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Measuring Health Information Exchange On a National Level Via Direct Data Collection: An Initial Study of Feasibility and Next Steps

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Contents

1 Introduction

The Office of the National Coordinator (ONC) commissioned Sujansky & Associates to conduct this study to assess potential strategies for measuring health information exchange (HIE[*]) in the United States in a comprehensive and consistent manner. To date, the national-level data available to ONC on information exchange have largely derived from surveys of health care provider organizations. Although these data are nationally representative, limitations of this approach include the inability to obtain transaction-level data and other quantitative indicators of the volume of information exchanged and of the usage/value of such information. Surveys are also subject to biases, including recall bias and desirability bias. Although surveys remain invaluable in collecting data on usability, methods, barriers and other perceptions related to health information exchange and interoperability, this study explores a complementary measurement approach: The collection and analysis of objective, system-generated data regarding the availability, adoption, usage, and value of HIE services.

To date, the objective measurement of HIE by various organizations that enable exchange has been fragmented. A patchwork of activities and differing approaches are undertaken across different geographies, by different health information exchange organizations, and for the benefit of different constituencies. No measurement approaches have yet produced a coherent picture of whether and how much the U.S. overall is advancing with respect to HIE, and little objective data exist regarding the extent to which different areas of the country may be engaged in and benefitting from HIE to different degrees.

Developing consistent, objective, and nationwide measures regarding the availability, adoption, usage, and value of HIE services depends on the existence or development of precisely defined metrics for these aspects of HIE, as well as on the availability (current or potential) of data needed to derive such metrics. The work described here collected and analyzed information from a number of existing HIE networks (or “HINs”) regarding the nature of the metrics they currently collect and report, as well as the types of data they could provide to enable the overall measurement of HIE in a more objective and accurate manner. This report summarizes the findings of that research and makes recommendations regarding feasible measures, remaining barriers to the operationalization of such measures, and appropriate next steps for ONC and HINs to take.

2 Measuring Health Information Exchange: Motivation and Definitions

Before reporting on the results of our research and our recommendations for feasible measurement strategies, it is useful to review the motivation for measuring HIE in the first place and the specific aspects of HIE that could be potentially measured. Laying out this background information will help to establish certain important terms and concepts that are applied in the remainder of this report.

2.1 Motivation

The accurate and consistent measurement of HIE requires effort and resources, so performing measurement must be worthwhile and justifiable. Any entity that encourages, incentivizes, funds, or compels HINs to participate in measurement and reporting activity should, therefore, provide a clear motivation for that activity. Potential reasons for measuring HIE include:

- Characterizing the different types of health information exchange transactions that are being made available by HINs, measuring the relative availability of these transaction types across all HINs, and tracking the trend over time in the availability of various transaction types. This

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[*] In this report, the term “Health Information Exchange” (HIE) is used to denote the *activity* of health information exchange (i.e., HIE the *verb*). Organizations that enable the exchange of health information are referred to as “Health Information Exchange Networks” (HINs) or “Health Information Exchange Organizations” (HIOs), not as “HIEs” (the *noun*).

information can be correlated with other data regarding the relative value of different types of HIE transactions (e.g., C-CDA document retrievals, event notifications, secure messages, etc.) to help determine whether the transactions available most frequently are the transactions that are the most valuable.

- Measuring the number and proportion of provider organizations that participate in various HINs and, therefore, have access to the types of HIE transactions that are available. To the extent that certain HIE transaction types are valuable in improving the quality and/or cost-effectiveness of care, measuring this participation rate and tracking it over time is important to gauging what proportion of the overall healthcare system (and, by proxy, patient population) is capable of benefitting from HIE transactions.
- Measuring the number of provider organizations that participate in multiple HINs. Healthcare organizations often participate in multiple HINs to achieve widespread interoperability, in the absence of a single HIN that spans all healthcare organizations or effective bridging capabilities across different HINs. Measuring the degree of multi-HIN participation can indicate the potential cost savings of an infrastructure that enables health information exchange across HINs (such as TEFCA), obviating the need for multi-HIN participation in the future.
- Measuring the number of HIE transactions that actually occur and that provide "external" clinical information to healthcare providers, i.e., information that was generated outside of their own organizations and would not otherwise be readily available to them. To the extent that certain such information is valuable in improving the quality and/or cost-effectiveness of care, measuring this transaction rate and tracking it over time can indicate the degree to which the overall healthcare system is actually using and potentially benefitting from HIE services. Beyond gross volumes, measuring HIE transactions undertaken by specific healthcare organizations in the context of specific patients can also be combined with clinical and economic outcomes data to study the benefit of such transactions.
- Assessing the impact of HIE transactions on the quality and/or cost-effectiveness of care and comparing the relative impact of different transaction types. These important measurement activities can help to identify which transaction types are already valuable and should be funded, incentivized, or otherwise promoted and which may need to be improved (and how they may need to be improved) before they are worthwhile investments on the part of HINs, their participants, and society at large.
- Comparing metrics of HIE participation, transaction volume, and/or transaction value across different geographical areas. Determining areas with varying performance can help to generate hypotheses for follow-up studies to identify factors responsible for the disparities and to develop strategies to improve participation, transaction volume, and/or transaction value in lower-performing areas.

2.2 Definitions

There are a number of aspects of health information exchange that could be measured, and several sub-types and variations of each. The decision as to what should be measured depends on an analysis of which aspects are possible to measure, now and in the future, as well as which aspects are useful to measure, based on the underlying goals of measurement. An initial step in making these decisions is characterizing the "menu" of items that might be feasible and useful to measure. The menu of items presented below is based on information collected from the HINs we interviewed, as well as on the authors' background knowledge of HIE.

2.2.1 Participants

"Participants" (most generally) characterize the organizations and/or individuals that HINs enable to exchange health information. Participants are counted in various ways and at various levels of granularity, both within and across HINs. Because there is no standard terminology across HINs for characterizing participants, we define the following classification for purposes of this report, to enable "mapping" of different HINs' definitions to each other and to specify consistent units of measurement:

- Signatory Legal Entity: An entity that signs the participation agreement, fee agreement, DURSA, BAA, and/or other legal documents that govern the rights and responsibilities of participants in the HIN. Depending on the HIN, Signatory Legal Entities may be healthcare organizations (large or small), HIT vendors, or even other HINs. For example, HIT vendors are Signatory Legal Entities in the Carequality HIN and solo-practitioner physicians are Signatory Legal Entities in many regional HIOs. Certain HINs count and report only their Signatory Legal Entities as a measure of their participants.
- Health Information Gateway Organization: A provider of technical services and related governance processes for the exchange of health information that serves as an intermediary between a HIN and a participating Healthcare Organization. Examples include regional health information exchange organizations that participate in national HIE networks such as eHealthExchange, as well as Health Information Service Providers (HISPs) that are members of the DirectTrust consortium for secure message exchange. Note that Health Information Gateway Organizations are often themselves HINs and can enable "local" information exchange independently of their participation in other HINs. Health Information Gateway Organizations are the sole direct participants in certain HINs such as Carequality and DirectTrust.
- Healthcare Organization: An organization that is the provider or consumer of the health information that is exchanged via an HIN. Participating Healthcare Organizations may be large multi-site hospital systems, multi-specialty medical groups, small-office practices, commercial laboratory firms, imaging centers, health insurers, public health departments, social service agencies, and many other types of organizations that share their health information and/or access others' health information via the HIN. Healthcare Organizations may technically connect to an HIN directly or via a Health Information Gateway Organization.
- Provider Organization: A Healthcare Organization that provides direct patient-care services, as distinct from payers, social services agencies, or certain public health departments.
- Provider Organization Facility: Individual hospital, clinic site, physician office, laboratory location, imaging center, or other physical facility where patient-care services are provided. Provider Organizations consist of one or more Provider Organization Facilities.
- End User: Any employee or agent of a Healthcare Organization that is authorized to use the services of the HIN in which the Healthcare Organization participates. End Users may have log-in credentials assigned directly by the HIN, or they may have log-in credentials assigned by participating Healthcare Organizations, which indirectly authorize them to use the HIN.
- Participating Physician: A licensed medical professional with independent authority to diagnose and treat patients at a Provider Organization Facility. Depending on the HIN and the state in which the Provider Organization Facility is located, participating physicians may include doctors of osteopathy, podiatrists, physician assistants, and licensed nurse practitioners. Participating Physicians are not necessarily End Users.

It is noteworthy that these definitions are by no means mutually exclusive, and individual organizations could fill multiple of these "participant roles" with respect to a particular HIN. For example, a solo-practice physician could, at the same time, be a "Participating Physician," "End

User," "Healthcare Organization," "Healthcare Organization Facility," and "Signatory Legal Entity" in a regional HIO such as MIHIN. Similarly, a large healthcare system with its own private HIE could be a "Provider Organization," "Healthcare Organization," "Health Information Gateway Organization," and "Signatory Legal Entity" in a national HIN such as eHealthExchange. Importantly, though, some "End Users" are not "Participating Physicians" (and vice-versa), some "Health Information Gateway Organizations" are not "Healthcare Organizations", some "Healthcare Organizations" are not "Provider Organizations," and some "Provider Organizations" consist of many "Provider Organization Facilities" whereas others consist of only a single facility.

Because HINs currently count and report only a subset of the participant types defined above, and different HINs use different terms for the same participant types, it is important to propose the "standard" definitions above to clearly determine what HINs are actually counting and reporting today, as well as to identify common units of measurement for aggregating participant data from different HINs. Lastly, the distinctions inherent in the standard definitions above allow us to consider which types of participants are most useful to measure and, in the long run, to encourage all HINs to measure those types completely and consistently.

Also, note that participants that are Healthcare Organizations may be further sub-divided into those that are capable of retrieving (consuming) health information provided by other Healthcare Organizations via the HIN and those that are capable of sending (providing) health information that is made available for consumption by other Healthcare Organizations via the HIN. Not all participants in an HIN may choose to or be able to fulfill both roles. Note that providers of information include both those that submit information *a priori* to a central repository that is subsequently available for shared access by other Healthcare Organizations, as well as those that respond to *ad hoc* requests for information made in real time by other Healthcare Organizations.

Lastly, participants can be counted as the absolute number of organizations and/or individuals participating in a specific HIN (the "numerator" approach) or they may be counted as the relative percentage of organizations and/or individuals who *could* participate in the HIN and have chosen to do so (the "numerator" and "denominator" approach). For example, certain HINs just report the number of hospitals that are participants, whereas others report the proportion of all the hospitals in their geographical regions that are participants.

2.2.2 Transaction Types and Volume

"Transaction Types" comprise the different kinds of events that could be counted when measuring the volume of health information exchange that took place during a period of time. Different HINs enable different types of transactions and may, therefore, count different events when measuring and reporting their transaction volumes. As with participant types, there is no standard terminology across HINs to describe the events that they measure, so it is useful to define a few distinct transaction types that do occur and could be measured (note these types are not necessarily exhaustive):

- Query/Response Transaction: A request for patient-specific health information via the HIN, followed by a Message Delivery containing the requested information (if it exists). The delivered information could be in the form of structured documents and messages (such as C-CDAs or FHIR resources) or unstructured documents and messages (such as PDFs, free-text, or images).
- Message Delivery: The delivery of a discrete unit of health information to a Healthcare Organization via the HIN, either in response to a specific request ("pulled") or not in response to such a request ("pushed"). The delivered health information can be in the form of structured documents and messages (such as C-CDAs or FHIR resources) or unstructured

documents and messages (such as PDFs, free-text, or images). Examples of Message Deliveries include:

  - Responses to IHE "patient discover," "find documents," and "retrieve documents" requests
  - Responses to FHIR API calls
  - Direct Secure Messages containing any health information
  - Responses to patient-record requests submitted via an HIE portal and displayed in the portal UI only.
  - Event notifications or alerts delivered in any electronic manner

- Document Delivery: The receipt by a Healthcare Organization, via a Message Delivery, of a discrete document containing health information pertaining to a specific patient. The document may be structured or unstructured. Multiple document deliveries may be made via a single Message Delivery. Examples include
  - Responses to IHE "retrieve document" requests
  - Responses to FHIR API calls that consist of document files
  - Document attachments in Direct Secure Messages
  - Event notifications or alerts that contain document attachments
- C-CDA Structured Document Delivery: A Document Delivery consisting of a C-CDA document (including, but not limited to, those using the CCD document template).
- Event Notification/Alert: A Message Delivery containing a notification that a specific type of event occurred for a specific patient. The Message Delivery is automatically "pushed" to the receiving Healthcare Organization (i.e., it does not occur in response to a specific query, although it may be triggered by a Healthcare Organization having "subscribed" to the receipt of notifications for certain event types and/or certain patients). The Message Delivery may or may not contain one or more documents, and any document(s) it contains may or may not be structured.
- Immunization Registry Lookup: A Query/Response transaction in which a regional or statewide immunization registry is queried via the HIN for the immunization history of a specific patient. These transactions may be subdivided into those that do or do not result in a response (Message Delivery) that contains the patient's immunization history.
- Prescription Drug Monitoring Database (PDMP) Lookup: A Query/Response transaction in which a regional or statewide PDMP registry is queried via the HIN for the prescription history of a specific patient. These transactions may be subdivided into those that do or do not result in a response (Message Delivery) that contains the patient's prescription history.

As with participant types, the types of transactions that can be measured are not mutually exclusive. Certain types are subsets of others. For example, C-CDA Structured Document Deliveries are subsets of Document Deliveries, which are subsets of Message Deliveries. Other types of transactions intersect with one another but are not strictly subsets. For example, some Query/Response Transactions include C-CDA Structured Document Deliveries (but others include free-text responses or FHIR resources), and some C-CDA Structured Document Deliveries occur within Query/Response Transactions (but others occur within Direct secure Message Deliveries or within Event Notifications). Hence, when different HINs measure the volumes of different transaction types, it may not be possible to aggregate or compare their volume measures in a reliable way.

Because HINs currently count and report only a subset of the transaction types defined above, and sometimes use different terms for the same transaction types, it is important to propose the "standard" definitions above to clearly determine what HINs are actually counting and reporting today, as well as to identify common units of measurement for aggregating transaction-volume data from different HINs. Lastly, the distinctions inherent in the standard definitions above allow us to consider which types of transactions are most useful to measure and, in the long run, to encourage all HINs to measure those types completely and consistently.

In particular, note that certain of the defined transaction types correspond to specific clinical use cases (such as Immunization Registry Lookups or Event Notifications/Alerts), whereas other transaction types are generic and can occur within a variety of use cases (such as Query/Response Transactions or Document Deliveries). It is worthwhile considering which transaction types are more useful to measure, as well as which transaction types are possible to measure across different HINs given that some HINs explicitly support use-case-specific transactions (e.g., many regional HIOs) and other HINs support only generic transactions (e.g., most of the national networks).

Beyond the types of transactions to measure, one must also consider several other aspects of measuring transaction volume:

- Gross totals vs. distribution by participants. Most HINs currently report only their total volumes of transactions across all Provider Organization participants. Because patient care occurs at all Provider Organizations participating in an HIN, however, it may be important to also assess the distribution of transaction volume among Provider Organization participants to assess how broadly the HIN is achieving the adoption and benefits of its health information exchange services. For example, is transaction volume distributed across Provider Organization participants proportionally to their volume of patient-care encounters, or is a small minority of Provider Organizations performing the vast majority of transactions, with most participants using the HIN only minimally? Measuring the distribution of transaction volume can help to assess the overall utility of an HIN, as well as identify why certain participants may not be using the HIN's services and how to improve those services to promote broader use.
- Intra-HIN vs. Inter-HIN transactions. A number of the HINs we interviewed support health information exchange not only among their own participants, but also with participants of other HINs via HIN "bridging" gateways. Examples include gateways between Carequality and CommonWell Health Alliance, between Carequality and eHealthExchange, between MIHIN and Carequality, between the regional HIOs participating in the SHIEC Patient Centered Data Home network, between the regional HIOs participating in eHealthExchange, and between the six regional HIOs in New York State's SHIN-NY. It may be important to separately measure intra-HIN and inter-HIN transactions for at least two reasons. First, if one aggregates transaction-volume data from multiple HINs, it may be necessary to know which transactions spanned two HINs to avoid double counting those transactions. For example, a Message Delivery from a Healthcare Organization in one HIN to a Healthcare Organization in another HIN (via a bridging gateway) may be counted by both HINs, although only one Message Delivery transaction took place. Secondly, enabling health information exchange transactions across HINs is the specific goal of certain new initiatives, such as TEFCA, so measuring the success of such initiatives will require specifically measuring the volume and trend of inter-HIN transactions.
- Absolute vs. relative transaction volumes. Like participants, transaction volume could also be counted as the absolute number of transactions that occurred within an HIN during a certain time period (the "numerator" approach) or it could be counted as the relative percentage of events for which a health information exchange opportunity existed that resulted in an exchange transaction taking place (the "numerator" and "denominator" approach). For example, an HIN could report just the number of Event Notifications delivered indicating a

hospital discharge or the HIN could report the proportion of hospital discharges that were accompanied by an Event Notification sent to the primary care physician of the discharged patient. Although the latter metric is more difficult to derive, it arguably provides more valuable information regarding the effectiveness of an HIN in notifying relevant caregivers of important clinical events.

2.2.3 Transaction Value

The ultimate and most useful measurement of health information exchange is measuring the value of HIE transactions to HIN participants and to society at large. Such measurement of value can be attempted at the level of “process” or at the level of “outcome”. Process measures generally assess the quality and actual use of exchanged health information in decision-making processes. Outcome measures generally assess the impact of exchanged health information on clinical or economic end points of interest, such as patient health, costs of care, and workforce efficiency. Some examples of measuring value at the level of process and outcome are listed below.

Process measures

- The quality and completeness of the patient information that is exchanged with respect to its usefulness in medical decision making, population-health management, quality reporting, etc.
- The degree to which external information received via the HIN is incorporated into local patient records (EHRs)
- The ability of the data that is exchanged to be “computer-processible” (for example, for automated decision support or quality-reporting purposes), as opposed to being human readable only.

Outcome measures

- The availability via the HIN of needed or useful patient information that would otherwise not be accessible in a timely manner (for example, for transitions of care or referrals that are known to have occurred)
- The overall impact of the information exchanged on care coordination, cost/utilization, provider productivity, patient engagement, or other health-system goals.

Measuring transaction value for HINs is generally much more difficult than measuring participation or transaction volume. Even simpler process measures may require access to and analysis of the specific health data that are exchanged and how these data are processed and used by the Healthcare Organizations that receive them. For example, assessing the quality and completeness of structured C-CDA documents requires accessing the protected health information within these documents, which is not always possible or allowed. Measuring the effect on outcomes that accrues specifically from health information exchange requires not only considerable data regarding what data were exchanged, which organizations received the data, and which patients the data pertained to, but also detailed information about subsequent clinical outcomes and economic costs drawn from multiple data sources (such as EHRs and claims records), all of which need to be integrated. Conclusively measuring the impact of HIE on clinical or cost outcomes also requires appropriate control groups to account for secular trends and other potentially confounding variables.

3 Methods of Inquiry

Data collection for this report consisted of structured interviews with the leaders of various HINs, as well as review of related HIN documents and published literature. The interviewed HINs primarily consisted of national and state-wide organizations involved in the governance and/or technical provision of clinical data-exchange activity on a large scale. The sample was selected to provide as broad a view of HIE-measurement capabilities as possible while constraining the total number of HINs interviewed during this initial study. Notably, very few regional HIOs were interviewed, although information was collected from the Strategic Health Information Exchange Consortium (SHIEC), which serves as a trade organization for over 70 regional HIOs and conducts an annual survey of its members' HIE activity. Table 1 lists the organizations we interviewed for this study by type, and Appendix A includes the specific personnel that we interviewed from each organization.

Table 1. Organizations interviewed for this study.

Type of HIN	HIN
National Health Information Exchange Network or Consortium	Carequality
	CommonWell Health Alliance ("CommonWell")
	DirectTrust
	eHealthExchange
	Strategic Health Information Exchange Collaborative ("SHIEC")
State/Regional Health Information Exchange Organization (HIO) or Consortium	Chesapeake Regional Information System for our Patients (“CRISP”)
	HEALTHeLINK
	Michigan Health Information Network (“MIHIN”)
	Statewide Health Information Network for NY (“SHIN-NY”)
EHR Vendor-Based Network	Epic Care Everywhere

Interviews were conducted using a structured interview guide (see Appendix C) that consisted of specific questions regarding technical architecture, supported HIE transactions, and existing efforts to measure participants, transaction volume, and transaction value at each HIN. The collected data were analyzed qualitatively to inform this report. No quantitative summary or analysis of the interview responses was prepared due to the small sample size of interviewed HINs and the open-ended nature of the key interview questions pertaining to measurement activity.

A draft copy of this report was reviewed by the ONC, the interviewed HINs, and several other interested parties prior to its finalization.

4 Key Findings

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