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Shared Longitudinal Health Records for Clinical and Population Health

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LEARNING OBJECTIVES

By the end of the chapter, the reader should be able to:

- Identify and describe the differences among an electronic medical record, electronic health record, and a shared health record.
- Explain the role of a shared health record in a health information exchange.
- List and describe the components of a shared health record.
- Discuss the role and benefits of a health management information system within a health information exchange.
- Define a population health indicator.
- Identify and describe application domains for a health management information system.
- Define a database management system.
- Compare the implications of implementing a shared health record using an electronic health record system versus a database management system.
- Discuss emerging trends likely to shape the evolution of shared health records and health management information systems.

INTRODUCTION

Health-care systems are organized differently around the globe. Systems vary in the proportion of care delivered by public versus private facilities, in their emphasis on primary, secondary and tertiary care, in the levels and sources of funding, by the populations they serve, in the burden of disease faced by their populations, and in the level of development of the environments of human and technological infrastructure. Nevertheless, there is consensus that health information systems may have a pivotal role to play in improving quality and efficiency in all of these contexts [1], though the nature of such technological systems as well as the roles and relative importance of their individual components and their sequence of emergence will be conditioned by sociopolitical, historical, and geographical realities.

Electronic medical record (EMR) systems can streamline the delivery of health care within an individual organization by archiving, monitoring, and facilitating operations [2]. These

systems assemble a digital representation of patient's legal medical record within a single health organization or network [2]. A patient's EMR contains information such as medical history, immunization records, physician notes, laboratory test results, and vital signs [2]. In the fragmented health-care system of the United States, many autonomous health networks coalesce to provide care for an individual patient [3]. Consequently, it should not be assumed that the EMR from an individual organization contains a complete medical history for an individual patient [2]. Key pieces of a patient's medical history such as a diagnosis or laboratory result that occurred in a different health network may not be available to a physician providing care.

In contrast, an electronic health record (EHR) system is designed to promote continuity of care across numerous health-care networks within a region through collaborative data sharing [4,5]. An EHR system consolidates health datasets that were collected from an array of different sources into a person-centric

health record in order to provide a more complete and longitudinal portrayal of an individual's medical history [4,5]. However, this information may only be useful within the network of collaborating organizations. A national or regional health information exchange (HIE) must be able to harmonize the clinical information that is being collected from multiple EHR systems into a single shared longitudinal health record. These comprehensive, longitudinal records are intended to decidedly enhance the quality and productivity of health care through reductions in medical errors, decreased redundancies in testing, and averted costs [5–9]. Additionally, longitudinal records can be aggregated to provide population-level indicators of health outcomes to support public health practice, disease surveillance, health systems management, and clinical research.

SHARED LONGITUDINAL RECORDS FOR CLINICAL HEALTH

The OpenHIE model includes a component system called the shared health record (SHR) that compiles a longitudinal, person-centric record of a patient's clinical encounters that are being shared among the organizations participating in HIE. The SHR system provides a permanent, centralized repository to store and manage the health information that are shared by the heterogeneous information systems of a regional or national health system. Contributing applications could include anything from a robust EMR system to a small-scale mobile application (recall the point-of-care applications from the model in the chapter: The Evolving Health Information Infrastructure).

The SHR component of OpenHIE facilitates a variety of interactions between the internal components and external point-of-service applications with the goal of supporting the delivery of clinical care. The SHR enables point-of-service applications (eg, EMRs or pharmacy

TABLE 10.1 Common Data Elements Included in a Shared Longitudinal Health Record

Data Type	Description
Structured Data	Clinical observations
	Care summaries
	Allergies
	Prescribed medications
	Laboratory reports
	Immunizations
	Medical histories
	Mental health assessments
	Nutritional assessments
	Action Plans
Unstructured data	Quality of life indicators
	Medical imaging documents (eg, X-rays)
	Narrative text

information systems) to store key clinical data such as a summary of care, laboratory test results, or vitals. The SHR can manage both structured data that is reconcilable with standard exchange formats (eg, discrete clinical observations) and unstructured data such as a digital image with associated patient information. Additionally, point-of-service systems can update existing patient records in the SHR with new information while preserving a version history. However, the data stored in the SHR should be restricted to include only information that is deemed relevant for sharing within the implementing nation or region [10]. The SHR should not necessarily contain a complete dump of information from all point-of-service systems in the nation or region, but rather contain relevant information that when shared gives a complete view of a patient's medical history. Table 10.1 provides a list of some of the pertinent types of clinical data that may be stored in an SHR.

An SHR also enables client services to retrieve clinical information from the repository as needed to improve the delivery of care. The SHR can provide end users with a complete longitudinal medical history for a particular patient. In addition, client systems can query the SHR to retrieve a partial subset of a patient's medical history that has been restricted to a specific time frame or a unique type of observation. For example, a physician caring for a patient with a high diastolic blood pressure may want to know if the elevated blood pressure is a trend or just an isolated occurrence in order to determine the appropriate approach for treatment. The physician could acquire this information by querying the SHR to retrieve a list of the patient's blood pressure during each previous encounter.

An SHR is also designed to semantically understand certain sections of the information that it receives from point-of-service systems. This is enabled through the use of standardized representations of the clinical information which support semantic descriptions of the data in the SHR. It is important for the SHR to semantically understand certain clinical information for a few main reasons. First, this enables the SHR to produce and return an accurate summary of a patient's clinical history and second it enables population health indicators to be produced more easily. Finally, semantic understanding of clinical information enables other, secondary uses of the clinical data, such as medical research.

SHARED LONGITUDINAL RECORDS FOR POPULATION HEALTH

In addition to improving the delivery of individual clinical care, sharing longitudinal health records also cultivates opportunities to improve health outcomes at the population level [11,12]. The OpenHIE model contains

a component called the Health Management Information System (HMIS) that stores and distributes cumulative population level information. The HMIS primarily supports management or administration of a health system, and it contains a wide range of aggregate level data. The HMIS aggregates individual clinical records that are shared within an HIE in order to provide indicators that characterize the health of the underlying population at the provider, facility, state, or national level. In addition, the HMIS should contain data on human resource distribution, population figures, service availability, and service quality such as the efficiency of the supply chain. This opens up for added value analysis of the aggregated clinical data. The information in the HMIS is available for reporting purposes and is intended to improve the administration and development of public health programs rather than the delivery of clinical care [11]. Aggregated health information can benefit the health of a society by enhancing surveillance capacities, promoting advancements in medical research, and supporting the development of effective health policies.

Dashboard of Indicators

The aggregation of individual clinical records through the HMIS component of OpenHIE provides a dashboard of health indicators that can improve understanding of community health status. A health indicator is a metric that is routinely reported to provide insight into the characteristics of a population or the performance of a program [13]. An accurate assessment of the current health status of the population and influential factors within the community is essential for elevating the overall health of the community [14]. Important health indicators may constitute clinical outcomes (eg, mortality rates for cancer) or the prevalence of important health risk factors such as obesity or smoking [14]. These health indicators can be leveraged to drive

public health action such as policy changes or interventions to address significant health issues [15]. Programs such as Healthy People 2020 use health indicators to help direct their agendas [13]. Aggregated health indicators allow Healthy People 2020 and other programs to identify crucial public health issues (eg, increasing prevalence of cardiovascular disease), institute goals for improving the issue (eg, reduce the mortality rate for cardiovascular diseases by 15% within 10 years), and then evaluate progress toward those goals (eg, compare the baseline mortality rate to the current mortality rate) [13].

Disease Surveillance

Recent threats to population health globally, including Ebola Virus (EBV), influenza (H1N1), Middle East Respiratory Syndrome (MERS-CoV), and severe acute respiratory syndrome (SARS), illustrate the importance of building capacities within countries to detect the presence of infectious diseases at an early stage of an outbreak [16,17]. Compiling information from individual clinical records can provide insight into the patterns and trends of disease throughout a population [11,15]. Integrating the information from the SHR and HMIS systems with traditional surveillance strategies, such as vital records reports, can provide a more complete picture of the prevalence and spatial distribution of important diseases [11,18].

Electronic, shared health records also offer the opportunity to conduct disease surveillance in real-time [18]. Clinical information in the SHR can potentially be actively monitored for symptoms that may indicate the emergence of important diseases rather than waiting for confirmation through test results [18]. Real-time information about disease trends increases the capability of public health organizations to detect emerging outbreaks at an early stage and implement appropriate control measures before the disease becomes widespread [19]. Capabilities that can integrate and monitor emerging patterns

of disease would be transformative to public health surveillance practice [20].

Medical Research

Available, semantically interoperable information contained in the SHR and HMIS could be leveraged to advance medical research [12,15,21]. Analysis of the cumulative clinical data that is available in the HMIS can be especially useful for the generation of hypotheses and when performing comparative assessments [6]. Currently, population health in the United States is predominantly assessed through nationally funded health surveys such as the National Health Interview Survey (NHIS) [6,11,22]. The information collected in these surveys is self-reported, and may be unreliable or lack critical information [6]. Incorporating the cumulative information from the HMIS that was collected as a part of routine care can complement and strengthen the value of existing data sources [6].

SHRs also have the potential to identify eligible participants for clinical trials [11]. Clinical trial participants have traditionally been recruited through advertisements, notices, or contacting physicians [11]. An SHR system can be designed to simplify the process by adding optional alerts that can be relayed to candidates eligible for clinical trials by their physicians [11]. The Indiana Health Information Exchange, described in “The Indiana Health Information Exchange”, is the only HIE known to routinely leverage its SHR for study recruitment, observational research, and comparative analyses.

IMPLEMENTATION

Due to differences in organizational needs and health information infrastructures, the most appropriate solution for the implementation of an SHR will vary across health systems and over time. In some cases, an EHR-based solution may be the most acceptable approach for

implementing an SHR, while other implementations may require that an SHR is developed on a database management system (DBMS) platform with tailored services. In order for an SHR to be supportive of the requirements of consumers and local contexts, a thorough assessment of the goals, systems, data, standards, and challenges associated with the pertinent health system should be conducted prior to implementation.

SHR Implemented as an EHR

The OpenHIE model implements the SHR system as an independent component within a larger infrastructure. The interoperability layer (IL; described in the chapter: The Evolving Health Information Infrastructure) receives transactions from the disparate point-of-service systems exchanging information and facilitates the interaction between the internal components of the HIE. The OpenHIE infrastructure includes client registry (see the chapter: Client Registries: Identifying and Linking Patients), health worker registry (see the chapter: Health Worker Registries: Managing the Health-Care Workforce), and facility registry (see the chapter: Facility Registries: Metadata for Where Care Is Delivered) components to verify that the patients, providers, and facilities involved in a transaction request are known to the HIE. A complete shared record must also reconcile the unique terminologies and coding used by different point-of-service applications interacting with the HIE [23]. The OpenHIE uses a terminology service to map local codes to the standardized internal format (see the chapter: Standardizing Healthcare Data Across an Enterprise).

The SHR component of the OpenHIE was developed on a modified version of an EHR platform called OpenMRS (www.openmrs.org) to serve as the centralized repository for the storage and management of clinical data within the OpenHIE infrastructure. The capacity to manage discrete values effectively, and a powerful API, made OpenMRS a favorable SHR

solution for OpenHIE [10]. OpenHIE provides three different types of modules that facilitate the processing and storage of data using the OpenMRS platform including interface modules, a content handler module, and processing modules (depicted in Fig. 10.1). The interface modules provide service interfaces that enable an external application to access the data in the SHR. A content handler module is used to receive data from the service interfaces, and pass the information on to the proper processing module for storage. Processing modules provide the capacity to decipher information in a specific format so that it can be stored in or retrieved from the OpenMRS system. For example, a robust HIE may require a processing module that accommodates Health Level Seven (HL7) version 2 documents, processing modules for multiple types of clinical document architecture (CDA) documents, and a processing module that supports unstructured documents. Fig. 10.1 illustrates the architecture of the components that would enable OpenMRS to be implemented as the SHR for OpenHIE.

The flexibility of the OpenHIE architecture permits implementers to replace or expand the storage model supporting the SHR as necessary. The most appropriate EHR platform for an SHR may vary based on the requirements and idiosyncrasies of the particular implementation [24–26]. Potentially more than one data storage model could be used for a single SHR. For example, OpenMRS could manage the discrete data within the SHR, whereas OpenXDS could manage the document store. The following EHR platforms could also be considered for use as a SHR:

- Mohawk EHRS
- RAMRS
- OpenXDS
- OpenEMR
- OSCAR
- HIEOS
- OpenVista

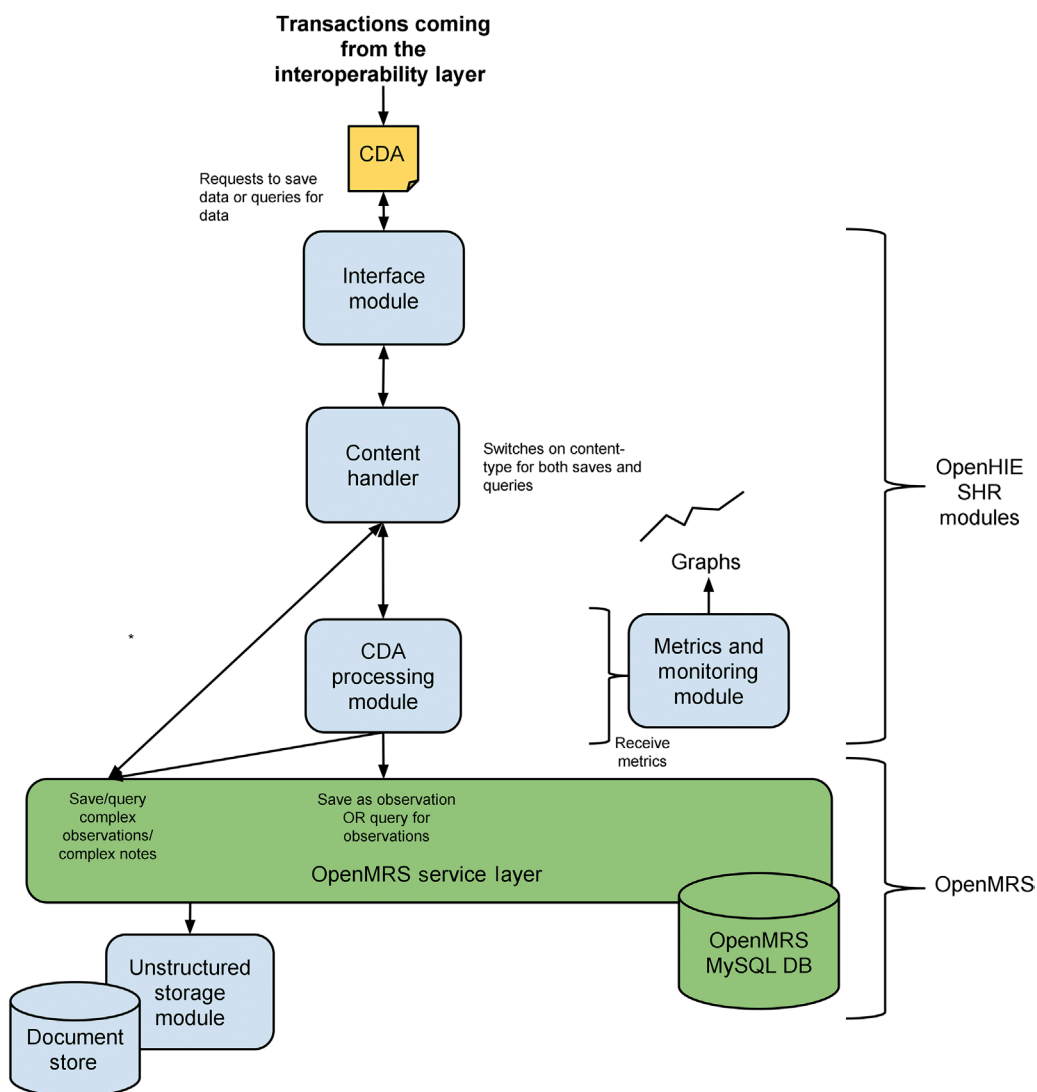


FIGURE 10.1 Architectural representation of the components of the shared health record as they could be implemented using the OpenMRS software.

SHR Implemented as a Database

An SHR can be operationalized as a database instead of an EHR system in order to provide a method of storing, organizing, and managing the clinical records. In this case, a database management system (DBMS) would be used to

empower users or other applications to interact with the SHR. A DBMS allows users or applications to perform tasks such as saves, queries, and updates to the database. Relational database management systems (RDBMSs) and NoSQL DBMSs are two of the most common DBMS models [27].

RDBMS

An RDBMS model manages a database by allowing users to define and ascertain relationships between multiple tables within a repository. A standard language called Structured Query Language (SQL) is used to communicate with and manipulate the database [27,28]. SQL allows users to perform complex queries and analysis with relatively basic syntax [28]. A relational database has tables that consist of rows that represent records and columns that contain descriptive characteristics such as heart rate, age, or gender. Assigning a unique identifier to each row enables the table to be linked to rows from other tables in the database that share the same identifier. For example, if a researcher needed to combine a table that contained patient heights with a table that contained patient weights in order to calculate BMI, an SQL statement could be written to link the two tables together by matching the unique patient identifier from each table.

However, using an RDBMS to manage and store clinic databases has some limitations that must be considered. An RDBMS does not easily support documents such as medical imagery or free text [27,29]. In addition, clinical databases often contain a large number of fields that primarily remain unpopulated [27]. An RDBMS managing an SHR with an excessive number of blank fields may experience substandard performance and inefficiencies [27].

NoSQL DBMS

The limitations of relational databases led to a demand for an alternative approach to database management [27]. There has been a recent shift toward the use of NoSQL data stores to manage large clinical databases [27]. NoSQL stands for “Not only SQL” and refers to a category of DBMSs that were developed with a contrasting approach to traditional relational databases [27]. NoSQL DBMSs do not depend on predefined relationships for the

management and storage of clinical data which allows faster processing [27]. NoSQL also supports structures such as key-value, document, and graph in addition to relational databases [27]. This flexibility allows a NoSQL DBMSs to manage the diversity of formats associated with medical data more easily than a traditional RDBMS. Additionally, NoSQL DBMSs enable horizontal scaling to increase system capacity if the need arises [27,30]. Horizontal scalability describes the capability of the DBMS to disburse the data and workload among multiple servers [30]. However, there are also some drawbacks to NoSQL DBMSs. RDBMSs are able to complete transactions without losing data or being corrupted with more reliability than NoSQL DBMSs [27].

HMIS Implemented as Data Analysis Platform

The implementation of an HMIS system within an HIE requires the standardization of indicators, an appropriate software platform, and methods of collecting and evaluating the quality of the data from a variety of sources. The indicators included in the HMIS must be standardized to facilitate meaningful comparison across health facilities and geographic areas. Indicator definitions and codes must be consistent throughout the HIE [25,31] to enable interoperability between the systems exchanging health information [32]. There should also be cohesion of the aggregated data from the facility level on up to the national level [25].

A challenge facing HMIS/EHR interoperability is the lack of development of mature data exchange standards in this domain—certainly in comparison with other domains of HIE. In 2009, the World Health Organization (WHO) led an effort to develop a standard called SDMX-HD for representing indicators and aggregate datasets [25,31] aimed primarily at global health reporting. The SDMX-HD standard never saw significant uptake.

In the same year, the HL7 consortium published the first edition of a standard for quality indicator reporting from EHR systems called QRDA (Quality Reporting Document Architecture). QRDA documents are contained within HL7 CDA documents (see the chapter: Standardizing and Exchanging Messages) and include a type (QRDA category 3) designed specifically for the representation of aggregate data. QDM (Quality Document Measure) is an HL7 standard for representation of indicator sets and their detailed definition and mappings into the EHR. QRDA together with QDM provide standards-based building blocks for automatic extraction of quality data—including aggregated indicators [33].

From the HMIS perspective, there are two challenges with QRDA. The first is that it is a complex, verbose, and difficult standard. The second is that it is premised on the fact that the data originate in an EHR (hence its encapsulation as a clinical document). The OpenHIE HMIS described below has its origins in a context of use where EHR systems have been thin on the ground. Aggregate health data messages could originate in an HL7 compliant EMR system, but are just as likely to be mined from the logistics management system for cold chain management data or from simple community health worker mobile phone applications. For this reason, the HMIS community within OpenHIE is actively driving the development of a new profile in the QRPH (Quality Research and Public Health) committee of IHE called ADX (Aggregate Data Exchange). ADX is not a CDA document, owing more of its ancestry to SDMX-HD. EHR systems which can and do produce QRDA should be readily able to map that content onto ADX (though the reverse mapping would not be possible).

The software platform that is used to collect, manage, and dispense aggregated health information for an HMIS can be a DBMS or a more flexible and customizable open-source model [25]. The OpenHIE HMIS was built on an

open-source platform called the District Health Informative Software (DHIS) v2. DHIS v2 enables implementing nations or regions to tailor the HMIS system to meet their requirements without the need for extensive programming [25]. The aggregated information captured by the SHR is imported into the DHIS v2 system to produce reports on a regular basis that can be disseminated through the HIE [25].

Of major importance to DHIS v2 is the flexibility to also rely on manual data entry, as the HMIS should contain a wide range of data for combinatorial analysis. In a majority of developing countries, an OpenHIE architecture is not supported by interoperable software applications, and data beyond the clinical encounter at the facility level is collected through a wide range of paper-based forms. Due to different maturity levels, it is important that the HMIS, given its importance for overall health service management, is able to function as a wholly or partly independent electronic system. The variation in contexts around the world calls thus not only for standardization of data exchange but also for flexibility in data collection to respond to a mix of electronic and manual processes.

Data Quality Challenges to Implementation

In order for the HMIS to provide a reliable method of measuring population health outcomes and evaluating the performance of public health programs and policies, it is critical that data quality is assessed effectively [34]. A high degree of data quality can be attained by regulating processes, identifying the underlying sources of errors, and correcting processes to eliminate failures [35]. A quality assessment should consider the data itself, the use of the data, and the collection process [34]. Many healthcare organizations have adopted a total quality management (TQM) approach to consistently improve the quality of their data

[36,37]. The TQM approach pursues quality improvement through the continuous refinement of existing systems and processes based on evaluations and feedback [36]. While originally used in the business sector, recent work has adapted it for use in health care [37].

Studies are revealing significant challenges in realizing the automatic extraction of indicators from EHR [38,39] in practice. This stems partly from a dominant institutional logic of EHR implementations driven by the needs of transactional use case requirements rather than quality reporting and the related consequences in completeness and quality of data. The study from the Netherlands [38], for example, shows that the accuracy of indicator data derived from EHR is not necessarily better than that which was obtained from the paper registers. This result is also consistent with what the authors have seen in implementations in Rwanda and has been described in India [40]. The results are also consistent with other studies examining the quality of data in EHR-captured clinical documentation [41] as well as HIE transactions [42,43]. With the increasing focus on quality reporting from EHR in OECD countries coupled with the continued growth of EHR in countries of the global South, we can expect these challenges to receive greater and urgent attention.

EMERGING TRENDS

The creation and management of SHR and HMIS components within HIE infrastructures in the United States as well as other nations are likely to both influence and be influenced by two emerging trends. First, the movement toward creating learning health systems that enable learning feedback loops on a national scale will ultimately benefit from SHRs and real-time calculation of population level indicators. Similarly, efforts to better understand the social determinants of health will benefit from

HIE components that can efficiently and effectively gather information across a wide range disparate sources. Yet these movements are also likely to influence design changes to the SHR and HMIS as they evolve.

Clinical databases are important sources of evidence that can be used to analyze and improve the quality, safety, and efficiency of medical care [44–46]. The Institute of Medicine (IOM) is working toward the development of a learning health-care system that harnesses this evidence to provide a patient with the best possible care, and then capture the results in order to enhance future treatment [44,46]. Physicians are currently forced to treat patients through medical procedures and pharmaceuticals that have a relatively small amount of evidence to document their effectiveness [45]. Leveraging the vast amount of information about diseases and patient encounters available in EHR systems could enable the optimization of treatment strategies for conditions such as cancer or coronary artery disease [45]. Supplying physicians as well as patients with this information could make a substantial difference health outcomes [45]. A future goal of the IOM is to ensure that at least 90% of all clinical decisions will be based on high quality, up-to-date evidence by the year 2020 [44,46].

Efforts to create learning health systems will therefore not only benefit from the SHR and HMIS components but also shape their evolution. Many learning health system initiatives are just now emerging, and their data needs are similar in nature to traditional observational and comparative research. Yet, given the broad scope of the IOM's vision, these efforts are likely to expand dramatically in the next 5–10 years. As they expand, data and analytical needs will morph which may require changes to the scope of both the SHR and HMIS components as we might envision them today.

The Robert Wood Johnson Foundation (RWJF) is seeking to promote a culture that considers the impact of factors beyond clinical

care on the collective health of a community or nation as a whole [47]. Social determinants, such as income level, educational attainment, family environment and crime rate, have a significant influence on both health outcomes and health disparities [47]. The increasing availability of large, up-to-date clinical datasets that bridge organizational boundaries, such as those in an SHR or HMIS, enables analyses that can reveal patterns of health outcomes and their underlying factors [48].

However, such analyses require integration not only of clinical data but also data from sources well beyond the health system. A report from IOM highlights that EHR systems in the United States currently do a poor job of capturing data on the social determinants of health. Therefore, for SHR and HMIS components to support analyses of social determinants, new types of data will need to be added to Table 10.1. Additional indicators will also need to be defined as they emerge in various nations (eg, which social determinants will be of highest priority will vary by nation). Pilot efforts in Indiana as well as Oregon are just starting to gather, integrate, and analyze social determinants in combination with data from EHR systems [49,50]. As these efforts grow, and others evolve both in the United States and globally, the requirements for the SHR and HMIS will need to be updated. Yet these components hold much promise for enabling the kind of integration and analysis envisioned by IOM and RWJF.

SUMMARY

Patient care is a multifaceted process that can involve a range of tasks such as personal consultations, blood tests, and X-rays [29,51]. As a result, clinical data are collected in many different formats including structured observations, image documents, transcribed notes, or laboratory results [29,51–53]. This information often resides in numerous heterogeneous

information systems. The ability to successfully assemble the data that are stored in disparate formats and systems into a single, integrated and longitudinal patient health record can benefit the individual patient, the healthcare organizations participating in the HIE, and the community as a whole [9,54,55]. An SHR simplifies interoperability between information systems by providing a centralized repository that stores the information moving throughout the HIE in order to improve the quality and efficiency of clinical care [56]. Shared, longitudinal health records can also be aggregated at the population level through systems such as the OpenHIE HMIS, and subsequently distributed through an HIE to promote the advancement of community health outcomes through policy changes, surveillance, and research [11].

QUESTIONS FOR DISCUSSION

1. What kind of stakeholders benefit from shared, longitudinal health records in a health system? What benefits do these stakeholder receive from access to SHRs?
2. How would the implementation of an SHR system in the United States differ from an implementation in other countries around the world?
3. What advantages does an HMIS component offer over traditional sources of health indicator data such as population-based surveys?
4. What are some of the benefits of NoSQL DBMS in comparison to an RDBMS for managing clinical data?

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