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Perspective

A Global, Neutral Platform for Sharing Trial Data

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Article

SHARING CLINICAL TRIAL DATA IS CRITICAL IN ORDER TO INFORM CLINICAL AND regulatory decision making and honor trial participants who put themselves at risk to advance science. A recent Institute of Medicine (IOM) report argues that availability of deidentified (anonymized) patient-level data from clinical trials can permit verification of original results, enhancing public trust and accountability; facilitate other critical research (e.g., evaluation of adverse event rates according to compound class or subpopulation or identification of surrogate end points); and avert duplicate trials, shielding participants from unnecessary risk.[1] If such goals are to be achieved, patient-level data must be readily findable and available for aggregation and analysis across multiple sources to enable the widest range of secondary research uses.

Recently, several data generators, including pharmaceutical companies and academic consortia, have shared patient-level data and pioneered transparency efforts by establishing electronic portals through which clinical trial data may be requested, shared, and analyzed.[1] However, data largely remain siloed