

HealthShare Exchange (HSX) Data Description

This is supporting information for the 2020 Health Data for Action (HD4A) Call for Proposals. To apply, or for more information about the funding opportunity, please visit www.rwjf.org/cfp/hd4a3.

HealthShare Exchange (HSX) is a regional Health Information Exchange (HIE) that *connects people*—patients, their caregivers, health plans, and community service providers—wherever they are in the healthcare system. By enabling interoperability among Health IT systems, we break down the information silos between patients and the people and organizations they rely on. Our technology helps ensure that if you wind up in any hospital, your primary care physician knows about it. We make sure that wherever you go for care, they're able to access your medical record. We help the health care system truly behave like a system.

Our broad membership includes over 400 healthcare organizations and community service providers using direct secure messaging, an Encounter Notification Service, query-based data exchange, and other services that enable real-time interoperability of clinical and administrative data. Our membership includes not only major payers and the majority of the hospitals in the Greater Philadelphia region, but also ambulatory care settings, long-term care, and community support organizations. The current list of data providers is available at <http://metrics.healthshareexchange.org>. Select HIE Metrics, Service Snapshot, Data Feed Implementation Status.

The data in HSX's repository supports the HD4A strategy of leveraging real world data to answer significant questions of public policy and population health. As an organization that integrates clinical information systems across diverse health systems serving very different populations, we have a unique lens into the healthcare delivery system.

The Greater Philadelphia area is an especially apt choice for answering big questions about healthcare and population health. Greater Philadelphia, despite being a healthcare nexus with some of the best health systems in the US, ranks below average in terms of health status. Philadelphia also has the highest poverty rate (25.8%) among the nation's ten most populous cities. While ours is among the most competitive regions in the country, with no single provider organization dominating, we also have a long history of collaboration on projects to improve healthcare access, quality, and safety for our region's patients. HSX is supporting multiple community collaboratives with our data, such as the American Diabetes Association's Diabetes INSIDE and the Jefferson College of Population Health's Regional Diabetes Prevention Collaborative.

Much of the data we receive each day is stored in HSX's Clinical Data Repository (CDR). Our Master Patient Index (MPI) indexes information from different providers to specific individuals, so that changes in patients' conditions can be followed longitudinally over time. We currently have data on approximately 12 million patients in the CDR derived from:

- Admission, Discharge, and Transfer (ADT) transactions
- Continuity of Care Documents (CCDs) generated following patient encounters
- Dedicated laboratory feeds generally for lab tests performed in the hospital

The CDR depicts a patient's longitudinal medical record across many contributing organizations. The CDR contains information such as:

- Patient demographics
- Patient's primary care provider
- Medications
- Allergies
- Hospital inpatient visits
- Emergency department encounters
- Outpatient practice visits
- Immunizations
- Diagnoses
- Procedures
- Lab results
- Radiology reports
- Social history
- Vital signs

HD4A applicants will not access the CDR directly but will receive files extracted from the CDR. What data are available to the applicant depends in part on whether the applicant's institution is a member of HSX. HSX members may request patient- and provider-identifying information under HSX's [Population Health Use Case](#). If identifying information is provided, we will follow HIPAA's minimum necessary standard, based on the purpose of the project.

For non-HSX members, aggregate data is available that is non-patient and non-provider identifying. If patient-level data are required for the project, HSX data contributors must be given a 45-day opportunity to opt out, and files will be deidentified with respect to both patients and providers and so will not be combinable with other data sets at this level. It may be possible to combine the data with other data sets about communities that include a field for zip code. If patient-level data are provided, only 3-digit zip codes will be included, consistent with HIPAA Limited Data Set guidelines. Applicants will need to sign a Data Use Agreement before receiving any data. [Ref HIPAA Privacy Rule (45 CFR 164.514)]

Data extractions for both HSX members and non-members will exclude patients who have opted out of HSX's HIE, as well as "super-protected data" involving substance abuse, mental health, and HIV/AIDS, unless patient consent is obtained.

Examples of questions that may be asked using these data include:

- How do patient demographics influence patients' trajectory after being diagnosed with heart failure, or asthma, or any other disease/condition?
- What factors affect the outcomes of patients diagnosed with COVID-19?
- Are rates of obesity in different geographic areas influenced by changes in public policy (e.g., smoking restrictions, soda taxes)?
- What role do social determinants of health (SDOH) play in predicting hospitalization or readmission rates?
- How do chief complaints or admitting diagnoses evolve during ED encounters, or between ED encounters and inpatient discharge?
- What factors influence whether a patient diagnosed with prediabetes will delay or prevent later development of diabetes?
- Whether a community health or quality improvement initiative has made an impact in rates of ED/hospital use or mortality.

HSX is developing a COVID-19 Patient Registry for the Delaware Valley that can support research into this continuing public health crisis. Depending on the timing of projects funded under this opportunity, COVID-related data may be accessed from the registry in the Observational Medical Outcomes Partnership (OMOP) Common Data Model format or from the HSX CDR.