HEALTH EQUITY DATA ANALYTICS

USER STORIES | 2019

INTRODUCTION & BACKGROUND

The Health Equity Data Analytics (HEDA) team was awarded funds by the Office of Health Strategy (OHS) to address and embed health equity within the forthcoming statewide exchange of health information that will enable data sharing necessary to improve the quality of care at the individual-level and health outcomes across the state. In the first phase of the project, the HEDA team identified three key data elements as critical to incorporating into a statewide data architecture being built by UConn Analytics and Information Management Solutions (AIMS). The Core Data Analytics Solution (CDAS) is responsible for extracting, processing, synthesizing, and visualizing healthcare data. UConn AIMS is collaborating with OHS to architect, design and implement the CDAS – this Data Architecture will also provide the foundational infrastructure that can support the exchange of health information.

In the second phase, the HEDA team was tasked to develop value propositions in the form of user stories to establish an initial foundation for designing analytic capabilities that respond to the needs of key end users working across various sectors to advance the health and well-being of all Connecticut residents.

The HEDA team identified the following 5 user stories that would provide high value for the identified end users as well as improve the quality of health and social services for Connecticut residents. The purpose of these stories was to integrate health equity data elements (race and ethnicity, geocoded residential address, and insurance status) as recommended in the HEDA June 2019 report[1]. These stories are as follows:

- All Payer Claims Database (APCD) Analytics
- Virtual Health Record
- Health Equity Dashboard
- Health Enhancement Communities
- Environmental Health Dashboard

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[1] Abraham, M., Everette, T. D., McGann, S., Rizzo, T., & Wang, K. (June 2019). *Health Equity Data Analytics.* Hartford: Connecticut Office of Health Strategy.

Purpose of User Stories

User stories originated from agile development, a collaborative process to develop requirements for systems and co-create software and other products. They describe essential information related to work activities of specific end users. The standard format follows, **"As a (type of user), I want (to achieve a certain goal), so that (some reason/value)"**.[2] Overall, user stories serve to establish a consistent understanding between system developers and end users of that system to ensure alignment of goals and functionality. Table 1 defines each aspect of the user stories as discussed in this report.

Table 1: Parts of a User Story

A	**Identifies a high-level outcome of the user story**
A1	(1) Defines a specific **user/stakeholder** that would interface with or benefit from statewide data sharing and the exchange of health information through their role, (2) followed by a statement of means outlining the action that they want to achieve or a requested feature of the system, and (3) culminates with a business value proposition that refers to the anticipated benefit or solution to an acknowledged problem[3, 4]. "As a stakeholder, I want to do [something], so that I can [solve this problem]"
Value	Outlines the end goal, which is the reason for accomplishing the user story. This includes bullets that clarify the means by specifying the needs that are addressed by this solution.
Additional data sources	Details known data sources that would or could contribute to achieving the user-specific outcome.

Alternatives: Provides the limitations related to the status quo also known as the current alternative state of operation without statewide data sharing and the exchange of health information.

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[2] Cohn, M. (2010). Succeeding with agile: software development using Scrum. Pearson Education.

[3] Thamrongchote, C., & Vatanawood, W. (2016, June). Business process ontology for defining user story. In 2016 IEEE/ACIS 15th International Conference on Computer and Information Science (ICIS) (pp. 1-4). IEEE.

[4] Lucassen, G., Dalpiaz, F., van der Werf, J. M. E., & Brinkkemper, S. (2015, August). Forging high-quality user stories: towards a discipline for agile requirements. In 2015 IEEE 23rd international requirements engineering conference (RE) (pp. 126-135). IEEE.

Dependencies: Provides essential underlying functionalities that must occur or be in place for this use case to operate as outlined in the user story.

KEY END USERS OF HEALTH EQUITY DATA

Health Systems

Connecticut health systems have some capacity to collect various health equity data elements from their electronic health records (EHRs), eligibility/enrollment systems and claims data, though the types and quality of data being captured and analyzed varies widely.

Currently, most healthcare organizations are collecting OMB level race and ethnicity data. The State Innovation Model's (SIM) Community and Clinical Integration Program (CCIP) spurred health systems to collect disaggregated categories of race/ethnicity (R/E) data that provides granularity needed to improve additional analytic capacity. Participation in CCIP strengthened organizations' ability to collect this data in a standardized manner and further enabled their analytic capacity. The purpose of CCIP was to collect and analyze granular race and ethnicity data in order to identify disparities in populations that may be overlooked when only collected in essentialized categories and create interventions to reduce those disparities. The CCIP program revealed that there were baseline assumptions made about health systems' ability to overcome barriers such as infrastructure capacity, workflow adjustments, cultural competency of workforce, and ability to adapt to political environmental shifts. In order to achieve standardized collection of race and ethnicity there will need to be additional guidance and technical assistance to ensure the uniformity and quality of data provided by participants in the HIE.

In addition, Connecticut has the ability to improve its analytic capability by addressing social determinants of health (SDOH), which can assist health systems in measuring their investments in SDOH-based interventions, for example, chronic disease management in neighborhood health clinics and the associated impacts on claims. A standardized means of collecting and analyzing health equity data elements will also provide health systems with a more comprehensive understanding of their patient population, which can inform resource allocation and provide opportunities to enhance and evaluate cost-effectiveness.

Providers

Providers need relevant, timely, accurate, and complete information to make patient-centered clinical decisions rooted in an understanding of patients' context beyond the clinical setting. This includes the social and structural determinants of health that historically and currently have prevented people of all backgrounds from achieving their full health potential and have created inequities in patients' risk of disease, their ability to optimize their health, and overall health outcomes.

By obtaining information from a variety of data sources, including state and jurisdictional health departments and participant data, this information can be displayed to providers accessing analytic services to improve the quality of life for their patient population.

Additionally, a better understanding of the coding system (Z codes for social determinants) and the capacity to know that this data can be analyzed can also improve the capacity to tailor support services.

With a constant flow of information from various entities in the healthcare enterprise (e.g. home care providers, pharmacies, therapists, etc.), providers will benefit from a central source of information that synthesizes accurate, context-specific information in a timely manner. This accessible information can help providers more effectively connect patients to tailored support services that may greatly improve their health outcomes.

Policymakers and State Officials

Activating analytics on data the state currently collects in conjunction with reliable data sources (e.g Census, federal databases, and other data) will support policymakers and state officials who need independent, reliable and objective data to be able to refine Connecticut's health priorities and inform effective policy change. The health equity data elements collected and integrated within the data architecture will enable standard and precise public health surveillance across different health systems and geographies. Decision makers will have access to enhanced, granular population-level data and analytics on health outcomes, demographics, and the quality, accessibility and cost of healthcare delivery, which, together, will provide evidence to support policies and promising practices that advance health equity without creating silos and/or additional burdens

Community-Based Organizations

For community-based and municipal agencies, non-profits, and philanthropies seeking to promote and improve local population health and health equity, Connecticut can connect and support the exchange of information to further improve specialized, hyper-local information. This can be utilized both in support of advocacy efforts and as a tool to aid in the development, funding, and monitoring of robust community-based health and social service programs that are accountable for meeting delineated health improvement priorities and other common objectives, including equity-informed delivery of services.

Healthcare Consumers

Centering the needs of diverse Connecticut healthcare consumers is foundational to advancing data quality and usability for the statewide exchange of health information. Thoughtful consumer education, outreach and engagement about the statewide health information exchange strengthens the capacity to achieve equitable health outcomes among individuals and communities. Consumers including patients, caregivers, and advocates also need secure platforms that are responsive to their personal information needs and accessible analytics to support their advocacy priorities. Furthermore, facilitating data accessibility to improve consumer's understanding of their health status and data ownership and sharing options provides greater opportunities for establishing partnerships between consumers and providers in the healthcare decision-making and delivery process.

Note these categories of end users do not encompass all stakeholders that may utilize or find value in health equity data elements (e.g. public health practitioners, researchers, etc.), however, *we have chosen to highlight the four aforementioned end users (health systems, providers, policymakers, community-based organizations and Healthcare Consumers) as they may be most likely to interact across the health care ecosystem.*

USE CASES

All Payer Claims Database (APCD) Analytics

Topline Story

The Connecticut All Payer Claims Database (APCD) was established in 2012 for the purpose of collecting, assessing and reporting healthcare claims data relating to safety, quality, cost-effectiveness, access, and efficiency for all levels of healthcare.[5] The APCD contains information on:

- Patients
- Providers
- Insurance types
- Care events (e.g. admission to discharge)
- Cost of care (e.g. who is billed, how much, out of pocket expense for patient)
- Medications

As a high volume, central repository of health care-related data, the APCD is an essential data resource. The APCD provides an opportunity to increase the availability of data to all stakeholders, including providers, healthcare systems, policymakers, and community-based organizations to improve access, quality, equity, and cost of care. Linking Connecticut's APCD with other data resources will enhance our ability to improve health equity in Connecticut.

User Stories

A	**Identifying patient needs and facilitating linkages to clinical and community programs**
A1	**Providers** want to know if their patients are facing instability (e.g. housing, insurance, food insecurity, etc.) at the point of care to better understand factors impacting a patient's health and well-being.

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[5] http://www.cga.ct.gov/2012/ACT/Pa/pdf/2012PA-00166-R00HB-05038-PA.pdf

Value	• I want to receive an alert for instances of probable housing instability, for example, patients that have moved addresses multiple times within the past year. • I want to be able to see a history of my patients' housing situation. • Geocoding of address can highlight instances when a patient has not reported homelessness, but is currently residing at an address that is a known shelter. • Specific ICD-9 and ICD-10 social codes for housing and economic circumstances allow providers to see present or historic housing insecurity, which put the patient at a higher risk for future housing insecurity.
Additional data sources	• Data collected from the Health-Related Social Needs Screening tool that is being used at sites participating in the Accountable Health Communities model through the Center for Medicare and Medicaid services. [6]
A2	**Health systems** and **community-based organizations** want to identify individuals who could potentially benefit from enrollment in care management programs offered at hospitals or in the community.
Value	• I want a high-level ability to visualize various factors impacting health in a single place so that I can examine and present interrelationships within the data. • I want to track admissions of patients with conditions that if intervened in the primary care setting could prevent a hospital admission (Ambulatory Care Sensitive Conditions[7]) and to map proximity from a patient’s residence to the closest primary care clinic covered by their insurance. • I want the ability to easily present graphics and visuals to a general audience. • I want a more reliable ways to track data on individuals with preventable ER admission. • I want health outcomes filtered by neighborhood, disaggregated by race/ethnicity categories, and stratified by risk so I can easily see how

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[6] Billioux, A., K. Verlander, S. Anthony, and D. Alley. (2017). Standardized screening for health-related social needs in clinical settings: The accountable health communities screening tool. Discussion Paper, National Academy of Medicine, Washington, DC. https://nam.edu/wp-content/uploads/2017/05/ Standardized-Screening-for-Health-Related-Social-Needsin-Clinical-Settings.pdf.

[7] AHRQ Quality Indicators—Guide to Prevention Quality Indicators: Hospital Admissionfor Ambulatory Care Sensitive Conditions. Rockville, MD: Agency for HealthcareResearch and Quality, 2001. AHRQ Pub. No. 02-R0203.

	healthy my population is to better target outreach efforts. ● I want to examine the trajectory of individuals with social codes. I want to stratify based on disaggregated race/ethnicity and insurance status. ● I want to map geocoded residential addresses of individuals with social codes and filter by condition to identify census areas needing additional support. ● I want to map providers caring for vulnerable patients.
Additional data sources	● Overlays of other social and geographic data. ● Linkages to related resources (e.g., statewide health equity reporting, vital statistics, advocacy resources, clinical risk groupers). ● US Census
B	**Facilitating understanding of barriers faced by vulnerable communities to inform policy priorities and program aims**
B1	**State officials** and **policymakers** need access to data related to health outcomes that can provide justification for policies supporting healthcare reform by advancing health equity.
Value	● I want to examine all trends in care across vulnerable populations, with the ability to filter by disaggregated race/ethnicity, insurance status and geocoded residential address, and legislative district. ● I want to link medication data to a prescription drug monitoring program (PDMP) to identify patients prescribed opioids who are at risk of under or over medication. ● I want to view medical conditions of individuals with a history of incarceration to track continuity of care during and after criminal justice involvement. ● I want to visualize transitions in insurance by type (Medicaid, Medicare, dual coverage, private) to identify populations at risk of insurance instability.

Alternatives

Currently, there is no standardized, high-quality, easily-accessible data source that collects social determinants of health (geocoded- residential addresses, race/ethnicity data, or insurance status) for providers or healthcare systems to use for either assessing social risk at the point-of-care or at the population level. This limits the ability of providers to make changes to care-management and practice-management plans that better address these social risks.

There is no data source that easily tracks insurance status across the lifespan to help understand how changes, even micro changes, in one's insurance status can influence health outcomes, quality, and cost.

To be meaningful, this data needs to be integrated with other health and health-related databases.

Dependencies

1. **Ability to maintain data quality:** Ensuring consistency of the data collected within the APCD is essential to maintaining the integrity of the analytics. This includes improving quality assurance procedures for flagging and reconciling missing data.

2. **Provider willingness to use ICD-9 and ICD-10 codes:** Research demonstrates that providers inconsistently use International Statistical Classification of Diseases and Related Health Problems (ICD) to catalogue social determinant of health (SDoH) information in inpatient settings; when ICD social codes are used, they are most frequently related to mental health, alcohol, and substance use.[8] This indicates a missed opportunity for collecting and analyzing SDoH data. Awareness campaigns promoting the utilization of ICD codes among providers and other members of the care team will be necessary to improve the completeness of the claims data received by the APCD.

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[8] Torres JM, Lawlor J, Colvin JD, et al. ICD social codes: an underutilized resource for tracking social needs. Med Care. 2017;55(9):810–816

Virtual Health Record

Topline Story

A Virtual Health Record (VHR) provides a comprehensive synthesis of a patient's medical history, including encounter information and demographic information, including geocoded residential address, insurance status, race/ethnicity and next of kin. Rather than trying to access patient information scattered across organizations and siloed within various systems, a VHR will integrate multiple data sources into a single, HIPAA-compliant portal for easy access among clinical and community providers working with patients wherever they seek care. In addition, the VHR will enable patients to achieve greater autonomy over their health status and healthcare coverage information.

The Core Data Analytic Solution (CDAS) will allow for data stratification by health risk. The integration of this significant analytic capability into the VHR will better inform decision-making and care coordination among providers of health and social services.

Overall, viewing the VHR through a lens of health equity ensures that this tool is used to promote information sharing that will advance the quality of care and present opportunities to reduce redundancies and improve cost-effectiveness among health systems.

User Stories

These user stories outline how various participants would utilize and benefit from a Virtual Health Record:

A	**Enabling synthesis of accessible health information through a single-use interface**
A1	**Healthcare Consumers** need access to their personal medical information and the personal medical information of their **dependents** so they can manage my family's health.
Value	• I want to sign into a single portal to securely access my family's medical information. • I want to sign into a single portal and provide demographic information about myself and family members so that the provider can make more informed decisions on our healthcare needs. For example, I would like to include my home address, insurance, car ownership or public transportation needs that will inform my provider's ability to provide the appropriate referrals.

	- I want to be able to easily access my VHR from a mobile app, tablet or desktop, so that if I go to a healthcare or social service provider, I can easily look up and share details about my medical history. It is important that it is a simple process for me to choose who has access to this information. - When I go to a healthcare provider, I want to be able to elect that they have access to general intake information and authorizations so that I can just review, make changes and approve information that I have provided in the past. - If I experience a change in insurance, I want my VHR to be automatically updated. - When my provider is referring me to a specialist or another provider, I want them to be able to consider the distance from my house and my transportation needs, through viewing my geocoded residential address in relation to the provider site. - When my provider writes a prescription, I want to be aware of my insurance status and if my prescription is covered, so I can know my out-of-pocket cost and if it is financially viable for me to take. - I want an accurate list of medications that have been prescribed so I can discuss if this is the appropriate medication I should be taking or if there are issues that I can have my provider address (i.e. contraindication; affordability; usage, etc.) - I want to view/download my clinical summary
A2	I am a **provider** working in an urgent care or Emergency Department setting. At the point of care, it is equally important for me to understand my patient's medical needs and encounters as it is to know their lived circumstances. I want to provide my patients with the most appropriate and effective care and lower the chance of unnecessary or redundant treatments.
Value	- I want clinical information that allows me to access multiple data sources including recent clinical encounters, drug prescriptions, procedures, reports (labs, x-rays, etc.) to best understand my patient's current medical history. - It is important for me to understand the context of a patient's life and their behaviors. I want an additional module that provides information on their insurance status, neighborhood and possible other determinants that

	impact health to inform discussion about additional community resources that would be relevant and beneficial for them. ● I want to stratify conditions by clinical risk groups to identify the disease severity of an individual in comparison to those in their neighborhood versus the wider population. ● I want to be able to see clinical guidelines and protocols side-by-side with patient information so that I can reconcile standards of practice with personalized approach to care. ● I would like to see a current list of prescription medications so I can mitigate any possible drug-drug interactions or contraindication. ● I want to be able to input new data into a diagnostic module that allows me to request and view tests and lab results. I would like to be able to map patients with similar health conditions by geocoded residential address to identify health hotspots. ● I want to improve care coordination during patient transition from one care setting to another. ● As an ED provider, I want to quickly search for information – this is invaluable if the patient is unconscious.
A3	I am a **community health worker**, working at a **community-based organization**. I would like to meet the essential needs of my clients by offering the right services and referrals. Accessing my client's VHR will allow me to better understand the barriers they face and meet the breadth of their health and social determinants-related needs.
Value	● I want to be able to access my clients VHR on a phone or tablet when I am meeting with them in a community setting. ● I want to be able to input information such as referrals or observations from home visits into their files, so it is accessible to any of my client's health or social service providers. ● I want to be able to input information from client interactions (e.g. appointments or home visits) into the VHR. ● I also want to be able to update information, such as changes in address, so that providers have the most current contact information.

	- It is important to know if my client has a change in insurance or is approaching termination of insurance, so that I can help them navigate changes in accessing health and other social services. - Having access to aggregate data can show how healthy or unhealthy a population in my community is and how I can target and reach them. It will also allow me to identify additional services that should be offered.
B	**Understanding the impact of VHR in reducing healthcare redundancy and improving outcomes**
B1	It is important for a **healthcare system** to have the capacity to measure the impact of consumer ownership of personal health data.
Value	- I want to know the frequency of use of how often patients within my system are accessing the VHR and if it positively impacts their quality of healthcare - I want a notification if there is a change in claims between patients using their VHR versus not. - I want to see a reduction in duplication of services and lower healthcare costs. I want to see trends that illustrate any improvements in coordination of physical care, behavioral care, and social care as a result of VHR use. - Based on data, I want to utilize CHWs to teach patients how to navigate their VHR to better maintain their health. - Aggregate data can show how healthy or unhealthy a population in my community is and how I can target and reach them. It will also allow me to identify additional services that should be offered.

Alternatives

In the current system, the patient has to identify resources to support their own healthcare needs. Providers have limited time and ability to support them in making informed decisions on healthcare needs that are relevant to other social determinants and extend beyond direct medical care.

Dependencies

1. **Reliability of patient-generated data[9]:** For providers to adopt VHR as a part of their daily medical practice, they need to be able to rely on the accuracy of the information provided by patients. Synchronization and feedback processes, among others, are needed to establish consistency and maintain the quality and integrity of the collected data.

2. **Patient concerns with data security and privacy[10]:** For patients to feel comfortable inputting data into the VHR and sharing this information with providers, data authorization policies and security mechanisms will require careful consideration. Furthermore, data backup and recovery systems are essential to ensuring that data is sustainable for continual access.

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[9] Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbon, K.A., & Strauss,S.E. (2011). Personal health records: a scoping review. *Journal of theAmerican Medical Informatics Association*, 18(4), 515–522.

[10] Raisinghani, M. S., & Young, E. (2008). Personal health records: key adoption issues and implications for management. *International Journal of Electronic Healthcare*, 4(1), 67-77.

Health Equity Dashboard

Topline Story

The standardized transmission and display of data is important to communities, providers, and agencies that seek to improve public health and social well-being across Connecticut. Up-to-date information can help these groups make informed decisions about health policy and health systems interventions, educational outreach, and many other efforts aimed at disease control and prevention.

A centralized health equity data dashboard can enhance the ability of communities and organizations to understand disease prevention efforts and address other persistent barriers to quality of life.

A health equity dashboard would allow users to compare relevant, local-level data (by neighborhood, race/ethnicity, gender, insurance status, and other factors) to surrounding city, regional, and state averages on issues related to social factors, healthcare, and health outcomes. It could serve as a portal to access publicly-available data for planning and evaluation.

User Stories

A	**Facilitating planning, communications, and advocacy activities related to improving the health of all Connecticut residents**
A1	**Policymakers** can better understand barriers to health and well-being.
Value	• I want to track progress in my area (e.g., data broken out by legislative district), as compared to statewide health goals. • I want to understand how information related to policy initiatives (e.g., efforts to improve community health outreach, efforts to expand services such as transportation to underserved areas) relates to overall population health improvement and potential barriers to health within specific groups.
Additional data sources	• Geographic or demographic data that are relevant to policymakers, such as legislative district information (see DataHaven's statewide legislative district profiles as an example: https://www.ctdatahaven.org/data-resources/connecticut-state-legislative-district-profiles). • Relevant program data (e.g., transportation routes

A2	**Community-based organizations** and **health systems** want to understand key health conditions among the population living in a neighborhood or service area and use that information to inform planning and advocacy.
Value	● I want more reliable ways to access data on health outcomes and health equity, broken down by neighborhood and specific populations. ● I want to benchmark my own program data against the population-level data to understand who I am serving. ● I want the ability to visualize various factors in one place to examine and present interrelationships within the data to my stakeholders. ● I want the ability to present graphics and visuals about health in my area to a general audience.
Additional data sources	● Overlays of other social and geographic data (U.S. Census) ● Links to related resources (e.g., statewide health equity reporting, vital statistics, advocacy resources).
A3	High-security, protected features could allow **qualified local agencies** to access real-time transmission of information that is useful for **public health reporting** and the prevention of outbreaks, such as syndromic surveillance, electronic lab reports, and trends.
Value	● I want to use granular data for real-time planning, action, and crisis response.

Alternatives

Without a Health Equity Dashboard, policymakers, community-based organizations, and health systems must rely on information from a multitude of sources. Reliable data may not be readily accessible at the neighborhood level.

Dependencies

1. **Capacity to collect and analyze accurate data at the neighborhood level**: Before different variables can be displayed, significant analytic resources are needed to ensure data quality and interoperability across various factors.
2. **User friendly design:** The dashboard needs to be intuitive due to potentially limited internal technical capacity.
3. **Data timeliness and longitudinal storage capacity**: To be most useful, especially for surveillance activity, data would need to be integrated into the dashboard in a timely fashion, as well as stored for aggregate and trend analysis.

Health Enhancement Communities

Topline Story

The Connecticut State Innovation Model (SIM) Program's Health Enhancement Community (HEC) model aims to improve the health and well-being of Connecticut residents and reduce rising healthcare costs by leveraging and building on community-based prevention activities that are underway across the state.[11] Because health inequities drive poor health outcomes, health equity will be embedded in the HEC Initiative.

HECs will initially focus on two health priorities that are critical for Connecticut:[12]

- Improving well-being for children (pre-birth to age 8) by ensuring that children are in safe, stable, and nurturing environments through preventing Adverse Childhood Experiences (ACEs), and by increasing protective factors that build resilience and mitigate the negative impact of toxic stress.
- Improving healthy weight and physical fitness for all residents through various prevention and health equity strategies.

Tracking local-level data that relates to health improvement, in many cases for vulnerable populations with complex social and health needs, is likely to be critical to the funding of this model. Over time, HECs may coordinate or supervise initiatives that use value-based payment models and require related evaluations.

It is likely that HECs will be accountable for demonstrating improvements in health within their geographies based on specific measures of health equity as well as on overall population health improvements. Payment models may call for evaluating the successful outcomes and implementation of evidence-based interventions that have been documented to improve health at a population level, though their impact on specific at-risk populations have not necessarily been evaluated. For example, there are some national efforts to use HIE-based clinical and social data to understand children at greatest risk of adverse childhood experiences (ACEs), who may have complex needs that are not served by current healthcare and social service systems.[13] For these reasons, health equity analytics enabled through the Core Data Analytic Solution (CDAS) may help HECs align existing interventions and implement new interventions that specifically address health as well as health equity.

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[11] Learn more in the Health Enhancement Community Model Design Report, available at https://portal.ct.gov/-/media/OHS/SIM/Population-Health-Council/2018/Meeting-10-29-18/HEC-Report-for-PHC-Review-Only-10-22-18---WEBSITE.pdf

[12] State of Connecticut HEC Pre-Planning Request for Proposals, August 2019.

[13] Nguyen, L. H. (2014). A public health response to data interoperability to prevent child maltreatment. *American Journal of Public Health*, 104(11), 2043-2048.

User Stories

These user stories provide examples of how decision makers and HEC initiatives might take advantage of health equity measures via Connecticut's data architecture.

A	**Harnessing the power of data sharing to enable more effective funding and organizational structures throughout the state that can foster multi-sector collaboration and accountability to promote community health improvement and equity**
A1	**HEC initiative leadership** can track improvements and/or reductions in health equity within HEC geographies and within small population groups residing within the HEC area.
Value	● I want to use small-area health estimates (e.g., estimates for health conditions as well as on inequities within specific neighborhoods or towns) to help pinpoint where the greatest opportunities exist to improve health and to address health equity concerns. ● I want to use data that are disaggregated by race/ethnicity, gender, age, insurance status and other factors in order to identify groups in need and allow decision makers to better target the resources that will be associated with each HEC.
Additional data sources	● High-quality geocoding and use of complex techniques to create usable estimates for small areas. ● Data provided through the HIA can be overlaid with other sources of local-level information (such as data on social needs, housing problems, or population growth) to help understand current and future trends. ● In the most disadvantaged communities, it could be useful to overlay datasets from the Connecticut Dept. of Corrections, the Homeless Management Information System, and various housing data to understand areas of highest risk for certain health conditions (such as injury).
A2	**HEC initiative leadership** can use disaggregated data to more effectively engage and empower the populations residing within the service area.
Value	● I want to develop a long-term plan for sustained resident engagement within my community and ensure that all voices are represented. Since the distribution of health-promoting resources within communities is a goal of this initiative, local residents should be empowered and engaged

	in all aspects of the planning process.
Additional data sources	- More granular race/ethnicity breakdowns to enable the creation of data products that are more tailored to specific communities within each area (e.g., one town may have a large South Asian population). - More granular breakdowns of data based on the experiences of residents within a particular area (e.g., persons returning from incarceration, recent graduates from a particular high school).
A3	**State policymakers and HEC funders** can analyze disaggregated data to create HEC performance measures that relate to populations at greatest risk of poor health outcomes, and use that information to monitor progress or award funding.
Value	- I want to develop new metrics that are based on the integration of cross-sector data about individuals with complex health and social needs, and then use them to better understand local differences in service outcomes and populations. This may enable a more informed and equitable distribution of funding, as well as advance the creation of HEC performance measures that relate to the most vulnerable populations (e.g., children experiencing ACEs, adults who are at greatest risk of nutrition-related illnesses). - I want to use performance measures to hold HEC organizations and communities accountable for serving the populations that are likely to experience the greatest health risks and contribute to high social service costs in the future. I want these measures to assess inclusivity and equity to ensure that no populations are excluded from receiving needed services.
Additional data sources	- Data from multiple sources at multiple levels that reflect individuals' experiences of the healthcare system, community and individual risk factors and exposures, including health equity measures (insurance access, demographics, and other social and environmental factors). - Ability to create and validate performance measures in an ongoing manner, using benchmarking data across the system.

Alternatives

While models similar to HECs may continue to grow, without capacity for conducting health equity data analytics within the context of other decision-making and evaluation tools, these initiatives will be limited in their ability to serve populations within their area(s) in the most equitable and effective manner possible. Information on health equity that could be gleaned from other methods may not align with sources used for program management. HEC leadership may miss the fact that even if health and well-being conditions are improving for a region overall, they may be worsening for a specific group.

Dependencies

1. **Limited and/or known reporting biases**: When using and displaying health equity data, efforts must be taken to ensure the completeness and accuracy of the underlying demographic and other characteristics. There will likely be some limitations to data sources pertaining to health equity, so interpreting the data correctly in the context of overall population health improvement will require it to be analyzed and well understood prior to use.
2. **Incentives for HECs to use equity within performance measures**: Without requirements or other incentives for HEC initiatives to use health equity information within decision making and program monitoring, the impact of health equity data to the operation of HECs may be limited, especially for HEC initiatives that cover geographic areas that have more homogeneous demographic or socioeconomic characteristics.

Environmental Health Dashboard

Topline Story

Environmental hazards such as lead, air pollution, asbestos and radon are known risk factors for various health conditions including cognitive and developmental issues, respiratory disease, cancer and heart conditions among others. To improve the health and wellbeing of communities, Connecticut has established Healthy Connecticut 2020 goals for mitigating exposure to environmental risk factors in the home, drinking water and outdoor air. Improving the environmental health surveillance infrastructure will promote accessibility of data to support these existing efforts including informing patient-centered care, targeting community interventions and advancing local and state advocacy efforts for policy change.

Overall, the environmental health dashboard will serve as the user-friendly platform that enables users to clearly understand, identify and demonstrate the pressing environmental health issues facing Connecticut residents. Medical outcomes data from the state's Core Data Analytics Solution (CDAS) will be paired with environmental hazards and exposure data from external sources. The CDAS will provide users needing to compare environmental factors contributing to poor health outcomes with the capability to stratify the population by health risk at both an individual and population level. This can be filtered by insurance status and expanded geographic and race/ethnicity categories.

There is potential for crossover or synergistic uses of the environmental health dashboard with other population-level analytics such as the Health Equity Dashboard.

*CDAS may obtain this information from a variety of data sources, including state databases, and local health departments, claims data from the All Payers Claims Database and from EHRs. Aggregated data will be available for public use while disaggregated data will be made available with additional agreements between OHS

User Stories

These user stories explain how CDAS capabilities are useful in enabling HIA participants to identify, monitor and address environmental exposures among Connecticut residents.

A	Notifying providers of environmental hazards or risks at point of care
A1	A **health system** wants clinicians to be notified of environmental risks facing patients at the point of care, so that they can prevent greater harm among patients.
Value	• Healthcare providers in my system can receive a notification for heightened environmental health risk when seeing patients that reside in areas proximate to exposure incidents (lead, asbestos, radon etc.). • It is important to know how many patients in our health system are living in areas where there are confirmed environmental exposures, and the proximity between a patient's home and the identified hotspots.

	Notifications could be color coded to indicate how concentrated the risk is, based on residential-level data, which could, for example, prompt providers to perform a lead screening. ● As a health system, I want to be prepared and ready for a possible influx of patients at a certain time of year, for example, seasonal trends of asthma and ER usage, or as a result of episodes of extreme weather, which can result in water contamination from flooding. ● I want to receive alerts if there is a concentration of hospital admissions related to environmental health exposures (e.g. positive lead screenings, waterborne disease). I want to use geocoded residential addresses to map patients that are admitted, with the ability to filter by race/ethnicity.
A2	I am a **clinician**, specializing in family primary care. Understanding environmental risks that my patients are exposed to is critical to informing treatment decisions and providing additional resources.
Value	● I want to receive an alert so I can provide anticipatory guidance to parents of children that are living in an area with a high risk of environmental health exposure (e.g. lead). ● I want to see where my patients live on a heat map that displays various environmental exposures by neighborhood, so that I can discuss and provide educational materials about environmental hazards (e.g. asbestos) and persuade patients to utilize a community health worker
A3	I am a **community health worker (CHW)**. I want to be able to assist my clients by reducing their exposure to environmental hazards and addressing their other social determinants of health, while helping connect them to clinical care and community resources.
Value	● I want to understand the type of environmental exposures that my clients may face in their most frequent environment, which includes the neighborhoods where they live, work, or attend school. ● I want to be able to see a neighborhood-level map of substandard housing conditions. ● I want the additional ability to know specific information about buildings in their neighborhood, for example if a house was built prior to 1978,and if their building and other buildings in the surrounding areas have received a Healthy Homes inspection over the past 5 years. This will help me monitor and take actions needed to improve the quality of life of children who may be negatively impacted by environmental health issues, such as those caused by lead exposure.

B	**Promoting the safety of communities and advancing accountability efforts to mitigate environmental health risks**
B1	I am a **community-based organization** and I would like real-time updates about exposure incidents, so I can raise awareness in my community and target educational campaigns and outreach activities that help to mitigate risk.
Value	● I want to use neighborhood-level aggregated clinical data to determine the need for a Healthy Homes initiative that targets specific hazards, such as asbestos or radon. ● I want a visual heatmap of environmental hazard hotspots to help me proactively offer clients assistance with reporting, seeking local enforcement action or renumeration, and connecting them with a CHW to provide home visits and educational awareness. ● I want to be able to filter the map by race/ethnicity and insurance status so that I can target outreach to specific areas in a culturally sensitive manner. For example, providing linguistically appropriate asthma educational materials to communities with a significant population of nonnative English speakers..
B2	I am an **advocate**. I need health data to help me talk to policymakers about supporting policies that seek to decrease environmental risk factors (e.g. establishing a minimum housing code for the state of Connecticut).
Value	● I want an interface that is easy to use and navigate. ● I want to examine trends between geocoded residential addresses and the frequency and types of claims related to environmental exposure with the ability to filter by expanded race/ethnicity categories, and health insurance status. ● I want to examine neighborhood-level data from the results of Healthy Homes inspections side-by-side with health outcome data of individuals living in these areas. ● I want to be able to compare trends of poor air quality days with ER admissions with the ability to filter by expanded race/ethnicity categories. ● I want to be able to map ER or urgent care admissions by geocoded residential addresses overlaid by other environmental exposure data to demonstrate the link between environmental exposures and health conditions (e.g. asthma among children). ● I want to see specific environmental exposures trend across neighborhoods. I want to be able to observe changes over time to assess if the initiatives that I am supporting on a policy level are making a tangible impact at the individual and community level. I am also interested to see these trends

	overlaid by insurance status and race/ethnicity to help link the issues of housing, economic investment and health.
B3	I am an employee at the **Department of Public Health**. As a state agency, we want to more efficiently use our resources to target direct city employees to take enforcement action (e.g. lead paint).
Value	● We want to have access to aggregated clinical data that can be mapped on to residential-level environmental exposure hotspots in order to proactively target enforcement and mitigation efforts. ● We want to be alerted if there is a concentration of hospital admissions related to environmental health exposures (e.g. positive lead screenings, or waterborne disease)., so that we are positioned to intervene before an exposure results in widespread consequences.

Alternatives

Without an Environmental Health Dashboard, policymakers, community-based organizations, health systems, and providers must rely on information from a multitude of sources. Reliable data may not be readily accessible at the neighborhood level.

Dependencies

1. **Capacity to collect and analyze accurate data at the neighborhood level**: Before different variables can be displayed, significant analytic resources are needed to ensure data quality and interoperability across various factors.
2. **User friendly design:** Need dashboard to be intuitive due to limited internal technical capacity.
3. **Data timeliness and longitudinal storage capacity**: To be most useful, especially for surveillance activity, data would need to be integrated into the dashboard a timely fashion, as well as stored for aggregate and trend analysis.

Socializing & Refining User Stories

Presentations

All In National Meeting 2019, Baltimore, MD | October 15–17

Dr. Tekisha Dwan Everette, (HEDA) and Alan Fontes (UCONN AIMS) led an engaging roundtable session at the meeting. During the session, they provided an overview of the HEDA work and the CDAS, and summarized the initial findings from the 2019 report as well as discussed the user stories. Main topics of interest included data governance and equity, clinical risk groupers as a means to diffuse white normativity, and curiosity about access to in-patient data. The following questions summarized the primary discussion that arose during the session:

- Will you have data at the population level and the individual level?
- What prompted the focus on equity?
- Will the system flag the provider based on risk?
- Who will own the analytic solution?

2019 CPHA Annual Meeting & Conference, Plantsville, CT | October 21

Dr. Tekisha Dwan Everette (HEDA), Dr. Karen Wang, MD (HEDA), Alan Fontes (UCONN AIMS), and Allan Hackney (OHS) presented at the Connecticut Public Health Association's Annual meeting on October 21st during the breakout session. They provided an overview of the work summarized in the 2019 HEDA report and discussed the user stories that were in development at the time. Topics of conversation at the conference included data governance issues; approaches for usability testing and who the team might target for further discussion (e.g. CT Health Foundation and a few select CCIP healthcare systems). The team also learned that the Department of Public Health (DPH) previously attempted to assess the existing data fields across the state agencies and synthesize them as a first step towards standardizing data practices. However, the initiative did not end up moving forward.

Key Stakeholder Discussions

2019 APHA Annual Meeting & Conference, Philadelphia, PN | November 3 - 6

Dr. Karen Wang and Tara Rizzo attended the American Public Health Association Annual Meeting in Philadelphia November 3-6. They engaged in several discussions with people who have integrated various sorts of data and convened user groups to get feedback. From these discussions, a key emphasis was the importance of *getting feedback from diverse end-users about the platform*. These various data integrators/visualization platforms held many focus groups/user groups feedback sessions. They recommended utilizing an agile formula for eliciting feedback: "As a ____, I want to _____, so I can _____."

HealthLandscape (www.healthlandscape.org), Mark Carozza, Founder of Health Landscape

HealthLandscape is an interactive web-based mapping tool that allows health professionals, policy makers, academic researchers, and planners to combine, analyze and display information in ways that promote better understanding of health and the forces that affect it. The tool brings together various sources of health, socio-economic and environmental information in a convenient, central location to help answer questions about and improve health and healthcare. HealthLandscape can be used to create maps from publicly available datasets including regional criminal justice, education, healthcare, and demographic data, allowing users to discover community characteristics and share information with health professionals, policy makers, and legislators. HealthLandscape has ingested publicly available BRFSS data from 500 cities into this platform. Their efforts right now are focused on disseminating this platform to as many public health researchers, other potential end-users of the data.

City Health Dashboard https://www.cityhealthdashboard.com/ ,, Chair of Population Health, NYU Langone Health

The City Health Dashboard is an online resource with 37 measures of health status, determinants, and equity for the 500 largest US cities, created to address a gap in actionable data specific to city boundaries. It seeks to improve population health by making knowledge and improvement strategies accessible to a wide range of change makers; to strike the right balance between accessibility and rigor, ensuring comprehensibility by lay audiences, while demonstrating integrity to experts. Accordingly, they solicited feedback from the City Advisory Committee throughout development and worked with communications specialists and defined our primary audience as city leadership, health department staff, and community groups and our secondary audience as researchers and academics. This distinction between users enabled them to tailor content, focusing on three core areas.

1. Site design, including "sensemaking" statements and data visualizations to communicate sophisticated data clearly and intelligibly.
2. Presented technical notes in an FAQ section for non-scientific audiences as an alternative to the Technical Document intended primarily for researchers.
3. Used plain language definitions, blog posts, and "how to" webinars, videos, and documents to distill complex information in a manner that encourages understanding and engaged use by our primary audience. They are continuing to get ongoing feedback from diverse stakeholders to meet the needs of Dashboard users for community-level health data.

County Health Rankings https://www.countyhealthrankings.org/

For nearly a decade, County Health Rankings & Roadmaps (CHRR) has provided a way to discuss the multiple factors that influence the length and quality of life with public health and non-public health audiences in order to improve health for all. The CHRR model was built using historical perspective, literature reviews, inferences from other rankings models, analytic considerations, and stakeholder engagement to balance scientific and communication needs. The model provides a way to communicate messages such as, "where you live, learn, work and play matters to your health" and "health is more than health care." It includes weighted measures in the health factor areas of health behaviors, clinical care, social and economic factors, and physical environment. The model and ranking system are underpinned with reliable county level data for 50+ measures calculated from 25+ sources. In order to help audiences understand and effectively communicate and use their data, CHRR has developed several tools including What Works for Health (WWFH) and Action Learning Guides (ALGs). WWFH provides a menu of evidence-informed strategies to support communities taking action. The ALGs blend guidance, tools, and hands-on practice for various activities regarding health and equity. These are intended to build foundational knowledge and skills to move communities to their next stage of work in that area. CHRR continues to advance science as they dissemination their model and data to audiences- ie. Policy makers/decision makers of the health of communities. CHRR is working on evaluating its platform – mostly around use and mentions.

Amy Carrol Scott, PhD, MPH, co-lead of the Policy & Community Engagement Core of the Drexel Urban Health Collaborative

Dr. Scott is a public health researcher who works to disseminate community-level data. We learned that their experience with their healthcare system data and health information exchange (HIE) has been poor. Currently, their research centers have aggregated a large amount of data across multiple stakeholders (from education, environment, and health systems). She noted that a significant amount of effort needs to be spent on engaging end-users in this platform. Engagement opportunities that they have organized and found to be successful include holding community meetings dedicated to reviewing and receiving feedback about dissemination materials.

Key Takeaways from Socialization

- In order to ensure a robust and responsive platform and data system, initial feedback from user groups about various aspects of the platform (display, content for buy-in) and an ongoing feedback system for calibration should be built into rollout and ongoing support mechanisms.
- Developing educational materials to accompany the data (depending on various user groups) is crucial to the rollout. The greatest need is to develop accompanying text with numerical representations.
- Currently, there seems to be no systematic evaluation of these platforms.

Next Steps

The HEDA team recommends further socialization to refine understanding of the value proposition. Organizing community sessions to solicit feedback from each type of end user described above is a crucial next step in advancing statewide data sharing in Connecticut.

Health Equity Data Analytics Team

Health Equity Solutions, Inc.

Equity Research and Innovation Center (ERIC) at Yale

DataHaven

Draft report prepared for the Connecticut Office of Health Strategy (OHS)

Submitted September 2020

OHS CONNECTICUT Office *of* Health Strategy