FAIR Equivalency in Indonesia’s Digital Health Framework

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ABSTRACT

The objective of this study was to assess the regulatory framework for health data in Indonesia in order to understand the policy context and explore the possibility of expanding the adoption and implementation of the FAIR Guidelines, which state that data should be Findable, Accessible, Interoperable and Reusable (FAIR), in Indonesia. Although the FAIR Guidelines were not explicitly mentioned in any of the policy documents relevant to the Indonesian digital health sector, six out of the eight documents analysed contained FAIR Equivalent principles. In particular, Indonesia’s Population Identification Number (NIK) has the potential, as a unique identifier, to support the integration and interoperability (findability) of data, which is crucial to all other aspects of the FAIR Guidelines. There is also a plan to build standards and protocols into the implementation of information systems in each ministry and government agency to improve data accessibility (accessibility), the integration of the various information systems is planned/ongoing (interoperability), and the need for a standardised arrangement for health information systems related to health data following the community standard is recognised (reusability). The documents at the core of Indonesia’s digital health/eHealth policy have the highest FAIR Equivalency Score (FE-Score), showing some degree of alignment between the Indonesian digital health implementation vision and the FAIR Guidelines. This indicates that Indonesia’s digital health sector is open to using the FAIR Guidelines.

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1. INTRODUCTION

Across the globe, digital health is applying technology such as smartphones and sensor technology, to improve patient health and health care delivery [1]. These technologies include both hardware and software solutions and services, including telemedicine, web-based analysis, email, mobile phones and apps, text messages, wearable devices, and clinical or remote monitoring sensors [2]. There are currently more than 300,000 health applications globally; these applications are used to access health services and encourage healthy behaviour with diet and nutrition control, lifestyle monitoring, stress measurement, and even applications supported by digital sensor connections from wearable devices such as smartwatches [3]. The potential for the use of technology in the health sector is very high. Therefore, at the 58th World Health Organization (WHO) meeting about Resolution WHA58.28, all of the members of WHO agreed to prepare for the implementation of eHealth. In line with this, WHO has launched the Global Observatory for eHealth (GOe), a project to help study the development and effect of eHealth in different countries [4].

Against this backdrop, Indonesia has an excellent opportunity to answer health challenges by using digital health. The latest Indonesian Internet Service Providers Association survey in 2019 reported that Internet penetration among the Indonesian population had risen by 10.12 percentage points to 64.8% (or 171.17 million people) in 2018 [5]. There has also been an increase in the number of information technology systems implemented in Indonesia. A survey by Sanjaya et al. in 2013 about information technology implementation found that 63.38% of 71 hospitals in the Province of Yogyakarta, one of the biggest cities in Indonesia, used hospital management information systems [6]. However, a severe weakness with these systems is their capability to share patient information between hospitals. Difficulties with interoperability are not only experienced between hospitals, but within hospitals as well.

The FAIR Guidelines—an acronym for ‘Findable’, ‘Accessible’ (under well-defined conditions), ‘Interoperable’, and ‘Reusable’—were first discussed in 2014 at the Lorentz workshop ‘Jointly Designing a Data Fairport’ and published in 2016 [7]. The 15 FAIR facets (sub-principles guiding data management systems) require data to be easy to locate and open, as well as interoperable, transparent, exchangeable and reusable [8]. The FAIR Guidelines identify distinct criteria that promote manual and automated deposition, discovery, sharing, and reuse in contemporary data publishing environments [7]. However, it is important to note that FAIR is not equivalent to ‘open data’; the letter ‘A’ in FAIR stands for ‘Accessible’ under well-defined conditions, which means that data should be free, but, in some situations, should be protected for a legitimate reason, such as personal privacy, national security, or competitiveness. The FAIR Guidelines are
primarily applied in European geographies (67%) and, to a lesser extent in American geographies (14%), together comprising 81% of implementation activities [9].

The FAIR Guidelines are suitable for adoption in Indonesia, as they have the potential to solve the interoperability problem and have been successfully applied in many different contexts. However, it is not known if the FAIR Guidelines are aligned with the governance framework for digital health/eHealth policy in Indonesia and whether or not a policy window is open for adopting and using the FAIR Guidelines. Hence, to determine if the policy environment is ripe for their adoption/implementation, we need to look at how aligned the regulatory framework for digital health/eHealth in Indonesia is with the FAIR Guidelines.

2. METHODOLOGY

2.1 Study Design

This research was conducted as a qualitative cross-sectional study involving the examination of information and communication technology (ICT) and health-related policy documents published by the Government of Indonesia from 2008 to 2019. It follows the methodology developed by Basajja et al. for measuring FAIR Equivalency with policy formulation in a certain geography [10, also see 11].

2.2 Objective

The general objective of the analysis was to check the regulatory framework for health data in Indonesia in order to understand the policy context and explore the possibility of expanding the adoption and implementation of the FAIR Guidelines. Therefore, the relevant research questions were: Are the FAIR Data Guidelines mentioned in the policy documents in Indonesia’s ICT and health/eHealth sectors? What is the level of equivalency of these policy documents with the FAIR Guidelines? FAIR Equivalency measures the degree to which policy documents refer to the relevant aspects of all facets of the FAIR Guidelines [10, 11]. The methodological steps are described in detail by Basajja et al. [10] and this research followed the same procedure. Figure 1 shows a flow chart of the methodology used to ascertain FAIR Equivalency in Kenya [12].

2.3 Identification of Relevant Documents

The first step to answer the research question was to collect key documents related to digital health in Indonesia and then analyse the documents for mention of the FAIR Guidelines or FAIR Equivalent principles. A total of 14 policy documents were identified: 4 as directly relating to digital health and 10 as the basis for making policies on digital health. However, not all of the documents were relevant to ICT/health. Table 1 shows the relevance and availability of policy documents and legislation on digital health.

Only documents relevant to digital health and which were available were included in the research (marked ‘yes’ in the two-last columns of Table 1). Therefore, six documents were excluded and eight documents were selected.
2.4 Coding and Labelling

The selected policy documents were carefully analysed using a code-labelling method [21] to determine whether or not they mentioned the FAIR Guidelines or FAIR-like (FAIR Equivalent) principles. The number ‘1’ was assigned if the document mentioned either the FAIR Guidelines (FAIR Mention) or FAIR Equivalent principles, whereas ‘0’ was assigned if they were not mentioned.

3. RESULTS AND ANALYSIS

3.1 Mention of the FAIR Guidelines in Policy Documents

The analysis found that although none (0%) of the documents refer explicitly to aspects of the FAIR Guidelines, 6 of the 8 documents (75%) refer to FAIR Equivalent principles. Presidential Regulation Number 96 of 2014 concerning Indonesia Broadband Plan and Law Number 14 of 2008 concerning Openness of Public Information made no mention of the FAIR Guidelines or FAIR Equivalent principles (see Table 3).
3.2 FAIR Equivalency in the Policy Documents

To answer the second question, on the level of FAIR Equivalency in the policy documents analysed, the policy documents were examined to see if they referred to the equivalent of the 15 sub-criteria of the FAIR Guidelines (also known as the ‘FAIR facets’) [7]. These consist of the following: ‘Findability’ (F1, F2, F3, F4); ‘Accessibility’ (A1, A1.1, A1.2, A2); ‘Interoperability’ (I1, I2, I3) and ‘Reusability’ (R1, R1.1, R1.2, R1.3). A systematic and through review of the mention of the equivalent of 15 FAIR facets in each policy document
Table 2. Documents selected for analysis [13–20].

| No | Document | Year | Type of document | Source | Website |
|----|----------|------|------------------|--------|---------|
| 1  | Minister of Health Regulation No. 97 of 2015 concerning Health Information System Roadmap 2015–2019 | 2015 | Regulation | Ministry of Health | https://www.hukumonline.com/pusatdata/detail/lt57176f52a508a/node/lt50ed1b7acfde5/peraturan-menteri-kesehatan-no-97-tahun-2015-peta-jalan-sistem-informasi-kesehatan-tahun-2015-2019 |
| 2  | Minister of Health Regulation No. 46 of 2017 concerning the National E-Health Strategy | 2017 | Regulation | Ministry of Health | https://www.kemkes.go.id/article/view/18052200002/peraturan-menteri-kesehatan-republik-indonesia-nomor-46-tahun-2017-tentang-strategi-e-kesehatan-nasi.html |
| 3  | Law No. 11 of 2008 concerning Electronic Information and Transactions | 2008 | Legislation | Government of Indonesia | https://web.kominfo.go.id/sites/default/files/users/4761/UU%2019%20Tahun%202016.pdf |
| 4  | Government Regulation No. 82 of 2012 concerning Implementation of Electronic Systems and Transactions | 2012 | Regulation | Government of Indonesia | https://jdih.kominfo.go.id/produk_hukum/view/id/6/t/peraturan-pemerintah-republik-indonesia-nomor-82-tahun-2012 |
| 5  | Government Regulation No. 46 of 2014 concerning Health Information Systems | 2014 | Regulation | Ministry of Health | https://luk.staff.ugm.ac.id/atur/PP46-2014SIKesehatan.pdf |
| 6  | Presidential Regulation No. 96 of 2014 concerning Indonesia Broadband Plan | 2014 | Regulation | Ministry of National Development | https://www.bappenas.go.id/index.php?cID=4848&cID=4848 |
| 7  | Regulation of the Minister of Health No. 92 of 2014 concerning Implementation of Data Communication in the Integrated Health Information System | 2014 | Regulation | Ministry of Health | https://www.kemkes.go.id/resources/download/peraturan/permenkes-no-92-thn-2014.pdf |
| 8  | Law No. 14 of 2008 concerning Openness of Public Information | 2008 | Legislation | Government of Indonesia | https://www.kpk.go.id/images/pdf/uu%20pip/UU_No_14_Tahun_2008.pdf |

was carried out using a coding-labelling method [21]. The documents were organised into rows using a Microsoft Excel spreadsheet with the FAIR elements arranged in columns. In each policy document, the mention of a FAIR Equivalent facet was labelled ‘1,’ while the lack of mention was labelled ‘0’ in the corresponding Microsoft Excel spreadsheet data cell; these scores were aggregated to give a FAIR Equivalency Score (FE-Score) for each document (see Table 4).
Table 3. Mention of FAIR Guidelines or FAIR Equivalent principles in the policy documents.

| Policy document                                                                 | FAIR Mention | FAIR Equivalent |
|---------------------------------------------------------------------------------|--------------|-----------------|
| Law No. 11 of 2008 concerning Electronic Information and Transactions            | 0            | 1               |
| Law No. 14 of 2008 concerning Openness of Public Information                    | 0            | 0               |
| Government Regulation No. 82 of 2012 concerning Implementation of Electronic Systems and Transactions | 0            | 1               |
| Government Regulation No. 46 of 2014 concerning Health Information Systems      | 0            | 1               |
| Regulation of the Minister of Health No. 92 of 2014 concerning Implementation of Data Communication in the Integrated Health Information System | 0            | 1               |
| Presidential Regulation No. 96 of 2014 concerning Indonesia Broadband Plan      | 0            | 0               |
| Minister of Health Regulation No. 97 of 2015 concerning Health Information System Roadmap 2015–2019 | 0            | 1               |
| Minister of Health Regulation No. 46 of 2017 concerning the National E-Health Strategy | 0            | 1               |
| Total mention                                                                  | 0            | 6               |
| Total policy documents                                                          | 0            | 8               |
| Percentage (%)                                                                  | 0            | 75              |

Figure 2. FAIR Equivalency Score by document.
Table 4. FAIR Equivalency in policy documents analysed.

| Policy document                                                                 | F1 | F2 | F3 | F4 | A1   | A1.1  | A1.2  | A2   | I1   | I2   | I3   | R1   | R1.1  | R1.2  | R1.3  | FE-Score |
|--------------------------------------------------------------------------------|----|----|----|----|------|-------|-------|------|------|------|------|------|-------|-------|-------|----------|
| Law No. 11 of 2008 concerning Electronic Information Transactions                | 0  | 0  | 0  | 0  | 0    | 0     | 0     | 0    | 1    | 0    | 0    | 1    | 0     | 0     | 0     | 1        |
| Law No. 14 of 2008 concerning Openness of Public Information                   | 0  | 0  | 0  | 0  | 0    | 0     | 0     | 0    | 0    | 0    | 0    | 0    | 0     | 0     | 0     | 0        |
| Government Regulation No. 82 of 2012 concerning Implementation of Electronic Information and Transactions | 0  | 0  | 0  | 0  | 1    | 0     | 1     | 0    | 0    | 0    | 0    | 0    | 0     | 0     | 0     | 3        |
| Government Regulation No. 46 of 2014 concerning Health Information Systems     | 0  | 0  | 0  | 0  | 0    | 1     | 0     | 1    | 0    | 0    | 0    | 0    | 0     | 0     | 0     | 2        |
| Regulation of the Minister of Health No. 92 of 2014 concerning Data Communication in the Integrated Health Information System | 0  | 0  | 0  | 0  | 0    | 0     | 0     | 0    | 0    | 0    | 0    | 0    | 0     | 0     | 0     | 0        |
| Presidential Regulation No. 96 of 2014 concerning Indonesia Broadband Plan      | 0  | 0  | 0  | 0  | 0    | 0     | 0     | 0    | 0    | 0    | 0    | 0    | 0     | 0     | 0     | 0        |
| Minister of Health Regulation No. 97 of 2015 concerning Health Information System Roadmap | 0  | 0  | 0  | 0  | 0    | 0     | 0     | 0    | 0    | 0    | 0    | 0    | 0     | 0     | 0     | 0        |
| Minister of Health Regulation No. 46 of 2017 concerning the National E-Health Strategy | 0  | 0  | 0  | 0  | 1    | 0     | 1     | 0    | 0    | 0    | 0    | 0    | 0     | 0     | 0     | 1        |
| Total                                                                           | 1  | 1  | 1  | 1  | 0    | 1     | 1     | 1    | 0    | 0    | 0    | 1    | 0     | 0     | 0     | 7        |
| Percentage (%)                                                                  | 12.5 | 12.5 | 12.5 | 12.5 | 37.5 | 37.5 | 37.5 | 37.5 | 62.5 | 0   | 0   | 12.5 | 12.5 | 0  | 0  | 37.5    |
4. DISCUSSION

4.1 FAIR Equivalency

Although the FAIR Guidelines were not mentioned directly in any of the policy documents relevant to the Indonesian digital health sector, six out of eight documents analysed mentioned FAIR Equivalent principles. For example, the Population Identification Number (NIK) has the potential, as a unique identifier, to support integration and interoperability (findability); there is a plan to build standards and protocols into the implementation of information systems in each ministry and government agency to improve data accessibility (accessibility); the integration of the various information systems is planned and ongoing (interoperability); and the documents acknowledged the need for a standardised arrangement for health information systems related to health data following the community standard (reusability).

Although all policy documents contained mention of FAIR Equivalent principles, very few of the FAIR facets actually appear in the documents. Facet I1 had the highest FE-Score, which indicates this sub-principle appears in almost all policy documents. Meanwhile, facets F3, A2, I2, I3, and R1.2 are never mentioned. Regarding the least-mentioned FAIR-equivalent facets, Wilkinson and colleagues [7] described these facets as follows: F3—‘metadata clearly and explicitly include the identifier of the data it describes’; A2—‘metadata are accessible, even when the data are no longer available’; I2—‘meta(data) use vocabularies that follow the FAIR Guidelines’; I3—‘(Meta)data include qualified references to other (meta)data’; R1.2—‘(Meta)data are associated with detailed provenance’. These FAIR Equivalent facets (F3, A2, I2, I3, and R1.2) are the least listed in policy documents because they explicitly deal with data and metadata information. However, because these documents are at the policy level it is not relevant for them to address these aspects. Only after the measures or recommendations in the policy documents have been applied is possible to determine whether they actual comply with these facets.

Some of the documents at the core of Indonesia’s digital health/eHealth policy had the highest FE-Scores (an aggregate score of the FAIR Equivalent facets in the policy documents). The result shows some degree of alignment of the Indonesian digital health implementation vision with the FAIR Guidelines. Although the Ministry of Health, as a regulator of digital health, is applying Satu Data Indonesia to build a digital health system, the FE-Scores indicate that a policy window is open for Indonesia to adopt and implement the FAIR Guidelines in achieving its goals under Satu Data Indonesia.

4.2 Findability Facets

Findability contains four facets: F1, F2, F3, and F4. Three of these facets—F1, F2, and F4—were found in the policy documents analysed, while facet F3 was not mentioned. Perhaps the most important among the FAIR Guidelines is ‘Findability’, especially facet F1, which requires that in order to be ‘Findable’, data and metadata should be assigned a globally unique and persistent identifier [7]. Without a unique identity, it is not easy for humans or machines to identify a digital object, let alone decide whether or not it is reusable in a particular context. The remaining three principles of FAIR (Accessibility, Interoperability, and Reusability) are partially, or even wholly, related to Findability.
Facet F1 was only found in Minister of Health Regulation Number 46 of 2017 concerning the National E-Health Strategy. This document sets out standards and interoperability requirements, which entails using the NIK and has the potential to support integration and interoperability between existing health care systems.

Facet F2 states that data are described with rich metadata, allowing a computer to automatically accomplish routine and tedious sorting and to prioritise tasks that currently demand much attention from researchers. The rationale behind this principle is that someone should be able to find data based on the information provided by their metadata, even without the data’s identifier [22]. This facet is found only in Government Regulation Number 46 of 2014 concerning Health Information Systems, which states that health data must follow a standard. Although it states that health data should have a type, nature, format, database, codification, and metadata that can be easily integrated, the policy statement is different from F2 facet.

The last facet of Findability found in the policy documents is F4, which states that (meta)data are registered or indexed in a searchable resource. Identifiers and rich metadata descriptions alone will not ensure ‘findability’ on the Internet. Perfectly good data resources may go unused simply because no one knows they exist. There are many ways that digital resources can be made discoverable, including indexing [22]. Article 21, section 8 of the Data and Information Storage of Government Regulation Number 82 of 2012
requires health data and information to be stored in a ‘database’ in a safe place and not to be damaged or lost by using electronic and/or non-electronic storage media. A database is a place/container for various data collected regularly, according to informatics principles that users can access at any time to produce the necessary information by using the concept of the data warehouse. The purpose of the statement in this article is consistent with facet F4, which require meta(data) to be placed in a searchable resource.

4.3 Accessibility Facets

Facets A1, A1.1, and A1.2 of Accessibility are mentioned in the policy documents, but none of the documents mentioned a requirement for access to metadata even when the data are no longer available (A2). Facet A1 acknowledges that it may not always be possible to allow fully automated access to data in the case of highly sensitive data. In these situations, presenting contact information such as e-mail address, telephone number, or other information for a person who can request access to the data also satisfies the FAIR Guidelines [22]. Two of the more recent policies that relate to digital health mentioned facet A1. The Minister of Health Regulation Number 46 of 2017 states that standards are the key to success in data transactions between information systems and electronic systems, and these standards can be developed independently or adopted from international standards (International Organization for Standardization/International Electrotechnical Commission [ISO/IEC]). In addition, it explains that standards can be seen from various perspectives, including the functional standards of electronic information systems, data standards and health terminology, security and privacy standards, as well as electronic data communication standards. The Minister of Health Regulation Number 97 of 2015 also mentions facet A1, stating that access to data and information from across units in the Ministry of Health and across sectors is still challenging. The unavailability of standards and protocols in implementing information systems in each ministry/agency is a central problem of accessibility. Therefore, phase five (which will be implemented from 2035–2039) of the health information system is directed at strengthening the application of health information systems based on electronic health (eHealth) by an integrated global network that is implemented with quality assurance according to international standards.

4.4 Interoperability Facets

None of the policy documents contained facets I2 and I3, but five out of the eight documents mentioned I1. Facet I1 requires (meta)data to use a formal, accessible, shared and broadly applicable language for knowledge representation. In other words, it is critical to use commonly used controlled vocabularies, ontologies, thesauri, and a good data model to ensure the automatic findability and interoperability of datasets.

Generally, the number of policies that mention interoperability shows that it is an important aspect of the implementation of digital health in Indonesia. All policies state the importance of communication between systems to achieve data exchange. Integration includes both technical systems (systems that can communicate with each other) and content (the same data set). Integrated health information system architecture is regulated in Minister of Health Regulation Number 97 of 2015, which mentions facet I1.
This regulation explains that the physical form of an integrated health information system is an information system application linked with other applications so that the interoperability of data between applications can be achieved. Regulation of the Minister of Health Number 92 of 2014 clarifies the definition of an integrated health information system as a system capable of providing a mechanism for interconnecting information subsystems in various ways as needed. In addition, the particular way to achieve interoperability is mentioned in Government Regulation Number 46 of 2014, which states that there is a need for an electronic-based data standard service utilising existing technology (web services, APIs) so that it can be used by eHealth stakeholders, especially for the development of a health service information system.

4.5 Reusability Facets

FAIR’s ultimate goal is to optimise the reuse of data. Therefore, metadata and data should be well-described to be replicated and/or combined in different settings. Facet R1 of the Reusability principle aims to make the data easier to find and reuse data by attaching many labels to the data. Principle R1 is related to F2, but R1 focuses on the ability of a user (machine or human) to decide if the data is useful in a particular context [22]. Facet R1.3 was found in three of the documents analysed and has the highest score among the Reusability facets.

Minister of Health Regulation Number 97 of 2015 highlights the need for a standardised arrangement of health information systems, carried out through data codification, the preparation of a health data dictionary, and the setting of priority indicators to address the issue of health data integration and exchange. The Minister of Health Regulation Number 46 of 2017 also mentioned standards, stating that standards can be seen from various perspectives, including functional standards of electronic information systems, data standards and health terminology, security and privacy standards, as well as electronic data communication standards (data exchange protocols). Both statements in these policies have the objective of making data meet domain-relevant community standards.

5. CONCLUSION AND FUTURE WORK

Indonesia has an excellent opportunity to address health challenges using digital health, evidenced by its high level of Internet penetration among the Indonesian population and the fact that most of the hospitals in Yogyakarta, one of the biggest cities in Indonesia, have adopted hospital management information systems. Nevertheless, the main problem experienced is the inability to share patient information between hospitals. The FAIR Data Guidelines—that data be ‘Findable’, ‘Accessible’, ‘Interoperable’, and ‘Reusable’—and its 15 facets are guiding principles for data management systems, requiring data to be easy to locate, open, interoperable, transparent, exchangeable, and reusable. The FAIR Guidelines could help the digital health sector in Indonesia to solve the problem of interoperability, as long as these principles are implemented with contextual awareness.

This study’s general objective was to assess the regulatory framework for health data in Indonesia to understand the context and explore the possibility of the FAIR Guidelines being used to extend Satu Data
Indonesia in the eHealth sector. In order to do this, 14 policy documents were identified as essential to the health/eHealth and ICT sectors in Indonesia, of which 8 were examined. A detailed coding-labelling approach was used to examine the documents to determine whether or not they contain FAIR Guidelines or FAIR-like/FAIR Equivalent principles, following Basajja et al. [10]. The documents were then reviewed using the same method to determine whether or not they mention the equivalent of any of the 15 FAIR facets. The analysis found that none (0%) of the 8 policy documents mention the FAIR Guidelines directly, but 6 (75%) mention the equivalent of the FAIR Guidelines (FAIR Equivalent). In addition, very few of the 15 FAIR facets were addressed in the documents. However, facet I1 appeared in almost all policy documents and, therefore, had the highest FE-Score. Hence, there is some degree of alignment of the Indonesian digital health implementation vision with the FAIR Principles, indicating that there is an opportunity (a policy window is open) for the adoption and implementation of FAIR Guidelines.

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**AUTHOR’S CONTRIBUTION**

Putu Hadi Purnama Jati (putuhadi2808@gmail.com, 0000-0002-6533-3709): Writing—original draft preparation, investigation, conceptualization.

**CONFLICT OF INTEREST**

The author declares that he has no competing interests.

**ETHICS STATEMENT**

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Uganda National Council for Science and Technology, Reference IS18ES, July 23, 2019-July 23, 2023
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