

Delaware's *My Healthy Community* Data Platform:

At The Intersection of Public Health Informatics and Epidemiology

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Introduction

“Delawareans need to have access to usable, meaningful, timely, and high-quality data about the health of the communities in which they live,”¹ so that data-driven evidence-based decisions result in community-focused solutions to affect positive change. This statement is the vision of the *My Healthy Community* (MHC) data portal,² which serves as Delaware’s population health platform. The MHC platform shares data on a myriad of population health areas such as social vulnerability, community characteristics, the environment (e.g., public and private drinking water, air quality), chronic diseases, mental health and substance use, healthy lifestyles, maternal and child health, health care utilization, and infectious diseases. MHC continues to expand in both data and functionality to serve as a tool to track the outcomes of implementing data-driven population health interventions and utilizing technology to monitor and evaluate the effectiveness of interventions. Shortly after the coronavirus disease 2019 (COVID-19) pandemic took a foot hold in the United States, in April of 2020, only 11 months after MHC was publicly launched, the site also became Delaware’s coronavirus disease 2019 (COVID-19) dashboard, presenting statistics on COVID-19 cases, hospitalization, emergency department visits, testing, deaths, vaccination, contact tracing, and in-person contagious school cases.

MHC’s origins lie in the intersection between public health informatics and epidemiology. Visionaries within Delaware’s public health agency paved the way to create MHC with the

support of DPH leadership and the perseverance and dedication of a small team of public health professionals. With their own unique lenses, one of public informatics and the other of epidemiology, the team's efforts materialized into a tool that continues to evolve and respond to Delaware's changing needs.

A Public Health Informatics Foundation

Public health informatics has long been recognized as a critical need in state and local health agencies; however, recent research estimates that informatics positions account for only 1% of state health agency workforces.³ Although historically the distinction between the role of informatics and information technologists has not been well understood, national efforts to clearly define the roles and skills of informatics professionals have provided a clearer picture of how these two branches of information science are distinct yet complementary.^{3,4} Informatics is categorized as a core science of public health where informaticians serve as the knowledge architects of public health information systems.⁴ Informaticians use their knowledge of data security, standards, and policy to translate public health program system needs into functional requirements for public health information and surveillance systems.³ As a team member, informaticians work in tandem with information technologists and public health programs.⁴ While information technologists design and implement database architecture such as network connections, database management, programming, security, and system performance, public health informaticians identify opportunities for data integration, ensure that data standards and security of protected health and personally identifiable information are met, and assess reporting, analysis, and visualization needs of public health programs.⁴ For example, when public health program staff need an application to onboard and process new laboratory test results or create new automated procedures for improving data consumption and integration in their existing infectious disease surveillance system, public health informaticians translate the public health program needs to the information technologists and assist throughout the duration of the project to its completion.

The Epidemiologic Lens

Epidemiology is the study of the distribution, determinants, and patterns of disease occurrence and health states in a population.⁴ The epidemiologic lens is one that is founded in science, exploring and understanding the interrelatedness of the components and factors that comprise the environment and world in the expanse of human behaviors, social constructs, and the impact of these aspects on health. Epidemiologists apply scientific methodologies to identify risk and protective factors, measure health related states, describe health conditions and their distribution, assess causality, and determine the effect of interventions on outcomes.⁵ Through the conduct of research, understanding of study designs and associated biases (selection, information) and confounding, and application of statistical methods, epidemiologists are intimately involved in describing the health continuum. Epidemiologists use these theoretical and applied underpinnings of the field in the analysis of data, presentation, interpretation, and dissemination of findings from both descriptive and analytic studies. Although most often thought of as focusing on infectious diseases, epidemiology spans a wide array of areas affecting health including but not limited to cancer and chronic diseases, social epidemiology, nutrition and physical activity, aging, injury, clinical, pharmacoepidemiology, and genetics.⁶ It's through this approach across the breadth of health areas that the epidemiologic lens plays a critical role; setting the framework for transforming data into information that describes, generates

hypotheses, and stimulates discussions to take a deeper look into the underlying contributing factors of health and health disparities.

The Intersection of Informatics and Epidemiology

The Delaware Department of Health and Social Services, Division of Public Health (DPH) recognized the significant need and benefits of public health informatics and envisioned improvements in coordination and efficiency through a centralized team of professionals dedicated to developing a robust, scalable information systems infrastructure. In 2006, DPH created the Bureau of Public Health Informatics and began efforts to ensure that the foundation of a public health informatics infrastructure were implemented. DPH also recognized the continued need for a cross-cutting epidemiologic presence to strengthen epidemiologic expertise and provide support to DPH programs with limited epidemiologic capacity. Subsequently, in 2014, DPH established the Epidemiology, Health Data, and Informatics Section (EHDIS) by marrying the Bureau of Public Health Informatics (BPHI), the Bureau of Health and Vital Statistics comprised of the Office of Vital Statistics and Health Statistics Center, and the Office of the State Epidemiologist. The Epidemiology Research Unit became the next epidemiology unit within EHDIS formed to provide epidemiologic expertise in injury surveillance, specifically substance use disorder and violent deaths (suicides and homicides). In response to the COVID-19 pandemic, the COVID Epidemiology Team also joined the section in 2020. From the creation of section with leadership in epidemiology, informatics, and health statistics, flourished the opportunity for epidemiology (including health statistics) and informatics together to achieve the section's vision that "Decisions about public health interventions, programs, and policies are informed by and developed using timely data that have been translated into usable, meaningful information." In other words, the intersection of public health informatics and epidemiology expertise work together to showcase the MCH data in innovative ways.

Using the epidemiologic lens, the conceptual design of the site originated from a review of public data dashboards, discussions regarding data needs shared by community partners, and the application of an informatics lens to translate the vision into a proposal and terminology that could be used by [Green River Data Analysis](#), the vendor selected to transform the vision into the MHC platform. Funding from the Delaware Department of Natural Resources and Environmental Control (DNREC) served as the seed funding to jump start development of MHC and initial focus on the its roots in environmental public health tracking data from CDC's National Environmental Public Health Tracking framework.. Funding from various other sources followed. Public health informatics and epidemiology began to work closely with Green River. It was evident from the outset that Green River shared DPH's vision, values, and mission to utilize data to benefit communities. From the design of the site to the presentation of the data and metrics, this intersection of not only informatics and epidemiology, but with software engineers and designers from Green River, is and continues as, the driving force behind the development and enhancement of the MHC platform informed by the needs of the community.

My Healthy Community (MHC) Platform

In 2018, DPH partnered with Green River Data Analysis to transform DPH's vision for usable, meaningful, timely, and high-quality data about the health of the Delaware communities into a data platform focused on population health metrics. The result was Delaware's MHC data portal,² a database and platform which lives online at myhealthcommunity.dhss.delaware.gov,

and has readily and publicly shared indicators of health outcomes since its launch on May 13, 2019. Achieving Health Equity is one of DPH's strategic goals. MCH was designed as a tool that can be utilized by a wide variety of audiences to access dis-aggregated data. This allows for access to information that supports the development of data driven, health equity centered interventions, policies, and programs. MHC serves as Delaware's population health dashboard as depicted in Figure 1 and since almost the beginning of COVID-19, has served as the state's pandemic-data dashboard and reporting platform as depicted in Figure 2. MHC implements an innovative methodology to facilitate the presentation of Delaware's health, demographic, and social determinant data, enabling communities, community organizations, and residents to explore health data at scales ranging from the state level down to the neighborhood or block group level. Users can type their address in the search menu and a selection of geographies including census block groups, neighborhoods, census tracts, State House Districts, State Senate Districts, zip codes, cities, counties, and the state level are available to explore. Drawing from a universe of data sources, the platform spans social determinants of health data, rigorously maintains confidentiality. It contains at least 10 broad areas of population health with 55 subcategories including data sources such as Delaware's vital records (births and deaths), surveys such as the Behavioral Risk Factor Survey and Youth Risk Behavior Survey, hospitalization and emergency department visit data, prescription drug monitoring data, U.S. Census, and CDC's social vulnerability index, to name a few.

Figure 1. Screen Capture of the My Healthy Community's Population Health Dashboard (<https://myhealthycommunity.dhss.delaware.gov/locations/state/community-characteristics>)

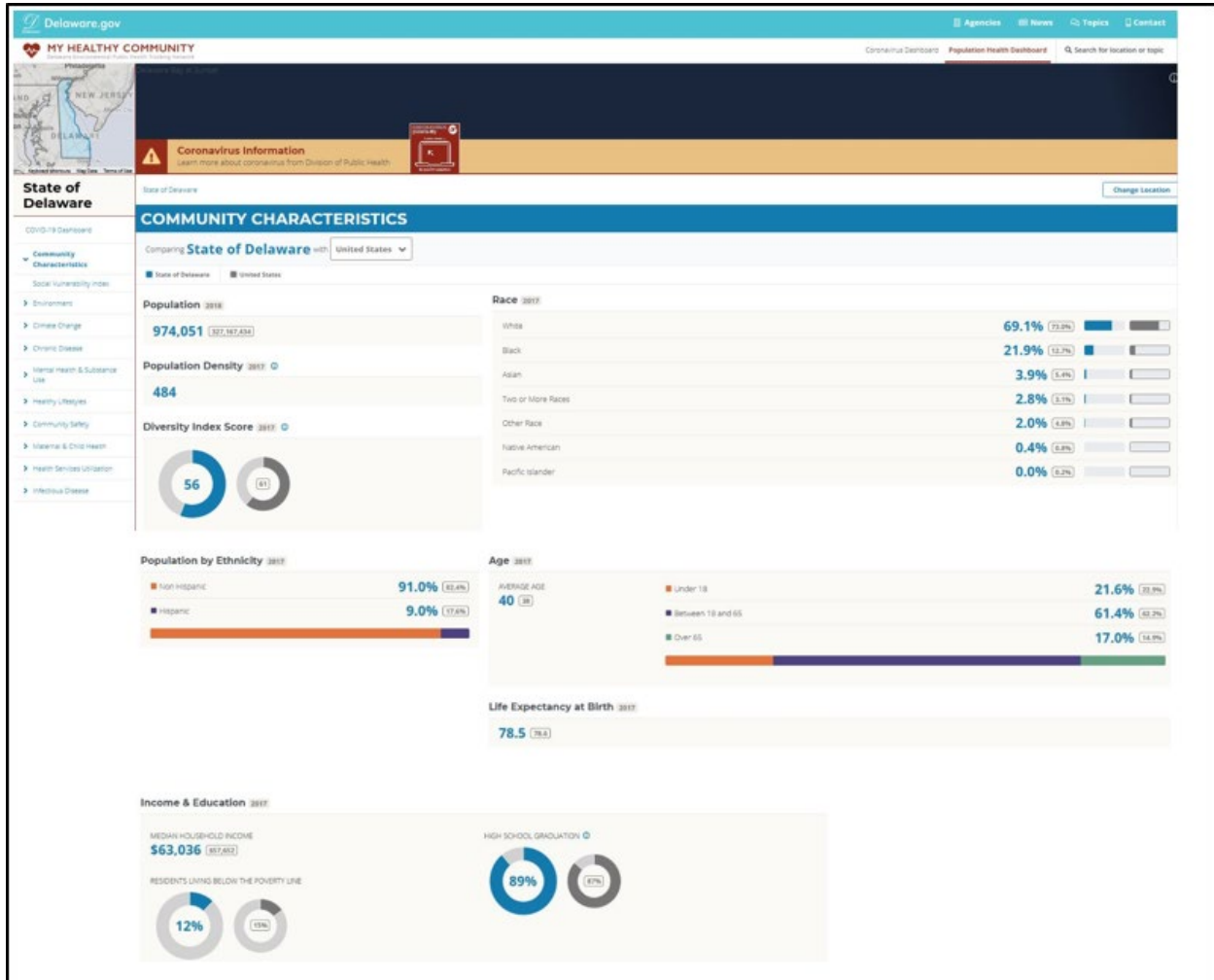
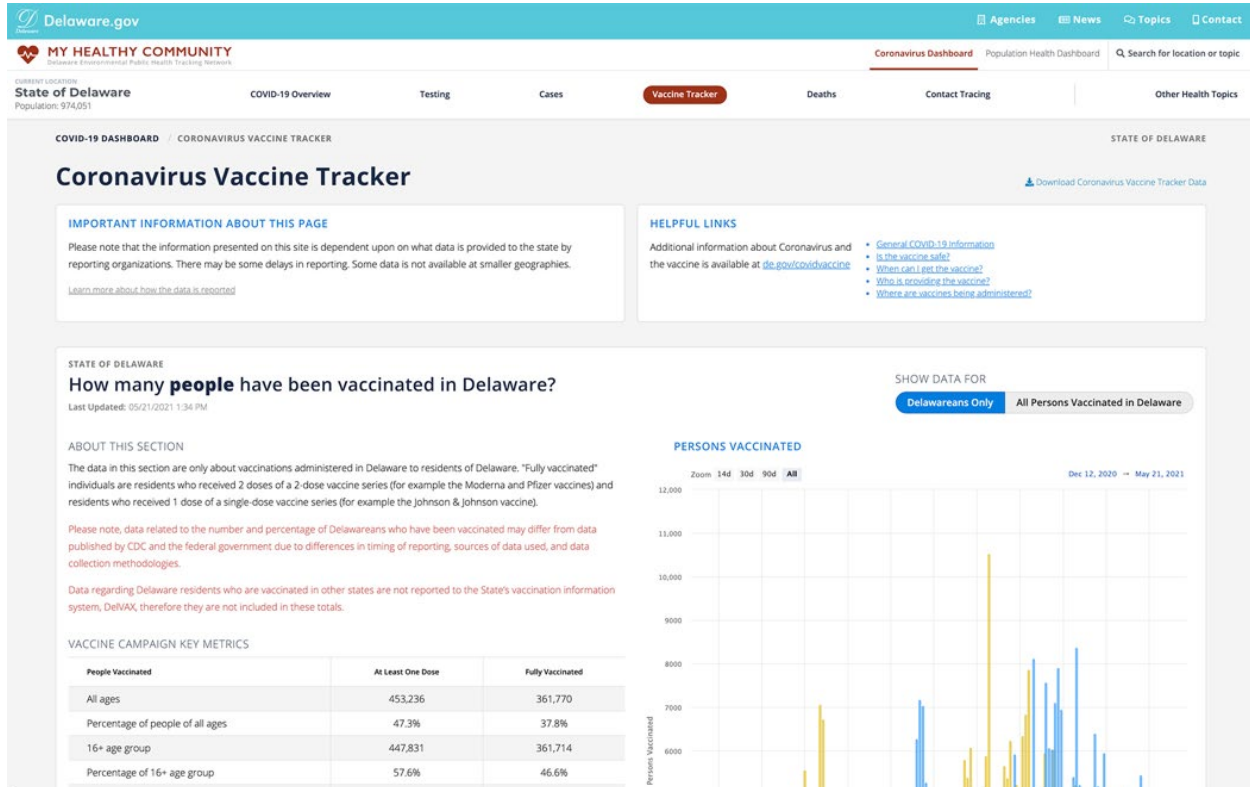


Figure 2. Screen Capture of the My Healthy Community's Coronavirus 2019 Vaccine Tracker (<https://myhealthycommunity.dhss.delaware.gov/locations/state/vaccine-tracker>)



The MHC experience – its functionalities, innovations, limitations, and potential – provides a better understanding of the role that public health informatics plays in population health. To successfully respond to COVID-19, policymakers, and the public require the most comprehensive data possible: information that is timely, readily available, easily communicated, and relevant at all geographic levels. In Delaware, rapid community-level reporting and coordination among DPH commercial laboratories, hospitals, and other critical information sources help residents and elected officials adopt appropriate mitigation strategies and ensure the state's residents are protected. The MHC data platform both pulls and pushes data daily and are presented in charts, tables, and interactive maps. MHC successfully presents COVID-19 data from diverse sources, communicating developments to the public, reporting internally, and provide data that can be used to strategize state and community level response and mitigation efforts.

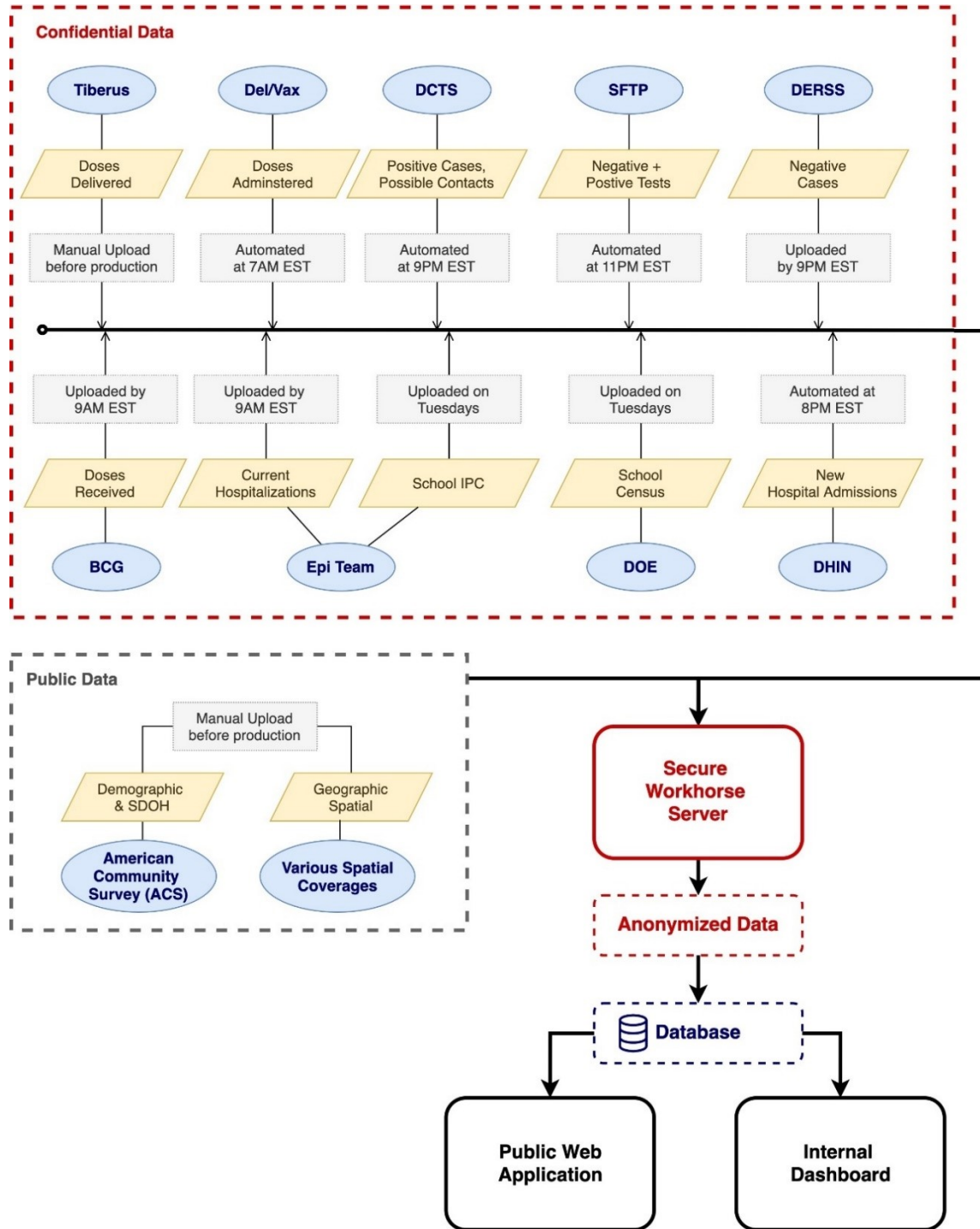
Data Integration

An integral component of effective public health informatics is data integration. Data integration can sometimes be viewed with different frameworks, (1) one in which disparate datasets are joined into one dataset using linking or matching variables (e.g, name, date of birth, unique identifier, etc.) or (2) one in which disparate datasets are combined through visualizations and analytics to display a unified view. MHC has successfully achieved the second framework of presenting data from disparate datasets into a unified form on the platform. Additionally, MHC has taken steps toward achieving the first framework of data integration in which disparate datasets are joined to provide a deeper understanding of health across the continuum. Intra- and

inter-agency siloes of information hinder the ability to monitor, report, and mitigate disease. By understanding health and illness in the context of both population demographics and social determinants of health, adequate efforts can be made to identify and protect those most vulnerable to poor health outcomes. Such analyses rely on expansive, combined data sets encompassing the demographic and social determinants of health information, health outcomes, and more. Those data are stored by – and must be integrated from – disparate sources with different timeframes, different resolutions (individual-level records, county-level data, etc.), and different formats (Application Programming Interface (API) calls to other systems, spreadsheet uploads, online collection forms, etc.).

A combined data store facilitates the generation of hypotheses about potential associations that would be otherwise difficult, and across all kinds of health topics. For example, with air quality and hospitalization data in a combined data store, the results can be charted over time and across a geography to depict similarities in trends between ozone levels and asthma. Given that the infrastructure and architecture for managing HIPAA protected data was already a part of the MHC platform, DPH was more readily able to transition COVID-19 data reporting to the MHC platform's existing menu of health topics. Through a mixture of automated and manual upload processes, it consumes a host of data flows, including: vaccination doses delivered to Delaware, pulled from the federal government's Tiberius system; doses administered, pulled from DelVAX (Delaware's immunization registry); positive cases and possible contacts, pulled from the Delaware Contact Tracing System; and other negative and positive test results compiled from other sources as illustrated in Figure 3. MHC also gathers daily and weekly data feeds on current hospitalizations, new hospital admissions, school in-person contagious data, and school census data. All of these data are processed and presented for government reporting and public consumption at varying levels of spatial and temporal resolution as illustrated in Figure 4.

Figure 3. Data Flow for the My Healthy Community's Coronavirus Dashboard Showing the Data Sources Required for Public and Internal Display



Note: MHC contains data on numerous other health topics, and this figure illustrates only the COVID-19 related data feeds. SFTP= Secure File Transfer; Source of the SFTP data is a data file that is generated from DERSS and uploaded to the secure MHC site. DelVAX- Delaware's statewide immunization registry; DCTS= Delaware Contact Tracing System; DERSS= Delaware

Electronic Reporting and Surveillance System; DOE= Department of Education; DHIN= Delaware Health Information Network; SDOH= social determinants of health.

Understanding Health in Terms of Social and Demographic Context

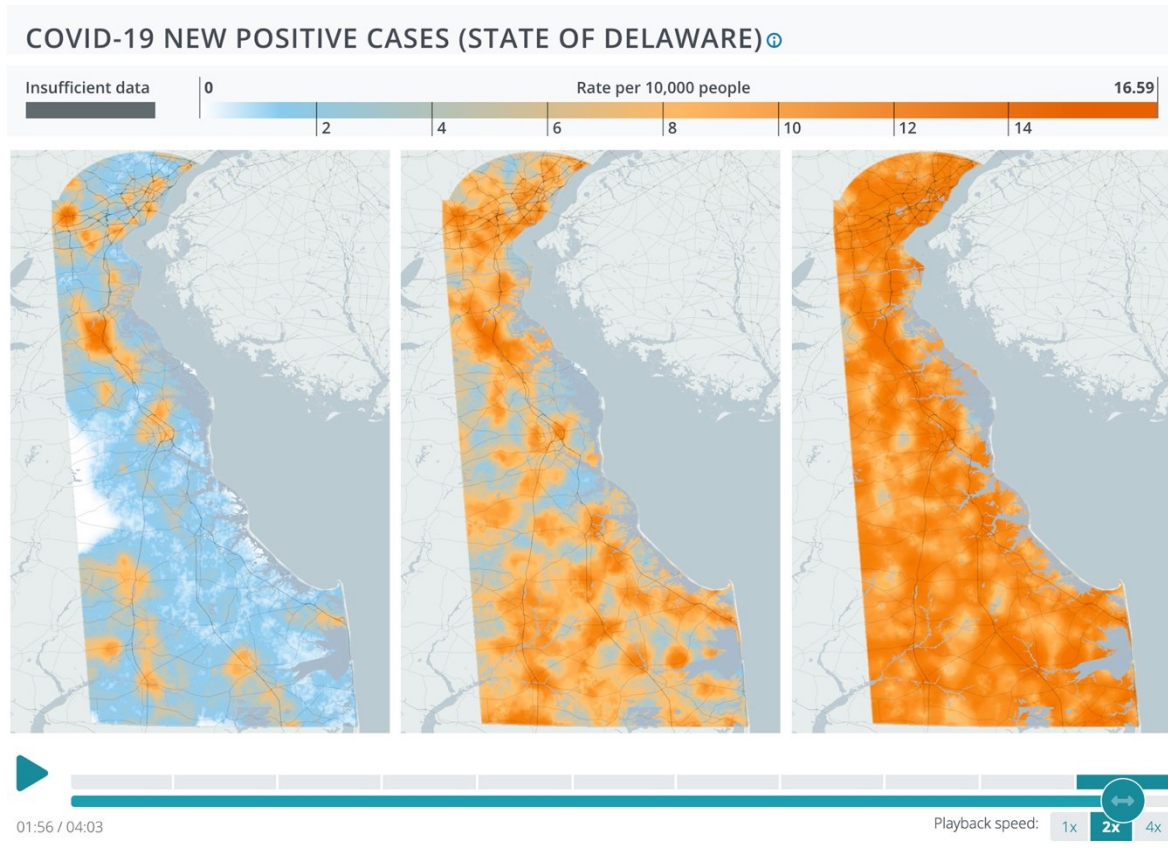
The application and utility of public health informatics and epidemiology is perhaps most evident when considering health in terms of social and demographic contexts and spatial and temporal trends. Both present considerable challenges. Structuring an effective social determinants of health construct is challenging because information must be organized both by health topic and geographic entity. Hierarchical classification, which works well for many types of information categorized on the web, is antithetical to an integrated public health approach striving to emphasize and promote understanding of the connections between environmental conditions, social determinants, demographics, and diseases – not each in isolation. Figure 5 illustrates MHC’s solution to this data-navigation issue through a search by community and topics.

A related challenge for MHC and any platform intended for a broad audience concerns breadth of functionality and ease-of-use. Whereas a researcher might benefit from data download capabilities and appreciate the presentation of statistical model findings, community organizations and citizens might focus more on findings that touch their neighborhood, and which aspects are notably better or worse than in other similar neighborhoods. This finding is consistent with MHC user research. Yet another concern is that an inadvertent emphasis on a few variables or datasets can lead to difficulty communicating the difference between causation and correlation. For example, visual presentation of a correlation between two variables is highly likely to be misunderstood by the public as causation. These are important considerations for presenting data on MHC and supports the key role of epidemiology and informatics involvement when partnering with information technologists.

Understanding Health in Terms of Spatial and Temporal Trends

MHC uses extensive geographic information systems and methods to portray disease cases through charts and tables. Users can evaluate temporal changes within a geography of interest, zooming in and out on a map. The use of animated maps of disease rates reveal trends, patterns, geographic clusters of disease, or random occurrences over space or time as displayed in Figure 4. MHC’s maps incorporate statistical techniques and algorithms to smooth rates over less populated areas. Furthermore, MHC’s animated maps of disease patterns define population groups independent of geopolitical boundaries, side-stepping the traditional but misleading use of county, town, and zip code boundaries on choropleth maps. Those are misleading because of the Modifiable Areal Unit Problem (MAUP), a bias whereby the geographic unit used to aggregate a measure actually determines the pattern seen.⁷ Likewise, the presentation of time must respect privacy and avoid granular details, as trendlines show whether a particular indicator is improving, getting worse, or changing randomly. As with geography, too much granularity risks revealing “who” and “when.”

Figure 4. Screen Capture of Animated Map of COVID-19 Case Rates Over Time (2020-2021)



Protecting Privacy

Implementing technology and legal processes to ensure privacy and compliance with the Health Insurance Portability and Accountability Act (HIPAA) are fundamental to the success of any public health informatics system. The MHC software is likely one of a few in the nation capable of presenting pandemic information and other health indicators at spatial resolutions as low as the census block group level, a small geography comprising as few as 600 people. The HIPAA-protection algorithm designed to detect and suppress data in these situations is one of MHC's most important innovations.

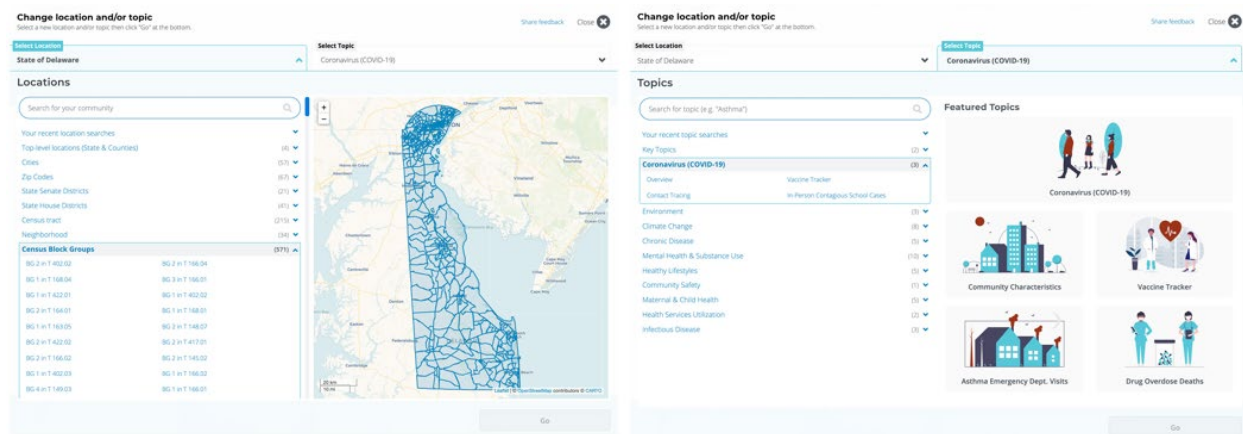
To ensure confidentiality, and consistent with HIPAA privacy rule 45 CFR § 164.514(b), the MHC team arranged outside expert review to determine that there is minimal risk that information on the platform could be used alone or in combination with other reasonably available information to identify any individual.⁸ As an example measure, MHC guards against displaying frequencies with fewer than 11 individuals.⁸ When counts fail to meet this threshold, the system aggregates data in three ways: automated aggregation over a longer period of time; automated aggregation over a larger geographic unit; and in some cases, aggregation of the attribute itself (*e.g.*, displaying an overall cancer category instead of reporting on separate cancer types). A related challenge is the incompatibility of different types of geographic level data. A smaller unit, like a neighborhood, may intersect more than one larger unit, like a census block group, causing difficult-to-analyze disclosure risks. Use of animated maps showcase MHC's anonymization processes while accurately depicting the movement of disease over time across the landscape.

MHC Expansion

Delaware's MHC platform is a resilient, stable foundation for transparent and timely public information and public reporting across all neighborhoods. This complete data publication and dissemination system helps support state agencies, the business and education sectors, and communities make informed data-driven decisions.

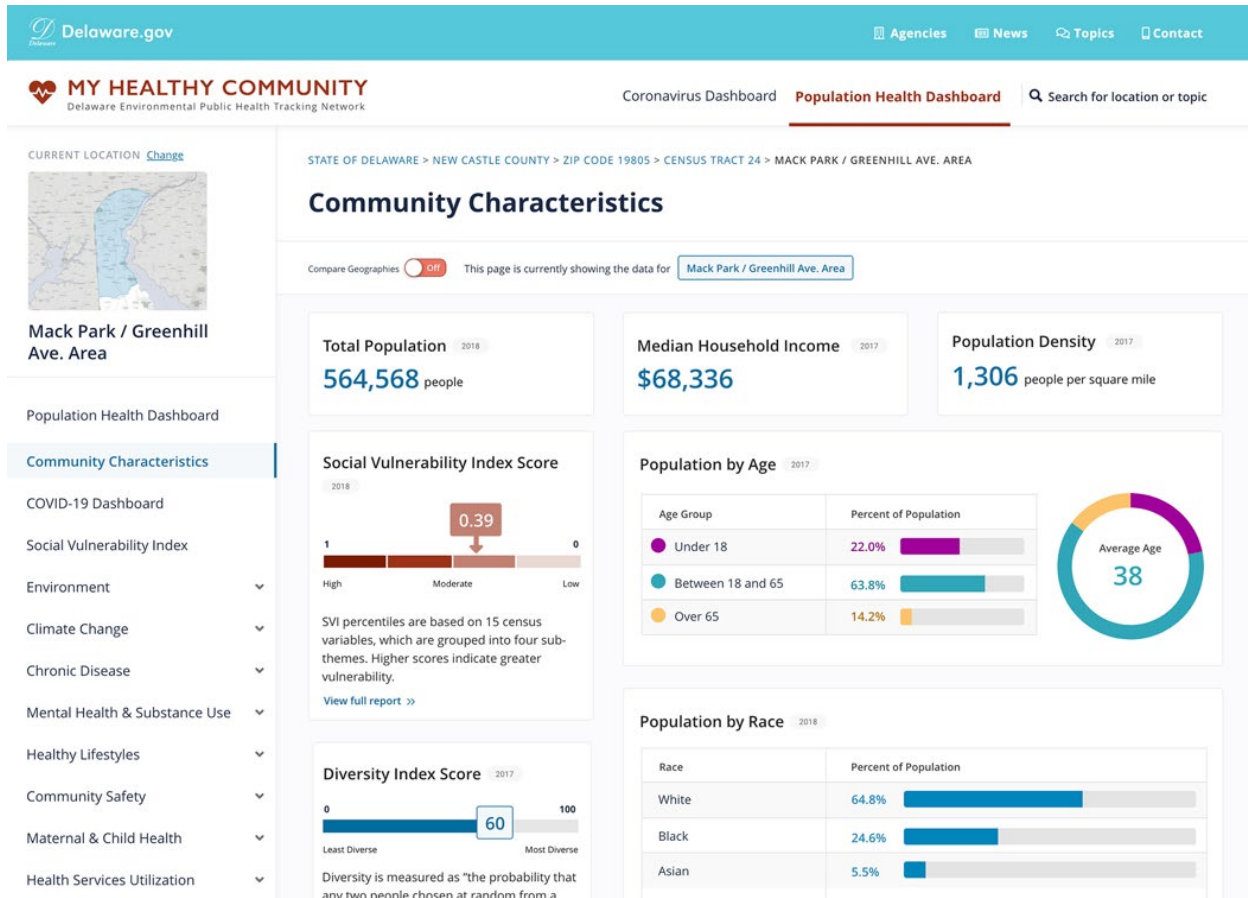
The next phase of MHC expands the provision baseline data for population-based and community-level interventions into opportunities to collect community specific intervention level data that measure the effectiveness of interventions, presents relevant data for monitoring the outcomes and impact of the interventions over time, and shares the stories of the data-driven solutions being used to affect positive change. Data on the MHC platform can be used to assist in the delivery of coordinated, neighborhood-specific, highly targeted mitigation strategies (figure 5). As attention eventually returns to managing other public health issues in Delaware, the data systems, analytic and information visualization tools, and mitigation support developed during the pandemic can be leveraged for use in health areas, including mental health, obesity, suicide, the impact of climate change on the health of vulnerable populations, and substance use disorder.

Figure 5. User interface facilitating navigation by both geographies and topics supported



Looking at the continued evolution of MHC to incorporate the COVID-19 dashboard, this serves as a powerful example of the significant role public health informatics can play in periods of crisis. In just over one year, the MHC platform has proven to be a dependable source through which DPH shares time-sensitive, actionable COVID-19 data. This is due in great part to the application of informatics working together with epidemiologists, communications, and technology driven functionalities developed and integrated into MHC prior to the pandemic. These functionalities include: geographic scalability of reports; presentation of social determinants of health to help encourage strategies toward healthy outcomes; geographically specific and timely visualizations to communicate effectively with community organizations (while maintaining individual privacy); and intuitive controls and user research to inform interfaces for health care providers, public health professionals, and community organizations. Later in 2021, DPH plans to apply the platform's advances to other population health topics of importance to Delawareans and which support public health interventions. A redesign of the demographic and social determinants of health section is under development that applies software design patterns built during the pandemic as illustrated in Figure 6.

Figure 6. Proposed New Layout of Community Characteristics Section within My Healthy Community Site



Since charts and animated maps have limitations, platform users must navigate a tremendous amount of information to discover and act upon findings. By supplementing the MHC site with narrative story, the presented data will be more useful for making data-driven decisions and providing a feeling of ownership over public data. Narratives as straight text or multimedia make data and findings more meaningful by contextualizing data points and analyses. DPH developed an initial data story around the impact of opioid use disorder in Delaware⁹ and community profiles so users understand why local events occur and how they compare to other neighborhoods. DPH views MCH as a useful tool for partnership with communities in expansion of health equity centered approaches through incorporation of additional indicators tied to social determinants factors that can influence improved health and wellbeing outcomes.

MHC's success is due to the application of public health informatics informed by epidemiology and working closely with subject matter experts. DPH's experience with the platform throughout the COVID-19 pandemic demonstrated the vital role of informatics and epidemiology in public health and the new fields that are necessary to make effective use of emerging technology. DPH is committed to an integrated data system with effective public reporting and mitigation support as this viable tool continues to expand and grow in its utility and functionality.

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