



# **Recommendations for a Global Framework to Support Health Information Exchange in Low- and Middle-Income Countries**

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## **Chapter 1 Acknowledgements & Disclaimer**

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The material presented in this report represents my personal interpretations and conclusions. The report does not represent the position of the Regenstrief Institute or any other individual or organization.

## Chapter 2 Introduction

eHealth is the use of information and communication technologies (ICT) to improve the electronic flow of information to support delivery of health services and the management of health systems.[1] eHealth is a tool to improve health and health care in an environment where technology and data availability are becoming increasingly available.[2]

More recent implementations of eHealth have applied the health information exchange (HIE) model as an architectural approach for data sharing. Data sharing enhances clinical care, community surveillance, and program evaluation activities. It is also essential for effective responses to global epidemic situations such as Ebola and Zika virus. “Health information exchange” is used in the health sector vernacular as both a noun and a verb. As a noun, HIE refers to a corporate entity of organizations that provides services focused on data exchange and sharing of patient data across disparate stakeholders at the local, state, regional, and national level. HIE as a verb refers to the provision of interoperable data, infrastructure, and technology for the exchange of data between and among health care providers who are not structurally or organizationally related to one another.[3]

OpenHIE supports interoperability by creating a reusable architectural framework that introduces a service-oriented approach, maximally leverages health information standards, enables flexible implementation by country partners, and supports interchangeability of individual components. The [OpenHIE](#) community improves the health of the underserved through open and collaborative development and support of country-driven, large scale health information sharing architectures.

Recent experience implementing HIE infrastructure has identified the need for effective policies and procedures for data sharing and HIE implementation. These policies and procedures act as key enabling areas for successful HIE (the verb) in resource-challenged settings.[4] Policies include laws, national strategies, and legal agreements and procedures include implementation guidance and standards. Policies and procedures for HIE can also address issues of data ownership, data sharing, data aggregation, data reuse, governance, and privacy and security.

The World Health Organization undertook a series of surveys of eHealth in Member States which informed the [Global Observatory for eHealth](#) (GOe) series of publications in 2010-2014.[5] While the GOe surveys and publications provide a strong baseline for understanding the use of eHealth in LMIC, they do not focus on HIE and interoperability through the lens of governance and data use issues.

This report provides findings from a review of HIE (the verb) in 28 low- and middle-income countries (LMIC) as defined by the World Bank.[6] The review focused on governance and data use issues identified in country policies and procedures. The findings are designed to identify the framework of key decisions that countries should address in planning for and implementing infrastructure for HIE. Real-world examples are provided

as options for each key decision point to provide benchmarks and a starting point for discussions.

## Chapter 3 Methods

A qualitative mixed-methods review was performed of countries defined as low- or middle-income by the World Bank (using 2014 data) from February-March 2016.

The review consisted of a non-systematic literature review and semi-structured interviews of individuals and organizations working on eHealth in LMIC. While the review focused on LMIC, data were also collected from high-income countries to determine if there were lessons learned that could be applied in LMIC settings (e.g., Canada, Australia, the EU, New Zealand). In particular, the author gathered a relatively significant amount of information from the United States due to the nature of the author's affiliations with U.S. stakeholders.

For the literature review, published literature indexed in PUBMED and MEDLINE was identified using keywords "low- and middle income country," "health information exchange," "interoperability," "big data," "policy," and "governance." Articles referenced by the published literature as well as the gray literature including countries' eHealth strategies, legislation, and other policies and procedures relating to HIE were also reviewed.

For the semi-structured interviews, individuals working in LMIC in the OpenHIE community known to be familiar with issues of governance and data use were contacted. Individuals were invited to hour-long semi-structured interviews regarding policies and procedures; data ownership, sharing, aggregation, re-use; governance; data use and sharing agreements; key principles for HIE; and country-specific use cases for HIE. Recommendations for additional LMIC contacts were sought from the initial experts in order to make a good faith effort to represent all regions of the globe. While an exhaustive review of every LMIC was not performed, the goal was to provide a snapshot of HIE in regions across the globe that could inform key focal areas globally.

These methods yielded information on 28 LMIC countries and one regional network (the [Asia eHealth Information Network](#)). The data collected for each country varied in completeness. For example, some informants were able to address every issue area while others could speak to one or a few issues depending on their experience. The information gathered represents a combination of "in the field" experiences as well as perspectives from some individuals working within their countries' Ministries of Health (MoH). **However, this brief does not represent any official country's MoH perspective.**

Table 1 provides the countries covered in this review and the proportion of the LMIC in the respective region. In total, 21% of all LMIC defined by the World Bank representing 45% of the total population in LMIC were covered in this review.

**Table 1. LMIC Countries and Proportion of LMIC Reviewed by Region<sup>a</sup>**

<b>Africa</b> (n=17) (33%)	<b>Asia</b> (n=5) (17%)	<b>Central America and Caribbean</b> (n=2) (12%)	<b>Europe</b> (n=1) (8%)	<b>South America</b> (n=3) (43%)
Angola	India	Haiti	Ukraine	Brazil
Cameroon	Indonesia	Jamaica		Colombia
Ghana	Malaysia			Peru
Guinea	Philippines			
Kenya	Vietnam			
Lesotho				
Liberia				
Malawi				
Mozambique				
Nigeria				
Rwanda				
Sierra Leone				
Somalia				
South Africa				
Tanzania				
Uganda				
Zimbabwe				

This was a high-level review focused on governance and data use issues in particular. Thus, the Key Areas for a framework discussed in Chapter 4 (page 8) feature more detail in the areas of governance and data use agreements compared to other Key Areas.

Lastly, this was not an exhaustive or systematic review. Due to the nature of the networking approach taken, it is very likely that policies and procedures exist for certain HIE areas but were not identified due to the review methods, knowledge areas of the information sources, and timeframe. Areas where additional information or exploration may be needed are identified in Chapter 6 (page 53).

<sup>a</sup> Note these classifications are by geographic region, rather than WHO region.

## Chapter 4 Recommendations for Key Areas of a Global Framework

The findings from the review yielded a set of common domains that countries have considered in the development of policies and procedures for HIE. These common domains are framed as questions or decision points and grouped into Key Areas for a suggested framework as detailed further in this chapter. The answers to the questions will differ by country based upon underlying principles and the culture. The Key Areas are:

- Key Area 1: Vision & Strategy (page 11)
- Key Area 2: Governance (page 15)
- Key Area 3: HIE Policies & Procedures – General (page 21)
- Key Area 4: HIE Policies & Procedures – Standards & Interoperability (page 26)
- Key Area 5: HIE Policies & Procedures – Privacy & Security (page 30)
- Key Area 6: HIE Policies & Procedures – Data Use Agreements (page 32)
- Key Area 7: HIE Implementation (page 48).

As described in Chapter 3 (page 6), this review focused on issues of data governance and data use agreements, thus Key Areas 2 and 6 contain more detail than the other Key Areas. However, all Key Areas should be addressed as countries develop and implement HIE infrastructure and interoperability. A country’s comprehensive framework for health information interoperability and data sharing should address each of these areas due to their interdependence.

Each Key Area includes a short introduction or remarks if applicable, a table of exemplar decision points and examples, and lessons learned/findings. Below, see a sample structure of the table and additional information regarding how to read the table.

### Sample Table for Key Area X.

Theme	Exemplar Question/Decision Point(s)	Example Option	Where Implemented or Planned	Digital Development Principle(s)
The general category or topic of the question/decision point(s) to assist with readability and classification. <b>Note</b> this column is not present for	Exemplar questions decision-makers should consider based on key principles and findings from the review.	Example(s) of directions or implementations taken as related to the question/decision point identified through the review. <b>Note</b> that examples are <u>not</u> exhaustive and meant for illustration and to offer contrast, if applicable.  Generally LMIC examples are presented. Occasionally high-income country examples are presented if LMIC examples are unknown through the review, or for contrast.	The region where example options are being implemented or are planned based on the mixed-methods review.	The primary Digital Development Principle(s) relevant to the question/decision point(s) based on the author’s discretion.
		If the review identified this area		



<b>Theme</b>	<b>Exemplar Question/Decision Point(s)</b>	<b>Example Option</b>	<b>Where Implemented or Planned</b>	<b>Digital Development Principle(s)</b>
every Key Area.		as a gap or examples are not known, this is indicated here.		

The table for each Key Area provides a quick view of various options regions have taken or plan on taking based on the review in order to maintain anonymity for specific countries. However, this does not mean that option has been taken throughout the entire region, only that it was found in at least one country in that region. Appendix A (page 60) includes information sources for specific countries as well as pertinent topics. Contacts who are included have consented to share their information.

The questions for each Key Area are meant to be addressed together, not necessarily as standalone issues. The questions are framed as straightforward as possible to get to the key matter at hand, but many of the decisions will be interdependent. For example, in answering the question “What are the key goals at outcomes for HIE and interoperability?”, related questions such as “For what use cases will data be exchanged?”, “Will data be exchanged at the individual or aggregate level?”, and “Will data be exchanged within country, with other countries, or both?” should also be considered as the decision-making processes are interrelated.

The Principles for Digital Development are “living” guidelines geared toward helping development practitioners integrate established best practices into technology-enabled programs. These Principles arose out of the development organization community need to institutionalize the lessons learned in the use of ICT in development projects.[7] Given their importance, the exemplar questions/decision points in the framework are cross-walked to the Principles for Digital Development to provide additional insights countries may consider in working through the questions/decision points.

[Principles for Digital Development:](#)

1. Design with the User
2. Understand the Existing Ecosystem
3. Design for Scale
4. Build for Sustainability
5. Be Data Driven
6. Use Open Standards, Open Data, Open Source, and Open Innovation
7. Reuse and Improve
8. Address Privacy & Security
9. Be Collaborative

The HIE challenges identified through the review and presented in the Key Areas are summarized in Chapter 5 (page 50): Identified HIE Challenges. The gaps and possible future research topics are discussed in Chapter 6 (page 53): Gaps for Future Research.

Finally, this report also includes four *Best Practices Features* that illustrate a case study example for a particular Key Area. Other best practices were also identified during the course of the review. These *Best Practices Features* plus one *Sidebar* provide examples of HIE models taken in different areas of the globe that countries may want to consider. The features are:

- *Best Practices Feature #1* – HIE Governance Framework in the Philippines (page 18)
- *Best Practices Feature #2* – Policies for eHealth and HIE in Peru (page 23)
- *Best Practices Feature #3* – Standards and Guidelines in Kenya (page 28)
- *Best Practices Feature #4* – Data Use Agreements in the United States (page 43)
- *Sidebar: Case Reporting as a Use Case* (page 55).

## Key Area 1: Vision & Strategy

This Key Area addresses the up-front questions about the vision and strategy for HIE that appear necessary for successful development of integrated infrastructure and ensuring that the right stakeholders are involved from the beginning. While many pilots and demonstration projects address a specific health issue, involve a small group of stakeholders, or are implemented in a small geographic region, the following decision points will help to ensure a shared vision and roadmap for HIE expansion.

Theme	Exemplar Question/Decision Point(s)	Example Option	Region Where Implemented or Planned <sup>b</sup>	Digital Development Principle(s)
<b>Value Proposition</b>	What are the key goals and outcomes for HIE and interoperability?	Universal health coverage	Asia	Design with the user; Design for scale; Reuse and improve
		Improved HIV, TB, maternal and child health outcomes	Africa	
		Access to health information for patients who cross country borders (e.g., travel, refugees)	Europe	
		Interoperability of many different systems	Africa	
<b>Use Cases</b>	For what use cases will data be exchanged? (e.g., clinical care, administrative needs, financial needs,	Government funded health clinics use data at the individual level for both clinical purposes (e.g., immunizations, prenatal counseling) and public health purposes	Central America and Caribbean	Design with the user; Design for scale; Be data driven

<sup>b</sup> At least one country in the region has implemented or is planning to implement the example option. This does not mean the option has been implemented throughout the entire region.

<b>Theme</b>	<b>Exemplar Question/Decision Point(s)</b>	<b>Example Option</b>	<b>Region Where Implemented or Planned<sup>b</sup></b>	<b>Digital Development Principle(s)</b>
	monitoring and evaluation, public health/population health including disease and surveillance reporting, research)	Claims processing	Asia	
<b>Use Cases</b>	Will the data exchanged be at the individual patient level or an aggregate level?	Aggregated HIV, TB, maternal and child health data for program M&E	Africa	Design with the user; Design for scale; Be data driven
<b>Vision</b>	Will data be exchanged within country, with other countries, or both?	Both intra-country and inter-country exchange	Asia, Europe	Design with the user; Design for scale
		Intra-country exchange, including at the regional and local level	Currently the focus in many LMIC	
<b>Current State Analysis</b>	<ul style="list-style-type: none"> <li>- Where are data collected and stored in the current state?</li> <li>- Which groups are the current main stakeholders?</li> <li>- Are there additional groups that should be engaged?</li> <li>- Who owns or stewards the data?</li> </ul>	Data collected through community health workers; at clinics, hospitals, and facilities.	Most LMIC	Understand the ecosystem; Be collaborative
		Individual patient level data must be stored (and cannot leave) the facility where it was collected. Only aggregate data are reported.	Africa	
		Data servers are located in the donor country.	Africa	
<b>Consumers</b>	- What groups of patients and consumers will be	Community-event based surveillance was piloted during the peak of the	Africa	Design with the user; Design for

Theme	Exemplar Question/Decision Point(s)	Example Option	Region Where Implemented or Planned <sup>b</sup>	Digital Development Principle(s)
	affected by HIE? - Are there special issues affecting certain groups of the population that should be considered?	Ebola outbreak because more traditional methods located contacts too late.[8] This factored in community-based methods of engagement because of the culture in Ebola-affected countries.		scale
<b>Sponsor</b>	Is there strong support or a champion/ influencer at the national or regional level?	Strong champion with influence and connections at the national level, strong government buy-in	Asia	Understand the ecosystem; Build for sustainability
		Public sector data hub project has not been implemented, possibly due to political and economic disincentives	South America	
<b>Patient-generated Data/Data Provenance</b>	- Will patient-provided data become part of the health record? - Have issues of data provenance been considered?	<b>Gap</b> – Policies are unknown. Most LMIC in the review do not appear to provide patient access to electronic health data today.	NA	Design with the user; Understand the ecosystem
		Concerns with the data provenance of data collected using mobile health technologies. For example, data collected by community health workers with education level equivalent to a high school degree should not be mistaken for a clinical diagnosis by a physician.	Africa	
<b>Risk Identification</b>	What are likely areas of challenges or where additional expertise may be needed?	Non unique patient identifier	Central America and Caribbean, Africa	Address privacy and security; Understand the existing
		No lever for regulatory enforcement of standards and guidelines	Africa	

Theme	Exemplar Question/Decision Point(s)	Example Option	Region Where Implemented or Planned <sup>b</sup>	Digital Development Principle(s)
		Diffusion of many vertical initiatives without a common architecture	Africa	ecosystem; Design for scale; Be collaborative; Build for sustainability; Design with the user; Reuse and improve
		Challenges engaging the private sector because of interpretation of law for personal data protection	Asia	
		Lack of health care provider awareness of policies and regulations and applicability to the health sector	Africa	

#### Lessons Learned:

- The use cases for HIE and interoperability will depend on country and funder priorities.
- LMIC that envision broad, cross-health issue and multi-sector HIE should plan for extensibility and integration from the beginning. Many LMIC are constrained by resources, donor priorities, and existing vertical programs. However, small-scale demonstration projects that factor in interoperability can be extended to additional use cases if planned thoughtfully.
- In most countries, the data collector or the place where data is physically located is seen as the “owner” or steward of the data. There is increasing discussion of the patient as the true owner of their health data, but few LMIC currently offer patient access to their electronic health information. The review indicates that the notions of “ownership” and “access” are viewed differently. Ownership may imply the entity that has the responsibility for storing, safeguarding, and making decisions about data flow and collection. Access may be a privilege granted by the “owner” to others to view, use, or edit data. Data “stewardship” may reflect a different perspective than the more traditional concept of “ownership,” implying more of a management and guardianship role rather than a right to data.

## Key Area 2: Governance

Governance defines the process and roles for coordinated decision-making. Governance for eHealth should be transparent and can include functions for oversight and steering, project management, subject-matter expertise across domains (e.g., national health system and services delivery, population health, national health strategy and policy, current ICT use and eHealth environment, other sectors like education, financing, telecommunications), stakeholder engagement and consultation, and communications management.[1]

Exemplar Question/Decision Point(s)	Example Option	Where Implemented or Planned <sup>c</sup>	Digital Development Principle(s)
<p><b>- Are all exchange participants bound to a common governance or trust framework?</b>  <b>- If yes, who developed the governance or trust framework?</b></p>	<p>Yes. AeHIN participants have agreed to use the Information Systems Audit and Control Association's COBIT 5, a business framework for the governance and management of enterprise IT. COBIT 5 embeds aspects of ISO/IEC 38500 and other international standards for organizational governance of IT.</p>	<p>Asia eHealth Information Network (AeHIN) countries</p>	<p>Understand the ecosystem; Build for sustainability</p>
	<p>No. A less formal governance structure because the MoH is the main decision-making body (and oftentimes there is a small private sector).</p>	<p>Africa</p>	
	<p>Depends. "Network of networks" model – where the private sector plays a large role in the system, there are many different exchange networks (e.g., state HIEs, public-private partnerships), each with their own governance and trust framework. Entities that join certain exchange networks agree to abide by the governance and trust mechanisms of the</p>	<p>North America</p>	

<sup>c</sup> At least one country in the region has implemented or is planning to implement the example option. This does not mean the option has been implemented throughout the entire region.

Exemplar Question/Decision Point(s)	Example Option	Where Implemented or Planned <sup>c</sup>	Digital Development Principle(s)
	particular network.		
<p><b>- Does the governance framework apply to specific use cases, or is it enterprise-wide?</b></p> <p><b>- If the framework applies to one or a few use cases, can it be expanded to apply for more use cases?</b></p>	Enterprise-wide, largely related to adoption of COBIT 5 governance framework and universal health coverage mandate. There have been challenges engaging the private sector, however.	Asia (e.g., the Philippines <sup>d</sup> )	Design for scale; Be collaborative
	A set of use cases, including individual treatment, payment activities of a care providers, limited health care operations, public health activities and reporting, to demonstrate “meaningful use,” uses and disclosures pursuant an authorization.	North America	
<p><b>What aspects are included in a governance framework?</b></p>	Technical requirements, testing requirements, policies, governance structure, accountability measures, process for adding and changing requirements	North America	Design for scale; Be collaborative
	<p><u>Universal principles:</u> HIPAA compliance, compliance with implementation guide for a use case, non-discrimination, accountability, cooperation, acceptable uses, universal customer flow downs, identity proofing and authentication, information handling and transparency</p> <p><u>Customizable principles</u> (different based on use case): Permitted purposes, permitted users, full participation, service level agreements, data sufficiency and integrity, customizable</p>	North America	

<sup>d</sup> Please refer to the *Best Practices Feature #1* (page 19) for more information.



Exemplar Question/Decision Point(s)	Example Option	Where Implemented or Planned <sup>c</sup>	Digital Development Principle(s)
	customer flow downs		
<b>Who are the major stakeholder groups affected by HIE and interoperability, and are they represented?</b>	Mainly government sector representation with participation from academia	South America	Understand the ecosystem; Build for sustainability; Be collaborative
<b>Does the governance structure include representatives from the public sector, private sector, or both?</b>	Representation from the public and private sectors (please refer to Best Practices Feature #1 for more information)	Asia	Understand the ecosystem; Build for sustainability; Be collaborative

**Lessons Learned:**

- Almost every eHealth Strategy reviewed includes a governance mechanism. This could be due to the World Health Organization (WHO)/International Telecommunicate Union (ITU) 2012 eHealth Strategy Toolkit, which suggests governance as a key component of an eHealth Strategy. In actuality, governance mechanisms are not always easily identified within countries (e.g., partners cannot easily identify the governance body) or sometimes do not appear to be utilized for decision-making at the national level. There may be separate governance bodies by disease or program that are not integrated or coordinated (e.g., in some African countries receiving donor funds for vertical programs in this review). In contrast, governance implementation tends to take priority in countries with a focus on universal health coverage and enterprise-wide architecture (e.g., seen in places in Asia and South America in this review).
- Many countries have delayed engagement of the private sector to-date or have experienced challenges engaging the private sector in governance of eHealth. Reasons cited include a mismatch in goals/vision between the public and private sectors (e.g., lack of value proposition or incentives for the private sector), legal barriers, lack of business agreements, lack of guidance to the private sector, and prioritization of public sector use cases.

If the governance framework addresses multiple use cases, a step-by-step design phase similar to a process map can assist in implementation (e.g., who needs what now, who will need what in the future, scenarios, personas, use cases, technical and business specifications).

## ***Best Practices Feature #1 – HIE Governance Framework in the Philippines***

### **Key Best Practices:**

- **Governance framework in place with representation from public and private sectors.**
- **Clear and simple decision-making process.**
- **Vision and priorities are agreed upon by all parties.**

### **Lessons Learned:**

- **Identify “triggers” and “pain points” early on that will galvanize support and broad outreach as well as address potential roadblocks.**
- **A unifying vision (e.g., universal health coverage) can help set direction and guide decision-making.**

In 2011, Dr. Alvin Marcelo from the University of the Philippines Manila and Dr. Boonchai Kijjanayotin from Thailand gathered like-minded representatives from six Asian countries and started the Asia eHealth Information Network (AeHIN). The founders of AeHIN agreed there was a need to develop capacity on national leadership and governance to accelerate eHealth in Asian countries. At the same time, the WHO and ITU released the WHO-ITU National eHealth Strategy Toolkit which provided the framework for national eHealth development.

Leveraging these events, Dr. Marcelo supported the Philippines Department of Health (DOH) in their adoption of the Information Systems Audit and Control Association (ISACA)’s COBIT 5, an internationally recognized business framework for the governance and management of enterprise IT. The basic COBIT 5 framework is available for free download and embeds aspects of ISO/IEC 38500, ITIL (formerly Information Technology Infrastructure Library), and other international standards. Representatives from the Philippines DOH accepted COBIT 5 because it was comprehensive and did not require deep technical expertise. It also provided a ready framework for decision-making around enterprise IT that is adaptable to the health sector.

The Philippines DOH worked with other sectors (e.g., ICT, health insurance, academia) to review COBIT 5 and the WHO/ITU 2012 eHealth Strategy Toolkit with guidance from the Regenstrief Institute. The Philippines established a leadership and governance structure (see figure below). The National eHealth Steering Committee is chaired by the DOH, co-chaired by the Ministry of Information and Communications Technology (ICT), and meets quarterly. The National eHealth Technical Working Group (TWG) advises the Steering Committee and seeks input from stakeholders, experts, and advisory groups.

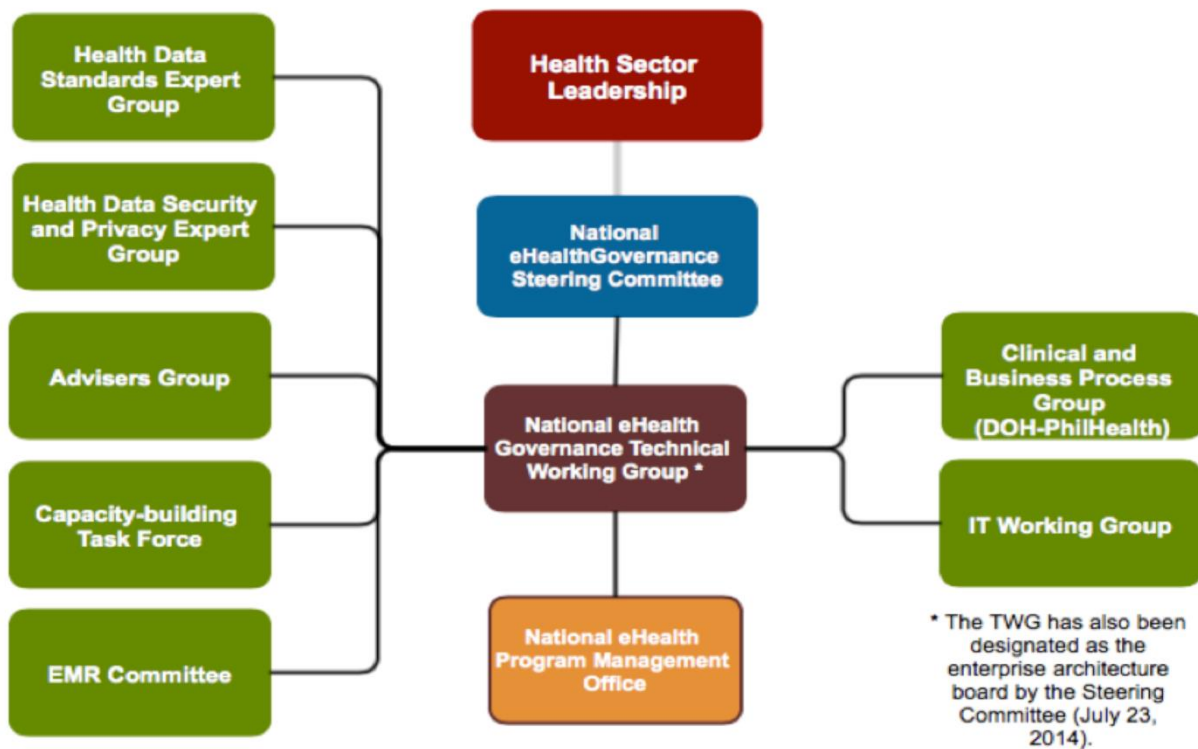
The Steering Committee granted the TWG permission to execute plans if the TWG reaches consensus without having to wait for a quarterly Steering Committee meeting. Issues for which the TWG cannot achieve consensus must be elevated to the Steering Committee for

decision-making. This simple yet clear decision-making process is essential to making progress.

The Philippines' governance structure also includes participation from the private sector, including representation from:

- Ateneo de Manila University
- National IT Confederation of the Philippines
- IT Association of the Philippines
- ISACA
- Medilink Inc.
- Philippine Medical Association
- Philippine Cancer Society
- Association of the Municipal Officers of the Philippines
- Philippine Hospital Association
- Drugstore Association of the Philippines.

**Figure 1. eHealth Governance Structure in the Philippines**



In 2016, the Philippines is working on the following priorities:

- Launching the Philippine Health Information Exchange with a focus on a Standards Catalog and a Standards Change Management Manual.
- Launching the Health Data Privacy Capacity-building Program.

The COBIT 5 framework has been instrumental in providing a framework for broad decision-making for eHealth. For example, COBIT 5 suggests that implementers identify “triggers” that help players realize they need additional expertise and support. Dr. Marcelo identified one of the early triggers for the Philippines was to ask “Can I do this eHealth ‘thing’ by myself?” The DOH and key players in the health sector realized they could not without additional participation and input from additional partners, providing the Steering Committee with an opportunity to further engage the right stakeholders. COBIT 5 also recommends the identification of “pain points” that have been bothering stakeholders. One example is when decision-makers balked at the risk of signing off on multi-million peso technology investments without thoroughly understanding how these will result in benefits to the Filipino people. For example, the Minister did not feel comfortable to commit a large amount of funding for purchasing servers. By adopting the COBIT5 framework, the Minister received assurance that there are processes and checks in place to ensure that sound decision-making would ensure the right technical inputs will result into improved health outcomes. This allowed the Minister to support the vision of an eHealth-enabled system and work with partners on achieving the vision.

*Source: Alvin Marcelo, MD, FPCS, CGEIT, TOFAG, ArchiMate, COBIT5 (F/I), Associate Professor of Surgery and Health Informatics, University of the Philippines Manila and Executive Director, Asia eHealth Information Network*

### Key Area 3: HIE Policies & Procedures – General

These decision points are linked to standards and interoperability as well as privacy and security. Thus they are classified as “general” or cross-cutting issues.

Theme	Exemplar Question/Decision Point(s)	Example Option	Where Implemented or Planned <sup>e</sup>	Digital Development Principle(s)
<b>Patient Identification</b>	How will patients be uniquely identified or matched?	National or unique patient identifier	South America, Central America and Caribbean, Africa	Be data driven; Address privacy and security
		Patient matching based on demographics and other data	Africa	
		Biometrics	No solution using biometrics identified	
<b>Patient Consent</b>	What kind of patient consent policy will be implemented? Who will “own” or “steward” the data?	Opt-in Opt-out	<b>Gap</b> – the review was not able to elucidate the existence of national level consent policies. All eHealth Strategies include privacy & security and/or confidentiality as a key issue, but the policies and	Address privacy and security; Understand the ecosystem

<sup>e</sup> At least one country in the region has implemented or is planning to implement the example option. This does not mean the option has been implemented throughout the entire region.

Theme	Exemplar Question/Decision Point(s)	Example Option	Where Implemented or Planned <sup>e</sup>	Digital Development Principle(s)
			implementation are unknown.	

**Lessons Learned:**

- The cultural attitude toward patient confidentiality and self-identification may affect the acceptability of a national identifier. Countries that have implemented a national or unique identifier appear better able to match records compared to those using patient matching based on demographics data.
- Experts indicated there is great potential for biometrics for unique patient identification, but challenges remain with the cost of the technology as well as practicality in LMIC (e.g., for populations engaged in manual labor, fingerprints would not be reliable for unique identification).
- While there is general acknowledgement that patient consent issues as related to confidentiality, privacy, and security are important, some countries appear to prioritize discussions about architecture and standards before deciding how consent will be managed. This may be especially true where interoperability has yet to be demonstrated or has only been demonstrated on a small scale rather than nationally. This could also be related to the lack of legal frameworks for making privacy decisions and the lack of national-level governance bodies. Decision-makers could benefit from concrete examples of different consent policy implementations and guidance on how to facilitate these conversations with the right partners and stakeholders.

## ***Best Practices Feature #2 – Policies for eHealth and HIE in Peru***

### **Key Best Practices:**

- **Legally enforceable policies for the use of ICT and eHealth provide a solid foundation and clear expectations for HIE and interoperability.**

Peru’s National Electronic Government Plan for 2013-2017 includes 28 projects. Of these, six priority projects in the health sector were included, as follows:

- Online registration system for live births
- Telehealth in rural and border areas aimed at strengthening the capacities of facility staff
- Telehealth for prioritized health care centers
- Electronic medical records
- Health care referral system
- Telemedicine, including videoconferencing and imaging transmission.

In addition, The Peruvian Digital Agenda 2.0 established the importance of increasing connectivity of hospitals and health care centers in Peru. In addition, the policy promotes the development of health information systems to improve hospital management, including online medical appointments and electronic prescriptions.

Peru has provided strong and clear guidance with a series of national level policies for eHealth and the use of ICT, detailed in Table 2.

**Table 2. Legal Policies for the Use of eHealth and ICT in Peru**

<b>Category</b>	<b>Legal Document</b>	<b>Description (Translated from Spanish using Google Translate)</b>
<b>Strategy</b>	Supreme Decree No. 066-2011-PCM	<a href="#">Development Plan of the Society for Information in Peru – The Peruvian Digital Agenda 2.0</a>
<b>Strategy</b>	Legislative Decree No. 604	<a href="#">Law on the Organization and Functions of the National Institute of Statistics and Informatics</a>
<b>Strategy</b>	Ministerial Resolution No. 61-2011-PCM	<a href="#">Guidelines that establish the minimum electronic content for government strategic plans</a>
<b>Strategy</b>	Ministerial Resolution No. 1942-2002 SA/DM	<a href="#">Approval of Directive “General Standards for the Conduct of Information Systems, Statistics and Information at the MoH.”</a>
<b>Strategy</b>	Ministerial Resolution No. 297-2012/MINSA	<a href="#">Technical document approves establishment of the conceptual framework for strengthening health information systems (HIS) and ICT in the MoH.</a>
<b>Strategy</b>	Ministerial Resolution 365-2008/MINSA	Requires that telehealth must be addressed in the following areas of development: provision of health or telemedicine; health care management; and information, education, and communication to the public and health care personnel
<b>Infrastructure</b>	Law No. 29904 and Supreme Decree 014-	Act promoting broadband and infrastructure for national fiber optics with enforcement through

Category	Legal Document	Description (Translated from Spanish using Google Translate)
	2013-MTC	Supreme Decree 014-2013-MTC establishes a national access network “Red Nacional del Estado Peruano (REDNACE).”
Systems	Management Resolution No. 001-2012/GOR/RENIEC	<a href="#">Approval of the live birth form for manual and online transmission</a>
Systems	Law No. 30024	<a href="#">Act establishing the National Register of Electronic Medical Records</a>
Systems	Ministerial Resolution No. 148-2012/MINSA	<a href="#">Approval of Ministerial Directive No. 190-MINSA/OGEI<sup>f</sup>/V-01 – Procedure for the registration of health facilities in the country</a>
Standards	Ministerial Resolution 576-2011/MINSA	Approved Administrative Directive 183 which sets specifications for standardization of electronic medical records
Standards	Law No. 27269	<a href="#">Law on digital signatures and certificates</a>
Standards	Ministerial Resolution No. 553-2002	<a href="#">Formalizes the use of ICD-10 in all health facilities in the nation, and instructs the OGEI to implement and train staff in its use</a>
Standards	Health Technical Standard No. 067/MINSA/PHD-V.01	<a href="#">Health standards in telehealth</a>
Privacy & Security	Law 29733 and Supreme Decree 003-2013-JUS	Law on Protection of Personal Data and subsequent regulations
Privacy & Security	Directorial Resolution 019-2013-JUS/DGPDP	Policy for Information Security of Databases – the conditions, requirements, and technical measures for databases

Table adapted from Curioso. Rev PAHO 2014 [9] and Curioso, Rev Peru Med Exp Salud Publica 2015 [10].

The policies for eHealth and ICT have provided the infrastructural and legal foundations for additional policies addressing HIE and interoperability, detailed in Table 3.

**Table 3. Legal Policies for Health Information Exchange and Interoperability in Peru**

Legal Document	Description (Translated from Spanish using Google Translate)	Notes
Ministerial Resolution No. 381-2008-PCM	Standards and Specifications for Interoperability in Peru	Adopts open standards as well as international standards (ISO).
Supreme Decree No. 083-2011-PCM	<a href="#">Platform for National Interoperability</a>	
Supreme Decree No. 024-2005	Approval of data standards for health; Describes the technical rules for the standard identification of core data, including an	Some systems at the institutional level can share data, but standards are not

<sup>f</sup> OGEI – Oficina General de Estadística e Informática (General Office of Statistics and Information)



Legal Document	Description (Translated from Spanish using Google Translate)	Notes
	analysis of processes and information flows and identification of health data standards used	implemented nationwide.
<b>Ministerial Resolution 537-2011/MINSA</b>	Technical interoperability and systems integration through definition of standards, data structures, and protocols for the presentation, gathering, exchange, and transport of data	Peru has been exchanging data with private sector clinics through SUSALUD.
<b>Ministerial Resolution 576-2011/MINSA</b>	Adopts HL7 standards for electronic exchange of clinical and administrative data and DICOM standard for electronic exchange of medical images	

Table adapted from Curioso. Rev PAHO 2014 [9] and Curioso, Rev Peru Med Exp Salud Publica 2015 [10].

Peru has applied its policies for successful implementation of an online registration system for live births, at the national level in public and private health care centers and hospitals, a partnership between the MoH and National Identification and Civil Status Registry. The system allows staff to register newborns and generate a birth certificate in real-time in the delivery room. It also provides a central hub of health information allowing for real-time statistics for timely public health decision-making (e.g., identification of high-risk subgroups for interventions). Peru is looking toward integration of this system with electronic medical records as well as building in telehealth services for rural populations.[11]

*Source: Walter H. Curioso, PhD, MD, MPH, Affiliate Associate Professor, Department of Biomedical Informatics and Medical Education, School of Medicine at the University of Washington, Seattle, Washington, USA*

## Key Area 4: HIE Policies & Procedures – Standards & Interoperability

Theme	Exemplar Question/Decision Point(s)	Example Option	Where Implemented or Planned <sup>g</sup>	Digital Development Principle(s)
<b>Data</b>	Is there a minimum common data set that should be collected/exchanged to meet the use case(s)?	Yes, identified in regulations	South America <sup>h</sup>	Design for scale; Be data driven; Use open data/ standards/ source/ innovation
		Yes (method of implementation unknown)	Africa	
<b>Standards</b>	Is there a minimum set of interoperability standards requirements (e.g., terminology standards, content exchange standards)?	Yes, published in national standards and guidelines documents	Africa <sup>i</sup>	Design for scale; Use open data/standards/source/innovation; Be collaborative
		Yes, identified in regulations (i.e., ICD-10, HL7, and DICOM)	South America	
		Yes, suggested but not enforceable by the U.S. government at this time. However, private and state networks may choose to require certain standards for participation. ( <a href="#">Interoperability Standards Advisory</a> )	North America	

<sup>g</sup> At least one country in the region has implemented or is planning to implement the example option. This does not mean the option has been implemented throughout the entire region.

<sup>h</sup> Please refer to the *Best Practices Feature #2* (page 23) for more information.

<sup>i</sup> Please refer to the *Best Practices Feature #3* (page 28) for more information.

Theme	Exemplar Question/Decision Point(s)	Example Option	Where Implemented or Planned <sup>g</sup>	Digital Development Principle(s)
<b>Platform</b>	Are participants required or encouraged to implement the same technology platform?	No, decentralized government structure with county autonomy to purchase software	Africa	Design for scale; Use open data/standards/source/innovation; Be collaborative
		OpenHIE (either implementing or considering)	Asia, Africa	
<b>Transport</b>	Are participants able to use multiple transport methods?	Yes	Europe	Understand the ecosystem; Use open/data/standards/source/innovation; Be collaborative

**Lessons Learned:**

- All eHealth Strategies reviewed include standards as a key piece for interoperability and improved HIS integration.
- Some countries either have no legal framework in place (e.g., Kenya) or have chosen not to enforce the implementation of identified standards possibly due to the health care environment (e.g., United States).
- Many countries without governance structures in place are working on standards and interoperability through pilot or demonstration projects. However, the lack of governance frameworks and/or legal tools (e.g., laws, regulations, data use agreements) may limit widespread or national-level interoperability.

## ***Best Practices Feature #3 – Standards and Guidelines in Kenya***

### **Key Best Practices:**

- **A focus on key priority areas/“low hanging fruit” with expansion toward more use cases.**
- **Practical application of standards to evaluate current systems.**
- **Involvement of key private sector partners in the development of standards and guidelines.**

### **Identified Challenges:**

- **Enforcement of standards and guidelines.**
- **Standardization and interoperability with a decentralized/federalized government structure.**

In 2010, the Kenyan MoH released the first *Standards and Guidelines for EMR systems* in support of the 2009-2014 Health Information Policy and Strategic Plan.

These standards focused on use cases for HIV/AIDS, TB, and maternal and child health. The guidelines address the minimum functionalities and standards for an EMR system, the implementation process, development, operations, and M&E of EMR systems. The guidelines also include a section on governance and policy.

In 2011, Kenya undertook a review of 17 EMR systems implemented in 28 districts across the country using the *Standards and Guidelines for EMR systems* to evaluate system functionality and implementation. Four EMR systems met the MoH’s standards. This review against the national standards allowed the MoH to identify areas for improvement for the 13 systems that did not meet the standards.

Who developed the *Standards and Guidelines for EMR systems*? The MoH’s Division of HIS, National Aids and STI Control Program, Kenya Bureau of Standards, and the International Training and Education Center for Health (I-TECH), through a technical working group of other implementing partners and donor organizations.

In 2014, Kenya released an additional set of Standards and Guidelines:

- *For primary health care EMR systems;*
- *For electronic laboratory information systems; and*
- *For electronic pharmacy information systems.*

The three guidelines reflect expanded use cases and goals to improve data sharing between systems, address the MoH’s reporting needs, promote increased use (particularly clinical) of the system by front-line health workers, and provide reliable support and sustainability for existing systems. These Standards and Guidelines specify minimum data sets that systems in each domain must collect to facilitate exchange of patient-level data. They were developed through financial and technical support from the U.S. President’s Emergency

Plan for AIDS Relief (PEPFAR), channeled through the Centers for Disease Control and Prevention (CDC), and implemented through I-TECH Kenya.

Who developed the *primary health care EMR systems Standards and Guidelines*? The MoH through a task force with representation from different MoH divisions and implementing partner organizations. Additional feedback was sought through a stakeholder meeting.

Who developed the *laboratory information systems Standards and Guidelines*? The MoH through the National Public Health Laboratories Services (a division of the MoH's division of HIS), supported by implementation partners.

Who developed the *pharmacy information systems Standards and Guidelines*? The MoH's department of Pharmacy through a task force team including specific stakeholder organizations and divisions (e.g., Division of HIS, Mission for Essential Drugs and Supplies).

The set of Standards and Guidelines provide a best practices example of national-level, stakeholder driven policies that can promote system integration, interoperability, and better data quality. Kenya began with a key set of health priorities and expanded to include additional priorities over time. However, Kenya currently has no regulatory means of enforcing their standards and guidelines and has been considering policy options to drive adoption, such as the United States model of the EHR Incentive Programs ("meaningful use"). Policy levers may be key to ensuring success as Kenya has moved to a decentralized government model with 47 counties that are implementing their own HIS. To partially address this issue, Kenya is developing an EMR certification framework based on the Certification Commission for Health Information Technology (CCHIT) model and will be encouraging individual system implementers to self-attest to meeting the certification framework's specifications.

*Source:*

*Steven Wanyee, MSc, EHR Implementation and Interoperability Manager, I-TECH, Executive Secretary, Kenya National Health Informatics Association*

*Steven worked for I-TECH between 2010 and 2015 October initially as a technical adviser and was directly responsible for development of the initial standards and guidelines, OEC proof of concept, technical liaison with MoH and other stakeholders, and generally all informatics tasks at I-TECH. Subsequently, his position changed to EMR/EHR Implementation and Interoperability Manager and he was directly responsible for design, development and implementation of KenyaEMR (achieved 343 implementations in 2 years), Lab Info System (22 implementations in 1.5 years), NUPI (National Unique Patient Identifier) design and initial prototyping, and generally, overall informatics technical leadership. Since Nov 2015, Steven is spending more time as the Executive Secretary of the Kenya National Health Informatics Association (KeHIA - [www.kehia.org](http://www.kehia.org)) spearheading a national informatics agenda that includes the policy and legal environment, human resources for health capacity, implementation best practices, and general sustainability efforts.*

## Key Area 5: HIE Policies & Procedures – Privacy & Security

Exemplar Question/Decision Point(s)	Example Option	Where Implemented or Planned <sup>j</sup>	Digital Development Principle(s)
<p><b>- Are there existing national laws regarding privacy and security requirements for health data?</b></p> <p><b>- What are the underlying principles and cultural considerations?</b></p>	<p>Per <a href="#">WHO 2013 survey</a> of 75 countries:</p> <ul style="list-style-type: none"> <li>• Laws to protect PII irrespective of format (paper or electronic): 10 of 28 (36%) in this review indicated laws in place; 10 (36%) indicated no laws in place; 6 (21%) were not included in the WHO survey; 1 (4%) indicated did not know; 1 (4%) did not respond.</li> <li>• Laws to protect electronic health data: 4 of 28 (14%) in this review indicated laws in place; 15 (54%) indicated no laws in place; 4 (14%) indicated did not know; 5 (18%) did not respond.</li> </ul>	<p>Countries with laws to protect PII irrespective of format: Ghana, Haiti, India, Indonesia, Philippines, Sierra Leone, South Africa, Tanzania, Uganda, Vietnam</p> <p>Countries with laws to protect electronic health data: Ghana, Indonesia, Peru, Rwanda</p>	<p>Address privacy and security; Understand the ecosystem</p>
<p><b>What kind of identification and authentication process will be used to grant data access to users?</b></p>	<p>Hospital exchange with national health insurance bureau for membership validation and provision of a unique patient ID – hospital sends request letter to national health insurance bureau, which reviews the request and provides a security key to</p>	<p>Asia</p>	<p>Address privacy and security; Understand the ecosystem</p>

<sup>j</sup> At least one country in the region has implemented or is planning to implement the example option. This does not mean the option has been implemented throughout the entire region.

Exemplar Question/Decision Point(s)	Example Option	Where Implemented or Planned <sup>i</sup>	Digital Development Principle(s)
	connect to the social health insurance system through APIs.		

**Lessons Learned:**

- Based on this review and the 2013 WHO survey, there appears to be a lack of legal frameworks in place to support privacy and security of health data. Some countries have broad non-health-specific privacy laws which could be interpolated for health data, but this may not be ideal. In many places where legal frameworks do not exist, contractual obligations of individual implementations or pilots have established the privacy and security protocols. These findings indicate that exemplar legal frameworks may help country decision-makers leverage the best practices of others in building a foundation for privacy and security.

## Key Area 6: HIE Policies & Procedures – Data Use Agreements

Not all of the questions/decisions points will need to be addressed in every data use agreement. The applicability of each question/decision point will depend on the purpose or goal of the data use agreement; the parties involved in the agreement; the structure of the health care system and the major stakeholders; the structure of the legal system; and cultural views on trust and liability.

Table 4 presents a high-level comparison of six data use agreements. All of the data use agreements examples presented concern exclusively personally identifiable information (PII), except for the MOU between Kambia District in Sierra Leone and Forécariah District in Guinea<sup>k</sup> which covers both individual data and aggregate data for Ebola surveillance.

Theme	Exemplar Question/Decision Point(s)	Example Option	Where Implemented or Planned <sup>l</sup>	Digital Development Principle(s)
<b>Data Use Agreement</b>	What is the anticipated use of data – site-to-site sharing or regional/national data sharing, and what type of data sharing agreement may be needed to support the outcome? For site-to-site data sharing, consider point-to-point agreements. For regional/national data sharing, consider multi-	No data use agreement in place. The MoH is the main decision-making party and there has not been a need for an agreement for intra-country data sharing thus far.	Africa	Understand the ecosystem; Address privacy and security; Design for scale; Be collaborative
		Data use agreement in place between the MoH, Ministry of ICT, and the national insurance corporation. (point-to-point) However, the agreement specifies requirements of participation for providers in the network.	Asia	

<sup>k</sup> The MOU between Kambia District and Forécariah District can be found in Appendix C (page 71).

<sup>l</sup> At least one country in the region has implemented or is planning to implement the example option. This does not mean the option has been implemented throughout the entire region.



Theme	Exemplar Question/Decision Point(s)	Example Option	Where Implemented or Planned <sup>1</sup>	Digital Development Principle(s)
	party data use and exchange agreements.	Formal MOU agreement between the social health insurance bureau and primary health centers must be signed by the District Health Office Director. (appears to be multi-party)	Asia	
Data use agreement in place between two districts sharing a country border for sharing of Ebola surveillance data. (point-to-point) Note this agreement also includes stipulations for sharing of physical resources (e.g., ambulances, laboratories, staff – surveillance and funeral teams).		Africa		
Scalable, multi-party trust agreement for a data sharing network and data sharing between different networks		North America		
<b>Laws and Regulations</b>	Are there existing laws and regulations that establish baseline compliance requirements for protection of PII? What legal tools can be leveraged to protect PII?	Per <a href="#">WHO 2013 survey</a> of 75 countries: <ul style="list-style-type: none"> <li>• Laws to protect PII irrespective of format (paper or electronic): 10 of 28 (36%) in this review indicated laws in place</li> </ul>	Countries with laws to protect PII irrespective of format: Ghana, Haiti, India, Indonesia, Philippines, Sierra	Understand the ecosystem; Address privacy and security

Theme	Exemplar Question/Decision Point(s)	Example Option	Where Implemented or Planned <sup>1</sup>	Digital Development Principle(s)
		<ul style="list-style-type: none"> <li>Laws to protect electronic PII health data: 4 of 28 (14%) in this review indicated laws in place</li> </ul>	<p>Leone, South Africa, Tanzania, Uganda, Vietnam</p> <p>Countries with laws to protect electronic health data: Ghana, Indonesia, Peru, Rwanda</p>	
<b>Use Cases</b>	Is there a specified or limited number of purposes for exchange? (e.g., clinical care, administrative needs, financial needs, monitoring and evaluation, public health/population health including disease and surveillance reporting, research)	Ebola data for public health surveillance	Africa	Understand the ecosystem; Address privacy and security; Design with the user; Be collaborative
		Insurance status validation and individual patient clinical data exchange for treatment	Asia	
		Initial focus on harmonization of applications and HIS. Then as approved, expansion to individual patient-level exchange for treatment and population/public health in	Asia	

Theme	Exemplar Question/Decision Point(s)	Example Option	Where Implemented or Planned <sup>1</sup>	Digital Development Principle(s)
		support of Universal Health Coverage (e.g., delivery of laboratory results, exchange of continuity of care documents, medication documentation).		
		A number of use cases – individual treatment, payment activities, limited health care operations, public health activities and reporting, to demonstrate “meaningful use,” and uses and disclosures pursuant an authorization	North America	
		For treatment, to exchange data to meet requirements for federal “meaningful use” incentive program, to provide patients access to their data	North America	
<b>Use Cases</b>	Is there any anticipated secondary reuse or re-exchange of data with participants in the network?	General lack of agreements addressing data reuse	Generally in LMIC	Be data driven; Reuse and improve
		Yes, an agreement exists for research purposes related to reducing poverty through a conditional cash transfer program. (social & behavioral services data)	Asia	
		Individually-identifiable data are not permitted to leave the facilities where collected	Africa	

<b>Theme</b>	<b>Exemplar Question/Decision Point(s)</b>	<b>Example Option</b>	<b>Where Implemented or Planned<sup>1</sup></b>	<b>Digital Development Principle(s)</b>
		Yes, for the permitted purposes outlined in the data use agreement	North America	
<b>Participant Obligations</b>	Are all participants required to be in production?	Agreement specifies that authorities must share data and certain minimum Ebola-related data must be exchanged weekly	Africa	Be data driven; Be collaborative
		Agreement does not explicitly require providers in the HIE be in production	Asia	
		Agreement explicitly requires participants in the network to be in production	North America	
<b>Participant Obligations</b>	Are all participants required to respond to queries/data requests?	Agreement explicitly requires participants in the network to respond to queries/data requests with either data or a message that the requested data are not available	North America	Be data driven; Be collaborative
<b>Participant Obligations</b>	What is the process for reporting breaches or addressing issue resolution?	In accordance with the country's HIE Manual of Operation which details Incident Response and Mitigation Guidelines	Asia	Address privacy and security; Understand the ecosystem

Theme	Exemplar Question/Decision Point(s)	Example Option	Where Implemented or Planned <sup>1</sup>	Digital Development Principle(s)
		Prompt notification of the governing body, Coordinating Committee, and other impacted participants	North America	
		Provide reasonable information to resolve issues or disputes	North America	
<b>Local Rules</b>	Can participants establish their own policies around which users can access and exchange data using the participants' system?	Yes, within the broader bounds of the overall agreement.	North America	Understand the ecosystem; Be collaborative
<b>Data Integrity/Quality</b>	Is there a need to guarantee clinical accuracy, content, or completeness of data exchanged?	Participating providers are responsible for editing or correcting information in the country's HIE as requested by amendment by the patient or other participating providers	Asia	Be data driven; Address privacy and security
		Participants must ensure accuracy of data during transmission reflects what is in their system at the time, but the agreement does not impose any responsibility or liability on a participant for the clinical accuracy, content, or completeness of message content	North America	

Theme	Exemplar Question/Decision Point(s)	Example Option	Where Implemented or Planned <sup>l</sup>	Digital Development Principle(s)
		Members must have processes in place to provide accurate and complete patient data that it provides to the HIE	North America	
<b>Dispute Resolution</b>	Is there a resolution process for disputes between participants? <sup>m</sup>	Mandatory non-binding dispute resolution process outlined in the agreement	North America	Address privacy and security; Understand the ecosystem
		Mandatory non-binding dispute resolution process. However, this agreement requires participants to adhere by cooperation requirements prior to entering a dispute resolution process.	North America	
<b>Liability</b>	What party/ies bear the risk for harm caused by breaches of the data use agreement? <sup>n</sup>	Each participant is responsible for their own acts and omissions, but not the acts and omissions of other participants. Participants are responsible for harm caused if they breach the agreement or if due to their negligence, there is a breach of data being transmitted.	North America	Understand the ecosystem; Address privacy and security
		Limits liability to circumstances where there is a breach of the agreement, with an aggregate limit on liability of \$3 million USD.	North America	

<sup>m</sup> This issue has only been identified in North America thus far per the review.

<sup>n</sup> This issue has only been identified in the United States thus far per the review.

Theme	Exemplar Question/Decision Point(s)	Example Option	Where Implemented or Planned <sup>1</sup>	Digital Development Principle(s)
<b>Auditing</b>	Who bears the responsibility for auditing access to and use of systems related to the data use agreement?	The provider participating in the country's HIE must report to the HIE Management Group any problems related to access to the HIE	Asia	Understand the ecosystem; Address privacy and security; Be collaborative
		Each participant must possess the ability to monitor and audit all access to the use of its system related to the agreement	North America	
		Each participant must possess, but is not required to use, the ability to monitor exchange activities and provide monitoring information per the network's reasonable request	North America	
		All parties are responsible for auditing application processes and user activities involving the interconnection and must record the event type, date and time of event, user identification, workstation identification, success or failure of access attempts, and security actions taken by system administrators or security officers	North America	
<b>Identity Proofing and Authentication</b>	Is there a need for identity proofing and authentication?	Each user who shares data in the network must be uniquely identified and verified prior to	North America	Understand the ecosystem; Address privacy

Theme	Exemplar Question/Decision Point(s)	Example Option	Where Implemented or Planned <sup>1</sup>	Digital Development Principle(s)
		gaining access to a participant's system per networks requirements		and security
		Members have the responsibility to determine the Authorized Users under its control and to implement security requirements	North America	

**Lessons Learned:**

- Contributors indicated a general lack of data use exchange agreements in LMIC. While this review was not exhaustive, some form of data use agreement was identified in Asia and Africa.
- The lack of data use agreements in LMIC could be related to the challenges countries have experienced developing the business processes to support HIE and interoperability. In cases where the focus for HIE is in the public sector and where the MoH is the main decision-maker for the health sector, data use agreements may not be viewed as necessary because of MoH-issued requirements or mandates for data sharing. Many countries indicated they are just beginning to engage the private sector and foresee a need for data exchange agreements in the near future.
- Contributors expressed that data sharing agreements would likely be necessary for any inter-country/cross-border sharing, where issues of data “ownership,” permitted uses/reuse, and liability can play a large role.
- Only one of the data use agreements reviewed include research as a permitted secondary use of data. Some contributors indicated research may be a lesser priority for countries in addition to perceived concerns about the lack of confidentiality and unknown ramifications of reusing data for research.
- Data use agreements can also extend to use cases including integration of social and behavioral data.



**Table 4. Issues and Questions Addressed in Data Exchange Agreements Reviewed**

Issue or Question	Kambia Sierra Leone/Forecariah Guinea	Philippine HIE	Philippine Social Welfare & Economic Development	eHealth Exchange (U.S.)	Carequality (U.S.)	Indian Health Service MPA (U.S.) <sup>o</sup>
Addresses exclusively PII (as opposed to aggregate data sharing)		✓	✓	✓	✓	✓
Discusses existing laws and regulations that create baseline requirements		✓		✓	✓	✓
Discusses the governance body for the network	✓	✓		✓	✓	✓
Specifies the permitted use cases for exchange	✓	✓	✓	✓	✓	✓
Explicitly addresses data exchange across country borders	✓					
Explicitly discusses secondary uses for exchanged data			✓	✓	✓	✓
Addresses the requirements for obtaining patient consent		✓		✓	✓	✓
Explicitly permits patient access to data				✓		✓
Specifies that participants are required to be in production	✓			✓	✓	
Explicitly requires participants to respond to data requests			✓	✓	✓	
Specifies the process for reporting breaches or addressing exchange issues		✓		✓	✓	

<sup>o</sup> Note that the IHS MPA requires its Members to comply with the terms and conditions of the eHealth Exchange DURSA. This Table only presents the content that is explicitly included in the IHS MPA, not what is implicit through the DURSA requirement.

<b>Issue or Question</b>	<b>Kambia Sierra Leone/Forecariah Guinea</b>	<b>Philippine HIE</b>	<b>Philippine Social Welfare &amp; Economic Development</b>	<b>eHealth Exchange (U.S.)</b>	<b>Carequality (U.S.)</b>	<b>Indian Health Service MPA (U.S.)°</b>
<b>Allows participants to establish local rules and policies on users who can access the system</b>				✓	✓	
<b>Specifies requirements around data accuracy and completeness</b>		✓		✓	✓	✓
<b>Requires a dispute resolution process</b>				✓	✓	
<b>Specifies responsibilities for liability</b>				✓	✓	✓
<b>Sets requirements for auditing system use and access</b>		✓		✓	✓	✓
<b>Explicitly includes requirements for identity proofing and authentication</b>		✓		✓	✓	✓
<b>Discusses additional privacy, confidentiality, and security requirements beyond identity proofing and authentication</b>		✓		✓	✓	✓

\*Note that standards and platform requirements are generally presented in onboarding requirements or in operational procedures that are separate documents from the formal data use agreement.

## ***Best Practices Feature #4 – Data Use Agreements in the United States***

*The data use agreement model implemented in the U.S. may not be applicable for every country. As noted above, the finer points included in a data use agreement will depend on the purpose or goal of the data use agreement; the parties involved in the agreement; the structure of the health care system and the major stakeholders; the structure of the legal system; and cultural views on trust and liability. However, the following information is presented as an example of one model with takeaways that may help countries make decisions about the necessity and content of data use agreements.*

### **Key Best Practices and Lessons Learned:**

- **A common, trust/principle-based data use agreement allows for scalability and can eliminate the need for point-to-point agreements.**
- **Initial experience with an early data use agreement in the U.S. led to a more simplified and modular approach to a data use agreement.**
- **A common data use agreement may not be needed for aggregate level data exchange because of reduced risk and concerns about sharing of individual-level data.**

### **Identified Challenges and Opportunities:**

- **Multi-party trust agreements may require significant time to develop depending on the goals and clearance processes of the different parties involved. However, the up-front investment can establish clear rules of the road and expectations for participants in the long-run, as well as provide a foundation for extension to other use cases in the future.**
- **If there is general nationwide legal uniformity or a single effective legal jurisdiction, a data use agreement can be used to address some of the legal requirements for exchange.**
- **A complex health system with a strong private sector such as the U.S. may have a number of networks, each with its own data use agreement, policies and procedures. This can present challenges for nationwide interoperability, however the Carequality® initiative in the U.S. is connecting networks and provides one model to address this challenge.**

### The eHealth Exchange™ “DURSA”

In late 2008, the U.S. was in the early stages of establishing national health information sharing and expanding the adoption of electronic health records. The U.S. system is characterized by a strong private health care sector and state autonomy to establish laws and regulations. There are a fair number of regional and state health information exchanges as well as private health systems with their own HIS.

The [eHealth Exchange](#)™ formed during this time as a public-private health exchange network with a vision to use a common set of standards, legal agreement, and governance. Today, the eHealth Exchange™ is the largest HIE network in the U.S.

The original organizations involved in the creation of the eHealth Exchange™ were either private sector organizations under grants or contracts which obligated them to establish an agreement for data sharing within a determined time period, known as the [Data Use and Reciprocal Support Agreement](#) or DURSA, or governmental agencies. The collective group of private sector organizations and federal agencies worked toward a common goal and enabled the group to come to consensus quickly and efficiently through a process driven by the legal counsels and business leads of the organizations. Despite the streamlined process, the participants debated over the use cases and requirements of the agreement and the near-final DURSA went through each federal agency's time-intensive clearance processes. The developers also deliberated issues such as the development of test data and the breach notification process.

The first DURSA was published in November 2009 and the DURSA has been revised twice since its initial publication.

The DURSA is based on agreed-upon [principles of trust](#) that establish the framework for the agreement:

- Shared rules of the road and shared governance
- Representative governance
- Participants in production
- Multiple exchange methods and profiles\*
- Privacy and security obligations
- Identification and authentication
- Permitted purposes
- Future use of data received through eHealth Exchange™
- Local autonomy\*
- Reciprocal duty to respond\*
- Responsibilities of party submitting data
- Authorizations
- Participant breach notification
- Chain of trust\*
- Mandatory non-binding dispute resolution\*
- Allocation of liability risk\*
- Other representations and warranties.

The principles asterisked above appear to be issues unique to the U.S. or only explicitly mentioned in U.S.-based agreements based on the review of the current state of data use agreements. The DURSA continues to evolve; the eHealth Exchange™ is discussing issues such as whether to expand the initial permitted data uses, revise the breach notification requirements, and address expectations for business associations of participants.

### Experiences and Lessons Learned in the DURSA Development

During the development of the DURSA, one federal agency worked with other eHealth Exchange™ partners on the issue of obtaining consent to share information. This federal agency is subject to statute that requires written permission to disclose information by Veterans with certain diagnoses, such as alcoholism, HIV, and sickle cell anemia. The DURSA authors and software developers had to decide how this requirement would translate to the world of electronic exchange. At the time, the agency's systems were not sophisticated enough to filter data by written diagnosis.

One option was to require written consent for every patient. While this approach was seen as overly burdensome, the agency elected this path to minimize the risk of unintended release of protected information. The DURSA authors decided on a policy that requires each participant health system to obtain the correct consent or authorization applicable to the responding Participant before releasing information to the network, whether these reflect state laws or institutional requirements. This approach ensures that one participant's requirements cannot be imposed on any other participants. Today, the agency is developing a more robust and nuanced way to filter by diagnosis to help address the original consent concerns. This illustrates one example of how the developers of the DURSA had to address a way forward to address the "strictest" requirements in a workable policy for the entire network.

Another federal agency developed its own federated data sharing services agreement to covered entities who desired to engage in electronic exchange as part of the "meaningful use" program. This was a novel legal tool for this agency because the organization historically entered into bilateral (point-to-point) agreements. The federated agreement creates a single framework and covers multiple purposes and needs, including security, privacy, health information management, and other legal requirements, and is modeled after the eHealth Exchange™ DURSA.

In terms of implementation and onboarding with HIEs around the country, the federated agreement participants have experienced resource challenges. One challenge includes the unique and varied regional and statewide standards and requirements regional and state HIEs have created. Facilities that wish to participate in local/ regional data exchange must interface with these specific requirements which has resulted in point-to-point exchanges rather than a cohesive, integrated network. The agency does not have the resources to support all of its HIE participants in onboarding with each state and regional HIE. Thus, there is an opportunity for a shared service on the national level to assist with these connections and reduce the cost and complexity of data exchange.

### Applying Lessons Learned from the eHealth Exchange™ Network – Carequality® Initiative

The [Carequality®](#) (pronounced "care equality") initiative is a more recent HIE initiative hosted by the same advocacy group as the eHealth Exchange™ ([The Sequoia Project](#)). Carequality® is a public-private, multi-stakeholder collaborative which aims to provide data sharing connectivity regardless of geographic or technology lines. Carequality® will enable networks like the eHealth Exchange to share data under a common network-to-network interoperability framework with providers in different data sharing networks.

Carequality® also benefits from increased trust in the health care environment compared to the early days of the eHealth Exchange™.

Carequality® has established a data use agreement built on a model of universal principles applicable to every use case along with customizable principles that differ upon the use case. These [principles](#) are similar to those in the eHealth Exchange™ principles with some changes based on lessons learned. For example, the Carequality®'s [Connected Agreement](#) (“DURSA” equivalent) requires participants engage in certain cooperative actions prior to using the dispute resolution process to encourage a more collaborative approach to address issues. The Connected Agreement also recognizes that certain principles need to be present but will differ based on the use case, reflecting a more modular approach with the Connected Agreement for the universal principles and implementation guides that establish the procedures for specific use cases. To-date Carequality®'s only established implementation guide is for a [query-based document exchange use case](#).

The Carequality® Connected Agreement was developed through a similar multi-party consensus-based process as for the DURSA. Carequality® experienced similar challenges in addressing local autonomy (e.g., federated legal system with state laws and regulations in addition to federal laws and regulations). Carequality® followed the same approach taken for the eHealth Exchange™ in permitting local autonomy.

Carequality®'s Universal Principles:

- HIPAA compliance
- Compliance with Implementation Guide for a use case
- Non-discrimination
- Local autonomy
- Accountability
- Cooperation
- Acceptable use
- Universal customer flow downs
- Identity proofing and authentication
- Information handling transparency.

Carequality®'s Customizable Principles (need to be present but will differ based on use case):

- Permitted purposes
- Permitted users
- Full participation
- Service level agreements
- Data sufficiency and integrity
- Customizable customer flow downs.

Carequality®'s approach reflects a step-wise progression addressing agreed-upon universal principles that can be applied to further use cases. The customizable principles need to be present but will differ based on the specific use case. This may be a model that other

countries may consider for development of their networks and data use agreements. While Carequality®'s participants are U.S.-based, the multi-network data sharing initiative is working with other countries to gauge interest and test applicability of the Connected Agreement in other settings.

*Sources:*

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## Key Area 7: HIE Implementation

While this review focused on policies and procedures for HIE, informants indicated some additional key factors would influence the success of HIE implementation and sustainability. Because the review did not focus on these issues, example options are generally unknown; this area is a gap for further research and/or fact-finding.

<b>Theme</b>	<b>Exemplar Question/Decision Point(s)</b>	<b>Example Option</b>	<b>Where Implemented or Planned<sup>P</sup></b>	<b>Digital Development Principle(s)</b>
<b>Infrastructure</b>	How will system infrastructure be developed, sustained, financed, and expanded?	While most projects in this country are funded by donors, the MoH set up an M&E task force that focuses on making strategic decisions to influence donors to invest in integrated HIS toward a single common architecture.	Africa	Design for scale; Build for sustainability; Reuse and Improve
<b>Training</b>	How will users and participants at all levels of the system be trained?	Review did not focus on this issue	NA	Design for scale; Build for sustainability; Be collaborative
<b>Consistent Processes</b>	How will consistent processes be established and implemented (e.g., patient registration, patient match)?	Review did not focus on this issue (refer to Key Area #3 for patient identification/match)	NA	Design with the user; Design for scale; Be collaborative
<b>Monitoring and Evaluation</b>	How will performance and success be measured? Will data be collected from use of the network to inform performance measures?	Review did not focus on this issue	NA	Design for scale; Be data driven; Use open data/ standards/ source/ innovation

<sup>P</sup> At least one country in the region has implemented or is planning to implement the example option. This does not mean the option has been implemented throughout the entire region.



Theme	Exemplar Question/Decision Point(s)	Example Option	Where Implemented or Planned <sup>p</sup>	Digital Development Principle(s)
<b>Supportive Services</b>	Will support services like record locators and provider directories be implemented?	One agency uses a record locator service in its HIE network	North America	Design for scale, Design with the user
		Provider directories used in many HIE networks	North America	

## Chapter 5 Identified HIE Challenges

This chapter culls together the challenges to HIE and interoperability identified in this review and grouped by the framework Key Areas. As applicable, the challenges include commentary about how country decisions may differ based on the government structure, culture, and funding issues, as well as other lessons learned.

### Key Area 1: Vision & Strategy

- Challenge 1a: Vertical programs and different donor priorities may support different technology platforms and goals.
  - Comments: Countries that rely heavily on donor funding or public-private partnerships could consider working on building integrated platform strategies during project planning stages.

### Key Area 2: Governance

- Challenge 2a: Separate governance bodies by disease or program that are not integrated or coordinated.
- Challenge 2b: Engaging the private sector, possibly due to a mismatch in goals/vision between the public and private sectors (e.g., lack of value proposition or incentives for the private sector), legal barriers, lack of business agreements, lack of guidance to the private sector, and prioritization of public sector use cases.
  - Comments: The extent of this challenge will depend on how large of a role the private sector plays in providing health care. If the larger vision involves data exchange with the private sector, countries should include the private sector in governance from the early stages.
- Challenge 2c: Engagement/buy-in from health care providers in the HIE vision and implementation.
- Challenge 2d: Decentralized government with local decision-making power may pose challenges with strategy, standardization, and interoperability.
  - Comments: The extent of this challenge will depend on the type of government structure. For countries with this concern, governance may need to work at both national the local levels. Countries may also need to consider other levers to ensure interoperability and standards adoption, such as regulatory enforcement, incentives/penalties, and conditions of participation (e.g., mandatory reporting or engagement in HIE to maintain facility certification).
- Challenge 2e: Identifying and ensuring the right partners are involved in governance decisions.

### Key Area 3: HIE Policies & Procedures – General

- Challenge 3a: Lack of legal frameworks or challenges interpreting existing laws.
  - Comments: Legal tools (e.g., laws, regulations, and enforcement) can provide the boundaries for HIE and interoperability. The culture and government structure may affect the effectiveness of legal tools. In some cases, they

provide the necessary protections and guardrails in which to operate; in others, very strict laws and regulations may be inflexible to innovation and changes in the environment, thus hindering progress.

- Comments: Countries may have existing laws for protection of personal data broadly, and it may be challenging to determine how to interpret a broad law for health data specifically.
- Challenge 3b: Deciding on how patients will be identified and records matched (e.g., unique patient identifiers, patient matching).
  - Comments: Unique patient identifiers may be the most efficient solution widely implementable today, but societies may differ in their views of patient identification and acceptability of a patient identifier. Where a patient identifier is less acceptable, countries may need to use other methods such as patient match based on demographics. Patient match may present challenges in countries where names are not distinguishable and birth dates are not commonly known or used.

#### **Key Area 4: HIE Policies & Procedures – Standards & Interoperability**

- Challenge 4a: Countries without governance structures in place may be working on standards and interoperability through pilot or demonstration projects. A lack of governance frameworks and/or legal tools (e.g., laws, regulations, data use agreements) may limit widespread or national-level interoperability.
  - Comments: See Challenge 1a.
- Challenge 4b: Enforcement of standards and guidelines.
  - Comments: See Challenges 2b and 2d.
- Challenge 4c: Standardization and interoperability with a decentralized/federalized government structure.
  - Comments: See Challenges 2d.
- Challenge 4d: Concerns with the data quality and accuracy.

#### **Key Area 5: HIE Policies & Procedures – Privacy & Security**

- Challenge 5a: Lack of legal frameworks in place to support privacy and security of health data.
  - Comments: See Challenge 3a. Also, example legal frameworks may help country decision-makers leverage the best practices of others in building a foundation for privacy and security.

#### **Key Area 6: HIE Policies & Procedures – Data Use Agreements**

- Challenge 6a: A lack of data use agreements in LMIC could reflect the challenges countries have experienced developing the business processes to support HIE and interoperability.
  - Comments: In cases where the focus for HIE is in the public sector and where the MoH is the main decision-maker for the health sector, data use agreements may not be viewed as necessary because of MoH-issued requirements or mandates for data sharing. Countries indicated they are

beginning to engage the private sector and foresee a need for data exchange agreements in the near future.

- Comments: Contributors expressed that data sharing agreements would likely be necessary for any inter-country/cross-border sharing, where issues of data “ownership,” permitted uses/reuse, and liability can play a large role. If countries envision cross-border data sharing, they should bear in mind the decision points in the framework for Key Area 6 (page 32). As discussed in *Best Practices Feature #4* (page 43), a multi-party data use agreement is one model that can help reduce or eliminate the need for point-to-point agreements.

### **Key Area 7: HIE Implementation**

- Challenge 7a: Basic infrastructure (e.g., reliable Internet connectivity, hardware).
  - Comments: This framework assumes a fair degree of basic infrastructure is in place in-country, however many LMIC are experiencing challenges in this area. Basic infrastructure is a prerequisite for sustainable and effective HIE and is necessary for sustainability.
- Challenge 7b: Financing.
  - Comments: Many LMIC may depend on donor funding sources and/or public-private partnerships (see Challenge 1a). In addition, countries may face challenges in creating a sustainable business model for HIE in the long-run. Experience with ongoing HIE implementation shows that careful planning is needed for a successful transition from scale-up to ongoing sustainability.
- Challenge 7c: In-country human resources and capacity to support and sustain HIE.
  - Countries working with donors and in public-private partnerships should plan for transfer of knowledge and proper training of health care workers at all levels.

## Chapter 6 Gaps for Future Research

This review revealed knowledge gaps in the following areas that warrant further investigation:

- Policies around patient access to electronic health information are unknown. Most LMIC in the review do not appear to provide patient access to electronic health data today.
- Country policies and procedures around issues of data provenance, how to indicate provenance during HIE (the verb), and policies about how to treat data depending on the provenance are unknown. These appear to be burgeoning issues that countries are beginning to consider. Further exploration of the policy and technology options available is warranted.
- The review was not able to elucidate the existence of national level consent policies. All eHealth Strategies include privacy & security and/or confidentiality as a key principle, but the policies and implementation are unknown. Further study and example legal frameworks may help country decision-makers leverage the best practices of others in building a foundation for privacy and security.

As noted in Chapter 3: Methods (page 6), this review does not present official MoH positions and may not have identified all existing HIE policies and procedures due to the networking method of information gathering. A more robust and quantitative review would require a standardized survey of the MoH's in LMIC.

This review also focused on LMIC. While information was gathered from high-income countries as time permitted, more information from HIE and interoperability initiatives in high-income countries (e.g., Canada, EU countries, Australia, New Zealand) can likely offer additional lessons learned and other models compared to the United States.

Finally, additional analysis of the data collected in this review as well as further information gathering to fill in the gaps could yield additional publications on specific topics that can enhance the knowledge in this area. These additional topics include:

- Geographic constraints of data sharing (e.g., cross-border vs. local/regional/national exchange)
- Public health/population health vs. individual-level data sharing
- Data for research beyond monitoring and evaluation
- An opinion paper on “What does monitoring and evaluation mean with patient empowerment? Do patients know that their data is being used for monitoring and evaluation? What are the changing perceptions of patient ownership and access to health data, and what are the implications for HIE?”
- A deeper dive into the privacy, security, and confidentiality policy issues as relates to HIE and interoperability
- Is there a “pyramid” or step-wise progression of interoperability that can be successfully scaled up in LMIC?

1. The review indicated that some countries may not achieve wide-spread HIE in the near future and may want to determine the most important factors for a scalable or hierarchical approach.

## Sidebar: Case Reporting as a Use Case

This review takes a global look at HIE broadly; however informants offered examples from public health surveillance of reportable diseases as a particular use case for the movement of and systems for data. Attention to recent epidemics including Ebola and Zika virus bring issues of global health security and cross-border data sharing to the forefront.

Below a high-level summary of some work in the international community for electronic case reporting as well as work ongoing in the United States is presented. Last, the questions/decision points that may be most relevant for case reporting from the recommended framework are listed.

### Case Reporting in the International Space

Groups like the Centers for Disease Control and Prevention (CDC) are examining opportunities for improved HIV case reporting in LMIC. The goal is to help countries understand the epidemic situation and better plan responses. The CDC is looking at countries where there is a mature surveillance and treatment program, patient-level data exists, and privacy laws are conducive to data sharing. Bidirectional data flow between the point of care and administrative groups/MoH could facilitate alerts or flags for providers to be aware of changes in an epidemic and adjust their care accordingly.

Many LMIC today use structured paper-based HIV reporting forms which are then entered into HIS. This could facilitate increasing use of semantic standards for case reporting that can be extended to electronic reporting of other reportable diseases using similar platforms. In fact, there is a strong emphasis on integrated disease surveillance for priority infectious diseases in the Ebola-affected countries of Sierra Leone, Liberia, and Guinea.

CDC is looking to pilot electronic-based HIV case reporting built on the recommendations of the Public Health Informatics Institute (PHII) for [EHR-based surveillance](#). These pilots will require attention to issues of patient confidentiality and patient identification for record matching. At this point, electronic case reporting has not been known to be demonstrated in LMIC and early efforts are focusing on the technology infrastructure.

### Case Reporting in the United States

The U.S. has a system characterized by a “network of networks” with electronic case reporting occurring in a number of regional and private networks using different standards. The U.S. is working toward national electronic case reporting to the CDC. Decisions on the content exchange standard at a national level proved to be one of the major decision points. In approaching these decisions, the U.S. utilized a different PHII tool, [Taking Care of Business](#), to define the business processes that affect electronic case reporting. The document also describes how public health entities can approach business process analysis and redesign to achieve the goal.

The U.S. is pursuing a structured data capture (SDC) model for electronic case reporting that pre-populates the electronic case report form with information already in the EHR and provides structured data fields for providers to complete the rest of the required case information. Because of the existing networks and processes in place for electronic case reporting, the community has to work through issues of standardization and business process alignment across the nation. This may be applicable to LMIC – an SDC-like model may be more efficiently implemented where there is one or just a few platform(s) or EHR system(s) in place.

### HIE Decision Points Applicable to Case Reporting

Based on the information provided by contributors during the review, the relevant decision-points for electronic case reporting from the general framework are listed. Almost all decision-points in the framework apply.

#### **Vision & Strategy**

- What are the key goals and outcomes for HIE and interoperability?
- Will the data be at the individual patient level or an aggregate level?
- Will data be exchanged within country, with other countries, or both?
- Where are data collected and stored in the current state?
- Which groups are the current main stakeholders?
- Are there additional groups that should be engaged?
- Who owns or stewards the data?
- What groups of patients and consumers will be affected by HIE?
- Are there special issues affecting certain groups of the population that should be considered?
- What are likely areas of challenges or where additional expertise may be needed?
- Is there strong support or a champion/ influencer at the national or regional level?
- Have issues of data provenance been considered?

#### **Governance**

- Are all exchange participants bound to a common governance or trust framework?
- (Depends if governance is for case reporting only or for other use cases) Does the governance framework apply to specific use cases, or is it enterprise-wide?
- If the framework applies to one or a few use cases, can it be expanded to apply for more use cases?
- What aspects are included in a governance framework?
- Who are the major stakeholder groups affected by HIE and interoperability, and are they represented?
- Does the governance structure include representatives from the public sector, private sector, or both?

#### **HIE Policies & Procedures – General**

- How will patients be uniquely identified or matched?



- What kind of patient consent policy will be implemented? Who will “own” or “steward” the data?

### **HIE Policies & Procedures – Standards & Interoperability**

- Is there a minimum common data set that should be collected/exchanged?
- Is there a minimum set of interoperability standards requirements (e.g., terminology standards, content exchange standards)?
- Are participants required or encouraged to implement the same technology platform?
- Are participants able to use multiple transport methods?

### **HIE Policies & Procedures – Privacy & Security**

- Are there existing national laws regarding privacy and security requirements for health data?
- What kind of identification and authentication process will be used to grant data access to users?

### **HIE Policies & Procedures – Data Use Agreements**

- Key question – What is the anticipated use of data (site-to-site sharing or regional/national data sharing? What type of data sharing agreement may be needed to support the outcome? (e.g., a scalable, multi-party data use and exchange agreement or point-to-point agreements)?
- **Note** – the following questions will only apply if a data use agreement will be used:
  - Are there existing laws and regulations that establish baseline compliance requirements? What legal tools can be leveraged to protect PII?
  - (If the agreement addresses more use cases than case reporting) Is there a specified or limited number of purposes for exchange?
  - Is there any anticipated reuse or re-exchange of data with participants in the network?
  - Are all participants required to be in production?
  - Are all participants required to respond to queries/data requests?
  - What is the process for reporting breaches or addressing issue resolution?
  - Can participants establish their own policies around which users can access and exchange data using the participants’ system?
  - Is there a need to guarantee clinical accuracy, content, or completeness of data exchanged?
  - Is there a resolution process for disputes between participants?
  - What party/ies bear the risk for harm caused by breaches of the data use agreement?
  - Who bears the responsibility for auditing access to and use of systems related to the data use agreement?
  - Is there a need for identity proofing and authentication?

### **HIE Implementation**

- How will system infrastructure be developed, sustained, financed, and expanded?

- How will users and participants at all levels of the system be trained?
- How will consistent processes be established and implemented (e.g., patient registration, patient match)?
- How will performance and success be measured? Will data be collected from use of the network to inform performance measures?
- Will support services like record locators and provider directories be implemented?

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## Chapter 8 Appendix A – Contributors

This Appendix provides the contact information for contributors and information sources based on those whom have consented to include their information as of April 1, 2016.

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Erik Pupo	Managing Director, North America Clinical and Health Management Services	Accenture	erik.pupo@accenture.com	Brazil, Kenya, Tanzania, Uganda, epSOS
Andrew Truscott	Partner	Accenture	andrew.j.truscott@accenture.com	Angola, Brazil, Australia, Canada, Denmark, epSOS, France, Germany, Norway, United Kingdom, Saudi Arabia, Singapore

### North America

<b>Contact Name</b>	<b>Title</b>	<b>Organization</b>	<b>Email</b>	<b>Country/Countries</b>
Dave Cassel	Director	Carequality®	dcassel@sequoiaproject.org	United States
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Joshua Vest	Associate Professor	Department of Health Policy & Management,	joshvest@iu.edu	United States

<b>Contact Name</b>	<b>Title</b>	<b>Organization</b>	<b>Email</b>	<b>Country/Countries</b>
		Richard M. Fairbanks School of Public Health, Indiana University		

### **Topic Areas**

<b>Contact Name</b>	<b>Title</b>	<b>Organization</b>	<b>Email</b>	<b>Topic Area(s)</b>
Betsy Humphreys	Acting Director	National Library of Medicine, National Institutes for Health	humphreb@mail.nih.gov	Standards, IHTSDO, SNOMED CT, LOINC, RxNorm
Eric-Jan Manders	Health Scientist, Informatics	Centers for Disease Control and Prevention	ejmanders@cdc.gov	Case reporting (Ukraine, Kenya)

## Chapter 9 Appendix B – Resources

*Note: These resources were used as part of the literature review for this review and are presented in alphabetical order by country or organization, as applicable.*

### Strategic Plans<sup>q</sup>

Asia eHealth Information Network Strategic Plan: 2012-2017.

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República de Angola Ministério de Saúde, Gabinete de Estudos, Planeamento e Estatística: Plano Estrategico do Sistema de Informação Sanitária: 2011-2015.

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Standards and Guidelines for Electronic Medical Record Systems in Kenya. Kenya Ministry of Medical Services and Ministry of Public Health and Sanitation.

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Safety and security on the Internet: challenges and advances in Member States: based on the findings of the second global survey on eHealth. Global Observatory for eHealth Series Volume 4. World Health Organization 2011.

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Management of patient information: trends and challenges in Member States: based on the findings of the second global survey on eHealth. Global Observatory for eHealth Series Volume 6. World Health Organization 2012.

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**Chapter 10 Appendix C – Memorandum of Understanding Between  
Kambia District, Republic of Sierra Leone and Forécariah Prefecture,  
Republic of Guinea Concerning Surveillance of the Ebola Virus Disease  
and Coordination of Cross-Border Interventions**

Please double-click on the title page image below to open the document using Adobe Acrobat. Note, the link will only work through Microsoft Word.

**MEMORANDUM OF UNDERSTANDING**

Between

**Kambia District  
Republic of Sierra Leone**

And

**Forécariah Prefecture  
Republic of Guinea**

Concerning

**SURVEILLANCE OF THE EBOLA VIRUS DISEASE AND  
COORDINATION OF CROSS-BORDER INTERVENTIONS**

**23 March 2015**

## Annexes for MOU (in French):

Annexe A :

### Membres du Groupe de travail Transfrontalier

7 mars 2015

Les personnes suivantes sont membres du Groupe de travail Transfrontalier. Ce groupe de travail a accepté de se réunir toutes les deux semaines dans le but d'assurer la coordination transfrontalière.

Les réunions auront lieu alternativement à Kambia, en Sierra Leone, et à Pamelap, en Guinée.

Forécariah, Guinée	Nom	Kambia, Sierra Leone	Nom
Préfet de Forécariah		DC	Dr Alfred Kamara
Sous-préfet de Pamelap		DMO	Dr Sesay
Coordinateur Ébola		DO	Abu Kamara
<i>Représentant pour la sécurité</i>		CO 11 Inf Btn	Lt. Col. Conteh RSLAF
Représentant de l'OMS		Police de la Sierra Leone (SLP)	Surintendant en chef Sesay
Représentant de l'Unicef			
Qui d'autre ?		Représentant de l'OMS	Margherita Ghiselli
		Représentant de l'Unicef	Jerome Kouachi
		Représentant du Royaume-Uni	Mike McKie
		MSF	?
		CDC	Jeff Ratto
		Chef d'État-major (COS) – Forces armées de la République de Sierra Leone (RSLAF)	Maj Sannah
		Société civile	Représentant
		Chefs principaux	Représentant (par ex., Honorable PC YEK II (Samu))

Les termes de référence pour les réunions sont les suivants :

1. Examen des conditions épidémiologiques tant à Forécariah qu'à Kambia
2. Examen des incidents transfrontaliers depuis la dernière réunion et leçons apprises
3. Examen des progrès accomplis par rapport au Protocole d'entente
4. Examen des questions opérationnelles depuis la dernière réunion et recommandations de solutions



Cette annexe présente les formulaires pro-forma à utiliser pour assurer la surveillance et le travail d'intervention à la frontière de Guinée/Sierra Leone, entre Forécariah et la Guinée.

Les formulaires ci-dessous sont les suivants :

1. **Formulaire de renseignements transfrontaliers** (en français et en anglais) à utiliser lorsqu'un cas confirmé a des liens de l'autre côté de la frontière.
  - a. En présence d'un cas confirmé ayant des liens de l'autre côté de la frontière, l'équipe chargée de l'enquête appellera la ligne d'alerte pour informer du besoin d'enquête/suivi de contact transfrontaliers :
    - i. Bureau d'alerte de Forécariah : +224 694188129 ou +224 624188130
    - ii. Bureau d'alerte de Kambia : +232 77845479 ou +232 77842507
  - b. La personne recevant l'alerte informera MSF à Kambia ou le chef de l'OMS à Forécariah. À Forécariah, le chef de l'OMS affectera un enquêteur pour le cas et informera l'équipe MSF en envoyant un SMS au numéro de téléphone suivant : +232 79515704 ; ou en envoyant un message électronique à l'adresse : [evdbordersil@gmail.com](mailto:evdbordersil@gmail.com)
  - c. L'équipe chargée de l'enquête remplira le « Formulaire d'enquête transfrontalière » (ci-dessous), incluant le minimum de renseignements nécessaires pour l'enquête/le suivi du contact au-delà de la frontière et les coordonnées du contact dans le cas en question, ainsi que celles du responsable de la surveillance. À Kambia, l'enquêteur remettra le formulaire rempli à l'équipe MSF qui le traduira en français.
  - d. L'enquêteur de l'OMS (à Forécariah) ou l'équipe MSF (à Kambia) fera suivre le formulaire rempli via courrier électronique à :
    - i. [evdbordersil@gmail.com](mailto:evdbordersil@gmail.com) (mot de passe : whowhowho) – Kambia, Sierra Leone
    - ii. [ebolabordergui@gmail.com](mailto:ebolabordergui@gmail.com) (mot de passe : omsomsoms) – Forécariah, Guinée
  - e. Les équipes d'enquêtes transfrontalières communiqueront régulièrement par téléphone pendant le suivi. Une équipe d'enquête conjointe pourra être établie, si possible

### Fiche d'information transfrontalière

Nom/prénom du cas		
Date:	Numéro d'identification	
<b>Sommaire du cas:</b>	Age	
	Genre	
	Statut du cas (vivant ou décédé)	
	Adresse et pays du domicile	
	Préfecture/District	
	Numéro de téléphone du cas et de la famille	
	Cas source: nom/prénom, adresse, no d'identification	
<b>Éléments d'importance transfrontaliers:</b>	Début des symptômes	
	Date d'hospitalisation	
	Centre hospitalier	
	Information disponible sur les contacts (adresse de contacts)	
	Point focal (Sierra Leone et Guinée) et numéro de téléphone	

### Formulaire d'enquête transfrontalière

Nom de famille/prénom du cas		
Date de remplissage :	Numéro d'identification	
<b>Résumé du cas</b>	Âge	
	Sexe	
	État (vivant ou décédé)	
	Adresse et pays de résidence	
	Préfecture/District	
	Numéro de téléphone du cas et de la famille	
	Cas source : prénom/nom de famille, adresse, numéro d'identification	
<b>Renseignements importants pour l'enquête transfrontalière</b>	Date d'apparition des symptômes	
	Date d'admission à l'hôpital	
	Nom du centre de maintien/traitement	
	Renseignements disponibles sur les contacts (adresse des contacts)	
	Nom du responsable de l'enquête (Sierra Leone et Guinée) et numéro de téléphone	

Annexe C  
**Répertoire des contacts**  
7 mars 2015

<b>Pays</b>	<b>Site</b>	<b>Description</b>	<b>Nom de famille</b>	<b>Nom</b>	<b>National/ International</b>	<b>Adresse électronique :</b>	<b>Téléphone</b>
Guinée		Épidémiologiste OMS/MG	SYLLA	Mounir	NAT	<a href="mailto:mounirgas@gmail.com">mounirgas@gmail.com</a>	624 617 907
Guinée		Épidémiologiste OMS/MG	CONDE	Sarata	NAT	<a href="mailto:conesarata@gmail.com">conesarata@gmail.com</a>	624 617 776
Guinée		Épidémiologiste OMS/MG	DIALLO	Aguibou	NAT	<a href="mailto:draguibou@gmail.com">draguibou@gmail.com</a>	624 617 788
Guinée		Épidémiologiste OMS/MG	DIALLO	Thierno Saidou	NAT	<a href="mailto:monembo7@gmail.com">monembo7@gmail.com</a>	624 617 820
Guinée		Épidémiologiste OMS/MG	SYLLA	Aissata Daouda	NAT	<a href="mailto:aissatadaouda90@gmail.com">aissatadaouda90@gmail.com</a>	624 617 782
Guinée		Épidémiologiste OMS/MG	TOURE	Ousmane	NAT	<a href="mailto:drotoure@gmail.com">drotoure@gmail.com</a>	624 617 836
Guinée		Épidémiologiste OMS/MG	KAMANO	Aly Antoine	NAT	<a href="mailto:aantoinekamano@yahoo.fr">aantoinekamano@yahoo.fr</a>	624 617 798
Guinée		Épidémiologiste OMS/MG	KOULIBALY	Mamadi	NAT	<a href="mailto:mdkoulibaly@yahoo.fr">mdkoulibaly@yahoo.fr</a>	624 617 799
Guinée		Épidémiologiste OMS/MG	MILLIMONO	Tamba Jacques	NAT	<a href="mailto:millimounotambajacques@yahoo.com">millimounotambajacques@yahoo.com</a>	624 617 906
Guinée		Coordinateur sur le terrain de l'OMS	TWAHIRWA	Gerard	INT	<a href="mailto:gtwahirwa@gmail.com">gtwahirwa@gmail.com</a>	621 845 378
Guinée		Épidémiologiste OMS/MG	KOUROUMA	Fode Sory	NAT	<a href="mailto:docteuridal@yahoo.fr">docteuridal@yahoo.fr</a>	624 617 882
Guinée		Épidémiologiste OMS/MG		Pascal	NAT		624 82 80 95
Guinée	Commu nauté urbaine	Superviseur de proximité	Dr Nanfadima	Condé			+224 664 88 32 16
Guinée	Maférin yah	Superviseur de proximité	Dr Ansoumane	Cissé			+224 664 35 39 88

Guinée	Kaliah	Superviseur de proximité	Dr Fassouma	Mara			+224 655 59 06 49
Guinée	Allassoyah	Superviseur de proximité	Dr Mohamed	Camara			+224 621 62 59 33
Guinée	Benty	Superviseur de proximité	Dr Lansana	Fofana			+224 669 27 23 30
Guinée	Kaback	Superviseur de proximité	M. François	Kamano			+224 628 56 71 59
Guinée	Moussayah	Superviseur de proximité	Dr Abdoulaye	Bangoura			+224 622 06 25 96
Guinée	Kakossa	Superviseur de proximité	Dr Moriba	Touré			+224 662 36 79 81
Guinée	Sikhourou	Superviseur de proximité	Dr Alsény	Barry			+224 628 00 22 00
Guinée	Farmoréah	Superviseur de proximité	Dr Homo Patrice	Goumou			+224 655 51 02 01
Sierra Leone	Kambia	Responsable de la surveillance pour le District	KANU	Hassan			076-831-946
Sierra Leone	Kambia	Responsable de la surveillance pour le District	SANDI	Christopher			030-804-137
Sierra Leone	Kambia	Responsable de la surveillance pour le District	SAMBA	Sheku			077-803-034
Sierra Leone	Kambia	Responsable de la surveillance pour le District	KOLOKOH	Joseph			076-946-414
Sierra Leone	Kambia	Responsable de la surveillance pour le District	BALLAH	Marrah			077-920-980
Sierra Leone	Kambia	Coordinateur sur le terrain de l'OMS	GHISELLI	Margherita		ghisellim@who.int	076-533-521

Sierra Leone	Kambia	Épidémiologiste OMS	COSBY	Michael		cosbym@who.int	079-411-147
Sierra Leone	Kambia	Épidémiologiste OMS	OTIM	Patrick		drpatrickotim@gmail.com	076-533-437
Sierra Leone	Kambia	Épidémiologiste OMS	SHARMA	Vikas		vikas76_in@yahoo.com	078-070-873
Sierra Leone	Kambia	Chef d'État-major (COS) – Forces armées de la République de Sierra Leone (RSLAF)	SANNOH	Foday		sannoh964@gmail.com	077842459 / 088821157
Sierra Leone	Kambia	Prise en charge des cas – RSLAF	BANGURA	Hamid		hamidabangura@yahoo.com	078517678 / 088458015
Sierra Leone	Kambia	Quarantaine – RSLAF	KELLIE	Richard		srichardkellie@yahoo.com	077842507
Sierra Leone	Kambia	Funérailles - RSLAF	KAMARA	Foday		baliakamarabambeno@gmail.com	077842733 / 088140586
Sierra Leone	Kambia	Coordinateur pour le District	KAMARA	Alfred		alfredmkamara@gmail.com	030123434
Sierra Leone	Kambia	Responsable médical du District	SESAY	Foday		fsesay27@yahoo.com	077844641
Sierra Leone	Kambia	Responsable du District	KAMARA	Abu		abubakarrkamara1975.ak28@gmail.com	076606077 / 077295194
Sierra Leone	Kambia	COS RSLAF	CONTEH	Brewar			076946565
Sierra Leone	Kambia	LUT – Police du Sierra Leone (SLP) (surintendant en chef)	SESAY				077867376

Beaucoup d'autres renseignements à ajouter, qui et comment ?

## Guide de poche concernant les points de passage de la frontière

7 mars 2015

Les formulaires suivants constituent un guide de poche pour les personnes responsables de la surveillance des points de passage de la frontière entre la Guinée et la Sierra Leone.

### Vue d'ensemble

- La frontière entre la Sierra Leone et la Guinée a de nombreux points de passage, la plupart non officiels.
- La circulation est très intense, surtout près des marchés et des gros villages.
- Nous avons besoin de surveiller qui entre et sort de la Sierra Leone, afin d'assurer que personne ne puisse propager Ebola dans le pays.

### Votre rôle

- **Surveiller** l'état de santé de chacune des personnes qui se présente à votre point de passage, entrant ou sortant de Guinée.
  - Demandez à ces personnes de quitter leur véhicule pour pouvoir les observer en train de marcher.
  - Demandez-leur de se laver les mains (en veillant à ce qu'il y ait du savon pour se laver les mains).
  - Prenez leur température.
  - Documentez l'événement (inscrivez la date, le nom de la personne, sa température et d'où elle vient et où elle va).
- Si la personne présente des symptômes, suivez l'organigramme des décisions fourni dans le présent guide.
- Si la personne ne présente pas de symptômes, **laissez-la passer.**

### Vos responsabilités

- Protéger la Sierra Leone contre l'importation d'Ebola en provenance de la Guinée
  - S'assurer que **chaque personne** qui passe la frontière soit surveillée
  - S'assurer que **toutes les fournitures** (poste d'eau [veronica bucket], savon, piles AAA, thermomètre, lampe solaire, téléphone pour cercle restreint d'utilisateurs [CRU], carnet de notes) sont prêtes
- Immédiatement **signaler** toutes les alertes au DERC

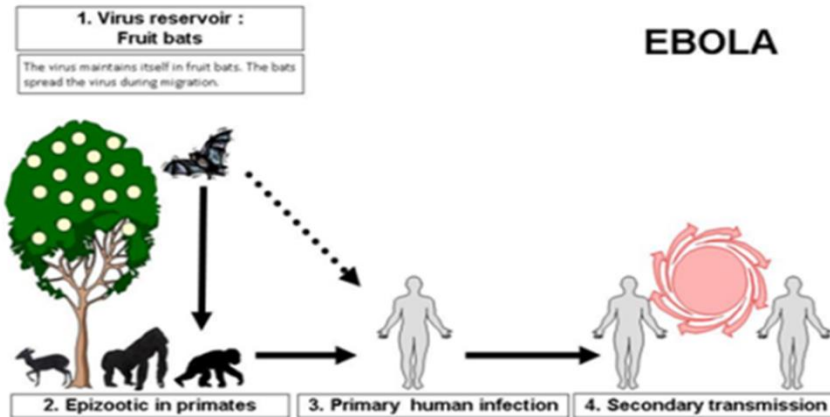
### Qu'est-ce que la fièvre Ebola ?

- La fièvre Ebola est une maladie grave causée par le virus Ebola
- Elle peut sévir dans toute l'Afrique, mais actuellement, nous savons qu'elle est présente à la Sierra Leone, au Liberia et en Guinée.
- Cette flambée est la plus étendue jamais enregistrée jusqu'ici et pour la première fois en Afrique de l'Ouest.
- Le virus Ebola peut être transmis par des animaux sauvages (gorilles, chimpanzés, porcs, chauve-souris, singes) aux humains.
- Il est transmissible de personne à personne, par contact direct avec : sang, urine, matières fécales, vomis, salive, sueur, lait maternel, sperme, organes.

### Comment la transmission se réalise-t-elle ?

- **Par la manipulation d'animaux infectés (malades ou morts)**
  - Chimpanzés, gorilles, chauve-souris roussettes, singes, antilopes des forêts et porcs-épics
- **Communautés (contact avec des corps infectés)**
  - Contacts en soignant des personnes malades ou en prenant soin des corps de patients décédés par des pratiques funéraires et des funérailles non sécurisées (contact de personne à personne)

- Contact indirect avec des environnements contaminés par des fluides
- **Hôpital**
  - Aiguilles, seringues, matériel contaminé
  - Consultation avec des patients sans conformité aux mesures de prévention et de contrôle des infections (PCI)



## Signes et symptômes de la fièvre Ébola

Symptômes de nature générale :	Ceux-ci sont souvent suivis de :
<ul style="list-style-type: none"> <li>• Fièvre soudaine</li> <li>• Faiblesse intense</li> <li>• Maux de tête</li> <li>• Douleurs musculaires</li> <li>• Maux de gorge</li> <li>• Conjonctivite</li> <li>• Nausée et anorexie</li> <li>• Gorge douloureuse</li> <li>• Douleurs abdominales</li> </ul>	<ul style="list-style-type: none"> <li>• Douleurs thoraciques</li> <li>• Diarrhée (aqueuse ou sanguinolente)</li> <li>• Vomissements (parfois sanguinolents)</li> <li>• Éruption cutanée</li> <li>• Confusion et irritabilité</li> <li>• Saignement des yeux, des oreilles, du nez</li> <li>• Dégradation des fonctions du foie</li> </ul>

	<ul style="list-style-type: none"> <li>et des reins</li> <li>• Avortement</li> <li>• Choc</li> <li>• Décès</li> </ul>
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## Traitement

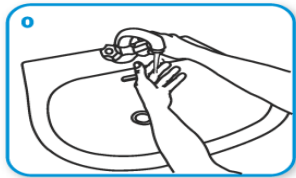
- Il n'existe ni cure ni traitement contre la fièvre Ébola.
- Les soins intensifs (réhydratation par voie orale et IV) sont le seul traitement disponible pour les patients et peuvent avoir un effet positif sur les résultats.
- De nouveaux médicaments et vaccins sont en cours de développement dans des laboratoires, mais ils ne sont pas encore prêts pour être utilisés par le public.

## Lavage des mains

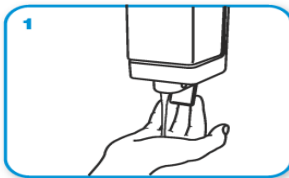
- Versez 1 cuillère à café de savon liquide sur vos mains ou utilisez un petit morceau de savon.
- Frottez le savon sur toutes les parties de vos mains et de vos poignets pendant 40 à 60 secondes.

Séchez-vous les mains avec une serviette propre en tissu ou en papier, ou laissez-les sécher à l'air.





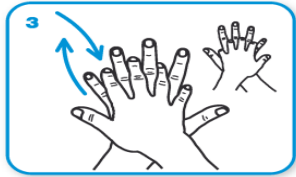
Mouiller les mains abondamment



Appliquer suffisamment de savon pour recouvrir toutes les surfaces des mains et frictionner :



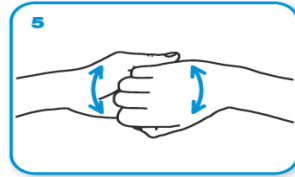
Paume contre paume par mouvement de rotation,



le dos de la main gauche avec un mouvement d'avant en arrière exercé par la paume droite, et vice et versa,



les espaces interdigitaux paume contre paume, doigts entrelacés, en exerçant un mouvement d'avant en arrière,



les dos des doigts en les tenant dans la paume des mains opposées avec un mouvement d'aller-retour latéral,



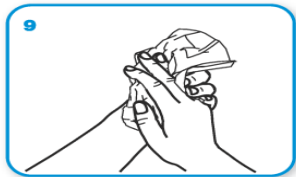
le pouce de la main gauche par rotation dans la paume refermée de la main droite, et vice et versa,



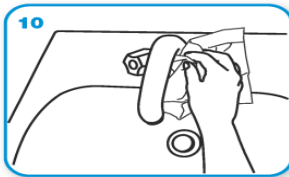
la pulpe des doigts de la main droite par rotation contre la paume de la main gauche, et vice et versa.



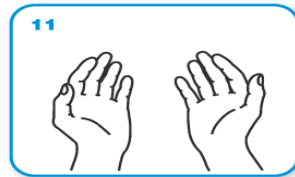
Rincer les mains à l'eau,



sécher soigneusement les mains avec une serviette à usage unique,



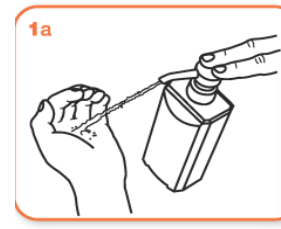
fermer le robinet à l'aide de la serviette.



Les mains sont prêtes pour le soin.

## Gel désinfectant pour les mains

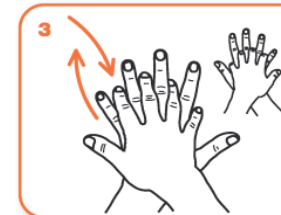
- Versez 1 cuillère à café de gel désinfectant sur vos mains.
- Frottez le gel désinfectant sur toutes les parties de vos mains et de vos poignets pendant 20 à 30 secondes ou jusqu'à ce que vos mains soient complètement sèches.



Remplir la paume d'une main avec le produit hydro-alcoolique, recouvrir toutes les surfaces des mains et frictionner :



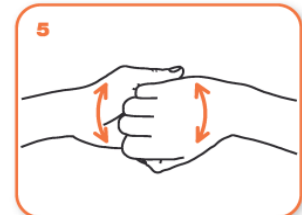
Paume contre paume par mouvement de rotation,



le dos de la main gauche avec un mouvement d'avant en arrière exercé par la paume droite, et vice et versa,



les espaces interdigitaux paume contre paume, doigts entrelacés, en exerçant un mouvement d'avant en arrière,



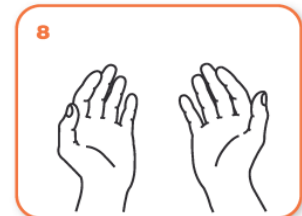
les dos des doigts en les tenant dans la paume des mains opposées avec un mouvement d'aller-retour latéral,



le pouce de la main gauche par rotation dans la paume refermée de la main droite, et vice et versa,



la pulpe des doigts de la main droite par rotation contre la paume de la main gauche, et vice et versa.



Une fois sèches, les mains sont prêtes pour le soin.

## N'oubliez pas :

- Quand vous vous lavez les mains :
  - Évitez l'eau stagnante (impossible de savoir si elle est propre).
  - Évitez l'eau non potable (impossible de savoir si elle est propre).

- Utilisez un petit morceau de savon (moins de personnes l'utiliseront avant qu'il ne soit totalement usé).
- Ne vous frottez pas les mains avec seulement de l'eau !

### Évitez tout contact corporel

- Évitez toutes les formes de contact physique.
  - Ne touchez aucun des contacts.
  - Ne partagez pas leur nourriture.
  - Ne partagez pas leur thé.
  - N'utilisez pas leur téléphone.
  - Ne touchez pas leurs affaires.
  - Maintenez 1 mètre de distance avec toutes les personnes.
- Si vous touchez quelqu'un accidentellement, lavez-vous immédiatement les mains et la zone exposée avec du savon ou du gel désinfectant pour les mains.
- Si vous touchez un cas suspect pour une raison QUELCONQUE, prenez immédiatement les mesures suivantes :
  - Lavez-vous les mains et la zone exposée avec du savon ou du gel désinfectant pour les mains.
  - Avertissez vos collègues et votre superviseur.
  - Ne touchez ni les personnes ni les choses.
  - Surveillez votre température pendant les 21 jours suivants, au moins 2 fois par jour.

### Prise en charge d'un cas suspect

Toute personne (vivante ou décédée) présentant une fièvre soudaine et 3 ou plus des signes suivants :

- Maux de tête
- Vomissements
- Nausée
- Perte d'appétit
- Diarrhée
- Fatigue intense
- Maux d'estomac
- Difficultés à avaler
- Difficultés respiratoires
- Hoquet



### Quand une personne est symptomatique

Si une personne a de la température à 37,5 °C ET/OU 3 symptômes :

- Faites-la asseoir à l'ombre pendant 10 minutes.
- Faites-la se débarrasser de ce qu'elle porte.
- Assurez-vous qu'elle s'est rafraîchie.
- Reprenez sa température.

S'il ou elle **a toujours** une température élevée :

- Dites à la personne qu'elle a de la température.
- Informez-la qu'elle ne peut pas continuer et qu'elle doit se rendre dans une USC pour subir des tests.
- Téléphonnez au DERC et informez l'agent qu'il existe une alerte et à quel point de passage de la frontière. Un responsable DSO se rendra sur les lieux pour enquêter sur le cas.
- Gardez la personne au point de passage de la frontière jusqu'à ce que le responsable DSO arrive.

Numéros de téléphone à utiliser

- Ligne gratuite : 306

- Bureau d'alerte 1 : 077.845.479
- Bureau d'alerte 2 : 077.842.507

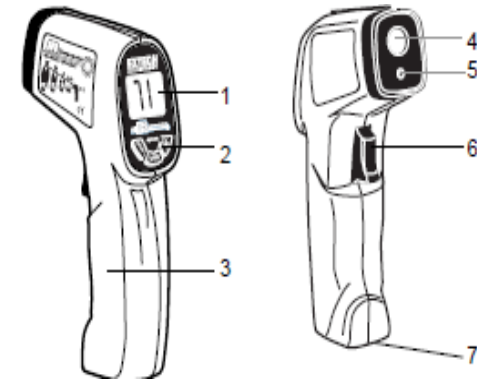
### Comment utiliser un thermomètre

- La température normale du corps est de 37 °C.
- La fièvre est souvent un signe que le corps lutte contre une maladie pouvant être infectieuse.
- Nous utilisons une fièvre mesurée de **37,5 °C** ou plus comme signe du virus Ébola (mieux vaut être prudent !).
- Les personnes infectées peuvent manifester de la fièvre à n'importe quel moment pendant la période d'incubation (jusqu'à 21 jours).
- L'usage d'un thermomètre sans contact est un moyen de prendre la température de quelqu'un sans toucher la personne.

### Comment utiliser l'instrument

1. Mettre le thermomètre en marche et attendre 15 minutes avant de l'utiliser.
  - a. Utiliser uniquement des **pile alcalines AAA**.
2. Demander à la personne de tirer ses cheveux en arrière, d'enlever chapeau ou lunettes et de s'essuyer la sueur du front.
3. Cibler la partie au-dessus de l'extrémité des sourcils.
4. Tenir le thermomètre à **5 cm** de la personne.
5. Prendre la température de la personne.
6. Si **elle est inférieure à 35 °C**, reprendre la température.
7. Si **elle est de 37,5 °C ou plus**, isoler la personne en la maintenant à une distance d'au moins 1 mètre des autres.

1. LCD Display
2. Function Buttons
3. Handle Grip
4. IR Sensor
5. Laser pointer beam
6. Measurement Trigger
7. Battery Compartment



### Réapprovisionnement et logistique

- Les responsables pourront satisfaire vos besoins en cas de problème quelconque en se déplaçant en motocyclette.
- Les demandes de piles, de rations ou d'autres fournitures doivent être sujettes à votre filière hiérarchique.
- Vous devez maintenir des stocks de rations et de piles pouvant durer au moins une semaine.

### Rassemblement des informations

- Il n'y a aucune exigence officielle de recueil de routine des informations, mais vous avez l'obligation de maintenir un journal avec le nombre de personnes traversant la frontière et d'en faire rapport chaque semaine.
- En outre, comme vous prenez la température des personnes, vous devez leur demander leur lieu d'origine, leur destination et la raison de leur déplacement afin de développer un modèle pour l'évaluation des modes de vie, que vous devez également soumettre chaque semaine.

### Prise en charge de la zone d'isolement

- Si vous avez besoin d'utiliser votre zone de décontamination, celle-ci devra être décontaminée par la suite.
- Vous devrez organiser ceci en suivant votre filière hiérarchique qui fera la liaison avec le DERC.

### ORGANIGRAMME DES PRISES DE DÉCISION

Si une haute température est enregistrée (plus de 37,5 degrés centigrades).



Placez la personne dans une tente d'isolement pendant 10 minutes et donnez-lui de l'eau.



Reprenez la température.



Si elle est toujours élevée, téléphonez pour signaler l'alerte en suivant la filière hiérarchique.



Un responsable DSO se rendra auprès de vous.



Si la personne répond à la définition d'un cas (ce que le responsable DSO décidera)



Organisez son transport vers un établissement de soins par l'intermédiaire du DERC.



Organisez la décontamination de la tente d'isolement.

Si la température de la personne baisse après l'attente de dix minutes dans la tente, laissez-la passer mais conseillez-lui de chercher de l'aide si elle ne se sent pas bien.

# Chapter 11 Appendix C – Abstract Submission to 2016 AMIA Symposium

Submitted March 10, 2016

## Comparison of Policies and Procedures on Governance of Data Use to Support Health Information Exchange in Low- and Middle-Income Countries

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### Abstract

*Low and middle-income countries (LMIC) are increasingly contemplating electronic health data sharing architectures using the health information exchange (HIE) approach. Successful large-scale interoperability depends on effective policies and procedures for data sharing. We undertake a review of policies and procedures for HIE in LMIC to determine the current state of and identify potential barriers to successful development and implementation of policies and procedures focused on data use and governance.*

### Introduction

Clinical care, community surveillance, and program evaluation activities are enhanced by a milieu where health data is easily shared. Health information exchanges (HIE) are a common architectural approach for electronic health data sharing, but their success is dependent upon the development and implementation of data governance at a country or institutional level. Historically, interoperability is deeply influenced by issues surrounding data ownership, data sharing, data aggregation, data re-use, and governance<sup>1</sup>. As low- and middle-income countries (LMIC) move towards increasing HIE and interoperability, developing a logical framework to resolve these sociotechnical ambiguities for a given environment becomes more critical<sup>2</sup>.

The World Health Organization undertook a series of surveys of eHealth in Member States which informed the Global Observatory for eHealth (GOe) series of publications in 2010-2014<sup>3</sup>. While the GOe surveys and publications provide a strong baseline for understanding the use of eHealth in LMIC, they do not focus on HIE and interoperability through the lens of governance and data use issues. We undertook a global review of policies (e.g., laws, national strategies, legal agreements) and procedures (e.g., implementation guidance, standards) (P&P) for health information exchange in LMIC, focusing on data use and governance. Our goals were to add to the existing knowledge and identify key focal areas for a potential framework that country decision-makers should consider when developing effective P&P for HIE.

### Methods

We performed a mixed-method review of P&P for HIE in LMIC as defined by the World Bank from February-March 2016. While the review focused on LMIC, we also collected data from high-income countries to determine if there were lessons learned that could be applied in LMIC settings.

For the literature review, we reviewed the published literature indexed in PUBMED and MEDLINE using keywords “low- and middle income country,” “health information exchange,” “interoperability,” “big data,” “policy,” and “governance.” We also reviewed articles referenced by the published literature as well as the gray literature including countries’ eHealth strategies, legislation, and other P&P relating to HIE.

For the semi-structured interviews, we first contacted individuals working in LMIC through the OpenHIE community (<http://ohie.org>). The OpenHIE community improves the health of the underserved through open and collaborative development and support of country-driven, large scale health information sharing architectures. Experts were invited to hour-long semi-structured interviews regarding P&P for HIE. We sought recommendations for additional LMIC contacts from the initial experts. While an exhaustive review of every LMIC was not performed, we sought to provide a snapshot of HIE in regions across the globe that could inform key focal areas for these policies and procedures globally. This review was qualitative in nature and thus the results presented represent the general themes and overall findings. It does not represent a quantitative perspective.

## Results

*Use Cases for HIE.* We gathered information on 27 LMIC and one regional network in Asia. The use cases and value proposition for HIE vary and appear to reflect country and funder priorities. For example, in some African and Caribbean LMIC, HIE focuses on infectious diseases such as HIV/AIDS, tuberculosis, and Ebola, often due to program monitoring and evaluation (M&E) requirements of donors. Other LMIC, such as in Asia and South America, are developing enterprise-wide HIE with a goal of universal health coverage. Most LMIC are prioritizing data exchange within the country rather than cross-border data exchange. Only one regional network in Asia was identified as working on two fronts— exchange within countries and cross-border exchange through a regional HIE “lab” structure that has a foundational commitment to the use of common standards and formats.

*eHealth Strategy and Data Stewardship/Ownership.* Countries’ eHealth strategies and HIE approaches generally address high level governance and partnerships; enterprise architecture; patient identification; standards for interoperability; and privacy and security. In most countries, the data collector or the place where data is physically located is seen as the “owner” or steward of the data. Generally, this has been the Ministry of Health (MoH) in the public sector; where there is a strong private sector, regional or local hospitals and clinics can also “own” or steward the data. However, there is an increasing shift toward discussing the patient as the true owner of their health data. Despite the shifting mindset, few LMIC offer individuals access to their electronic health data.

*Governance.* While all countries’ eHealth strategies featured some governance structures, their implementation and maturity vary. In countries focusing on enterprise-wide architecture and universal health coverage such as in South America and Asia, governance tends to take priority and is implemented early. Countries with a strong centralized government and/or MoH have been able to develop and implement governance from the “top-down,” but enforcement remains an issue. Where there are health issue silos and a strong dependence on donor and private sector funding, governance may not exist nationally and may vary in structure by the health issue.

*Data Use, Exchange, and Patient Identification.* A number of countries have concerns about how data will be reused; this has manifested through policies that require individual-level data remain at the site where the data was collected to one-way data flow to the national/MoH level but not back down to the point of care for real-time care decision makers. Data are frequently reported to the MoH at aggregate levels, supporting M&E reports for donors. However, most LMIC envision HIE supporting individual level health exchange. As expected, patient identification was identified as an important concept for matching records with legal, cultural, and governance factors to consider.

*Legal Tools for Data Exchange, Privacy, and Security.* Where the MoH is the main player and policy setter, there normally exist data use and exchange guidance promulgated from the MoH. However, only one LMIC informant in the review indicated a legal data use and exchange agreement was in place. While many LMIC are investing in data infrastructure and standards, the majority indicated challenges in establishing business agreements for data exchange. Some LMIC have laws or policies in place regarding privacy and security of health information. There appears to be a dearth of overarching legal frameworks for privacy and security, though procedures have usually been established through individual projects and implementations.

## Discussion

These findings provide a snapshot of HIE efforts in LMIC across the globe, illustrating significant variability in the completeness of and success implementing policies and procedures that support in-country HIE and governance of data use. Great attention is being paid to HIE; however LMIC have experienced challenges moving from strategy to implementation. Variation exists around use cases, governance models, data stewardship, patient identification, composition of legal agreements, and the role of privacy and security. Addressing intra-country and future inter-country or cross border regional HIE needs will require consistent agreements that rely upon a clear or common understanding of data provenance, including data ownership. As we have seen with recent epidemic outbreaks, the ability to acquire and share regional health data is critical to ensure timely collective action.

Technology solutions are available for HIE but the implementation of business processes and legal tools have lagged behind the technology. Based on these findings, we suggest that 1) countries and regions should ensure there is a consistent governance model for HIE and interoperability, and 2) development of a global framework for the key policy and procedure decisions supporting HIE and interoperability can accelerate the actualization of data sharing, leading to improved data use and better health outcomes.

## References

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3. World Health Organization. Global Observatory for eHealth Publications. <http://www.who.int/goe/publications/en/>. Accessed 28 Feb 2016.