Health Data Governance Issues in Healthcare Facilities: Perspective of Hospital Management

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Abstract— Health data from healthcare facilities are helpful to monitoring and planning national health, research in health, healthcare performance, and improvement of patient care. Health data governance is used to increase the benefits of health data and reduce the risk of health data itself. Through the One Data Indonesia program, Indonesia encourages health data quality that the government can use. This research was conducted to analyze the issues in healthcare facilities related to health data governance with a qualitative approach. We used a semi-structured interview with three different healthcare facilities in Jakarta with six participants; hospital director, IT manager, and medical record management. We find five major health data governance issues in healthcare facilities; IT resources and responsibility, data quality, data security, data standard, and policy. It leads to how we should design health data governance in health care to provide high-quality health data for health research, health decision-making, patient care, and national health strategy.

Keywords— *eHealth, Health Data Governance, Healthcare Facilities*

I. INTRODUCTION

Data in healthcare grows very fast, in structured, semi-structured, and non-structured formats [1]. Health data were generated from medical records, insurance claims, surveys, bio-banks, laboratory reports, radiology, pharmacy transactions, and behavioural and environmental monitoring device [2]. While data keep growing, there are so many issues about data quality, data accuracy, and reliability in the healthcare industry [3].

Health data from healthcare is useful in monitoring and planning national health, research in health, healthcare performance, and improving patient care [4]. In addition, organizations created specific compliance for sharing, protection, and analytics to achieve final output [3]. Compliance requirements can differ across the organizations, which might be an additional burden when requesting healthcare [3][5]. In 2019, Indonesia launched a policy regarding the One Data Indonesia program through the data.go.id portal, including health data. This policy is related to national data governance, which aims to create quality data, easily accessible and shared between Central and Regional Agencies [6].

As a complex organization, healthcare facilities generate health data during day-to-day patient healthcare captured in many different ways. Reusing health data give benefit and risk; health data governance is used to increase the benefits of health data and reduce the risk of the health data itself [4]. Healthcare organizations have been relatively slow in adopting health data analytics due to the critical challenges associated with the management, processing, and security of patient data [7]. Data governance in healthcare includes stakeholders within and across the continuum of care; it creates reusable data through its formal process of standardizing data values and meaning; it bends the curve in the speed of integration and reform of healthcare [8].

COVID-19 has forced many organizations to adopt work from home immediately. It makes the organization's IT teams work more to support a new condition, especially in healthcare organizations. They struggled to provide in-hospital information technology and at-home IT services [9]. It also creates new technology such as contact tracing and virtual healthcare services; both give issues in security and privacy in health data [10].

In Indonesia, the COVID-19 pandemic has triggered the acceleration of digital transformation, especially in the health sector [11]. Some health applications are developing, such as telemedicine and information health management in healthcare facilities. The pandemic has also caused problems related to data privacy, such as the leaking of information about COVID-19 patients [12][13], data validation problems such as mismatch of reporting dead cases data between regional data and central data [14], and data access problem such as information on bed occupancy ratio (BOR) in hospitals to the citizen [15]. Those problems are related to data governance issues in healthcare facilities.

Challenges in health data occurred in data collecting, sharing, and collaborating. Incomplete data, different data structures, data accuracy, and data principles become significant issues in healthcare facilities that need data governance [3][16]. Research on health data governance in healthcare facilities is still rare; some of them try to make a health data governance framework to solve health data quality, data accessibility, and data standardization problems in healthcare facilities [17][18][19].

This research was conducted to analyze the problems in healthcare facilities related to health data governance, that we could find the challenges faced by healthcare facilities in health data governance to support national health data. Our contribution is to find major issues that lead to how we design health data governance in healthcare facilities. This paper is organized into six sections; section one describes the research background, section two describes health data governance, the methodology described in section three, the result from our research explained in section four, discussion and conclusion from this research would tell in sections five and six.

II. HEALTH DATA GOVERNANCE

The COVID-19 pandemic has quickly spread health data exchange between organizations and countries. It prompted WHO (World Health Organization) to hold a Health Data Governance Summit in July and September 2021 to identify

the potential solutions in challenges to implementing a standard, data governance framework, and solutions in infrastructure to increase values of health data sharing [20]. WHO suggests being FAIR (Findable, Accessible, Interoperable, Reusable) and CARE (Collective Benefit, Authority Control, Responsibility, Ethics) principle as a framework health data governance for the country to support health data as a good public [21], with CARE principles should be done in health data collectors, like healthcare facilities.

Data governance refers to making the effective decision about asset data and who make the decision [22]. It is focused on improving data quality, compliance with policies and procedures [23], data storage, communication and data management, and data asset valuation [1][24]. The term data governance consists of two levels, micro and macro level. The concept in the micro-level is the management of part of organization governance, whereas in macro-level related to the political issue, country, inter-organization, and international relationship [25][26]. A people-centred and trust-oriented approach was proposed for Low Middle-Income countries to help achieve Universal Health Coverage (UHC) in the era of a data-driven society, as a sample of health data governance at the country level (macro-level) [27]. This study compared three national health data governance approaches in Japan, China, and the United States of America [27]. In comparison, OECD proposed 12 high-level principles of data governance frameworks so that more countries can use health data for research, statistics and healthcare quality improvement [28].

Micro-level data governance focus areas are consistency, availability, data integrity, usability, and data security to provide high data quality during a period of data use [25]. As a stakeholder, healthcare facilities generate and act on health data, and data stewardship and data processor in health data governance [29]. Governing data in healthcare facilities build in 3 pilar as data quality, data compliance, and business transformation [17]. We used these themes to analyze our data.

III. METHODOLOGY

We adopt a qualitative approach to analyze data governance issues in healthcare facilities. A qualitative approach has been used in health data governance both in practical and scientific research [30][18][31][17]. The semi-structured interview was conducted to understand the issues in healthcare facilities. We combine frameworks from DAMA, Data flux, OECD, and Maturity assessment for HIS to construct a list of questions [32][24][33][34]. The listed questions are below:

1) What are data being managed?
2) Is all data stored in electronic form?
3) What applications do you have?
4) Is there any policy regarding data privacy issues?
5) Is there any policy regarding data security issues?
6) Does each data have data documentation?
7) Do you use one standard for clinical coding?
8) How do you define the quality of data?
9) What is the procedure to ensure the data is complete and correct?
10) Who is responsible if there is a problem with data?
11) How is the process to correct the problems related to the data?
12) Is the report data used automatically generated from daily medical records and daily patient registration/payment data?
13) How do you provide the report?

We interviewed six informants from different hospitals. In this study, we limit only hospitals implementing Electronic Medical Records. We had three hospitals as respondents. Due to time constraints, we could not increase the number of hospitals in this study, details the hospitals listed on Table I. The medical record keeper manager and the director were included as informants to give more perspective about health data from non-IT. Interviews were conducted online and offline in time of October – November 2021, by face-to-face with a duration of between 30 – 60 minutes. Table II shows the demographics of the interviewees. We analyzed the results using the thematic analysis with NVivo 12 version software for windows.
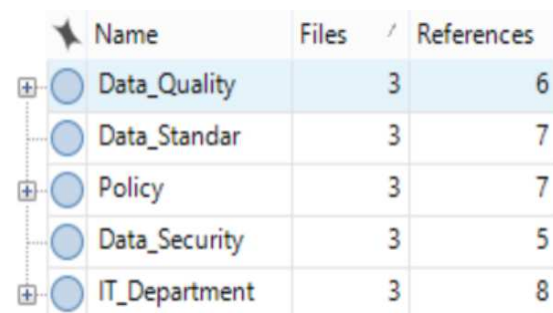
TABLE I. DEMOGRAPHIC OF HOSPITALS

Hospital	Hospital Type	EMR Status	Hospital Accreditation
H1	Regional Special Hospital Public Hospital Type A	Fully implemented	National Plenary level
H2	National Special Hospital Public Hospital Type A	Half Implemented, only for outpatient	National Plenary level
H3	General Hospital Private Hospital Type C	Half Implemented, only for outpatient	National Plenary level

TABLE II. DEMOGRAPHIC OF PARTICIPANTS

Participants	Hospital	Role of Participants
P1	H1	Hospital Director
P2		IT Manager
P3	H2	IT Manager
P4		Medical record Manager
P5	H3	IT Manager
P6		Medical record Manager

IV. RESULT

Several issues were discovered during the analysis process. Fig 1 shows the frequencies of coding reference per theme using NVivo, and Fig 2 shows a visualization of the connection between themes and sub-themes.

Fig.1 Frequencies of Coding references

Fig.2 The Concept Map

A.   Data Quality

Data quality has an issue in the healthcare industry due to the complexity of clinical system data structure, lack of standardization and massive growth of the data [17]. The problem occurs from collecting in terms of completeness and accuracy [2]. We find most healthcare focuses on the completeness of data for insurance claims. They have an internal team to validate the medical record and other patient administrative data. Our partisipan P4 said:

"... the case mix team will later fill in the completeness of the contents of the medical resume...... Now the case mix team is a combination of doctors, nurses, and other health workers such as pharmacists and labs... that main purpose for insurance claims..."

In private hospitals, completeness of data refers to the validation of financial data. The statement from P6 was:

"... since we still use the partial system, data validity processed by comparing the manual and the system.... for example, there are nine medical record data, but ten payment data. Then the data referred to and must be completed is ten, and will be completed from manual data.... "

Healthcare facilities focus on health data quality in terms of internal financial purpose; there is no process in data correctness to support research or decision support in non-financial aspects.

B.   Data Standard

Even though the participant uses the same clinical coding, the purpose is compatible with the national health insurance system (*Badan Penyelenggara Jaminan Sosial Kesehatan; BPJS*). Many healthcare facilities build their hospital system by their organization needs, without one standard from the national regulation. The statement came from participant P1; as a director, he explained the main problem is not completeness but the standard. Without standards from the regulator, it is very hard for the hospital to support good data for the regulator.

Hospital standards refer to SNARS (National Standards for Hospital Accreditation), such as standards for the operation of hospital information systems [35]. However, it is more of a process standard. SNARS requires SIMRS to perform interoperability with other systems, but there is no standard for interoperability with other systems. The Hospital needs national technical standards from regulator to know the type, the field, and measure of data the system should provide.

C.   Data Security

Health data governance reduce social risk in data privacy and security [2]. Many healthcare facilities ensure compliance with internal privacy and security policies and comply with externally legislated regulations [17]. Healthcare facilities still depend on the IT team for security and quality issues. No organization has a data security policy, is handled by the IT team using username, password, and levelling user protocol. Some develop a complex system log to cover data security and quality issue.

D.   Policy

Healthcare facilities do not have their policy regarding data privacy, although there are rules regarding public information national policy. As P3 said;

"We create based on government regulations regarding freedom of public information...... but We do not have internal regulation."

The same statement from participants P4 and P6, although there is no internal policy, they work according to the oath of the profession.

It happens because electronic health record is newly implemented in hospital, some in half. Organizations still focus on developing a system with high user acceptance. We conclude it from a statement from P1, as:

"We have been developing this only for 1.5 years, and currently we still focus on meeting user needs regarding applications that are still developing..... internal policy are made when the system is stable."

In the process aspect, healthcare facilities lack awareness of the internal policy. Some of the procedures are work based on individual initiative, as explained by P4;

"Usually we do cross-checks to the heads of each unit, ... whether it is an SOP or a policy that does not exist yet, because there has not been any socialization to me, but the work system is already running."

E. IT Departement

Business transformation is a change in the healthcare management strategy to align people, processes and technologies more closely with its business strategy [17]. We find people issues in digital transformation in the healthcare industry. Healthcare facilities have limitations in the number and skills of IT personnel, and this is a challenge to develop applications to manage complex health data. In a private hospital, all healthcare system information and application are developed using a vendor (third party), but public hospitals develop with limited internal IT resources. Statement from P3 explained the limitation.

"... we do not have a human resource in IT architecture... we developed the system only with two

programmers, and work for six months...... the covid-19 also something new for us, so electronic medical records are only used for outpatients. "

A similar statement also came from P2.

With the limited number of IT personnel, they are also responsible for managing, reporting, and improving data. For all the errors in health data, the IT department involved in correcting and completing the data, as mentioned by P3:

"For all data problems, an event report will be made by us, if the error is due to human error, we will fix the data right away; if the error is due to the application, we will fix it too..."

A similar statement also came from P5, as:

"Data correction is carried out together with IT teams."

The IT team provides data reporting to management and external parties, such as national and local governments. Some hospitals have dashboard data for internal management, but none report tools to the government; due to no standard reporting health data from the governments. These all responsible are given by the organization, as mentioned by P1:

"... IT team in charge of data management..... some reports were also made by the IT team, especially reports to government, because they could not give as the standard report they need."

With the large responsibility of the IT team, the information system being developed does not have good documentation, such as data dictionaries and technical documents for system development.

V. DISCUSSION

This qualitative research found five health data governance issues in healthcare facilities. There is no issue related to technology. The IT department condition was an issue related to people; they have a limited number of programmers and have many responsibilities. Due to no national standard in reporting to the government, the IT team kept busy providing many reports to the government party.

The organization issues are data quality, data security, data standard, and policy. National health insurance is a driving force in data standards and data completeness. The ICD-9-CM and ICD-10-CM as clinical code is used based on the clinical code standards by BPJS, and the completeness of health data is carried out based on the need for BPJS insurance claims. Even though we have one Indonesian data [6], the National Ministry of Health needs to make a national standard regarding applying health data in hospitals. This standard becomes a guideline for hospitals in preparing data to support national policies.

Some national policies have been adopted by organizations, especially for privacy and security issues, but some do not have an internal policy to ensure these rules are enforced internally. It is because the organization is still focused on developing its internal system, so the policies regarding health data have not been made. Data governance is about compliance with policy and procedures [23]. Internal policy is needed to ensure that the organization compiles national regulations.

VI. CONCLUSION

As mentioned in the introduction, research on health data governance in health facilities is still rare in developed and developing countries. This study enriches research on health data governance in health facilities by looking at the perception of hospital management on the challenges in implementing health data governance, both internal and external aspects.

We find internal challenges healthcare facilities face in health data governance to support national health data. Data quality composes of completeness, correctness, and accuracy of the data. The healthcare facilities only focus on the completeness of the health data related to internal financial problems, such as reporting financial data and insurance claims. The issue of accuracy and correctness of the data needed in research and decision-making using health data have not become the main focus of healthcare. As an external factor, no national standard for health data triggers the lack of these healthcare facilities to provide high-quality data to support national decision-making in the health sector during the pandemic.

The limited number of IT personnel is the main obstacle to building a complete information system, so health data is still digital and non-digital. It makes hospitals still focus on system development and have not prioritized reusing health data, which requires data governance. Other issues are in security and policy; security and policy still depend on national regulation, no internal policy and compliance.

This research leads to how we should design health data governance in health care to provide high-quality health data for health research, health decision-making, patient care, and national health strategy. It also maintains data privacy and ensures data security during the data life cycle process.

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