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The challenges of cross-organizational patient data sharing in medical consortium: a study within the context of two-way referral systems

Lihong Zhou, Hanyu Miao, Ruiyang Tu, and Jiangfeng Hu

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Abstract

Objective. Under the background of two-way referral in medical consortium, the provision of high-quality hierarchical care requires active integration and cross-organizational sharing of patient data. However, cross-organizational data sharing among hospitals is not always spontaneous, comprehensive, and effective.

Methods. This paper reports on a research study aiming to identify the barriers of patient data sharing. Due to the exploratory nature of this study, two medical consortiums in central China were chosen to conduct a case study. Specifically, a mixed qualitative-quantitative approach was employed for the case study analysis and verification.

Conclusions. The analysis of qualitative interview data pointed to 27 barriers of data sharing under three main themes: psychological ownership; territorial behaviours; cross-organizational dynamism. The quantitative Kano analysis revealed the manifestation of these barriers, and their prioritization were classified into four types: must-be, one-dimensional, attractive, and indifference.

Implications. This study provides valuable references for enhancing the effectiveness of patient data sharing and optimizing the allocation of healthcare resources. The case setting is based on China's medical consortium, but the findings offer useful insights and indications that can be shared across international borders.

Introduction

Data, commonly understood as statistical observations or collected evidence (Zins, 2007), has become a crucial asset in modern societies (Hilbert, 2016). However, data is often only used to a limited extent or frequently only in an internal organization context (Prajogo et al., 2018). Data sharing refers to breaking down the data barriers between organizational departments, establishing a unified data sharing mechanism, and accelerating the flow of data resources within the organization (Harris et al., 2007). It also encompasses making research data publicly available with minimal reuse restrictions, known as open data (Thoegersen & Borlund, 2022). While data sharing increases the complexity and quantity of data (Kowalczyk & Shankar, 2011), it plays a vital role in advancing scientific collaboration (Priego et al., 2022), urban governance (Palm et al., 2019), public health management (Brand et al., 2022), and social development.

The hospitals are typically data-intensive organizations. Health decision making has become increasingly complex, and the use of patient data has become essential in this information age (Van, 2014). Integration of patient data has been perceived to be a breakthrough for the discovery of timely, cost-efficiency therapies, and a crucial step towards enhancing the quality of medical care for curing diseases (Weitzman et al., 2010). Two-way referral serves as a classic example of patient data sharing. It refers to the transfer process between hospitals of different levels, specialized hospitals, or between general and specialized hospitals (Huang et al., 2023) based on the health needs of the population. Nowadays, the integration and cross-organizational sharing of patient data has become a key part of achieving the goals of hierarchical diagnosis and two-way referral.

Recognizing the importance of addressing these medical needs and challenges, the Chinese government attempted to improve medical development through the establishment of medical consortium (Li et al., 2017). Medical consortium includes urban medical groups led by tertiary public hospitals, county medical communities led by county hospitals, and specialist alliances and telemedicine collaboration networks with specialist associations as the link (Cai et al., 2018).

Nevertheless, barriers exist to integrated working, including technical and ethical issues, organizational resistance, financial costs, and privacy concerns (Houtkoop et al., 2018; Li & Cong, 2024; Reddy et al., 2024). Meanwhile, different hospitals have different regulations and willingness on sharing patient data in the two-way referral process, which has made the implementation of hierarchical diagnosis and treatment less effective than expected. Yet current research in this field is notably limited.

The paper reports on a research project that aimed to identify and solve existing barriers to cross-organizational sharing of patient data in the context of two-way referral in medical consortium. To further the analysis, the following research questions were formulated:

> RQ1. What are the barriers of patient data sharing?
>
> RQ2. Which are the priorities of these barriers?
>
> RQ3. What are the practical strategies to address these barriers?

Research methodology and design

To answer our research questions, and considering the exploratory nature of this study, a case study approach is employed. According to China's current '*Hospital Classification and Management Measures*', 3A hospitals are the highest level in the classification of hospitals in Mainland China. After careful consideration, Xiangyang First People's Hospital Medical Consortium and Xiangyang Traditional Chinese Medicine Hospital Medical Consortium is adopted as the research case. Both hospitals are Grade 3A hospitals, which ensures the representativeness of the research and can accurately reflect the situation in the entire medical field.

The research was carried out in two stages. In *stage one*, qualitative research was undertaken to identify the barriers of patient data sharing. Semi-structured interviews were used to gather qualitative data, with guaranteed access to interview respondents. All interviews were recorded using a digital recorder and transcribed verbatim into MS Word files. NVivo 14 was used to facilitate the analysis of interview data.

After that, a Kano model analysis was carried out in *stage two* to verify and validate the barriers identified in the qualitative study. In this stage, Kano model analysis was used to prioritize barriers of patient data sharing. It was expected that through the prioritization processed, effective strategic suggestions could be formulated.

Stage one: qualitative research

Research methods and processes

As discussed previously, semi-structured interviews were used to collect qualitative data, which were then analysed using a thematic analysis approach. A framework proposed by Brown et al. (2014) was used as a basis for data collection and analysis, as shown in Figure 1. The framework comprises three categories which are psychological ownership, territorial behaviours, and cross-organizational dynamism (Brown et al., 2014), that can help understanding barriers in patient data sharing.

- Psychological ownership: hospitals have invested a lot of manpower, material resources and time costs to maintain patient data, so that they have regarded patient data as their inseparable assets.
- Territorial behaviours: are actions can be adopted by hospitals for the protection of their perceived ownership over data. Hospitals are inclined to keep and safeguard their data instead of sharing it willingly.
- Cross-organizational dynamism: can moderate the influence of psychological ownership on territorial behaviours.

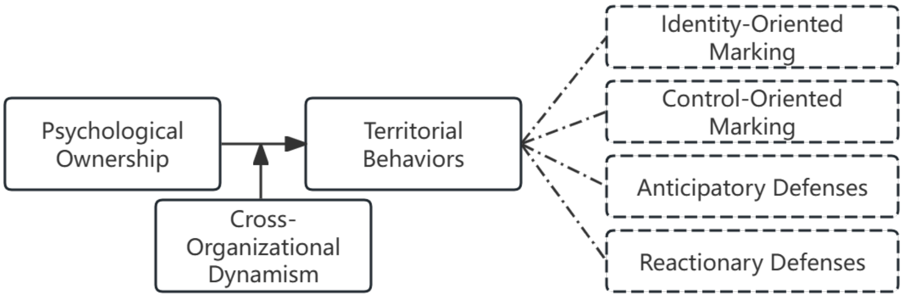

Figure 1. A preliminary analytical model based on the research of Brown et al. (2014)

The semi-structured question script was designed based on Figure 1 and consisted of 15 questions, including 1 ice-breaking question and 14 theoretical probing questions. Before entering the case study, the question script was proofread and trialled with two professors in the field of cross-organizational data sharing. A total of 13 staff and patients were approached and interviewed. The demographic profile of the participants is illustrated in the Table 1 below:

No.	Interviewer	Department/Section
A	Engineer	Information Center
B	Engineer	Information Center
C	Department Leader	Information Center
D	Clerk	Medical Office
E	Clerk	Medical Office
F	Department Leader	Information Center
G	Engineer	Information Center
H	Department Leader	Medical Office
I	Head Nurse	Nephrology
J	Nurse	Nephrology
K	Chief Physician	Nephrology
L	Referral patient	Orthopedics
M	Referral patient	Neurosurgery

Table 1. Information on interview participants

All interviews were interviewed in March 2024. At the beginning of every interview, the participant was consulted if the use of digital recorder could be accepted. The participants were assured that they can stop the recorder whenever they feel uncomfortable.

Instead of directly diving into the question-answer dialogue, the interviews started by making some irrelevant and light conversations. After obtaining informed consent, all interview recordings were then transcribed verbatim by the research team. The transcripts were analysed using a thematic analysis approach.

In the research, the Brown et al. (2014)'s framework was considered as generic requirements and were converted into a preliminary set of codes in the early stages. Throughout the data analysis, these codes were reconceptualized, expanded and revised, according to the statements, interpretations, and perspectives of the individual interview participants.

Findings

The analysis of the interview data inherited the thematic analysis strategy of the model (Figure 1), the themes and codes resulting from the analysis are shown in the Table 2.

Theme	Sub-theme	Coding	Identifier
Psychological Ownership	-	Fear of declining status after sharing	A1
		Reluctance to give up data assets	A2
		Lack of access to required data	A3
Territorial Behaviours	Identity-Oriented Marking	Using different data systems	B1
		Different data processing standards	B2
	Control-Oriented Marking	Complex approval process for declarations	C1
		Self-determination of the form of sharing	C2
	Anticipatory Defences	Distrust of shared patient data	D1
		Passive response to data sharing construction	D2
		Insufficient resources in primary medical institutions	D3
		Lack of personnel in data sharing positions	D4
	Reactionary Defences	Excessive accountability for data accidents	E1
Cross-Organizational Dynamism	Cross-Organizational Management	Deviation between government planning and real needs	F1
		Lack of clear policies and regulations	F2
		Lack of government supervision and guidance	F3
		Limited results of medical insurance reform	F4
	Cross-Organizational Relationships	Lack of high-level cross-organizational mechanism	G1
		Lack of preliminary cooperation foundation	G2
		Lack of trust between organizations	G3
		Interest game of tertiary hospitals	G4
		Loose cooperation of medical consortium	G5
	Cross-Organizational Risk	Unclear rights and responsibilities for sharing	H1
		Lack of incentive and compensation mechanism after sharing	H2
		Low level of informatization of medical institutions	H3
		Lack of financial support	H4
		Concerns about data quality	H5
		Concerns about data security	H6

Table 2. Requirements, themes, coding, and identifier

The data analysis shows that the interviewees frequently highlighted psychological barriers related to the perceived ownership of data assets. A significant challenge for hospitals is the fear of diminished status after data sharing. This concern is particularly pronounced among community and secondary hospitals, as an interviewee noted, '*liberalising data sharing will enable doctors at the next level of care to improve their standards, which poses a threat to us*' (Interview F). Besides, in the context of big data, '*data are considered assets*' (Interview A). Hospitals invest considerable resources, including manpower, material, and time, into maintaining patient data, treating it as a crucial and inseparable asset. As a result, they are unwilling to engage with or learn how to use data-sharing platforms, which further complicates their ability to access data through these platforms.

The data analysis showed that territorial behaviours can significantly affect patient data sharing, with four specific manifestations identified. Identity-oriented marking refers to the fact that '*each* *hospital has its own HIS system*' (Interviewee B), enhancing the complication of integrating systems to achieve data sharing. Besides, '*data processing standards*' (Interviewee A) varies, with no unified stipulation to realize data cross-authentication. Control-oriented marking is evident in the lengthy approval processes of data sharing request, with '*several people need to sign only a piece of file and taking at least three working days to approve it*' (Interview M). Anticipatory defences especially reflect a passive response and prudent attitude to obtained data. Meanwhile, deliberate procrastination can also be a common action to defend settled data sharing request, since '*they even do not arrange people to specifically designated to handle this issue*' (Interview E). Reactionary defences generally occur when hospitals actually experience data infringement by others. There is evidence showing that an excessive accountability for data accidents will be taken as a defensive action to the specific hospital. As a doctor stated that '*if they fail to take the necessary security measures and cause a data breach, they must take the responsibility*' (Interview L).

Furthermore, the interviews revealed significant barriers to cross-organizational data sharing, primarily related to management, relationships, and risk. The most important barrier for management issue is the current legal framework lacks clarity, as noted by an interviewee, '*the overall plan does not conform to the actual situation*' (Interview G). To enable effective data sharing management, a unified data centre is essential. However, the absence of a high-level cross-organizational mechanism exacerbates this problem. In terms of relationships, hospitals express concerns about '*data security*' (Interview B/C/J) and '*data quality*' (Interview H/I/J), which affect the trust and collaboration for data sharing. Additionally, issues following data sharing include '*unclear sharing rights and responsibilities*' (Interview F) and an '*absence of an incentive compensation mechanism*' (Interview A). These risks highlight the need for clearer guidelines and effective incentives.

Stage two: Kano model analysis

Research methods and processes

Kano model is composed of two important concepts, one is the objective realization of requirements, the other is the subjective satisfaction of users. *Stage two* employs the Kano model to validate and verify the barriers identified in *stage one*. Moreover, *stage two* measures the priority of the barriers and classifies the barriers into four categories (sorted in the order they should be solved): Must-be (M); One-dimensional (O); Attractive (A); Indifferent (I) (Xu et al., 2009). Data collection is divided into three main steps.

- Questionnaire design. This study transforms the identified disorders into demand items. Excerpts from the interview transcripts from Stage One were used as evidence for the design of questionnaire.
- Grading of questions. Every option setting refers to the Likert 5-point scale method (Adelson & McCoach, 2010). And respondents can choose from one of the following five indicators: I like it that way, it must be that way, I am neutral, I can live with it that way, and I dislike it that way.
- Questionnaire distribution. This study uses both online and offline methods to place and collect questionnaires. The questionnaires were distributed and returned in April 2024, yielding 98 valid responses.

Findings

Defining primary quality attribute (PQA) was the first step in Kano model analysis. In the analysis, responses from the questionnaire survey to the functional and non-functional questions of the requirements were combined and then assigned to a Kano evaluation matrix (Table 3). Using the matrix, a requirement can be defined and categorized into one of the M, O, A, I, R and Q categories. For instance, the analysis of requirements B1 is shown in Table 4. B1 is an A requirement because A represents the highest ratio. Repeating the above analysis processes, all requirements could be calculated.

Requirements		**Non-functional issues**				
	Scale	I dislike it that way	I can live with it that way	I am neutral	It must be that way	I like it that way
Functional questions	I dislike it that way	Q	R	R	R	R
	I can live with it that way	M	I	I	I	R
	I am neutral	M	I	I	I	R
	It must be that way	M	I	I	I	R
	I like it that way	O	A	A	A	Q

Table 3. Kano evaluation matrix

Requirements	**A**	**O**	**M**	**I**	**R**	**Q**
B1	48.0%	10.2%	18.4%	23.5%	0	0

Table 4. A sample of Kano evaluation matrix for B1

User satisfaction coefficient (UCS) measures a situation whereby achieving a requirement of patient data sharing can prevent dissatisfaction. It comprises two indicators: satisfaction index (SI) and dissatisfaction index (DSI).

$$SI = \frac{A + O}{A + O + M + I} \qquad (1)$$

$$DSI = \frac{(-1) \times (O + M)}{A + O + M + I} \qquad (2)$$

Based on the calculation of SI and DSI, a satisfaction impact matrix can be developed with an X-axis presenting the DSI values and a Y-axis illustrating the SI values.

$$X = DSI(DSI_{min}, DSI_{max})DSI[-1,0] \quad (3)$$

$$Y = SI(SI_{min}, SI_{max})SI[0,1] \quad (4)$$

$$O(X, Y) = (X_{ave}, Y_{ave}) \quad (5)$$

Therefore, the UCS is developed as shown in Figure 2. Moreover, the barriers are divided into four sections: Attractive (A): B1, C1, D4, E1, F2, G2, G4, G5, H4. One-dimensional (O): B2, H2, H6. Must-be (M): A2, A3, D2, F1, G1, H1, H3, H5. Indifferent (I): A1, C2, D1, D3, F3, F4, G3.

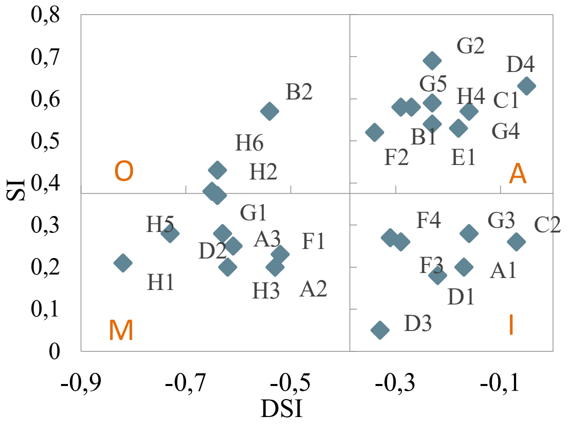

Figure 2. User satisfaction impact matrix

Discussions and conclusions

This paper uses a comprehensive approach to identify barriers to patient data sharing and validate the prioritization of barriers. Using deductive qualitative methods, 27 barriers of data sharing were identified under three main themes. Subsequently, these barriers were categorized into four levels using Kano analysis based on the quantitative measurement. This study generates the following specific strategic suggestions.

First, establishing standardized patient data specifications is a critical prerequisite for effective data sharing. It is recommended to systematically categorize data types, encompassing essential attributes such as format, storage methods, and access rights. A comprehensive and compatible standardization framework should be developed. Based on this, a specialized team should be established to oversee the implementation of these data standards. Additionally, hospitals should prioritize the development of new technologies and increase capital investment to ensure the real-time updating and seamless transmission of critical medical information.

Second, to enhance the diagnostic and therapeutic capabilities of medical consortium, it is crucial to prioritize comprehensive training programs to ensure all employees are equipped with the essential skills and knowledge. This training should focus on fostering a robust understanding of collaboration and resource sharing within the network. As this awareness deepens, employees will gain a deeper understanding of data sharing. This understanding will ultimately foster a cooperative culture, enabling smooth and effective sharing of medical data and resources across organizations.

Third, to address the challenges of financial support and benefit distribution in data sharing, it is imperative to enhance government involvement. Specifically, the government should urgently increase financial support and establish a dedicated subsidy system for patient data sharing. Additionally, a cross-organizational communication framework centered on data sharing should be developed, with a committee comprising hospital representatives overseeing this initiative.

Fourth, for the sake of improving the staff's ability to understand and utilize the medical consortium effectively, hospitals should implement targeted educational activities emphasizing the importance of data quality, including holding lectures, seminars, etc. At the same time, hospitals should collaborate with data experts and software developers to design comprehensive training courses for the medical information system, covering system functions, operating logic, application scenarios, etc.

In conclusion, cross-organizational patient data sharing in medical consortium offers a unique opportunity for hospitals to redefine, reposition and reinvent themselves. This research adds to the general knowledge base by proposing a comprehensive set of barriers of patient data sharing and strategic suggestions, which can be adopted as a knowledge base and a starting point for future studies. Also, future work can aim at expanding the sample coverage and conducting research on different types of medical consortium.

About the authors

Lihong Zhou is a Professor in School of Information Management, Wuhan University, Hubei, China. He received his Ph.D. from the University of Sheffield and his research interests are in library management and data sharing. He can be contacted at L.zhou@whu.edu.cn

Hanyu Miao is currently pursuing a master's degree in Library Science at School of Information Management, Wuhan University, Wuhan, China. Her research interests are in library management and data sharing. She can be contacted at Miaohyeah@163.com

Ruiyang Tu received his master's degree from School of Information Management, Wuhan University, Wuhan, China. His research interest is in data sharing. He can be contacted at trysim@whu.edu.cn

Jiangfeng Hu is a Ph.D. student in School of Information Management, Wuhan University, Hubei, China. Her research interests are in library management and data sharing. She can be contacted at jiangfeng.hu@whu.edu.cn

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