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HEALTH INFORMATION EXCHANGES AND DATA-INTENSIVE SYSTEMS

MEDICAL DATABASES PERFORM A VERY CRITICAL FUNCTION IN HEALTH CARE. IN THE STUDY OF RARE DISEASES, FOR INSTANCE, THEIR CONTRIBUTIONS ARE INVALUABLE.[1] THIS IS BECAUSE THE INCURABILITY OF SOME RARE DISEASES PROCEEDS NOT FROM THEM BEING IRREVERSIBLE, BUT RATHER FROM THE LACK OF AVAILABLE INFORMATION ABOUT THEM.[2] THIS MEANS, OF COURSE, THAT ACCESS TO MORE INFORMATION FROM DIFFERENT REPOSITORIES CAN CHANGE THINGS DRAMATICALLY. WHAT COULD POSSIBLY FACILITATE SUCH ENHANCED ACCESS? HEALTH INFORMATION EXCHANGES.

Data intensive systems (DIS) like health information exchanges are behind many of the most powerful processing technologies available today. They help make possible what were previously thought of as impossible—like finding a cure for a rare disease.

INTRODUCTION

A DIS is basically a system that accumulates, stores, and processes streams and/or large volumes of data. At the moment, they are gradually becoming a staple among the world's emerging economies. It certainly has not hurt that their use has been promoted by a United Nations panel when it called for a so-called "data revolution"—an idea premised on the use of both existing and new sources of data to improve decision-making in organizations and the promotion of open access to and the use of data.[3]

To establish a DIS, different data silos are usually merged. When personal data is involved, this means making all available information about a particular person easily accessible through a centralized infrastructure. The collected data are then often used to generate more data about the individual. Ultimately, the collected and generated data become the basis for decisions that affect (or at least, tend to) the person involved.

The potential uses for a DIS seem endless. That and the trove of information they contain make them irresistible for many different sectors, which eventually become dependent on their services.[4]

In government, DIS use is usually justified as a means to deliver social services better. Common examples of its application include the establishment of smart cities, national ID systems, voter registries, SIM card registration systems, and health information exchanges. They are all supposed to provide more comprehensive profiles of individuals and societies, which then allow governments to serve their constituents better by promoting security and social welfare more effectively.

There is some truth to such claims. Voter registries, for instance, can increase transparency in the electoral process by allowing citizens to scrutinize voters' lists. This reduces opportunities for electoral fraud, while allowing an appeal process for excluded voters.[5] Nonetheless, the merits of these systems should not be exaggerated. After all, they do not always get to deliver on their promises. Poor data collection, or the lack thereof, become the government's usual scapegoat (sans any concrete proof) when pressed to explain such failures.[6] And it's not only that. DIS also pose a number of inherent risks—tracking and covert surveillance of persons and groups, profiling, function creep,

and discrimination, to name a few.[7] Thus, a balanced assessment is a must for any entity contemplating on adopting such a system for its own purposes.

This briefing paper will focus on health information exchanges as an example of a DIS, zeroing in on the Philippine Health Information Exchange (PHIE). It hopes to highlight the benefits, challenges, and risks associated with HIEs, based on the experiences of early implementers, including insights from one of the implementing agencies of the PHIE.

HEALTH INFORMATION EXCHANGES

Proponents describe health information exchanges (HIE) as an innovative solution to problems relating to health record management. Each one is an information system that connects health care providers and allows the electronic sharing of health information. It offers significant help in the management of data exchanges and in the reduction of duplicate services and operational costs.[8]

There are currently three recognizable types of HIEs: (1) Direct HIE - allows the electronic sharing of medical data between health care providers; (2) Query-based HIE - allows the searching of health information from a large network of participating health care organizations and providers; and (3) Consumer-mediated HIE - allows a patient to maintain a repository of his or her health data online, while letting him or her control the sharing of (aggregated) health data to the health care providers of their choice. It also allows the patient to correct inaccurate information.[9]

According to a 2016 report developed by the Regenstrief Institute, twenty-eight (28) low- and middle- income countries (including the Philippines) and some developed countries (e.g., Canada, Australia, and New Zealand) now have an HIE in place, although they are at different stages of implementation.[10]

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So far, the following benefits have been attributed to functional HIEs:

1. **Accessibility.** Patients do not have to worry anymore about their (forgotten) medical history because their medical data are stored electronically. They can access, monitor, and share the data with health care providers anytime. Storing voluminous piles of paper records is also avoided.[11]
2. **Support for optimal decision making.** Having access to similar sets of medical records provides physicians a holistic view of a patient's health, thereby minimizing errors in diagnoses and medications.[12]
3. **Care coordination.** Duplicitous laboratory tests may be prevented, while referrals to other health care providers become easier. In some cases, prescriptions are also sent directly to pharmacies.[13] HIEs also motivate patients to become proactive in monitoring their health.[14]
4. **Standardization and interoperability.** Data encoded in a uniform manner makes it easier for health practitioners to share and search for their required information, and to combine them with other sources.[15]
5. **Aid in health policy and program development.** Large sets of medical data can help generate reports and statistics (e.g., disease outbreaks, notifiable diseases, etc.) that can be used as reference when developing policies and programs for better health care service delivery.[16]
6. **Savings.** The availability of data in an HIE saves treatment and diagnosis time and costs.[17]

These positive elements go hand in hand with some concerns. They primarily involve the impact of HIEs on human rights and other related challenges and risks:

1. **Data protection and security.** Access to online medical data by hackers or fraudsters[18] and the perceived lack of data protection (i.e., data sharing without consent) in the basic setup of HIEs[19] are common concerns of patients. Recent news[20] about data breaches involving HIE systems have amplified these fears. People whose personal data are found in an HIE are also inherently more visible than their counterparts who remain "off the grid". This puts them at risk of becoming objects of surveillance and profiling. Those not in the HIEs, on the other hand, are at risk of being relegated to the shadows and excluded in planning and decision-making processes.[21] Finally, there have also been problems involving the failure of frontline officers of health institutions to obtain the informed consent of patients during data collection.[22]
2. **Accountability.** The seamless integration of systems could also create a "blurred sense of control"[23] because the sources and uses of data become untraceable and invisible over time.[24] Accountability may at some point become extremely difficult—if not impossible—to enforce; something which goes against a central objective of HIEs.
3. **Weak legal safeguards, politics and function creep.** The lack of clear provisions on the scope and limitations of data collection and processing makes a good program susceptible to the influence of different parties. In the case of the Dansk Almen Medicinsk Database (DAMD),[25] the amount of data the system created and generated piqued the interest of third parties who sought to process the datasets for purposes not previously identified and relayed to the patients and their respective doctors.[26]

4. ***Poor user capacity and unreliability of infrastructure.*** Weak communication infrastructure, incompatible application systems, and the inconsistent use of codes and terms are also common problems in HIE use. In Nebraska, US, technical glitches (i.e., data loss, poor internet connection, power outages) caused missed consultations and unpurchased medications, which then sowed distrust in the HIE.[27] The lack of internet connection in rural areas and users' ineptness vis-a-vis technology made the HIE difficult to navigate.[28] Meanwhile, in other HIEs, information overload makes data analysis harder and less meaningful.[29]

5. ***Sustainability.*** In some countries, the sustainability of an HIE is a constant cause for concern because competition among different HIE providers make some reluctant to share their data with other providers. This results in the HIE having very limited amounts of data available for use.[30] Without adequate data, HIEs are nearly useless.[31] Other related problems include: (a) maintenance difficulties due to lack of regular funding;[32] (b) abandonment or non-use of the HIE;[33] and (c) witholding of information by patients from their health care providers.[34]

6. ***Human error.*** Mistakes in encoding and in the retrieval of medical records are common in HIE implementation. Most attribute this to the users' poor attention to details. These incidents do not only breach the confidentiality of the medical data, but it could also result in incorrect diagnosis and medication.[35]

To help address these issues, proponents have come up with a number of concrete recommendations:

1. ***Establish strong regulatory mechanisms.*** Any law governing HIE use should have clear goals. It ought to identify the data fields involved and their intended uses. There should also be a regulatory body to enforce checks and balances (e.g., accreditation body for health care providers) to prevent misuse.[36]

2. ***Ensure the readiness of technology and its users.*** The technology involved must have a high processing capacity and effective security measures in place. Users should also be trained on the proper use of the technology, including how all relevant information ought to be relayed to the patients.[37]

3. ***Limit data collection.*** Information on the database must be limited to the minimum amount necessary to facilitate its operation. This will lessen the risks involved and could even generate more meaningful data analysis.[38]

4. ***Respect patient's data privacy rights.*** Different countries have different data privacy laws. Most (if not all) of them provide for rights that may be exercised by individuals vis-à-vis their medical records (e.g., right to be informed, right to object). HIEs should be implemented in accordance with these laws.[39]

5. ***Incentivize the use of HIE.*** Assuming their security and effective use can be guaranteed, the sustainability of HIEs in countries where their use is not mandatory or is decentralized[40] can be assured by providing health care providers with discounts on overhead costs as an incentive to their connection to and use of the HIE.[41]

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THE PHILIPPINES: A CASE STUDY

In the Philippines, it is easy to make a case that HIEs will benefit the population. The accounts of people like Kaye (not her real name) are quite common:

> Within a span of six days, Kaye had been confined twice for two different but related ailments and had visited three different hospitals. She was initially confined in one hospital for an appendectomy. She recalls how stressful it was to respond to similar questions being asked by different doctors, and to fill out multiple forms while enduring abdominal pain and waiting for her surgery. Fortunately, she was able to ask her parents to fill out some of these forms. A few days later, as she was recovering, she had an allergic reaction that could be traced back to her surgery. She went to a different hospital where she had to go through the same process of filling out forms and answering questions. To her misfortune, she had to transfer to another hospital after learning the second facility did not provide tertiary care. Of course, that meant another round of questions and another series of forms to fill up. To cap off her ordeal, she had to obtain copies of her medical records from all three health care institutions before she could process her health benefit claim.[42]

Health record management in the country continues to follow a provider-centric model and still uses paper records, for the most part.[43] Medical records have to be requested from each health care provider.[44] The same goes for laboratory examination results, since these are not reflected in medical records. Consequently, physicians are prevented from having a holistic understanding of their patients' health, and patients are deprived of the best possible care they would otherwise be entitled to.

THE PHILIPPINE HEALTH INFORMATION EXCHANGE

Unknown to many, there is already a so-called Philippine Health Information Exchange (PHIE). A query-based HIE,[45] it is a component of the eHealth strategy of the government towards its ultimate goal of universal health care.[46] Through it, the government is aiming for a responsive, efficient, cost-effective, and integrated delivery of health care services using real-time medical data.

The PHIE operates under the supervision of the Department of Health (DOH), the Philippine Health Insurance Corporation (PhilHealth) and the Department of Science and Technology (DOST)[47] who are bound by a tripartite agreement.[48] Together with the Commission on Higher Education (CHED) and the University of the Philippines—Manila, they make up the core implementation team providing overall direction, technical guidance, and resource-support to the System.[49]

Implementation of the PHIE began in 2016, although it continues to be in a testing phase until today.[50] In the meantime, PHIE Lite was developed to define and harmonize the datasets used by the different stakeholders involved.[51] At present, it is being used to process electronic Primary Care Benefit claims, and is expected to expand to four (4) other use cases.[52] Its online portal is still not available as of this writing.[53] Nonetheless, the DOH already plans to develop a module that will allow people to access their own medical records online.[54] Its shortcomings notwithstanding, there are those who believe the PHIE Lite has already achieved some of the objectives of its full version, particularly the harmonization of datasets and the interoperability of systems.[55]

ACKNOWLEDGING THE RISKS

An electronic medical record (EMR) is arguably one of the most comprehensive records about an individual. This is because, apart from health information, it often contains demographic, historical and financial information, as well.[56] In many cases, it is also immutable[57] and is therefore more valuable to hackers and fraudsters compared to credit card information.[58] On the black market, it has been valued at a thousand dollars[59]—a complete set could be as high as $500,000.[60]

As such, implementation of the PHIE, which relies heavily on technology and the capacity of its users, leaves a lot of privacy advocates worried. The massive data breach in 2016 involving the country's electoral commission[61] legitimize their concerns. After all, there remains no credible assurance that the government is more equipped today and better prepared to handle large amounts of personal data. The DOH, for instance, may already have a Data Protection Officer (DPO), but its privacy management program is not yet in place. Most of its policies relating to data privacy consist mainly of practices, instead of written rules. The agency's lack of manpower to enforce its policies is also a problem.

Meanwhile, the entry of two new laws gives rise to new threats and has even caused some confusion as far as the future of the PHIE is concerned. First, there is the recently-passed Universal Health Care Act (UHC). The law, among others, calls for the establishment of a health information system (HIS), which is poised to collect more data points compared to the PHIE. Naturally, that means more risks. But more than that, the impact of this new HIS on the PHIE remains unknown. It has been suggested that the ideal approach

would be to merge the existing infrastructure and architecture of the PHIE with the planned HIS to ensure data flow and avoid wasting efforts and existing resources. But this is all conjecture at this point. And then, there is the enactment of the Philippine Identification Systems Act, which facilitates the creation of a national ID system. The new law requires the assignment of a unique ID number[62] to every covered individual. Together with other demographic and biometric data, this number will be stored in a national ID registry. It is likely that the PHIE (and/or the HIS) will be linked to the ID registry once the latter becomes operational. The overlap may mean more efficient transactions, but it also lead to more data breaches and more frequent misuse or abuse of data.

EXISTING SECURITY MEASURES

Given all the risks and potential problems, there must be adequate security measures in place that ensure the stability of the PHIE system.

For now, there is the system's Implementing Guidelines, which feature the data protection principles enshrined in the country's Data Privacy Act of 2012 (DPA). In the case of use limitation, the rules do provide for limits as to the kinds of uses the medical data may be subjected to by PHIE users. Other provisions of the law also appear in the Guidelines including the criteria for the lawful and fair processing of patient information, the rights of participating patients (i.e., data subjects), the obligations of the participating health care providers (which include the security measures they must adopt and implement to protect medical data), and penalties for proven violations. For the DOH personnel interviewed for this paper, they consider these elements enough to deter unauthorized access and disclosure of the data stored in

the PHIE. They do acknowledge, however, that additional policies are necessary to further improve the system's data protection and security mechanisms. One of such policies could be the Health Privacy Code, which has long been under development by the agencies and institutions behind the PHIE. Once in force, the policy will cover all entities handling health data in the public and private sectors.

On the part of EMR system providers subcontracted by health care institutions, they are made to undergo a standardized vetting process. The DOH-Knowledge Management and Information Technology Service (KMITS) first validates whether their EMR system contains the datasets required by PhilHealth and is compliant with the standards for interoperability.[63] It does not attest to the security of the system. PhilHealth then accredits the service providers, with the validation of the DOH as one of the requirements.[64] Only accredited service providers may have access to the PHIE.[65] EMRs are encrypted during transmission from the health care providers to the DOH.

Proponents of government databases like the PHIE often point to the country's data protection law as some sort of impenetrable shield against all risks and potential threats. Their confidence is misplaced. The existence of the DPA offers some benefits but it can only do so much. And while it is somewhat reassuring that the National Privacy Commission has been guiding the implementers of the PHIE in the course of its implementation,[66] people would do well to steer clear of such mindset where the DPA and the NPC in and of themselves represent the only security necessary for the PHIE. Indeed, even if the country is now on its third year of actively "implementing" the DPA, the statute is far from being the effective data protection policy it is expected to be.

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CONCLUSION

HIEs will lead to many tremendous breakthroughs and can help address a lot of the inefficiencies afflicting health care services today. They are poised to improve significantly the operations of health care providers and will empower patients by allowing them to assert their rights better in relation to their health information. Things can and will always go wrong, though, so stakeholders from across the entire spectrum must be prepared to attend to these problems swiftly with effective and efficient solutions.

In the case of the PHIE, implementers should be proactive in incorporating data protection principles in the relevant policies and in building a culture of privacy in their respective organizations. They should expand their efforts to include other stakeholders, too. Their efforts should include, as a minimum: (a) regular review of all applicable laws and policies to facilitate the identification of policy gaps; (b) inclusion of data protection and information security in the validation of EMR systems and in the accreditation of health care institutions and service providers; (c) close coordination with the NPC and other regulatory bodies; and (d) consistent and effective consultation with all stakeholders.

And as for data intensive systems, in general, they will continue to influence innovations as people unceasingly look for ways to make sense of the vast amounts of data being generated by the world. Since they are often controlled by government agencies and private companies who may not always have the people's best interests in mind, it is crucial that people maintain a critical perspective at all times when presented with the purported benefits of such systems. All perceived challenges and risks posed by these systems ought to be taken seriously and addressed head on. Properly crafted responses, backstopped by adequate planning and resources, should be developed to make sure that they do not cause problems that far outweigh their intended benefits.

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