

Dear Colleague,

We have contacted you previously, as someone with responsibility for one or more sets of TB patient data, about the new TB-individual patient data (IPD) platform that we are setting up at UCL with WHO. You have indicated that you are prepared for the data you are holding to be transferred either without a new Data Sharing Agreement (DSA), or that you are in principle willing, but will require a new DSA.

This is an email to update with our progress and the current status. There is also a specific request for you at the end about how we can acknowledge your contribution.

News

This is a project that we expect to evolve with time, and we want to highlight a few changes to the proposal outlined in the original concept note:

Scope and name: This was originally launched as an IPD that focused on drug-resistant TB. However, we now believe that this a priori limitation in scope is not required. We are in principle open to include data from any type of TB, whether drug-resistant or drug-sensitive. We have therefore removed 'DR-' from the name of the IPD, and have renamed it the 'TB treatment IPD platform' (TB-IPD for short)

Language: In the concept note we referred to you as "Data Owners". In light of sensitivities about the idea of owning another person's data, but recognising that there is also a legal issue here as to who can make decisions about datasets, we are now referring to you as "Data Contributors". In some cases you represent larger institutions, currently we are not distinguishing unless necessary, though this may change.

Separation of data access review and oversight: The initial concept note proposed an Oversight Committee that included selected Data Contributors in addition to WHO and the data curator, which had a dual role of both reviewing research proposals, and overseeing the project as a whole. We have decided that these roles should be separated, and there will be a Data Access Committee which will review proposals, and a separate Steering Group for oversight of the project.

Governance - an interim structure and process: We put in place an interim structure and process that we anticipate being in place for one year, and being replaced after that by a longer term solution based on feedback from you and other stakeholders. This interim solution includes WHO/UCL appointing the initial members of the Data Access Committee, based on the amount of data contributed as well as other considerations; and WHO/UCL providing the Steering Group function.

DSAs: The data sharing agreements between UCL and data contributors, and UCL and researchers are near completion and we expect to make them openly available within January 2023. Please note, as some of you have asked if you should use your own institutions DSAs, we have considered this, but realise that we will have to standardise our systems, and we will only be able to accept the new project DSA.

Important, please complete the table below if you have agreed to share your data without a new DSA. It is important to us to acknowledge you appropriately

Of course we will be unable to formally acknowledge you if a DSA is pending