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A Discussion about the Importance of Laws and Policies for Data Sharing for Public Health in the People's Republic of China

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Abstract

This paper introduces the current status of data sharing in the People's Republic of China. It discusses barriers to data sharing and proposes three key solutions to overcome these barriers in China. The establishment of national laws and policies for data sharing is considered the key prerequisite to ensuring the successful implementation of resource sharing activities in public health. Driven by established laws and policies, the relevant operational models should be developed. It is also important to have strategies in place to ensure the established laws and policies are implemented by various organizations in different jurisdictions. These discussions are supported by relevant local and international evidence.

Keywords:

data, data sharing, public health, law, policy, implementation

Introduction

Scientific data is the original measurement or characteristic of a person or thing that is collected from various scientific activities, or extracted from databases or data warehouses by various data mining techniques. It may be 'a clinical measurement, a laboratory record, a medication dosage, or even a listing of treatment'.[1] Only after scientific treatment to comply with certain data standards of the relevant regulation bodies can data be used effectively for various public health purposes. 'Data are an expensive and valuable resource. Data have market value; they represent a revenue stream for many academic and governmental agencies'.[2]

The essence of sharing public health data involves the sharing and publication of information. Data sharing among organizations is important for (1) developing an essential information infrastructure that supports public health services and functions; (2) reducing duplication of effort in data collection and increasing the usability of the data that has already been collected; (3) providing information effectively and efficiently to inform public health policy and management decisions; (4) improving communication and standardization of core procedures and assessment to facilitate best practice in health care[3] and (5)

realizing the scientific, economic and social value of scientific data. Therefore, to benefit society, the data stored in various databases owned by various departments and jurisdictions should be open to the public.

This paper will focus the current status, challenges and prospects of data sharing for public health. First, it will introduce the current practice of data sharing in China. It will then discuss the challenges to this data sharing in China. Finally, through a comparison of the practice of several countries, it proposes three essential strategies to overcome the barriers encountered.

The current practice of data sharing in the People's Republic of China

A significant amount of data has been collected in China. According to statistics, there are several billion bytes of scientific data collected by various levels of government departments and scientific research organizations sponsored by the government. The three major sources of these data include: (1) the administrative data collected by the health administrative organizations; (2) the scientific data generated from the scientific activities undertaken by staff in research, business and management organizations funded by government; and (3) the scientific data generated from scientific or productive activities undertaken by privately owned scientific, business, education or health organizations. These data are scattered in the databases of various organizations located in different jurisdictions. Although there is a critical need to compare these data to support public health research and policy making, the differences in data elements, the method of collection, the coding system and the structure of database tables that store these data etc. make comparison of these data impossible. As these heterogeneous, incompatible data are not readily usable for statistical analysis and reporting, they have rarely been published, despite the significant effort and resources spent in collecting them.

In recent years, the importance of data sharing has been emphasized by the Central Government in China. After a two-year, continuous, persistent effort, the Department of Health has gained considerable experience in the development and establishment of data-sharing policies. The Department of Science in China has implemented a scien-

tific data-sharing project to establish a platform to facilitate the sharing of scientific data. To date, more than 600 databases of varying size and quality have been established. Meanwhile, resources have been invested in digitizing the original paper-based data and establishing various databases to store these data. Some organizations that own these databases have initiated data-sharing services, which have resulted in some social benefits. However, the level and scope of scientific data sharing in China is still very limited.

There are many barriers to effective data sharing and the following section will discuss these barriers. Then, three essential strategies are proposed to overcome these barriers in China.

The barriers to sharing scientific data in China

Scientific data sharing in China is yet to break away from the custody of departments in various jurisdictions. The appropriate technology and model is yet to be developed for large-scope data sharing, the integration of heterogeneous data, and the distribution of collaborations to researchers and policy makers. To date, there is no network-based platform that is able to provide data services for clients in different regions that is underpinned by technology services, effective support mechanism and quality assurance.[3] The identified challenges fall into one of the following four categories: (1) a lack of laws and policies to guide the practice of data sharing; (2) a lack of coordination of effort, which leads to numerous isolated data sources that cannot communicate with each other; (3) a lack of an enabling structure and operational mechanism to sustain data-sharing services; and (4) a lack of a culture of sharing data. The following sections will provide a detailed explanation of each of these four categories.

A lack of laws and policies to guide the practice of data sharing

'Laws provide the mission, functions, and powers of public health agencies, set standards for their actions, and safeguard individual rights … They are an essential tool for improving public health infrastructure and outcomes.'[5] Therefore, the establishment of laws and policies are prerequisites for achieving data sharing for public health. However, the relevant data-sharing policies, the standards for data exchange, quality assurance and information services, and the relevant terminology and classification system have yet to be developed in China. Without the above regulatory protections, the owners of the relevant databases will not give end users access to databases to download data for the purposes of scientific research, disease prevention and control. If they are lucky, these end users can acquire a very limited amount of data, such as abstract of a publication. Conversely, the utilization rate is poor for databases established through public funding, which is a waste of public investment.

A lack of coordination of effort, which leads to numerous isolated data sources that cannot communicate with each other

Different levels of government and their departments have their own needs and targets for data collection and storage. Currently, there is no mechanism to achieve collaboration on data sharing among local, provincial and central governments. The reasons for this are similar to those identified in Canada: 'unclear constitutional roles and responsibilities for public health and the potential for disputes to arise over funding and data sharing'.[6] As in Australia,[7] there is a lack of national vision or a mechanism to implement data sharing. The consequences are duplicated effort and overlap in data collection, and the establishment of numerous heterogeneous databases at central, provincial, city and county levels of government departments and the private sector. Therefore, interoperability and data sharing among information systems is not possible.

A lack of an enabling structure and operational mechanism to sustain data sharing services

Data sharing is a process of social system engineering that needs the coordination of government departments in various jurisdictions. The limitations of the current government organizational structure in China mean there is a serious lack of communication between organizations in various industry sectors. This lack of coordination in information management has led to an inability to identify the availability, place of storage, ownership, accessibility, scale and scope of data stored in a database. Although a national identification system has been established for public servants, currently the system does not include the increasing number of employees in the private sector and farmers. In addition, there is no common data exchange standard that clearly defines how the organizations should share data with each other.[8] Therefore, it is difficult to link two information systems together. Even when two information systems are connected, it is challenge to integrate their data as these data are captured in different formats and semantics.

A lack of a culture of sharing data

As in Australia,[7] there is a lack of incentives for data sharing among the different levels of government without direct reporting relationships. To share data among organizations, an inter-organizational information network should be established to link data sources within organizations. This novel model of information networking challenges the traditional organizational structure and ownership of data in China. Therefore, its implementation will only be possible after significant organizational cultural change has been achieved.

In the following section, we will propose three essential strategies for overcoming the barriers discussed and facilitating scientific data sharing in China.

Our proposed solutions to overcome the barriers for scientific data sharing in China

We believe the following five key factors have to be satisfied before sharing of scientific data can be realized: data sources, data organization and management, regulations about data sharing, the development of technology to enable data sharing, and the interaction between these four factors. Therefore, to overcome the barriers for data sharing and optimize the benefits of these scientific data to the public, three key strategies are proposed: (1) the establishment of laws and policies for sharing data for the sake of public health (this action should take into consideration the culture and political structure in China); (2) the development of a comprehensive data-sharing mechanism that is guided by established laws and policies; and (3) the establishment of a mechanism to safeguard the implementation of the laws and policies. The following sections will discuss these three strategies in detail.

The establishment of laws and policies for data sharing in the context of China's culture and political structure

For the purpose of establishing an effective approach, the experiences of foreign countries should be examined if these countries have already taken action to achieve data sharing and interoperability in health care. For example, the Turning Point Model State Public Health Act in the USA has established clear definitions about the acquisition, use and disclosure of identifiable health information, security safeguards and fair information practices.[5] In Britain, the use and sharing of personal information in the public sector is governed by a number of laws including (1) the law that governs the actions of public bodies (administrative law); (2) the *Human Rights Act 1998* and the European Convention on Human Rights; (3) the common law tort of breach of confidence; (4) the *Data Protection Act 1998* and (5) the European Union law.[9] There are laws that define information management practice in either the public or private sectors in Australia. Canadians have also established their code of practice.[10, 11] However, as cautioned by Hodge *et al.,*[5] 'reforming public health laws is a delicate process that involves good timing, political will, and willingness to compromise'. Therefore, the Chinese political, social, cultural and organizational context has to be carefully considered, and the relevant stakeholders have to be thoroughly consulted when establishing laws and policies.

Data sharing can only be realized through negotiation between the organizations or stakeholders who own the data. Therefore, an adequate security protection mechanism has to be in place to ensure the scientific data owned by various entities will only be made available to the general public after the explicit consent of these entities. The legislation should clearly define the intellectual property of the owner(s) of the data. The interests of various stakeholders (such as individuals, organizations and society), should be appropriately balanced; whereas the information related to national security and commercial confidentiality should be adequately protected.

Before the establishment of such national laws and policies, different jurisdictions or industries could establish their own short-term policies or regulations for public health data sharing. Only through such practice could data sharing be achieved and scientific evidence acquired through analyzing these data. Such evidence will, again, support scientific research or management decision-making.

The development of a comprehensive public health data-sharing model that is guided by laws and policies

The fundamental requirement for public health data management is the proper configuration of these data to maximize their potential in serving the society. The federal governments in Australia, Britain and Canada have taken the lead in their efforts to establish a national health information network for sharing health care information across the continuum of care.[12, 13, 14] It is proposed that the Chinese Central Government should take the leadership and coordination role and provide incentives to encourage various organizations, such as various levels of health departments and public and private health care organizations, to collect and share data.[15]

An incremental update model[6] that uses a five-step implementation may be useful in achieving data sharing in the short term. Baker[6] defined the five steps as (1) the data authority is identified; (2) data are consolidated/redistributed: making sure the authority has the data; (3) the data authority allocates a persistent identifier for each feature within each theme; (4) data are redistributed: the data authority redistributes data with identifiers attached; and (5) incremental updating of the whole process. As mentioned previously, a national identification system has been established for public servants. This is in the process of being extended to the general public, including the rural population.

The best scenario is the complete publication of scientific data after acknowledging and protecting the intellectual property of its owners.[16] Of course, appropriate compensation should be given to the owners of these data to provide incentives for them to share data. The relevant regulations should also be established to define the rights and responsibilities of the providers of public health data, as well as the end users of these data. A possible definition might be: if a customer is an end user of the data, they have no right to redistribute the data; whereas the data provider should share authorship with the end user in the publications that result from the data sharing. Whether the data leads to a product for the end user or not, the data provider should always be given financial compensation to maintain the data-sharing system.

The establishment of structure and process to enforce the implementation of laws and policies for data sharing

Necessary mechanisms should be in place to enforce the implementation of laws and policies for data sharing. In fact, China has established a comprehensive primary health care network from village to town to county to province.[17] The system was established in the early 1950s based on the former Soviet Union model of epidemic pre-

vention and education, with focus on the hygiene and prevention.[17] This network has played an important role in controlling and preventing infectious diseases for the past 50 years. It will also be an effective structure to enforce the implementation of laws and policies for data sharing once these laws and policies are in place. The China CDC has established a four-tiered network of disease control (centrality, province, city and county) that is managed at different levels. In addition, the China CDC has close working partnerships with non-government organizations such as the Chinese Medical Association, the Chinese Preventive Medicine Association and the Chinese Epidemiological Association.[17] Therefore, the structure for public health data-sharing management and services already exists.

The experience of other countries in this area can also be valuable. For example, to enhance public servants' understanding of the country's complex legal framework, the Department for Constitutional Affairs (Justice, Rights and Democracy) published *Public sector data sharing: guidance on the law* in 2003 as a map to guide the practice of data sharing in Britain.[13] In the USA, the implementation of environmental justice at the federal level was matched by state programs.[18]

Conclusion

In summary, any complex social problem can only be solved by following certain laws and policies. In addition, any creative theory and strategy can only be implemented after following certain procedures. The established laws, policies and procedures can only be effectively implemented after an adequate assessment, reporting and feedback mechanism is in place. Therefore, the establishment of sound laws and policies is the first step towards achieving public health data sharing. Afterwards, the implementation of the clearly defined laws and policies and a strong monitoring mechanism for this implementation will lead to improving data sharing for public health in China.

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