Data Access and Use Policy of ClinEpiDB, a EuPathDB Database

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Clinical Epidemiology Database Resources, ClinEpiDB (http://ClinEpiDB.org) is operated under funding from the US National Institute of Allergy and Infectious Diseases (NIAID) and the Bill and Melinda Gates Foundation. ClinEpiDB is charged with ensuring that epidemiologic datasets are conveniently accessible to the worldwide community of biomedical researchers. This document summarizes policies associated with the access and use of datasets on ClinEpiDB.

General principles:

ClinEpiDB is committed to high standards for the protection of all submitted study data provided to ClinEpiDB and made available through the ClinEpiDB platform.

Data from research studies is not made publically available until thorough quality control both internally with ClinEpiDB and with original data providers. Research data is made available to data providers through an internal protected site prior to public release in order to ensure adequate representation and accuracy.

ClinEpiDB.org operates on a Secure Sockets Layer (SSL) which ensures secure internet connection and safeguards any sensitive data that is being sent between two systems.

Each dataset that is submitted to ClinEpiDB is unique and each may require different levels of data access restrictions. At the most conservative, for some studies we will have implemented a three tiered data access system or some approximation:

Tier	Data Type	Description
One	Variable display filters, restricted data row display and summary data tables	Open access, any public user of the site with no log-in required. Access to search wizard and results pages enabled.
Two	Full on-site data access and display	User will be required to log-in to access and upon login will have full access to the search wizard pages, results data tables, analysis tools & individual results records pages.
Three	Data available for download	All of the above however users may be required to submit documentation that will require either active or passive approval from the data providers. Once approval is granted, users will be allowed to download the full dataset.

Users of the data provided through ClinEpiDB agree to responsible use and the principles presented through our general platform tiered access system as well as any additional requirement that may be requested by the data provider.

The ClinEpiDB platform has received ethics approval from the University of Pennsylvania under IRB#7, Protocol #828806. All studies that are included in ClinEpiDB have undergone ethical approval at applicable institutions prior to protocol execution and ClinEpiDB is generally not involved in this process.

We respect the principles of confidentiality and acknowledge the dissemination of human subjects research data. We will not make data available that allows for the identification of study participants and apply processing algorithms to ensure potentially identifying information is obfuscated appropriately. If any concern exists from the data provider we will not make data publically available or withhold data variables that data providers are not comfortable with disseminating.

While ClinEpiDB aims to make data broadly accessible and reduce technical barriers to data exploration, we fully endorse proper attribution to original study principal investigators, study teams, staff and acknowledgement of participation of study participants. We aim to provide clear access to data provider information and contacts and it is the responsibility of data users to contact study teams when appropriate and if they have any questions or concerns specific to the study.