

Global Health Data Access Principles

Mission of the Foundation

Guided by the belief that all lives have equal value, the Bill & Melinda Gates Foundation works to help people who are most in need lead healthy, productive lives. The foundation supports this mission by harnessing advances in science and technology to reduce health inequities and save lives in poor countries.

Rationale for these Principles

In accordance with its charitable mission, the foundation is committed to optimizing the use of health-related data to translate knowledge into life-saving interventions. To this end, it is essential that data are made widely and rapidly available to the broader global health community through good data access practices.

Data access is intended to promote:

- *Innovation*, by encouraging diversity of analysis and opinion, facilitating evaluation of alternative hypotheses, permitting meta-analysis, and facilitating synthesis of results from individual projects into a larger whole, thereby promoting potentially lifesaving new insights.
- *Collaboration*, between teams and institutions, and among diverse disciplines, resulting in greater productivity and creativity.
- *Efficiency*, by preventing unnecessary duplication of effort, enabling secondary analyses of existing data, and enabling the redirection of resources to the most promising research endeavors, thereby maximizing the potential impact of investments.
- *Accountability*, by encouraging independent verification and analysis, thereby improving data quality.
- *Capacity Strengthening*, by facilitating the education of new researchers and evaluators and enabling broader access to data for secondary analysis, which is of particular importance to investigators in developing countries.

Scope

These principles apply to data generated from activities sponsored in whole or in part by the Bill & Melinda Gates Foundation, where data refers to final, annotated quantitative and qualitative datasets and accompanying information such as metadata, codebooks, data dictionaries, and questionnaires. Data may arise as a primary output of a grant, or as a product of other activities, such as program evaluations.

Goal

The goal of this document is to articulate the guiding principles of responsible and ethical data access. These principles are intended to optimize the impact of data on global health, often accomplished by ensuring that data are made as widely and rapidly available as possible.

Guiding Principles

Promotion of the Common Good

Data will be shared as broadly and as promptly as possible to optimize prospects for the translation of findings into life-saving solutions. Data access should enhance the value of research and program effectiveness.

Respect

Respect must be given to matters of identity, privacy, and confidentiality as they pertain to the individuals and communities from or about whom data are collected. Respect must also be given to matters of attribution as they pertain to researchers, evaluators, and their collaborators.

Accountability

All processes and procedures for data access will be transparent, clear, and consistent with data management standards that ensure quality data, appropriate security, and equitable access.

Stewardship

All who produce, share, and use data are stewards of those data. They share responsibility for ensuring that data are collected, accessed, and used in appropriate ways, consistent with applicable laws, regulations, and international standards of ethical research conduct.

Proportionality

The needs of investigators and program evaluators must be balanced against those of communities and sponsors that expect health benefits to arise from the activities to which they contribute information or resources.

Reciprocity

The aim of benefiting the individuals and communities who enable and support inquiry should be furthered to the extent possible and is of particular importance when involving individuals and communities from developing countries.

Requirements

Grantees will be required, as a condition of a grant award from the Bill & Melinda Gates Foundation and in support of the foundation's Global Access policy, to facilitate the prompt and broad dissemination of data in accordance with these principles. For grants over \$500,000, this will begin with development and submission of a plan that addresses how data access will be ensured, including a timeframe for data release. The costs involved with making data widely available may be included in the proposed budget and will be subject to review and approval. Prospective grantees are encouraged to consult with their Program Officer in developing a suitable Data Access Plan.

When possible, data should be deposited into public-access repositories. When relevant public access repositories are not available for a given dataset, prospective grantees should propose alternatives for access, with consideration given to ease of discovery of

the existence of the data set and maintenance of long-term access. Program Officers can assist in identifying suitable repositories.

We recognize there may be circumstances where data are subject to intellectual property protection, laws, or regulations that may delay or preclude access. In such cases, prospective grantees should provide justification for the foundation's consideration. It is important that these factors be thought through carefully during the development of the Data Access Plan, as a grantee's adherence to previous plans could be a factor in ongoing funding decisions.

These principles are meant to articulate the Global Health Program's intent with respect to data access. For further guidance on the implementation of these principles, please speak to a Program Officer.