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Preparation for precision medicine: International data sharing practice of two Chinese national data sharing platforms

Jian Guan
Peking Union Medical College Hospital, China

Advances in genome sequencing together with big data analytic tools lead to the introduction of precision medicine particularly in the field of oncology. To turn this promise into reality will require establishing a relationship between phenotype data in EHRs, and genetic and expression data at the "omics" level in large scale, through computational frameworks, enables the ability to clarify disease mechanisms in unprecedented detail; require individuals who will contribute extensive amounts of medical, genetic, genomic, behavioral, phenotypic and biomarkers data, as well as lifestyle and other personal information. Thus, this requires one of the main sources of ethical, legal and social concerns regarding personalized medicine. In addition, data sharing at the patient-level is a potential financial pathway to obtain big data in healthcare. However, it is difficult to share high-level data in practice. How to establish continued collaboration and long-term data sharing remains unknown. We explore international collaboration of data sharing and propose potential governing principles and key features for a managing system of expanded access to patient-level data after reviewing the practice of operating national data sharing platforms. During the practice, we established win-win data sharing principles and regulation with legal and ethical considerations. Under these principles, data sharing is conditional, and data providers are paid for data sharing and transfers. Those who provide data that is shared in the platform should be fairly compensated when others use the data and derive financial value from that usage, or offer other benefits for the sharing data (shown in Figure 1). In addition, based on the special data sharing platform on oncology, the International Data Sharing and Mining Cooperating Group for Translational Oncology (IDSMC Group) has been organized. The author believes that this collaboration will be of benefit for cancer patients around the world.
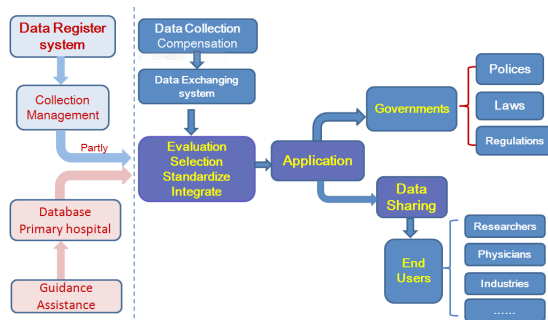

Figure 1 Here shows three data collection pathways for sharing. The two pathways left of the dotted line were under the win-win principle, data shared with little financial compensation, or not paid.

Biography

Jian Guan completed her Doctor of Medicine at Peking Union Medical College (PUMC), China in 2001 and; Post-doctoral research work at Law Institute of Chinese Academy of Social Sciences in 2012. Currently, she is a Professor of Management, Associate Professor of Pathology, and a Lawyer. She has her expertise in "Big data healthcare and molecular pathology, medical law and ethics". She is the Vice Executive Director of Clinical Data Centre, National Population and Health Scientific Data Sharing Platform (National Program) and; PI of the International Data Sharing Platform on Translational Oncology (National Program). She is familiar with molecular diagnosis and therapy of oncology. She is Managing Editor of *Frontiers in Bioscience*.

gjpumch@126.com

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