

Discussion on the Basic Principles for Healthcare Data Sharing

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Abstract: Healthcare data sharing in China is in its infancy. Numerous issues, including healthcare privacy security, unclear data ownership and copyright, and unclear benefits have long hindered the growth of healthcare data sharing in China. Basic principles of sharing can boost progress in the field, helping to reap the benefits of the shared data. In this paper, we summarize 43 typical principles established in international healthcare data sharing from the perspectives of law, ethics, and practice, with particular focus on those followed by the international community. The study reveals that value, respect, trust, fairness and justice, security, evaluability and evaluation, normativeness, and accountability are the primary principles that are highly valued in international healthcare data sharing activities. Based on these findings, the basic principles with the highest consensus are established for healthcare data sharing. They may guide and promote reasonable and legal sharing of healthcare data in China and deepen the application of Internet Plus in healthcare and medicine.

Keywords: data sharing; healthcare; data sharing behavior; basic principle

1 Introduction

As an important national basic and strategic resource, healthcare big data exerts a profound impact from multiple perspectives, such as management decision-making, public health, clinical research, public services, industry governance and industrial development. In the Internet Plus context, the moderate opening, reasonable and orderly sharing of healthcare big data will help further deepen the reform of healthcare system, and boost the development of innovative healthcare service applications. In April 2020, the *Opinions of the Central Committee of the Communist Party of China on the Construction of a Market-Oriented Allocation System and Mechanism for Factors* requested that the cultivation of data factor market should be accelerated by enhancing access and sharing of government data, promoting the value of social data resources, and reinforcing data resource integration and security. Secure and large-scale promotion of healthcare data sharing becomes crucial for further activating the healthcare data flow and accelerate the value release.

Domestic research on healthcare data sharing started relatively late. Over the last five years the number of related studies gradually increased, and the majority of them focused on the development and improvement of data sharing platforms [1–4]. Meanwhile, aiming at privacy protection, interconnection, and other key issues involved in the data sharing process [5], some scholars have conducted research on healthcare data sharing strategies [3,6,7], technology applications [8,9], standards [10], and legal supervision [11], trying to seek effective solutions. This study mainly analyzes relevant guiding principles for healthcare data sharing in foreign countries, optimizing and

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establishing the basic principles for healthcare data sharing in China and making some suggestions based on the status of healthcare data sharing in China. The ultimate aim is to provide theoretical references for boosting healthcare data sharing and activating the healthcare data market.

2 Status and problems of healthcare data sharing in China

2.1 Data sharing pattern

Healthcare data sharing activities in China rely on platforms across all scales, namely healthcare data interconnection and sharing are promoted by constructing state-, provincial-, municipal-, and county-level healthcare data platforms. With the establishment of hierarchical healthcare data sharing platforms, healthcare big data sharing patterns have been basically established. Currently, some flowing data have been applied to healthcare services, government supervision, scientific research, and industrial development at different levels in business-oriented and service-oriented forms.

The horizontal and longitudinal development of healthcare data sharing in government sectors have been gradually enhanced, owing to the construction of government service cloud platform and deepened collaboration among government sectors across the entire nation. According to a survey on 82 local government service platforms in China conducted by researchers from the Fudan University, healthcare-related data accounted for about 5% of open government data [12], a little higher than that in the United Kingdom (UK) and the United States. However, sharing basic healthcare data context is limited in China, and there is still a huge gap from leading countries like the UK and the United States [13]. Relying on the constantly improving digital transformation and system interconnection in the medical field, the degree of internal data sharing in medical institutions and inter-institution data sharing has already remarkably enhanced. In the meantime, the number of healthcare APPs oriented to medical staffs and patient service increases rapidly. However, owing to the inadequate construction and update of related data sets and limited access to shared data, the open sharing of high-value clinical data still lags behind [14]. Regarding the sharing of scientific research data, the National Scientific Data Sharing Platform for Population and Health, E-BioBank, and other platforms have boosted healthcare research in China. However, they still face various problems, such as low-quality data resources, unsmooth access to certain databases and data sets [15], and dissatisfaction in data effectiveness. In addition, defining related standards and implementing management rules also lag behind. In terms of industrial cooperation, owing to the asset attribute of healthcare data in business relations, most enterprises support only internal data sharing, whereas healthcare data sharing activities among private enterprises are rarely launched [16].

2.2 Data sharing behavior

Data sharing behaviors are reflected in the core of every data sharing activities, and are generally conducted by data holders, data processors, and data users constituted by the government, medical institutions, scientific research institutions, patients, etc. The sharing process covers the collection, processing, storing, sharing, and utilization of healthcare data.

In terms of behavior roles, data owners, such as medical institutions, have more control over the data, and the role of patients in the multi-party sharing of healthcare data is evidently diminished [17]. Regarding the sharing process, it is urgent to consistently manage the data sharing process and construct a scientific regulatory system. There are huge risks in the security and interest guarantee during the sharing and circulation of healthcare data. Although the signing of certain necessary protocols such as data sharing agreement (DSA), data use agreement (DUA), data protection agreement (DPA) guarantees data sharing activities to a certain extent, the effect of such protocols in the healthcare data sharing practices has not been fully implemented [18] owing to the lack of effective regulatory mechanisms. With respect to behavior stimulation, the profit distribution mechanism for healthcare data sharing has not yet been developed, while the value realization cycle of healthcare data sharing is still long, resulting in limited rewards of data sharing within a short term, and limited enthusiasm in healthcare data sharing [5].

2.3 Basic elements for data sharing

Ideal governance of healthcare data sharing covers the deployment of an overall guidance framework on development on a macro level, management provision and control basis for constructing sharing rules on a medium level, and guidance on good practice with technical standards and rules on a micro level. At the macro

level, *Temporary Measures for the Management of Government Service Resource Sharing*, *Measures for the Management of Scientific Data* and other documents have offered basic guidance and formulated related requirements regarding healthcare data sharing within a specific jurisdiction. At the medium level, although understanding of healthcare data sharing issues in China have deepened and a consensus has been reached on some issues, there is still lack of guidance from regulations and mechanisms, and few studies on related principles and regulations. At the micro level, a healthcare data sharing standards system and health information interconnection standards provide basic guidance for healthcare data sharing activities [19].

At present, scientific research institutions, medical institutions, and related enterprises are unwilling and dare not to share healthcare data, largely because of inadequate regulations and mechanisms for healthcare data sharing. On one hand, various parties fail to reach a consensus on the sharing of basic healthcare data. A number of prominent problems regarding healthcare data ownership, unfair interest distribution, and privacy protection, prevents the progress of inter-agency, cross-regional, and interdisciplinary data sharing. On the other hand, healthcare big data is an important data asset of strategic significance, essential to guarantee the safety of open data sharing in any informal and formal activity. Illegal actions on the Internet, such as cyberattacks and illegal data trading, have resulted in an ambiguous attitude of government across all levels toward open data, cross-agency data sharing [15]. Compared with the data sharing infrastructure that gradually enlarges, regulations on behaviors such as sharing willingness and participation of data subjects become a more important focus.

3 Frame analysis of international healthcare data sharing principles

Combining theoretical research and practical experience, basic healthcare data sharing principles can provide key guidance on launching data sharing activities. The UK, the United States, Canada, and some prestigious international organizations have already studied and published a series of frameworks and guidelines. The regulations can be roughly classified into three types, including ethics, law and practical experience orientation.

The focus should be placed on “ethics” as the basic guidance. Ethics is a basic element that must be followed in human-oriented healthcare data sharing. Shona Kalkman, et al. systematically examined 41 data sharing principles and moral codes published in the medical and health field of PubMed, Scopus, EMBASE, and Google Scholar as of August 2018 with “ethics” as the basic guidance. According to the statistical results of principle-related keywords, there is already a global consensus on the segmentation principles, such as data privacy respect and protection, accountability, transparency, participation, accessibility, data quality, and confidentiality. [20]. Of course, there are still differences in the definition details of these principle frameworks and standards, including the necessary quantity and contents of standards for protecting a certain principle, and corresponding methods of using principles and standards.

Attention should be paid to “laws” as the basic guidance. Relevant laws of healthcare data sharing provide basic regulations and bottom line support for sharing behaviors. In July 2019, the Information Commissioner’s Office, the data protection agency in the UK, compiled *Data Sharing Code of Practice* based on the *General Data Protection Regulation* (GDPR) of the European Union and the *Data Protection Act* of the UK, proposing six main points of data sharing behaviors. These include launching data protection impact evaluation, formulating data sharing protocols, implementing the accountability principle, determining the legal basis of data sharing, ensuring fairness and transparency of data sharing, as well as guaranteeing the legal rights of data subjects and handling personal data safety. It reasonably regulated the data sharing process [21]. This code launches data processing and sharing activities, with “the accountability system” as the starting point and rights of data protection entities as the core. It shifts the emphasis of data sharing supervision, urging enterprises and organizations to “be responsible and law-observant. Related enterprises and organizations should be responsible for data protection by promoting data protection impact assessment (DPIA) and making data sharing agreement (DSA) before data sharing. In other words, enterprises and organizations shall provide DPIA documents and DSA to reveal possible interests and risks brought to data subjects and organizations. The responsibilities and obligations of all data sharing parties should be clarified through legal agreements to prove that related data sharing activities meet the requirements of data protection laws like GDPR.

“Practical experience” also plays a vital role in the basic guidance. The promotion and standardization of healthcare data sharing stem from increased understanding and continuous experience and lesson gathering. In May 2017, Chatham House published *A Guide to Sharing the Data and Benefits of Public Health Surveillance* to

promote the sharing of public health surveillance data during the launch of global sanitary safety projects. The guide has summarized expert consensus from international healthcare sharing activities. Additionally, it has proposed seven principles, namely trust building, establishment of data sharing protocols, confirmation of legal background, plan data sharing, data monitoring and evaluation, quality data implementation, and value clarification, to help create a correct data sharing environment, and achieve good practice in data and profit sharing. Chatham House also determined four key ethics principles, namely social value, respect, justice, and transparency, and proposed that these principles shall be the basis of any data sharing protocols to guarantee the fairness, justice, and final success of this guide. Respecting the seven principles of data sharing also means respecting the four key ethics principles.

These international data sharing principles, covering ethics, legal norms, and practical experience, have remarkable effects on promoting the healthcare data sharing worldwide. According to the international healthcare data sharing principles and guidelines, no principle framework can cover all contents, and different principles may overlap and supplement each other. Although the emphases and application objects of the aforementioned three types of data sharing principles differ, there are similarities on how the data sharing principles were formed. For instance, most data sharing frameworks and guidelines have emphasized the importance of establishing data sharing protocols and set detailed requirements [21–25]. How to optimize and develop a coordinated governance framework from confirmed data sharing principles and standards in numerous studies, guarantee the public trust and promote data sharing to contribute to the development of healthcare data sharing in China are important topics that need to be addressed.

4 Design of basic principles for healthcare data sharing in China

To draw experience from international practice, this paper gathers 43 key principles from international guiding frameworks for healthcare data sharing. Analysis findings show that: (1) Principle design for healthcare data sharing based on ethics is relatively abundant. It is mainly launched by focusing on the value, respect, trust, fairness, and justice, and needs to be human-oriented. (2) Principle design under the legal guidance establishes legal rules for healthcare data sharing mostly from a regulatory perspective. (3) Principle design under the guidance of practical experience focuses more on the solution of practical issues, such as data quality, trust relationship, and planned data sharing, to ensure the sustainable launch of data sharing. (4) The above principle frameworks have emphasized the importance of establishing data sharing protocols, law observance, evaluation, and accountability from an implementation perspective.

Based on the status of data sharing in China, this paper further summarizes the above series of principles from the perspective of promoting healthcare data sharing behaviors (Table 1). These principle keywords are eventually extracted to eight basic principles, namely value, respect, trust, fairness and justice, evaluability and evaluation, normalization, accountability, and security (Fig. 1). Value, respect, trust, as well as fairness and justice are the key basic principles of ethics that allow constructing and providing a healthy data sharing environment, and encouraging and promoting data subjects to launch healthcare data sharing activities. The evaluability and evaluation principle can be applied to ensure smooth implementation of data sharing, and improve the data sharing quality and efficiency. The normalization principle can be applied to standardize the healthcare data sharing activities and ensure the compliant and lawful launch of activities. The accountability principle can be applied to regulate practical healthcare data sharing behaviors, and emphasize the law-based and morality-based accountability. The security principle can be applied to strengthen healthcare data protection, which is the basic “assessment” of healthcare data sharing behaviors, ensuring the safety of healthcare big data as the strategic basic resource of China. There is no absolute order in the eight basic sharing principles, and these principles can be ranked according to the practical conditions and application scenarios of healthcare data sharing. Aiming at the healthcare data sharing activities in general conditions, core factors will be elaborated in detail from the perspective of data sharing participants and behavior.

4.1 Value principle

Healthcare data sharing activity shall illustrate its social value. For instance, it can improve national health, serve regional hierarchical diagnosis and treatment, reinforce doctors’ abilities, monitor the health system, and control risks of infectious diseases over time. Or it can clarify the target value, for instance, it can support the completion of a certain scientific research or product development. Currently, regarding the value principle of healthcare data sharing, more emphasis can be laid on value generation, including but not limited to the data

sharing and exchange, and quality assurance. In terms of healthcare data sharing participants, measures like value generation and value feedback of sharing behavior encourage the participation in healthcare data sharing. Therefore, both non-profit sharing and paid sharing shall take the reflection of all party demands and value expectations into account.

Table 1. Analysis and design of healthcare data sharing principles.

Practical illustration [25]	Law-dominated [24]	Ethics-dominated [23]	Summarization	Basic principle
		Accessibility; sustainability; efficiency; interoperability; collaboration and capacity building; duty to share; scientific validity; engagement/participation	Ensure value generation basis	Value
Achieve quality data		Data quality		
Articulate the value		Social value; societal benefit; health-related public interest; promote health and well-being; protect life, health, and well-being	Achieve social benefits and values	
		Scientific progress/value; improved clinical care; improve public health; enhance healthcare decision-making		
		Respect individuals; respect/protect privacy; respect individual rights; individual autonomy; respect dignity of individuals; prevent discrimination; respect (the dignity of) communities; respect families	Respect participants	Respect
		Respect welfare of individuals; individual benefit; benefit sharing	Respect interests of participants	
Build trust		Professionalism; Responsibility; Solidarity; Maintain integrity	Confidence building	Trust
	Guarantee transparency	Transparency; maintain public trust; health democracy	Enhancing confidence	
	Guarantee fairness	Equity and fairness	Fair and equitable sharing	Fairness & Justice
		Reciprocity; recognition and attribution; attribution; proportionality	Fair and equitable distribution	
	Process personal data securely	Ensure data security; protect confidentiality	Ensuring data security	Security
Planned data sharing			To be evaluable	Evaluability & evaluation
Monitor and evaluation	Launch data protection impact evaluation	Risk-benefit evaluation	Implementation of shared assessments	
Understand the legal context	Determine the basis of legitimacy; protect the legal rights of data subjects	Legal compliance; protection of intellectual property; ownership; legal compliance	Abide by laws and regulations	Normalization
Create data sharing agreements	Sign data sharing agreements		Determining data Sharing specifications	
	Implement the "Accountability"	Accountability	Accountability	Accountability

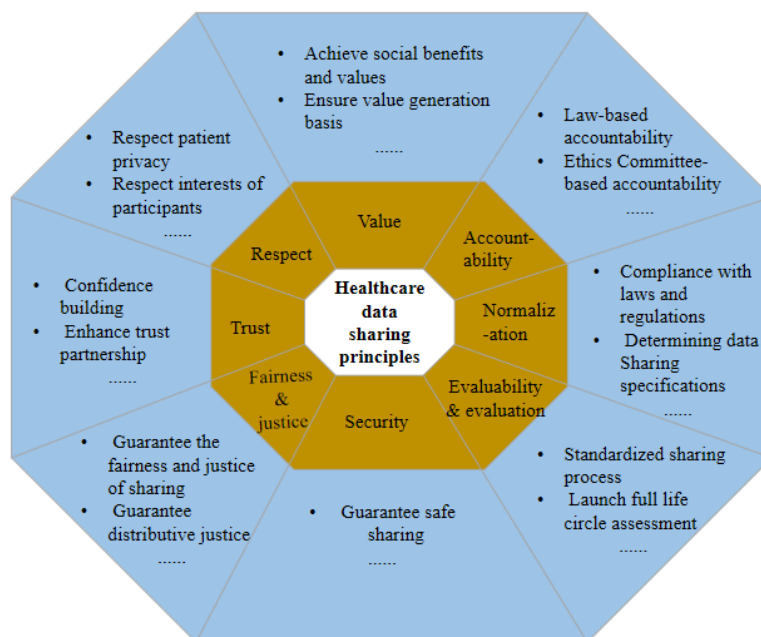


Fig. 1. Healthcare data sharing principles.

4.2 Respect principle

Respect principle is indispensable for healthcare data sharing. Healthcare big data integrates the information of patients. For individuals, health information belongs to sensitive information. Privacy is a fundamental human right, so healthcare data sharing and technological progress do not need to sacrifice personal privacy. To this end, strict requirements on data protection should be imposed. In addition, the launch of data sharing activities relies on the participation of various parties. To guarantee healthcare data sharing participation, the basic rights of data subjects shall be ensured. Particularly, the protection of intellectual property when sharing scientific experimental healthcare data is a fundamental approach for promoting valuable data sharing.

4.3 Trust principle

Establishing and maintaining a trust relationship is critical for promoting healthcare data flowing and sharing. The launch of healthcare data sharing is usually based on the mutual understanding and mutual integrity of participants. Standardization and transparency of data sharing processes would help enhance trust among partners, and further promote healthcare data sharing activities. Consequently, some necessary approaches can be taken from the individual or organizational level to reinforce the trust, which will contribute to the healthy development of sharing environment. While launching cross-region and interdisciplinary healthcare data sharing, it is especially necessary to follow the trust principle.

4.4 Fairness and justice principle

The reflection of fairness and justice in the profit distribution of data sharing is crucial for progress in healthcare data sharing. Healthcare data sharing shall realize fairness and justice in front of all participants, implying the coordination of power and responsibility and benefit guarantee for data sharing parties, namely the joint construction and sharing of healthcare data and joint sharing of risks; the coordination of power and responsibility of data recipients and access to fairness, namely joint data sharing and risk sharing, and right to access. On this basis, regulations on data exchange and sharing and profit distribution can be formulated guided by fairness and justice principles that can make data sharing and utilization transparent, realize mutual benefits to enhance the exchange and sharing of healthcare data, and reinforce the willingness of participants to share.

4.5 Security Principle

Security is an important premise for the launch of healthcare data sharing. The orderly opening in proportion is the best mechanism of maintaining and stabilizing healthcare data opening and sharing. In the context of big data,

while healthcare data sharing is launched in a large scale on the basis of necessary and proper principles, more attention shall be paid to the balance between data confidentiality and safety. Therefore, safe healthcare data sharing shall emphasize transparent and traceable data sharing processes, as well as security education and supervision of personnel participation in the sharing.

4.6 Normalization principle

Normalization principles emphasize more on the laws and regulations, codes of conducts, and process specifications that should be followed during the implementation of healthcare data sharing. Legitimacy is a basic principle that should be followed in healthcare data sharing activities, and legal background must be confirmed for implementing any healthcare data sharing activities. For instance, the launch of healthcare data sharing activities in China must comply with *Cybersecurity Law of the People's Republic of China*, *Civil Code of the People's Republic of China*, etc.; the launch of cross-border healthcare data sharing activities shall abide by GDPR of European Union, *Health Insurance Portability and Accountability Act* of the United States, etc. In addition, considering the incomplete laws and regulations on data sharing, the formulation of healthcare data sharing regulations can be regarded helpful supplement to standards on healthcare data sharing activities.

4.7 Evaluability and evaluation principle

Evaluability and evaluation principle emphasizes data sharing evaluation, as well as the implementation and operability of evaluation contents. "Evaluability" is reflected by healthcare data sharing and flowing reference in general and special conditions based on the establishment and standardization of laws and moral standards, and rights and obligations of corresponding personnel equipped in all steps, so as to realize the traceability and evaluation of healthcare data sharing. "Evaluation" is reflected by: reasonable division of behavioral steps before, during, and after the launch of healthcare data sharing activities and indicative standards, for the convenience of the timely traceability of sharing behaviors and proper adjustment of data sharing plans.

4.8 Accountability system principle

The establishment of an "accountability system" can effectively promote all roles in data sharing activities to undertake obligations and abide by laws and regulations on which data sharing activities are based. Relevant Chinese laws and regulations provide the fundamental basis of accountability for possible illegal behaviors in data sharing activities. Regarding the incomplete but necessary parts of laws and regulations, supplementary terms of accountability from the perspective of ethics reached by Ethics Committees and other organizations under the mechanism of multi-party consensus can be regarded as a flexible supplementary basis for conciliation and accountability.

5 Countermeasures and suggestions

The sharing and activation of healthcare data is significant for promoting the development of Internet Plus and artificial intelligence technology in the healthcare field, improving the social pension and people-benefiting service quality, and boosting the development and progress of medical science in China. Based on the theoretical guidance of the fundamental principles for healthcare data sharing and combining the challenges in healthcare data sharing in China, the following suggestions are proposed.

5.1 Following a human-oriented approach to stimulate the driving force for healthcare data sharing

The role and control of individuals in personal healthcare data sharing should be strengthened. Patients should be endowed with the absolute right to know, control, and choose over the personal healthcare data in general healthcare data sharing, including the authorization, transfer, and suspension. A data owner system should be established to clarify the rights and liabilities of "owners" over non-individual-patient healthcare data of scaled values, including the right of data sharing and transaction, data protection, and data maintenance and update obligation. A value incentive mechanism for healthcare data sharing should be built to fully mobilize the enthusiasm of all parties in launching and participating in the healthcare data sharing activities. The construction of a profit distribution mechanism should be promoted for healthcare data sharing, and paid or free sharing conditions or different types of healthcare data in general and special conditions should be clarified, including source data,

natural regeneration data, and artificial regeneration data. By virtue of solidified trading rules and profit distribution rules like intelligent contract mechanism of block chain, reliable healthcare data sharing applications can be built from the technical level.

5.2 Establishing a tracing mechanism for healthcare data sharing based on data sharing protocols

A transparent sharing system should be established featuring pre-event filing (approval), during-event traceability, and post-event accountability for healthcare data sharing activities based on standardized healthcare data sharing protocols. The launch of any healthcare data sharing activity shall submit corresponding data sharing protocols and change information to the enterprise management and supervision department. According to different data sharing purposes, data sharing protocols shall assess data sharing value as well as quality and effectiveness of shared data, guarantee the rights of participants and all contracting parties, clarify data sharing plans, and provide detailed information of factors, such as circumvention principles for data abuse. In addition, drafters and signers of healthcare data sharing protocols must profoundly understand the legal meaning of data safety and legal tools for promoting this process, to flexibly supplement disagreements or ambiguity in laws. Healthcare data sharing activities can be included in the government service platform for integrated regulation.

5.3 Improving the management standards for healthcare data sharing

Based on the *National Healthcare Big Data Standards, Safety and Service Management Measures*, the formulation and application of management standards for healthcare data sharing should be accelerated, and promote the application of middleware, such as standardly nested full lifecycle evaluation and alerting procedures and data authorized access control models, in data sharing infrastructure platforms. The prior-evaluation procedure should be guided by risk aversion and profit maximization of healthcare data sharing; the in-process evaluation procedure should pay attention to the examination the related conditions of data according to planned safe sharing and attainment of expected goals, to ensure the realization of expected results; and the post evaluation procedure should pay attention to summarize the problems in the process, and take feedback records for further optimizing the data sharing workflow.

5.4 Creating a safe and harmonious market environment for healthcare data sharing

The laws and regulations of the data element market should be improved, and a negative list system for healthcare data sharing activities should be established. The cooperative mode for healthcare data sharing and opening should be further innovated between governments, government and people, government and enterprises, and particularly between enterprises. For instance, a blockchain-based crowd-sourced platform can be created for healthcare data sharing. A themed interactive community can be created to promote target-oriented seamless interactions among various stakeholders on the entire healthcare data sharing chain, such as individuals, data intensive sectors (private and public sectors), technology enterprises, researchers, academic institutions, and capital providers. Moreover, a long-term communication mechanism should be established to enhance trust and to create a harmonious healthcare data market in an open and diversified cooperative mode.

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