Dear Colleague,

Thank you for your willingness to share your data with the WHO/UCL TB-IPD platform, either under a new Data Sharing Agreement (DSA) or otherwise. We have made significant progress this year, and this email aims to update you on the current status.

News

- **Data-IN:** We are excited that the IPD currently holds data from **35,767 participants** which have been contributed through **47 datasets**. Further details and summaries can be found at this link: [Summary of datasets | Institute for Global Health - UCL – University College London](#).
  In 2023 we expanded the platform's scope to include trials, paediatrics, and pregnancy data. We are in contact with ~20 trials to invite them to share their data with this platform. The inclusion of pregnancy and paediatrics data is made possible through our collaboration with Stellenbosch University. We aim to include trial as well as paediatrics and pregnancy data starting in the first quarter of 2024.

- **Data-OUT:** We are pleased to report that we have received our first formal data request, along with several informal inquiries. The formal request, from a PhD student in Health Metrics Sciences at the University of Washington, was reviewed on September 1, 2023, and feedback has been provided. We are expecting a revised proposal in accordance with our feedback, after which we will provide the data. The informal requests came from a UCL CTU PhD student, a UCL Research Fellow, and two pharmaceutical companies, Otsuka and GSK. This milestone was achieved thanks to your generous data contributions.

- **Governance - Interim Structure and Process:** We are delighted to report that the Data Access Committee (DAC) for the platform set up in 2022 met three times in 2023. The inaugural meeting was used to review the platform's objectives and outcomes and agree Terms of Reference and confidentiality agreements, subsequently signed by the members. Subsequent meetings discussed data access requests and emerging issues which included discussion on increasing platform accessibility (e.g. beyond academia) and the platform principle of non-commercial use (e.g. when discussing requests from

pharmaceutical companies). The website will be updated to make sure this principle is clear.

A special thank you to Professor Anneke Hesseling, Professor Salmaan Keshavjee, Professor Norbert Ndjeka, Dr. Carla Winston, Dr. Bern-Thomas Nyang'wa, and Dr. Ezio Távora dos Santos Filho for availing themselves for their contributions as members of the DAC.

- **Data Sharing Agreements (DSAs):** We have established a data sharing agreement and shared it with some of our data contributors. Following feedback, we have refined the standardised agreement to: to make the indemnity clause mutual; increase the liability limit from £25,000 to £100,000. We welcome suggestions on the DSA and other platform resources and will continue to engage individual contributors and discuss major concerns. Version 2.0 of the DSA is now available.

- **Promoting the Platform:** To enhance engagement and the platform's utilization, we are focused on increasing its visibility. We are proud to announce that the project abstract, titled "Creating a global individual patient data platform for tuberculosis treatment (TB-IPD)", was presented as an oral presentation at The UNION conference in 2023. If any of our contributors wish to publicise the platform and require promotional materials or slides, please do not hesitate to contact us.

We look forward to collaborating successfully with you in 2024!

If you have any questions or comments, please do not hesitate to email us either at **igh.tb-ipd@ucl.ac.uk.** If you do not wish to receive future updates, please let us know.

Kind regards,
Assica Hakiman