a number of different models, and that different models may apply to different phases of platform implementation. It was suggested that the committee consider a model similar to that adopted by H3ABioNet. Key agreements of the discussion include:

- The chosen model should be that which can be implemented most effectively for the launch of the platform. This may not be the model which incorporates all possible functionalities of the platform or its governance, but the model can be adapted based on experience with the initial model.
- There is a need to consider ethical issues within data access decisions. This may be done by an additional layer of review by an independent ethics committee for proposals which raise these issues. This decision can be taken after the initial launch of the platform and the body can be built over time as needed.
- Members of the Guinea, Sierra Leone and Liberia national ethics committees should be nominated to the Data Access Committee.
- An application will be made to the national ethics committees which requests approval of all research included on the research agenda, within the governance framework of the platform.

The proposal that low risk data could at some point be made openly available on the platform was put forward for future consideration.

3. Next Steps

Objectives: Discuss data hosting locations. Determine approval pathway. Agree on next steps.

Locations of data hosting were discussed. The committee agreed that data should be hosted on a server in the country of origin, with a back-up of this data held in Oxford to facilitate data security and enable mentoring of data managers working in-country to curate data. This design will result in three separate datasets, one in each country, which contain the data collected in that country. Furthermore, each country-level dataset will be copied to a single aggregated dataset under the custodianship of WAHO. This will facilitate integration of the platform with other WAHO initiatives. All data access will be governed by the platform governance framework. Following launch of the platform, integration of the platform with prospective surveillance and outbreak response data collection initiatives should be explored. A future application to the national ethics committees can include prospective data collection.

Agreed actions:

- Liaise with institutions that will host data in West Africa to understand the technical, software, hardware and human resource needs of hosting platform data (IDDO).
- Produce a data security model which incorporates regional datasets (IDDO).

It was decided that the **nomination of a Chair of the committee** would be actioned upon launch of the platform.

Submission to national ethics committees is planned for the end of January. Discussions with the committees should be planned to ensure understanding and identify any key issues. Discussions have already been held by IDDO with members of the Guinea and Sierra Leone national ethics committees. It is recognized that some SC members or data contributors may have their own institutional approval processes, and also agreed that these should not slow the progress of the platform launch. A timeline for submissions will be decided by the SC.

Agreed actions:

- Meet with representative of Liberia national ethics committee (IDDO).
- Offer follow-up meetings with all ethics committees post submission of project application (IDDO and SC country members).

To help guide the platform's **stakeholder engagement activities** going forward, a history of activities undertaken to date is needed. A definition of "stakeholders" is needed. Should include data holders, survivor communities, research organisations, social mobilization groups, academic institutions, public health agencies, WHO, WAHO, WARC, and more. All SC members should take responsibility for identifying and engaging with stakeholders.

Agreed actions:

- Compile a list of all stakeholder meetings held to date on the Ebola Data Platform (IDDO).
- Draft a definition of stakeholders (IDDO).
- Identify and engage with stakeholders. Inform the secretariat for the recording of such activities (all SC members).

An approval pathway was drafted as below. It is, however, recognised that these are ambitious targets and that WAHO would need to be consulted on the item which require their action.

Task	Target Date
Revised charter shared for execution	5 Dec 2017
Draft governance documents shared	8 Dec 2017
Nominate Sierra Leone coordinator	20 Dec 2017
WAHO legal review of governance documents	30 Dec 2017
Summary of stakeholder meetings produced	30 Dec 2017
SC member meetings with key government and ethics stakeholders	10 Jan 2018
Charter signed by all members	15 Jan 2018
Comments on governance documents from SC members	15 Jan 2018
Research agenda input	Ongoing
Communications strategy	Ongoing
Ethics submission in Liberia, Sierra Leone, Guinea	30 Jan 2018
Invite external data for curation	30 Jan 2018
Accept government held data for curation	30 Jan 2018
Curate data	Ongoing
Data Manager training	Spring 2018
Build WAHO Platform	Spring 2018
Steering Committee governance documents approval	Mar 2018
Ethics approval	May 2018
Nominate Data Access Committee	Jun 2018
Nominate Steering Committee Chair	Jun 2018
Launch of Platform for access	Jul 2018
Data analysis	Sep 2018

4. Sustainability

Objectives: Communicate current support. Discuss options for prolonged sustainability.

Sustainability of the platform depends on a) sourcing funds to administer the secretariat, and b) sourcing funding for all activities not currently funded. The platform is currently funded for basic coordination and technical architecture activities until June 2019. It was recognized that launch of the platform is critical to attract new funding. Options for funding mechanisms were discussed, including charging an access fee. This could be a tired approach, charging researchers from high income countries more than those from low income countries. There is a preference for central funding at this stage of the platform, which may be sustainable if/when the platform expands to other emerging infections with different funding sources. A multi-faceted model could also be considered.

Agreed actions:

- Assemble estimated running costs in advance of next discussion on sustainability.

5. Communications

Objectives: Agree on media and website plans. Understand other communication needs.

As follow up to the last Steering Committee call held in September, the Secretariat produced a set of **Q&As** as a response to any media enquiries, noting this is not for proactive media solicitation.

Agreed actions:

- Distribute the Q&A for SC input, feedback and use.
- Share the Q&A with your communications teams for comment (SC members with institutional communications teams).

IDDO is developing a platform **website** which will feature the SC member institution collaboration as a key element. Biographies of each SC member will be included. All governance documents and other platform documentation will also be available to enable full transparency.

Agreed actions:

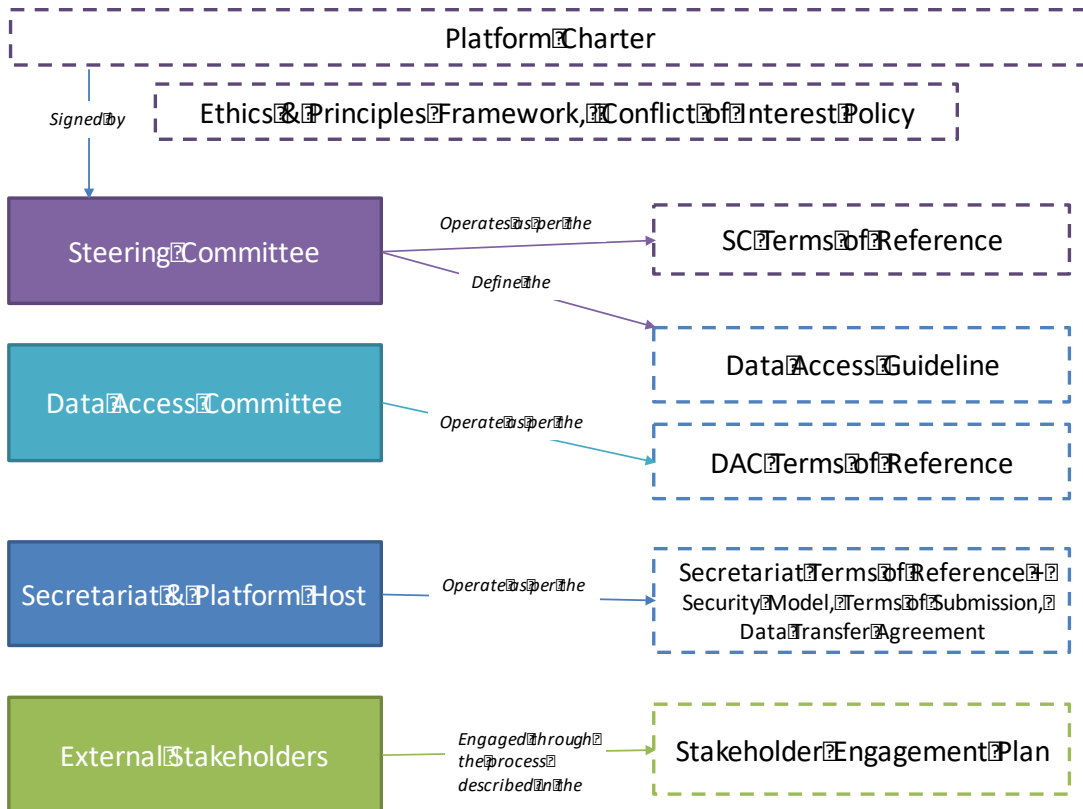
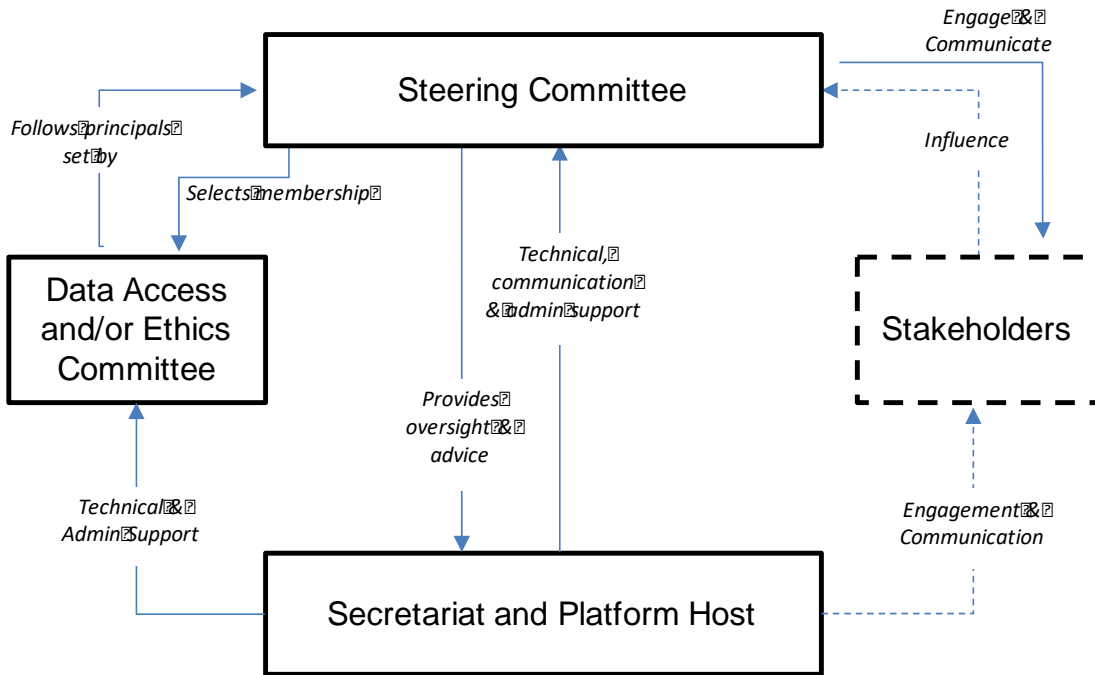
- Send a short (max 300 word) biography and high-resolution photo for use on the SC member page of the website.

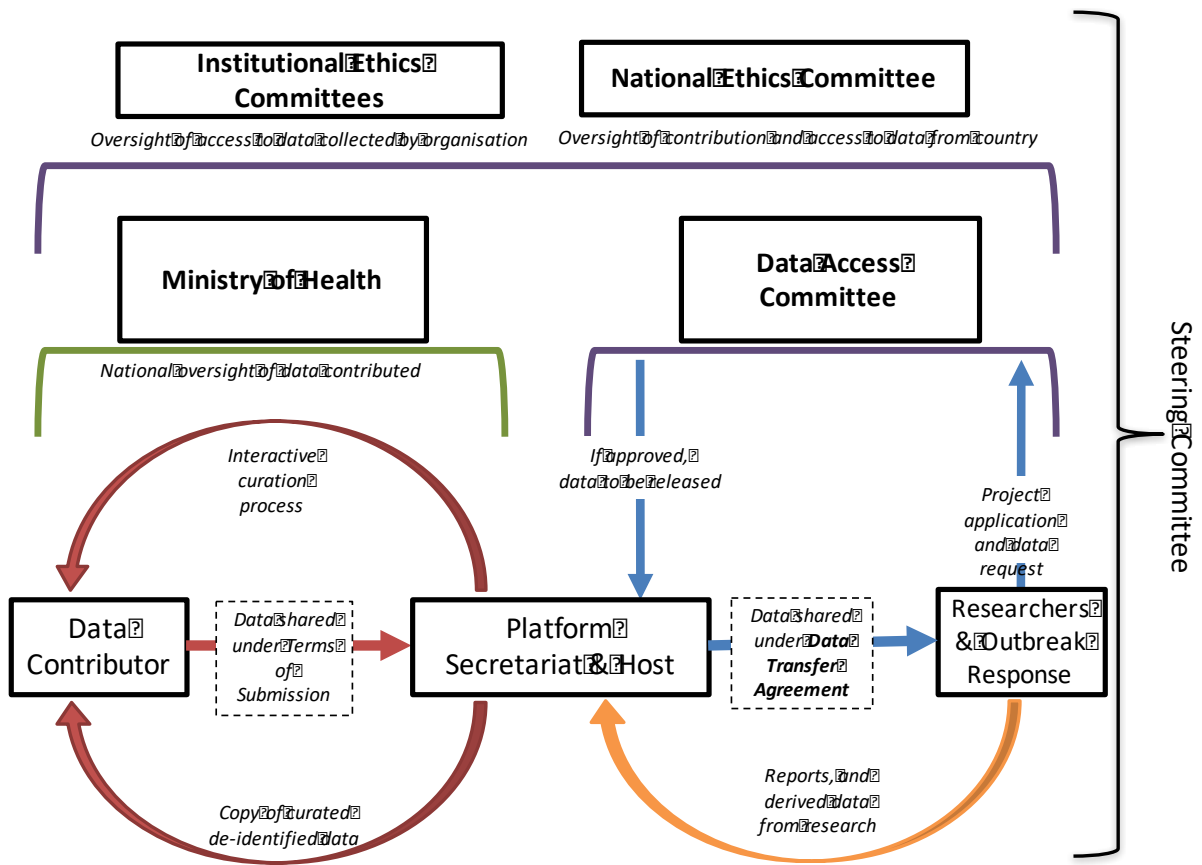
WHO's role in communications was discussed. WHO has a key contribution in engagement and credibility for the platform/ It was emphasized that collaboration on developing robust governance and data access processes are of particular interest to WHO. Communications across WHO departments is important, as is communications with the country and regional offices.

Agreed actions:

- Summarise what and how WHO communications will flow from the SC to other departments, country offices and regional offices, and ensure the flow is actioned (PO).
- Define how WHO and WAHO will communicate regarding the platform (PO & AS).
- Link Piero to AFRO office contacts who are aware of the platform (IDDO & JA).

Governance Structure





Ebola Data Platform Steering Committee

Wednesday 20 September 2017, 2pm BST

Teleconference Minutes

Attendees

Javier Gabaldon
Alice Proby
Adam Levine
Philippe Guerin
Katherine Littler
Laura Merson
Alice Hawryskiewicz

Apologies

Abdourahmane Sow (Contacted later by phone for discussion. Thoughts integrated below.)
John Amuasi (Contacted later by phone for discussion. Thoughts integrated below.)
Piero Olliario (Contacted later by phone for discussion. Thoughts integrated below.)

Activities

An update on platform activities was received from LM. Please refer to SC September Activity Report.

Governance

The MSF Ethics Committee are due to review the package of governance documents in the coming weeks. As the MSF EC may have additional comments, SC members on the call agreed to hold further amendments or signatures of the governance documents until this feedback is received. AS, JA and PO concurred in subsequent discussions.

Leadership

In light of feedback from the recent meeting of the West African Research Consortium, strategies on how to further promote the integration of West African leadership into the platform strategy were discussed. The possibility of representation by the West African Research Consortium (WARC) on the Steering Committee was discussed. It was agreed that the most affected countries could be optimally involved by the invitation of a Steering Committee member from each of the Ministries of Health of Liberia, Guinea and Sierra Leone. As there is overlap between the WARC members and each country's Ministry of Health, an invitation to the Ministry of Health may be filled by a WARC member, thus meeting both objectives. There was strong preference for representatives with technical skills and for those who were most likely to be able to retain the position for the full 3-year term. There was also agreement that advice should be taken from colleagues in country regarding who the letter should be addressed to. The many priorities of the Ministers were recognised as a potential barrier to this approach, and it was agreed that assigning a Steering

Committee member was not a requirement for advancing the platform, provided all other approvals were in place.

The need to reiterate the platform objective of serving all Ebola-affected countries was reinforced.

Current SC membership includes 6 members and 1 observer. The draft Terms of Reference state that membership can be up to 10 members. **It was agreed that a letter of invitation would be sent to the Minister (or suitable representative if so advised by colleagues in country) of Guinea, Sierra Leone and Liberia to invite a representative from each country to the Steering Committee. AS, JA and PO provided feedback, advice and agreed with this approach during subsequent discussions.**

AH will draft invitation letter to Ministries for SC to approve and add signature.

Collaborations

CDC – LM relayed details of the CDC SLED project which is active in Sierra Leone. We have sent copies of our data tools to the CDC rep in country and welcomed a conversation or sharing of their tools to collaborate on data curation.

AL will be visiting CDC shortly and offered to follow up with relevant persons in Atlanta.

LM to forward details of SLED leaders to AL and later to discuss data collection in emergency response project.

Njala University –We have been contacted by researchers at Njala University and their colleagues at Wageningen University. The collaboration is looking to establish an Ebola Museum and Data Archive. LM and AH have a call with them next week and will relay the discussion to the SC.

HDX – Humanitarian Data Exchange is a platform for data to support humanitarian response by the United Nations Office for the Coordination of Humanitarian Affairs. They do not host clinical or epidemiological data. We will explore how we can link the Ebola platform to this initiative in order to make data more discoverable by the humanitarian community and will relay discussion to the SC in the future.

Ebola data sources - Members of the SC asked if a list of potential data contributors was available and at what point each would be contacted. It was agreed that requests for data would be issued after approval from the Ethics Committee of the relevant country was in place. **In preparation for data requests, LM will create a list of Ebola data sources.**

Media

The recent publication of an article on the Ebola platform in *Nature* was discussed. **The SC agreed that we should prepare for future media requests with a communications plan which sets out key messages, responses to challenging questions, timing, purpose and target of communications. AS, JA and PO concurred with this approach during subsequent discussions. In principal, the group agreed that we should not be proactive in gaining media attention at this time, however we should respond to requests.** In advance of platform launch, the plan can be amended with a clear proactive strategy.

LM and AH will devise a media plan as above and circulate to the SC for input.

Face to Face Meeting

During the next F2F we hope to:

- To finalise governance documents
- Agree a longer-term media plan
- Discuss strategy
- Introduce new representatives

It was agreed that the meeting will take place at the start of December 2017. London, Amsterdam, Kumasi and Accra have been suggested as potential locations.

LM will consult with AS and PO regarding timing and location.

AH will send out calendar hold for the first week of December.

AOB

Capacity Strengthening - PG had a recent discussion with Stephen Kennedy (Liberia) regarding the platform, during which the importance of capacity building was the focus. While it is a key output of the platform, participants at the WARC meeting in Conakry emphasised that the timing of capacity strengthening activities was optimised after governance and approvals for the platform are well advanced. **The SC members on the call reached agreement that this should not be the focus of the Secretariat at this stage of platform development.** In later discussions, AS suggested that WAHO could support the distribution of information about capacity building initiatives and help to identify potential trainees. Consensus that this was outside the remit of the Secretariat, and that funders needed to take the lead on providing resources for such activities. However, it was recognised that some activities may support engagement of necessary stakeholders at this time. Specifically, it was suggested that a Sierra Leonean trainee be sought to strengthen the impact of Julius (Liberian coordinator / Masters student) and Sama (Guinean coordinator / fellow).

LM and AH will put together a small scale proposal for capacity strengthening activities.

Ebola Platform Steering Committee Meeting

Teleconference

23rd May 2017

SC Attendees:

Javier Gabaldon	MSF
Adam Levine	IMC
Philippe Guérin	IDDO
Katherine Littler	Wellcome

Other Attendees:

Laura Merson	IDDO
Alice Hawryszkiewicz	IDDO
Alice Proby	MSF

Apologies:

John Amuasi	WATER
Piero Olliaro	WHO/TDR
Sow Abdourahmane	WAHO

Actions:

LM/AH: Follow-up with Stephen Kennedy regarding dates for the Post-Ebola Health Systems Strengthening meeting in Guinea, August 2017 and revert to SC to explore possibility of scheduling a simultaneous SC face-to-face meeting.

AH: Distribute governance documents via email to SC for final comments, aiming for ratification at face-to-face meeting.

AH/JA/KL: Move forward with capacity strengthening plans including a letter to WATER and WAHO communities regarding the research agenda and suggestions for training and benefits sharing

AH: Circulate DAC questions that were not answered for comment from SC over email.

SC: Comment on DAC questions before Monday July 10th

Key Developments:

WAHO and LM have met at WAHO offices and recently completed a mission to Sierra Leone and Guinea. Outputs and actions are summarised in the circulated WAHO Meeting Report APR17 and the SC Update Report MAY17 respectively. Key developments are as follows.

Principal Investigators have been identified to lead ethics submissions and provide national oversight in all 3 countries. These include:

Mohamed Samai (College of Medicine and Allied Health Sciences Sierra Leone – to be invited)

Victor Matt-Leby (Ministry of Health and Sanitation Sierra Leone – verbally agreed)

Stephen Kennedy (Ministry of Health Liberia – verbally agreed)
Fotorma Bolay (National Institute of Public Health Liberia – verbally agreed)
Lamine Koivogui (National Institute of Public Health Guinea – verbally agreed)
Sakoba Keita (Ministry of Health Guinea – to be invited)

A meeting with the Sierra Leone Ministry of Health and Sanitation Ethics Committee gave opportunity for some in-depth discussion around platform governance. **The committee stressed that they must approve each unique research question to be undertaken with platform data.** This highlights the importance of a complete research agenda, and the need to re-apply to the committee with any updates to the agenda.

Capacity Building & Sustainability:

Suggestions regarding the need for sustainability were discussed including the possibility that researchers requesting platform data could be charged for the costs of providing access. Tiered pricing was suggested to ensure affordability for low- and middle-income countries. There was recognition of the merit in creating a sustainable resource, but also concern regarding affordability, the possibility of criticism and the possibility of costs acting as a barrier.

It was agreed that data access fees would not be applied at the launch of the platform, but that they would be reconsidered after the platform is operational as a part of efforts to pursue sustainability.

The imperative for the platform to be used as a tool for developing research skills in west Africa was accepted by all. The requirement to include training of a west African scientist as a condition of access was suggested. **There was agreement that listing the collaboration of a researcher based in west Africa was not sufficient,** especially a senior researcher who may have minimal involvement. A priority for training of “young” or “early career” researchers was discussed.

It was agreed that JA and KL would continue to contribute to the development of capacity development plans, coordinated by AH.

Exploration of ways to leverage the platform to enable infrastructure development was agreed.

Data Access Committee:

Specific questions posed by the Governance Working Group were posed to the committee. Not all questions could be addressed due to time. Answers to those which were are listed below, others will be addressed via email.

Maximum membership for DAC should be 10. External expertise can be brought in for consultation on specific issues/applications as required.

Consider including lay member(s).

A **diversity of expertise** is needed including laboratory, clinical and anthropological.

There should be a **mix of representation from affected regions** and international experts. The Steering Committee will appoint DAC membership.

DAC are independently responsible for making access decisions. Decisions should reflect principals established by the SC. The SC will verify that the DAC is acting within its remit and according to the Terms of Access and their Terms of Reference.

An appeals process is important to have. Rejected applications can be resubmitted to the DAC after revision. Appeals can be made to the SC when revised applications are rejected (therefore after a second DAC review).

DAC requires **experts who can evaluate the scientific merit** of an application for data access and **who can evaluate the ethical validity** of the reasons for access. This should not look to mimic a peer review process, but should identify if the question proposed can be answered with the data requested.

IDDO will seek to make statistical and other expertise available upon request of the DAC. IDDO will provide DAC administration and will not be involved in DAC decisions.

Ebola Steering Committee call – 16 FEB 17

Minutes and action points

Attendees: IDDO - Laura Merson, Aurelia Vessiere; MSF - Javier Gabaldon, Alice Proby; IMC - Adam Levine; UNIVERSITY OF OXFORD - Philippe Guerin

Absent/excused: WATER – John Amuasi; WELLCOME - Katherine Littler; WAHO – Abdourahmane Sow

Introduction of Alice Proby, new Legal Adviser for MSF (replacing Cecile Neuvens).

1. Update on the Platform activities

- ***Privacy Impact Assessment (PIA)***

- The technical and procedural aspects relating to personal data protection have been assessed, and recommendations have been provided for mitigating and managing risks (see attached document).

Two main issues need further reflection:

i/ Patients' data must be de-identified, while remaining compatible with a research purpose. Statistical disclosure techniques will be needed as a complement to the Safe Harbour method for data anonymisation prior to release to external requestors.

ii/ Make data contributors, as *data controllers*, aware of their responsibilities towards patients (such as informing them about their right to withdrawal, etc.). A "privacy notice" could be developed and published on the IDDO website.

- The PIA is currently being reviewed by WAHO's legal adviser and IT system specialist.

- ✓ IDDO to circulate the PIA to the SC and forward WAHO's comments.

- ***Data contributions***

- New contributor: International Rescue Committee (IRC)

- Pending contributions: Tulane University – Kenema Hospital data; Save the Children

- ***Data Experts Group***

IDDO is organizing a group of experts from current data contributors to consult on harmonisation of EVD patients data. The first conference call will take place on **mid-March** (date to be confirmed). Contributors have been sent an initial set of questions in preparation for the discussion, focusing on the major standardisation issues and curation bottlenecks to date. The main expected output is the finalization of the master Ebola Data Dictionary.

2. Update on the Platform governance framework

- ***Charter; Terms of Reference and further governance agenda (proposition below)***

- IDDO and MSF will meet on **22 February** to summarise previous discussions and identify remaining governance gaps that need to be addressed. Each SC member organisation is asked to identify a relevant legal expert who would volunteer to participate in a small drafting group to move forward with governance documents.

- AL: what is the timeline to identify an expert?

- AP: a governance agenda will be circulated early March, the drafting group is expected to meet on the second week of March. A full governance structure will be suggested to the SC for review.

- PG: is the latest version of the Charter available?
- LM: a simplified version of the Charter has been prepared; details on governance will be moved to the Terms of Reference. Circulation of the pre-final version of the Charter has been put on hold as it will come in a package with the ToR.

- ✓ IDDO to circulate to the SC the governance agenda.
- ✓ SC members to identify a volunteer legal/technical expert.

3. Engagement of countries

- **Role of WAHO; Submission to ERBs**

- LM will discuss with Dr Sow and Dr Brito during the WANIDS meeting in **Accra, Ghana, 1-3 March** on WAHO's role and engagement in governance, Research Agenda and capacity building.
- JG: John Amuasi will be in Accra and is happy to join the meeting.
- PG: WAHO's input is very important and goes beyond the current Ebola platform; it will be essential also for retrospective and prospective data on Ebola as well as future projects on emerging diseases.
- LM: submission of the Platform proposal to ERBs should be done by a local PI. WAHO could take leadership on this.
- AL: will the countries accept WAHO as their representative?
- LM: WAHO is confident about that. Dr Sow has offered to accompany us and introduce us to WAHO's local representatives when we visit the countries.

- **Research Agenda** - A MSc student will work with IDDO on a project to encourage countries' participation in prioritising the Research Agenda. He will perform a qualitative survey targeting in-country stakeholders.
- **Capacity strengthening** – IDDO is organising a consultation process for needs assessment, first targeting high-level experts (including WAHO). This will be further discussed in Accra.

4. Stakeholders in-person meeting - Agenda, organisation and attendees

- JG: Who are these stakeholders?
- LM: we will invite representatives from MoH, ERBs, NGOs and laboratories, as well as patients/survivors groups. A key point of consultation will be the legitimacy of the Platform's governance framework and committees.
- AL: consulting stakeholders is very important, but do we have proper funding to organise such meeting?
- LM: We should first define if/why this meeting is necessary and important, and seek funding.
- PG: the best strategy is to organise a single meeting (to avoid too much influence from individual countries' agendas). We could possibly take the opportunity of another Ebola meeting in Africa. Note that the Chatham House has planned a meeting in Nigeria end of March/beginning of April.
- JG: GET should also have a meeting on the Ebola biobank project in Lagos.
- LM: We must start planning the event now, for a pre-launch in late spring.

- ✓ LM to ask Katherine/WT and Piero/WHO about possible sources of funding.
- ✓ LM to ask A. Abayomi and S. Kennedy about forthcoming meetings/events, as well as Chatham House for invitee list.

5. AOB

- AL: many people are asking when the Platform will be ready for researchers to apply for data access.
- LM: we expect the Platform to be fully functional by the summer. The next key milestone is the DAC Terms of Reference, in particular how members will be selected. The current Wellcome-DAC transitioning to serve as the Platform-DAC is an option (previously evoked during the last SC face-to-face meeting).
- JG: this question merits further reflection, we need a robust selection process for the DAC.
 - ✓ LM to send information on the WWARN-DAC selection process (Note: process for the WT-DAC has not been made public).

**EBOLA DATA SHARING PLATFORM
STEERING COMMITTEE FACE-TO-FACE MEETING
23 NOVEMBER 2016, PARIS**

ATTENDEES/MEMBER REPRESENTATIVES

- **IDDO/Secretariat:** Aurélie Vessière AV, Laura Merson (LM)
- **IMC:** Adam Levine (AL)
- **MSF:** Javier Gabaldon (JG), Cécile Neuvens (CN – *item 3 only*)
- **University of Oxford:** Philippe Guérin (PG)

- **Wellcome:** Katherine Littler (KL)
- **WAHO:** Abdourahmane Sow (AS)
- **WATER:** John Amuasi (JA)
- **WHO:** Piero Olliaro (PO)

AGENDA (revised)

1. Introductions and overview of the Platform structure: governance system and infrastructure

2. Update on WAHO/R-CDC activities

3. Review of the SC Charter, Terms of Reference, mandate and function

4. Update on the Platform activities

- Repository & Data Access Committee
- Data contributors; data sharing status
- Data management; curation challenges
- Timelines and targets

5. Moving forward with countries' approval

- Role of WAHO
- Submission to affected countries' ERBs

6. Health and Research Partnership Plan

- Feedback on the initial draft
- Research Agenda: top research questions and engagement with West African investigators

7. Community engagement

- Ideas and action plan: workshops, participatory research ...
- How to engage with survivors, public, other communities

ACTION POINTS

	STATUS
PLATFORM STRUCTURE	
AV to circulate revised slides to the group (Re the DACs and anonymisation process)	done
AV to re-circulate the last version of the ToS (18OCT16)	done
IDDO Comms to make the “two platforms” message clearer on the website and assess it on a test audience	
WAHO/R-CDC	
AS to send slides to the group about the WAHO/R-CDC initiative	
SC CHARTER	
LM to reformulate mission statement, short-term goals and bigger aims of the Platform	done
LM to update the Governance Structure section as discussed	done
LM to circulate the revised Charter next week	done
DATA CONTRIBUTIONS	
PO to write to Marie-Paul Kieny and Pierre Formenty regarding PHC lab data and how to proceed with other organisations	
KL to send draft Glolid-R Data Sharing principles	done
AV to draft a letter of support from WAHO based on JA’s draft	
AV to circulate monthly updates of data contributions	done
COUNTRIES’ APPROVAL	
AV to add language to the Platform Proposal Re a central governance system for countries to access the data	done
IDDO to write conditions of storage for WAHO and the countries	
WAHO to support a visit to each country to discuss with ERBs & appropriate authorities. Timeline: January	
IDDO to complete ERB submission documents	
RESEARCH PARTNERSHIP PLAN	
IDDO to consolidate comments from the group and organize a separate teleconference	
IDDO to add details on its current activities and hosting environment/arrangements	
IDDO to contact GET, WAHO, WATER and others to articulate activities	
JA and AS to source people who could benefit from capacity strengthening activities	
KL and JG to check possible funding opportunities to support West African Researchers	
COMMUNITY ENGAGEMENT	
AL to check about current activities of the IMC Ebola survivors programs	
LM to ask Astrid to send protocol for community engagement in CL	
LM to ask GET what they are doing in community engagement (Akin and Jennifer)	

MINUTES

1. OVERVIEW OF THE PLATFORM STRUCTURE: GOVERNANCE SYSTEM AND INFRASTRUCTURE

- **Presentation of the platform** (*slides*)

- KL, JA and JG requested clarifications about the two platforms, i.e. the EVD trials repository vs. the full Ebola Data Sharing Platform: purpose, relationship, type and content of datasets. Details of this difference need to be very clear on the website.
- JA and JG asked for details about the current Data Access Committee (trial-DAC), how it was constituted, what were the eligibility criteria for membership and if the future Platform-DAC will be the same.
- LM: the decision about the composition of the future Platform-DAC will be up to the Steering Committee.
- PG mentioned that the EVD trial repository was created because researchers were urged by funders and journals to make their data available and is to be seen as the phase 1 of the project.
- KL suggested that the data released post-curation should be labelled “de-identified” rather than “fully anonymised” in order to reflect the de-identification process.
- JA: the development and implementation of a CDISC-like format for EVD could be part of the capacity building plan and an opportunity to deepen collaborations with and involve the African research community from the beginning.
- AS expressed his interest for WAHO to be involved in the data management process, from collection to harmonization.

- AV to circulate the corrected version of the slides to the group (Re the DACs and anonymisation process)
- AV to re-circulate the last version of the ToS (18OCT16)
- IDDO Comms to review the website to make the “two platforms” message more clear and assess it on a test audience.

2. UPDATE ON WAHO/R-CDC ACTIVITIES

- AS: due to the EVD epidemic, heads of West African states decided to implement a Regional Center for Surveillance and Diseases Control (R-CDC), funded by ECOWAS. The R-CDC has four components: A. Laboratories; B. Surveillance & early warning; C. Work force (response); D. Training & Research.

Its current main activities are:

- 1) Creation of a regional Reference Laboratories Network in 5 West African countries
- 2) Construction of a BSL-4 biobank hosted by the Pasteur Institute in Abidjan, Côte d’Ivoire (project endorsed by 15 countries)
- 3) Development of a data sharing platform for weekly epi data (human, animal, and environment) to develop a One Health concept framework in West Africa. WAHO has mandate to establish the platform in West Africa and is open to collaborate with different partners
- 4) Set-up of a regional rapid response team as well as national teams in each country.

- PG highlighted that knowing about WAHO/R-CDC activities is critical so that we work in connection with them.

- AS to send slides to the group about the WAHO/R-CDC initiative

3. REVIEW OF THE SC CHARTER, TERMS OF REFERENCE, MANDATE AND FUNCTION

- **Mission**

- AS, on behalf of WAHO: we are not sure how this platform can achieve the objective stated, referring in particular to JA's comment about reducing the time to declare a PHEIC. Generally, we don't understand the mission stated in the draft Charter and think it is unrealistic.
- PG: we can't reduce time to declaration of an emergency; however the Platform aims to facilitate this in the future.
- AS suggested that we change the name of the Platform because it is too restrictive.
- AS asked, with regard to the legal aspect, who is supposed to sign the Charter: representative, director?
- LM: the decision is up to each institution's rules on signatories.
- JA suggested that if the Platform cannot exist now because of governance issues, then we should release the data publicly. This platform should provide rapid evidence to support knowledge regarding Public Health crises.
- KL: we first need to demonstrate the short-term proof of concept around Ebola data sharing, and then it can be expanded.
- JA: rather than making it an aim, the current mission should be an output of the platform.
- PG: the Platform is not in competition with the R-CDC, but complementary; it is seeding and supporting a long-term goal.
- KL: we need to clarify that the platform can achieve the bigger aims only by working with others groups and organizations.
- JG: we should be ambitious and not limit to data sharing.

- **LM to reformulate and generalize the mission statement, short-term goals and bigger aims of the Platform in the document**

- **SC Representation**

- JA: the wording is different between the Charter and the Governing Bodies Terms of Reference (ToR) document with regard to the 'Stakeholders', and the number of seats allocated. The definition of this community is not clear enough and there is a risk of bias and conflict of interest (CoI).
- CN: there are some differences between the ToR document and the Charter. Signatories must have the ability to extend membership to other Members. A formalised document is needed to avoid a nebulous structure: this Platform is run by different organizations, all of those being Members and electing a SC.
- JA: the point is about the seats allocated; you may come with the same organizations being represented several times on the SC thus creating a high risk of CoI.
- Philippe: we must be careful of being too precise and should rather be sufficiently inclusive.
- JA: one solution is to remove the reference to the number of seats within the Charter (but keep it in the ToR).
- CS, AS asked how the seats will be allocated and suggested that the best would be to have all the initial signatories represented on the SC.
- KL suggested changing the language regarding composition of the SC, rather using "an appropriate core set of skills" to open the SC to different types of expertise (including research).
- The group decided that the details of SC seat allocation would be addressed in the Terms of Reference only and that this document would be revised at a later date, after the completion and signature of the Charter.

- **LM to update the Governance Structure section as discussed**

- **Quorum**

- AL commented on the need to clarify the quorum for meetings and votes, especially if no further agreement is entered into between the Members.
- LM: the ToR already address that question.
- CN: from a legal position, we then need the ToR to be agreed by the Members.

➤ **The SC will review the ToR for quorum after the Charter is signed**

- **Timeliness for sharing of data**

- KL: not only the data but also the methods should be shared timely to increase knowledge dissemination and collaborative work with other groups.

- **On legally binding**

- JA asked about the meaning of a “legally-binding” agreement.
- JG reminded that this document was suggested by MSF to define the principles and formalize the governance structure of the Platform and is not legally binding its signatories.
- KL suggested that we add a few sentences at the beginning of the document to explain that the purpose of the document was to make a statement of principles regarding the Platform.

- **Intellectual property (IP)**

- CN asked how to address existing IP rights. The group needs to define its IP rights policy, especially if the ultimate goal of the research is to find a cure or a vaccine.
- JA: addressing this question now can be too complex; we mustn't be too stringent.
- LM: we do not expect this platform to generate outputs with IP rights; if that arises, this committee will have mandate to address it.
- PG: the need for data requestors to address IP will be covered by the Data Transfer Agreement and it will have to be judged on a case-by-case basis.
- JG: even if the position is not clear now, we need a line in the document.

➤ **LM TO CIRCULATE THE REVISED CHARTER NEXT WEEK**

4. UPDATE ON THE PLATFORM ACTIVITIES

- **Data contribution update (Slides)**

- As per a MoU with WHO, Public Health Canada lab data have to be requested to WHO.
- NIH research data will be made open access and anonymised according to HIPAA guidelines.
- AL mentioned that Kenema Hospital data are now openly available.
- KL suggested that the Platform should link to other sources of related data to encourage cross-disciplinary research.

➤ **PO to write to Marie-Paul Kieny and Pierre Formenty regarding PHC lab data and how to proceed with other organisations**

- **Data ownership**

- JA: we don't want to circumvent the countries even if the question of data ownership should fall under the contributor's responsibility.
- LM: all countries have been contacted, but we have yet to achieve approval from in-country authorities.
- PO: WHO wants to move away from this concept of ownership; data do not belong to investigators.

- KL: we cannot resolve this issue but for data sharing, we can operate on a high-level data sharing agreement that data producers sign up to, and follow best practice.
- PG: the Chatham House principles on sharing data in public health emergencies could be leveraged.
- KL: we need to agree on which principles to adopt as there are many existing. Chatham principles cover surveillance data but could work for the Platform, as well as Glopid-R Data Sharing principles.
- PO: WHO could only provide a letter of support, but will not endorse any data sharing platform.

- KL to send draft Glopid-R Data Sharing principles
- JA to draft a letter for PO to bring to WHO for signature
- AV to draft a letter of support from WAHO based on JA's draft
- AV to circulate monthly updates of data contributions

5. MOVING FORWARD WITH COUNTRIES' APPROVAL

- LM believes that approval from the national health authority is needed from countries where data originates (in addition to approval from the ERBs), though no progress have been made on this point, and asked how can WAHO help with this.
- AS: WAHO has two conditions to advocate for the Platform with the countries:
 - 1) A server is established in West Africa which holds a copy of the data
 - AND** 2) WAHO has direct access to the server with updated information;
 As well as three additional requests (but not conditions):
 - 1) The involvement of West African data managers in the curation process, in order to have well-trained human resources to prepare the Regional Platform
 - 2) When the Platform is set up, ensure that young researchers in West Africa will have opportunities to do research
 - 3) If there are vaccines or products resulting from the platform, The West African community requires affordable access to them.
- LM reminded that it was previously agreed that a copy of the database will be located in West Africa and that it will be updated on a regular basis. It is critical that all access to data falls under a single, central governance system. Regarding the additional requests, these are a part of the principles of the platform.
- PG: data on the mirror server will be curated, anonymised data. WAHO will take responsibility for ensuring that the countries have appropriate security and control. The question is not where the server sits, but how the governance is structured and managed.
- AS: WAHO cannot impose conditions on countries to access their own data.
- KL cited the example of H3Africa initiative, for which a mirror copy is held in South Africa but access to data is controlled centrally by the H3Africa Consortium.
- PG: for researchers using the platform data, publications will have to be made open-access but for access to open-source data this will have to be made through the Platform.

- AV to add language to the Platform Proposal regarding a central governance system for countries to access to the data
- IDDO to write conditions of storage for the WAHO and the countries

- **Submission to Ebola affected countries Ethical Review Boards (ERBs)**

- LM asked what should be the next steps to submit the Platform proposal to the countries ERBs
- AL suggested submitting to ERBs now, while continuing to work on obtaining agreement from the Ministry of Health in each country.

- PG asked if we could possibly obtain ERB approval which covers the execution of a variety of research studies within an acceptable ethical framework; who should be the named PI for each country, and is there a precedent for a consortium submitting to an ERB?
- LM: we should send a preliminary package to ERBs framing the type of data and the type of research we want to do, then ask ERBs what additional information they need.
- AS mentioned that WAHO has focal point in each country and could help with the submission, in particular with identifying the relevant high-level official, as well as the person(s) who could benefit from the capacity building activities.

- WAHO to support a visit to each country to speak to ERBs and discuss with the appropriate authorities – Timeline: January
- IDDO to complete ERB submission documents

6. RESEARCH PARTNERSHIP PLAN

- PO: we need to identify which stages of the process people could benefit the most from (data curation, etc.). IDDO cannot do and fund everything. We must consult the data generators in countries and see what their needs are.
- KL, JG: we need to think about the future of the platform before answering to these questions. We should articulate a strategy that has more than one strand.
- JA: many activities in the Research Partnership Plan are already proposed by others. IDDO should concentrate on issues relating to the creation of the platform, such as data curation, harmonization, etc. Within the proposal circulated, data management should be separate from the research skills section.
- PG: even if IDDO cannot do everything, we need to package capacity building with the platform activities, going beyond data sharing. We want this model to expand in the future (especially outside of Oxford).
- JA: we should include 'Study subjects and Community' as an additional level within the Research Partnership Plan (Table 1).
- PO mentioned that WHO-TDR is currently running two SORTED training modules for post-Ebola phases in Sierra Leone and Liberia.
- LM: IDDO plans to set up and provide support to a group of researchers to analyse collaboratively the top questions from the Research Agenda.

- IDDO to consolidate comments from the group and organize a separate teleconference to discuss the document
- Add details on the current activities, as well as the hosting environment/arrangements in Oxford
- Contact GET, WAHO, WATER and others to articulate activities
- JA and AS to source people who could benefit from capacity strengthening activities
- KL and JG to check possible funding opportunities from Wellcome (and possible others funders) and MSF respectively to support West African Researchers

7. COMMUNITY ENGAGEMENT

- LM mentioned that the community engagement plan is still at a very preliminary stage.
- KL: this should fit with activities that other people have started.
- JA: researchers and the community must be integrated in the project from the onset.

- PO: we need to identify relevant groups in the countries (social scientists, anthropologists, clinicians). There is a methodology for approaching the survivor community about their views on Ebola research (mixed methods). The cutaneous leishmaniasis project could serve as a starting point.

- LM: IDDO would like to contribute but does not have the capacity to lead it. It's a remit of the Platform and therefore the SC should work together to find solutions.

- AL to check about current activities of the IMC Ebola survivors programs
- LM to ask Astrid to send protocol for community engagement in CL
- Ask GET what they are doing in community engagement (Akin and Jennifer)

**Ebola Data Sharing Platform
Steering Committee Call Minutes 28 September 2016**

Attendees: MSF - Javier Gabaldon (JG), Cécile Neuvens (CN)
WELLCOME - Katherine Littler (KL)
WATER - John Amuasi (JA)
IMC - Adam Levine (AL)
WHO - Piero Olliaro (PO)
WAHO - Abdourahmane Sow (AS)
IDDO - Aurélia Vessière (AV), Laura Merson (LM), Philippe Guérin (PG)

ACTION POINTS :

- LM to send of SC the ASTMH event details when available
- AS to share documentation on the WAHO platform with IDDO
- KL to send information regarding H3Africa server architecture to LM
- MSF to circulate a draft MOU shortly so that each member has time to consider the need and content and discuss with its legal department before the next meeting
- PO to send LM the WHO Conflict of Interest policies to consider
- LM to update the Terms of Submission with the help of AL and finalise the document for circulation
- AV to contact SC members shortly for website profile information.
- AV to contact SC members with details of next meeting in due course

Agenda

- **Introduction of Dr Abdourahmane Sow**
- **Update on platform activities**
- **Stakeholder engagement**
- **Formalising platform governance**
- **Data governance policy**
- **Other business**
- **Next meeting date**

INTRODUCTION OF DR ABDOURAHMANE SOW

Dr Abdourahmane Sow, Professional Officer/Epidemics Control-Public Health laboratories, West African Health Organisation (WAHO) was welcomed to the SC by all members, each of whom introduced themselves.

UPDATE ON PLATFORM ACTIVITIES

Activities of the Secretariat were summarized by LM as per the *EVD Activity Report SEP16* distributed to SC members

- PO requested details of the Data Sharing Symposia and meeting to be held at ASTMH, including contents.

- LM to send to SC the ASTMH event details when available

STAKEHOLDER ENGAGEMENT AND DATA GOVERNANCE

AS confirmed the intention of WAHO to participate in the efforts to engage the governments and health authorities of Ebola endemic countries (with an initial focus on Liberia, Sierra Leone, Guinea) in discussions regarding the platform, with the aim of moving forward with acceptance or approvals of the governance structure and activities.

AS suggested the creation of a mirror (or duplicate) platform based in Africa, to which WAHO and governments of countries where data is sourced could have open access to the global dataset. AS stated that WAHO currently has a functional data-sharing platform which will be relocated to the new regional-CDC in Abudja in the future.

- PG: Regarding data access, we would like to understand whether WAHO or regional CDC is best suited to host and access this type of data. Note that the platform is designed to include Ebola data from all countries, not only West Africa.
- JA: Reiterated the discussion from the April 2016 Steering Committee meeting in Geneva, where he supported the idea of an African-based server and the engagement of African researchers in the operation of the platform, including curation.
- LM: Server location is an important question and will need to be resolved in the future after the platform is constructed
- KL: Suggested that the model used in H3Africa collaboration could serve as a model.
- LM: Requested suggestions from SC members on how to engage researchers or data managers from West Africa in the development of the platform
- PG: Server location is not the current priority as the ideal system is likely a cloud-based approach. The current focus should be the training of data managers and clarification of the data access process.
- AS to share documentation on the WAHO platform with IDDO
- KL to send information regarding H3Africa server architecture to LM

FORMALIZING PLATFORM GOVERNANCE

• STEERING COMMITTEE CHARTER DOCUMENT

- CN: Organisations willing to participate to the SC as voting members should commit to the Platform by entering into a collaboration agreement. This would not create a new legal entity; signatories may decide on the most appropriate title for this document (Consortium Agreement, MoU, etc.)
- JG, AL, JA, AS: support the principle of their organisations reviewing a MoU regarding the platform.
- PG: Agrees with the spirit of a MOU, but notes that it may not be necessary and may create unneeded complication as we each need to operate within the legal framework of our respective institutions
- PO had a number of comments and questions about the collaboration agreement:
 - The Steering Committee Charter should not contain mention of an MOU or Consortium Agreement (it is a matter of general governance and not specific to the SC).
 - asked for clarifications on such 'Consortium Agreement' and, if that means the creation of a 'quasi-legal entity', what that entails and who would be the signatories ('Parties') and what their legitimacy would be
 - pointed to the fact that, if we take 2.1 *Initial SC* to the letter, the current SC does not exist

- WHO Legal Department will have to review these documents.
- PO: Re section 2, Conflicts of interest – Queried to whom the Col applies and **if the Col statement for each of these will be published (or simply registered as ‘no conflict declared’)**. He also pointed to the fact that an overarching statement would be needed at start as well as a declaration of conflicts on specific subjects signed at each meeting, and what parameters of conflict would be assigned. LM confirmed that this had not been defined and requested PO to send the WHO examples for consideration. LM: Suggested that a draft MoU be circulated for consideration of the members in advance of the next meeting.
 - **MSF to circulate a draft MoU shortly so that each member has time to consider the need and content and discuss with its legal department before the next meeting**
 - **PO to send LM the WHO Conflict of Interest policies to consider**
- TERMS OF SUBMISSION FOR DATA CURATION
 - LM requested feedback from the SC regarding the *Terms of Submission dated 8SEP16*.
 - AL requested that the most recent comments from the IMC legal team be reviewed to ensure that they are integrated in the document.
 - All SC members agreed that a revision of version 8SEP16 can be circulated for execution by data contributors once any outstanding IMC comments had been incorporated.
 - **LM to update the Terms of Submission with the help of AL and finalise the document for circulation**

OTHER BUSINESS

The IDDO Head of Communications at IDDO has requested to include information regarding the SC on the platform website.

- All SC members confirmed that they agree to have approved photos and profiles posted once the status of the SC is confirmed.
 - **AV to contact SC members shortly for website profile information.**

NEXT MEETING DATE

SC members agreed that the next meeting will take place via teleconference at the end of October. An in person meeting will be considered for the coming months.

- **AV to contact SC members with details of next meeting in due course**