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Charter

endTB Data Sharing Initiative

The signatories of this Charter wish to establish a repository for endTB data to foster access to data used in the public interest and in the interests of the individuals and communities from which data originate. This Charter lays out a common understanding of the principles and remit of the endTB Data Sharing Initiative (eDSI). In the future, this repository may be expanded to contain additional datasets on TB following the same principles and remit.

Background

endTB is a project designed and implemented by Partners In Health (PIH), Médecins Sans Frontières (MSF) and Interactive Research and Development (IRD) in collaboration with Harvard Medical School (HMS), Epicentre, the Institute of Tropical Medicine-Antwerp (ITM) and public- and private-sector partners involved in TB care in 18 countries. It was funded by Unitaid, MSF, and PIH. The aims of the endTB project are to generate evidence on efficacy and safety and to expand access to the new (bedaquiline and delamanid) and repurposed (clofazimine and linezolid) TB drugs for the treatment of multidrug-resistant/rifampin-resistant (MDR/RR) TB.

The endTB data represent a unique set of high-quality, detailed longitudinal data on MDR/RR-TB with >3,700 participant records, across diverse geographic settings.

Principles

The eDSI will promote ethical, equitable and transparent access to endTB data for a range of users who share the common goal of increasing knowledge and disseminating information to improve care for MDR/RR-TB patients.

Six key principles have been identified for the endTB data sharing initiative (not listed in order of priority):

- Apply best practices for equitable, timely and transparent governance and processes to access endTB data.
- Promote research by researchers, research institutions and other relevant users from MDR/RR-TB affected countries—with priority to those that participated in endTB—through collaboration, training and capacity strengthening.
- Ensure prompt dissemination of results produced with the endTB data and acknowledgement of—due credit to—the data contributors.
- Promote equitable sharing of any benefits that may arise from—and resources that are required for—the use of the data. Benefits must be shared with endTB patient

Gratefully adapted (without endorsement) from the Ebola Data Platform Charter (v. 4 December 2017).

communities, and with scientific communities, health institutions and general populations in countries affected by MDR-TB.

- Protect the rights and welfare of individuals and communities who contributed the data and comply with ethical requirements and applicable laws and regulations.
- Act as a custodian of the data that were collected and generated from the patients and respect all the related rights.