Population Health *Matters*

Defining Population Health Use Policies for a Regional Health Information Exchange

Regional health information exchanges (HIEs) primarily aim to improve healthcare by facilitating clinicians' access to information about their patients from electronic health records maintained by other providers[1] or from claims records maintained by insurers. This might include information on diagnoses, medications, test results, or care encounters.[1] In addition, information in HIEs can be used for multiple population health applications.[2,3,4] For providers and insurers, this might include improving the completeness of data for performance monitoring and quality improvement or for assuring the delivery of recommended services.[2,3] For public health agencies, this might include improving disease monitoring systems or supporting linkages between clinical and public health services.[2,4] Incorporating population-level uses into HIE operations requires consideration of governance and policy questions that are distinct from those that underlie direct clinical applications. During 2016-2017, HealthShare Exchange (HSX), a regional HIE centered in Philadelphia, PA,[5] initiated such efforts by convening a workgroup that included representatives from member organizations (hospitals, insurers, accountable care organizations, clinicians, community health centers) and the public health field (a list of participants is available at https://www.healthshareexchange.org/hsx-population-health-workgroup). In this article, we summarize the key issues that arose in these deliberations and the strategies the workgroup identified to address them, with the aim of providing a resource to other HIEs interested in adding or expanding population health activities.

HSX is an increasingly mature HIE serving the greater Philadelphia metropolitan area and the Delaware Valley region, including southern

Table 1. Examples of scenarios used to develop population health use policies for a regional health information exchange.

Healthcare uses	A consortium of providers participating in a neighborhood health improvement project seeks to characterize patients who use ED services excessively in order to formulate interventions.
	An individual provider is interested in assessing and improving cancer screening rates among her patients.
	A primary care practice is interested in better understanding birth outcomes within its patient population, including infant birthweights and maternal post-partum visits.
	As part of its periodic community health needs assessment, which is required for maintenance of not-for-profit status, a hospital seeks to assess the prevalence of hypertension among Asian people residing in its service area (a population that is insufficiently represented in a local community health survey).
Public health uses	A metropolitan health department endeavors to assess the prevalence of obesity by selected demographic characteristics across the city, based on body mass index calculations derived from height and weight measurements recorded in medical records, in comparison to other methods for obtaining such measures.
	A healthcare provider wishes to submit mandated reports to a health department on certain infectious diseases and immunization services.
	As part of an outbreak investigation, a local public health department seeks to assess the extent of the problem in order to inform its response.

New Jersey.[5] Participants include large hospital and healthcare systems, insurers, primary and specialty care providers, accountable care organizations, behavioral health providers, and post-acute-care entities.[5] HSX policies and procedures have been defined through "use cases" that describe the purpose, scope, and terms of specific data uses, such as automated retrieval of information when patients are seen in hospital emergency departments and notifications to primary care providers when patients are discharged from hospitals or emergency departments.[6] The growth of HSX has been enabled by a shared recognition among members of its utility for improving patient care, attention to data security and data-use policies, and trust engendered among users by their participation in governance and policy committees.

In examining potential population health uses of HSX and its data from healthcare

Jefferson
**Philadelphia University +
Thomas Jefferson University**
HOME OF SIDNEY KIMMEL MEDICAL COLLEGE

and public health perspectives (Table 1), the workgroup identified multiple questions (Table 2) that set the agenda for its deliberations. The resolution of these questions is summarized in the remainder of this article.

The workgroup **defined population health uses** as queries that seek to **characterize a group of patients** (e.g., those under the care of a particular provider, enrolled in a particular health plan, with a particular diagnosis or health risk, or residing in a particular geographic area), regardless of whether those queries prompt follow-up with individuals. For example, characterization of persons diagnosed with hypertension would be a population health use, which might inform improved prevention services or outreach to those whose blood pressure was not well controlled. Envisioned population health uses reflected insurers' interests in improving care coordination and quality for their members, providers' interests in improving their care quality and outcomes, and public health entities' interests in monitoring and protecting the health of populations within their purview. HSX can enhance capacities to address these needs because its data repository includes information about patients or clients that is maintained in record systems outside members' individual systems and because it allows geographically-based queries. Such population health uses are distinct from clinical uses where queries seek information about an individual patient or client.

Population health data users would include HSX members or authorized governmental public health agencies. Because the scope of population health uses is to inform services or functions directly connected to users' responsibilities and not to develop more generalizable knowledge, the latter objective being a defining attribute of research in Federal regulations that protect

Table 2. Examples of scenarios used to develop population health use policies for a regional health information exchange.

Topic	Question(s)
Definition of population health	What distinguishes population health versus patient care uses of an HIE?
Applicability of federal regulations that protect research participants	Are population health uses of an HIE research?
	Is institutional review board (IRB) review and approval required?
Data access and data-use agreements	Should users have access to individual-level patient/client data with or without identifying information versus data on numbers of patients in different classification strata (i.e., aggregate data)?
	Should users have access to information regarding the identity of providers who had seen population members?
	Should data extracts be released to analysts for use outside HSX, or should analysts be required to work onsite at HSX or to access HSX data via a secure channel?
	Would the user be restricted from accessing data for patients with HIV or mental health diagnoses?
	Could HSX members obtain data only for those with whom they have an ongoing provider or insurer relationship?
Potential conflicts between the interests of payers and providers	What is the boundary between performance assessment for informing service improvement versus informing reimbursement incentives or rates?
Project approval and transparency	How would proposed population health uses be approved?
	What requirements would analysts have to share findings?

research participants,[7,8] the workgroup concluded that **population health uses were not research** and thus not subject to institutional review board approval and oversight. This conclusion, which was affirmed by HSX legal counsel, was also based in part on the analogy between proposed population heath uses of HSX and investigations in public health practice that are classified as "nonresearch."[9]

Questions regarding the level of data granularity that should be provided to analysts and procedures for granting analysts access to HSX data (Table 2) consumed considerable attention. The

group resolved that data should be provided **at a level of detail necessary to address a proposed query**, but not beyond, under terms specified in data-use agreements that protect confidentiality and data security. Depending on the nature of specific requests, as exemplified in Table 1, data would be provided in ways that are also **commensurate with a user's established relationships** to patient or client populations, **adherent to the Health Insurance Portability and Accountability Act of 1996 (HIPAA) privacy rule**,[10] and **compliant with other state and federal regulations** that govern uses of personal health information. For example, in the

scenario involving a primary care practice interested in assessing birth outcomes within its patient population, the practice has established relationships with patients who might have delivered at multiple hospitals. Thus, the HIE would provide patient data from those hospitals. In addition, a proposed analysis might require individual-level data to explore risks for adverse outcomes, and needs for patient follow-up might be recognized that would require access to patient identifiers. In the scenario where a hospital is conducting a community health needs assessment using data for people residing in its defined community service area, the population of interest would likely include a mix of people who are or are not its patients. In that situation, hospital analysts would be provided data that does not include personal identifiers, and, as in any instance where de-identified individual-level data are provided, the data-use terms would prohibit analysts from making any effort to re-identify persons represented in the data. If that same hospital were interested in assessing the prevalence of HIV within its service area, HSX would provide aggregate counts of persons living with HIV but would not provide analysts with individual-level data because of special protections surrounding personal-level HIV data under Pennsylvania state law.[11] In the scenario where a local health department seeks to assess the prevalence of obesity communitywide, aggregate counts of the number and percentage of people who are

obese, would likely be provided; although, HSX staff effort would be needed to conduct the analyses and prepare the tabulations. For people who elect to opt-out of having their personal health data exchanged through HSX, only de-identified data would be provided for any project.

The workgroup also determined that all population health projects would be **subject to approval and oversight under existing policies and governance procedures of the HIE**.[6] For example, HSX member-contract terms prohibit payers from using data derived from the system to leverage contract negotiations with providers. The terms also **prohibit any member from using HSX data for market analyses**. The workgroup recognized that, in some instances, the distinction between data that could be used for performance management (an accepted population health use) and prohibited uses might be ambiguous. It concluded, though, that HSX member organizations were unlikely to engage in prohibited data uses, given the spirit of collaboration among them that had created and sustained the exchange and their commitment to transparency regarding planned population health uses.

Ultimately, the workgroup recognized that population health data uses by HSX members and public health authorities were sufficiently distinct to require the development of separate use case documents for each. These

documents, which address the workgroup's resolution of the critical questions in detail, were approved by the HSX board in July 2017 and are available online (www.healthshareexchange.org) along with other HSX policies.[6,12,13] Going forward, an informal user group will be established to share insights and experiences and to foster best practices for population health uses of HSX data.

James W. Buehler, MD
Clinical Professor
Dornsife School of Public Health
Drexel University
jwb87@drexel.edu

Debbie S. Bernstein
Vice President, Client Implementation and Relations
HGE Health
Debra.Bernstein@hgehealth.com

Pamela E. Clarke, MSW
Senior Director
HealthShare Exchange
Pam.Clarke@healthcareexchange.org

Karla Geisse, MS, MPH
Karla is a recent graduate of the JCPH MPH program and a Management Fellow with HealthShare Exchange
Karla.Geisse@Jefferson.edu

REFERENCES

1. Office of the National Coordinator for Health Information Technology. Health Information Exchange (HIE), What is HIE? https://www.healthit.gov providers-professionals/health-information-exchange/what-hie. Accessed November 27, 2017.

2. Meyer M. How HIEs Use Data to Improve Population Health. J Am Health Information Management Assoc, Blog posted April 19, 2017. http://journal.ahima.org/2017/04/19/how-hies-use-data-to-improve-population-health/. Accessed November 27, 2017.

3. Lento J. The Relationship Between HIE and Population Health Management. Phillips Wellcentive, Blog posted January 2, 2013. https://www.wellcentive.com/blog/the-relationship-between-hie-and-population-health-management/. Accessed November 27, 2017.

REFERENCES

4. Shapiro JS, Mostashari F, Hripcsak G, Soulakis N, Kuperman G. Using Health Information Exchange to Improve Public Health. *Am J Public Health*. 2011;101(4):616-623.

5. HealthShare Exchange. https://www.healthshareexchange.org. Accessed November 27, 2017.

6. HealthShare Exchange. HealthShare Exchange Approved Policies (Governance, Use Cases). https://www.healthshareexchange.org/HealthShare Exchange-approved-policies. Accessed November 27, 2017.

7. U.S. Department of Health and Human Services. Protection of Human Subjects. Code of Federal Regulations, Title 45, Part 46 (45 CFR 46), 2009. Part 46.102(d), https://www.hhs.gov/ohrp/regulations-and-policy/regulations/45-cfr-46/index.html. Accessed November 27, 2017.

8. U.S. Department of Health and Human Services. Federal Policy for the Protection of Human Subjects, Final Rule (2017 Revision). Federal Register 2017;82(12), Part 46.102(l), January 19, 1017, p 7260. https://www.federalregister.gov/documents/2017/01/19/2017-01058/federal-policy-for-the-protection-of-human-subjects. Accessed November 27, 2017.

9. Centers for Disease Control and Prevention. Distinguishing Public Health Research and Public Health Nonresearch, July 29, 2010. https://www.cdc.gov/od/science/integrity/docs/cdc-policy-distinguishing-public-health-research-nonresearch.pdf. Accessed November 27, 2017.

10. U.S. Department of Health & Human Services. The HIPAA Privacy Rule. https://www.hhs.gov/hipaa/for-professionals/privacy/index.html. Accessed November 30, 2017.

11. Pennsylvania General Assembly. Confidentiality of HIV-Related Information Act, 35 P.S. § 7601 *et seq*. http://www.aidslawpa.org/wp-content/uploads/2011/04/Act-148-as-amended-2.pdf. Accessed November 30, 2017.

12. HealthShare Exchange. Participants Population Health Use Case, July 18, 2017. https://www.healthshareexchange.org/sites/default/files/pdf/participants_population_health_use_case_7-18-2017.pdf. Accessed November 27, 2017.

13. HealthShare Exchange. Public Health Authority Population Health Use Case. July 18, 2017. https://www.healthshareexchange.org/sites/default/files/pdf/public_health_authority_population_health_use_case_7-18-2017.pdf. Accessed November 27, 2017.