

# **Sharing Public Health Data to Advance Global Health: Ethical Challenges and a Principled Way Forward**

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## **Abstract**

Since the Human Genome Project began granting free access to pre-publication data on gene sequences in the 1990's, we have seen tremendous progress in the concept of open access to scientific data. But despite the momentum that has been building for almost two decades, and repeated calls for broader access to public health data -- including recent efforts led by major funders of health research, the sharing of public health data remains the exception rather than the norm. In part, this is attributable to complex and vexing ethical challenges such as the privacy of data subjects, data ownership and control, and inequity in data sharing, particularly between producers and consumers of data. These challenges may be further exacerbated in the context of global health where practical challenges related to capacity and infrastructure in developing countries may also exist. This presentation will examine some of the ethical issues that arise in the sharing of public health data to advance global health, and will propose principles to address the normative challenges.