DMI

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Utah's open-source surveillance system paves the way for data modernization

Utah is now recognized as an innovative and longtime player in the data modernization space—but for many years, it shared the same data challenges as other jurisdictions. Rachelle Boulton, Utah's Division of Population Health Informatics Program Manager, says problems included siloed systems and manual, time-consuming processes, especially in case surveillance, case investigation and reporting. "Everything coming from healthcare providers and labs were emails, faxes and phone calls." Kirk Benge, Health Officer at Utah's TriCounty Health Department, agrees, saying, "Local health departments were relying on faxes for reportable diseases and using different databases for lab data."

Utah's health department, now the Utah Department of Health and Human Services (DHHS), began envisioning a new disease surveillance system in 2007. After in-depth input from across the public health ecosystem in Utah and a false start with a vendor that eventually went out of business, their efforts evolved into a system built on open-source technologies called EpiTrax. Boulton says, "**Open-source was more fiscally sustainable because we could develop, maintain and host the system in-house.** We would be in control of the feature prioritization and development timeline, so **we could add new features quickly to the system and rapidly re-prioritize development due to changing public health surveillance needs.**" Additionally, she says they would be able to build on the work of other public health agencies using the system and pool resources to continue to enhance the system.

Rachelle Boulton and Alina Paegle of Utah's DHHS review the features of EpiTrax. EpiTrax was built on open-source technology so new features could be added quickly.
Photo credit: Nick Sokoloff

A milestone in data sharing


Rachelle Boulton

The implementation of EpiTrax in 2017 represented a major achievement in data sharing. EpiTrax is designed to support Utah state and local public health agency surveillance and epidemiologic needs, including receiving or entering disease reports, conducting case/outbreak investigations, managing cases/outbreaks, analyzing data and reporting to the Centers for Disease Control and Prevention (CDC). Boulton says, "We were able to consolidate data from the local health departments and the Department of Health and Human Services including epidemiology and case investigation activities into one system. All communicable diseases are managed through that system, and we've even been able to use it to expand to noncommunicable diseases such as blood lead and e-cigarette or vaping use-associated lung diseases (EVALI)."


Kirk Benge

Benge says **Utah's data modernization really starts with EpiTrax**. "When a diagnosis is made or when a lab result comes in, those records are automatically sent into EpiTrax. A record is created in a shared database that all local health departments can see, but it's geographically filtered. So, I can log in and only see the cases from my jurisdiction, from my three counties. And almost in real-time, as a lab result comes in, I can log in and see all of the records associated with that."

He adds: "And there might still be missing data. There often is, right? Maybe the phone number isn't there or it's not correct. But that is a very different world today than what we were operating in 20 years ago."

EpiTrax also includes a number of different applications, such as the Electronic Message Staging Area (EMSA) where electronic lab and case reports are received. Boulton says a number of different data sources come in via different formats through EMSA. "The purpose is to parse, translate those messages, and then run them through a rule set which allows us to automate a lot of processes. So, we can determine what cases those messages should go into, in what timeframe, and whether they should update [an existing case or create a new one]. We also have a holding area for data so we can determine sometime down the line that the information we received, which wasn't relevant at the time, is now valuable. There's automation looking for that data and pulling it in."

She says with the interoperability and integration with EMSA, **they can centralize all electronic data collection for electronic lab records (ELR) and electronic case reports (eCR) at the state level**. The tool also allows them to onboard new providers' data sources very quickly. "There's a lot of flexibility that allows us to manage some of the differences that we can see in different incoming messages. Again, to parse, translate, utilize that rules engine. Nearly 96% of all of the messages we receive are processed into EpiTrax entirely automatically, so they don't require a person to touch them. That level of automation is really beneficial."

The EpiTrax suite also includes **CENDS, the Centralized Electronic Notification Design System**. This was designed to send HL7 messages for case notification to CDC through the National Notifiable Diseases Surveillance System (NNDSS) Modernization Initiative. "But the idea is that this can be expanded and enhanced so any system can connect to it and send data anywhere. It's highly user-configurable, so users can map and translate data. It doesn't involve day-to-day IT support and management. There's a lot of flexibility there," says Boulton.

EpiTrax governance

EpiTrax is used by the state health department, the 13 local health departments in Utah (representing 29 counties) and 6 tribal public health agencies. It has also been deployed in the states of Colorado, Kansas, Wyoming, Nevada, Missouri and the local jurisdictions of Tarrant County (TX) and southern Nevada—representing a multitude of users and organizations. For that reason, Utah manages two separate but integrated governance processes. "One is specific for Utah's implementation of EpiTrax, and prioritization happens there. And then there is consortium governance, which is a process among all of the other public health

Established governance processes and user groups help drive the functionality for EpiTrax. Pictured here from Utah DHHS: Katie Zimmerman, Rachelle Boulton and Nicole Yerkes. Photo credit: Nick Sokoloff

agencies that utilize EpiTrax," says Boulton.

Within Utah, the **EpiTrax Core Team**, a group of seven people, includes three representatives from local health departments. "We try to have one representative from a large urban jurisdiction, one representative from a medium-sized jurisdiction and one from a rural jurisdiction, so we have voices that span the public health ecosystem. We also have our state epidemiologist or their designee who participates, our lead application developer, our product manager and our product owner," says Boulton.

The purpose of the EpiTrax Core Team is to set internal or statewide strategies for EpiTrax and to assist with requirements gathering and the approval of new functionality for Utah. Core Team members serve as EpiTrax champions who ensure visibility on projects; they participate in different local work groups, which might address specific local issues relevant to EpiTrax.

Boulton says they also have **a user group that meets monthly, and work groups can evolve out of that to develop new functionality**. "We put together a work group where end users can engage and really drive the features and functionalities. They can approve of what is ultimately developed and determine if we need to make modifications. But the user group is for training, for vetting new functionality, for gathering input."

Governance also occurs at the consortium level, which includes jurisdictions outside of Utah. Boulton says Utah's role is to be the steward of the code and to ensure all consortium members have a voice and are represented. Boulton's team in the Division of Population Health Informatics Program also actively promotes the EpiTrax suite of applications and engages with jurisdictions that are implementing or interested in using these systems.

"We have consortium documentation that we've developed with all of the consortium members, and we review it annually at our annual consortium meeting. This specifies the different roles and responsibilities of agencies but also identifies specific roles within each of those agencies. For example, a release manager, a code contributor," says Boulton.

She adds, "The consortium is well-organized and is driven by the governance document that was developed among all of the members and is really a living document which is adjusted over time as needed."

Impact of EpiTrax

Boulton says the benefits of EpiTrax include **data sharing, efficiency and broad access to tools across different programs and organizations.** "We have participation from all of the DHHS programs that oversee any communicable disease surveillance, all of the local health departments and six tribal public health agencies."

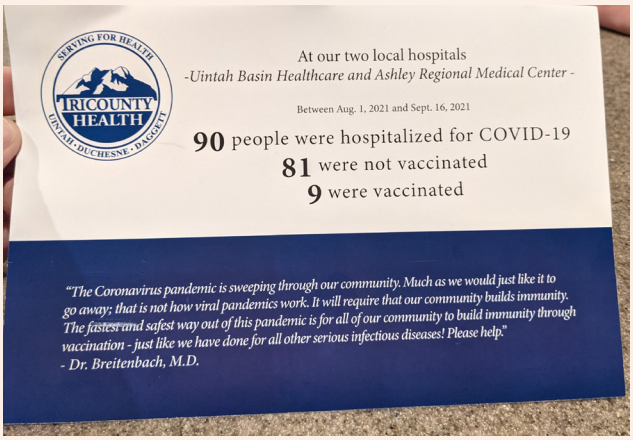
Another benefit is **user configurability**, which allows

Kirk Benge, TriCounty Health Officer, at a community event in Vernal, Utah. Benge says EpiTrax has improved his team's ability to respond to infectious diseases.

EpiTrax shines a light on local hospitalizations

Benge recounts a story when EpiTrax data were helpful in motivating more people to get vaccinated in the TriCounty area. During the pandemic, his team saw the large gap between the rates of COVID-19 hospitalizations in unvaccinated people vs. vaccinated. With distrust in his community toward vaccination, they ran an analysis in EpiTrax to look closely at two local hospitals in the community area. The data showed most people in the hospital with COVID-19 were unvaccinated.

His team created a mailer with the facts: "At our two local hospitals, in this (six-week) time period, 90 people were hospitalized due to COVID-19; 81 of them were unvaccinated; 9 of them were vaccinated." For Benge, it was a message that "helped cut through all of that concern about national politics and propaganda and what was going on and just saying, 'We're local, these are your local hospitals and this is what's happening today right now.' And I felt like that was really valuable for our community at that time."



her team to quickly respond and react to changing surveillance needs. "It allows for that flexibility of different groups who might have different processes, workflows, priorities or needs. The flexibility built into EpiTrax is a big component of its success."

"It's user-driven and developed, which I think is really important because it engages users. It is their system. They own it. They drive the prioritization. It's developed to meet their needs as those needs arise."

Benge appreciates the speed and convenience of sharing data among the hospitals, health departments and the state. He says, "**EpiTrax improves our ability to work as a team at approaching our response to an infectious disease or an infectious disease outbreak**, and it improves our ability to analyze and look at data tremendously."

Meeting the needs of different audiences

When it comes to data sharing, Boulton says, "COVID-19 taught us that data sharing is complex. There are many different audiences and partners. We have the public, we have our clinical partners, community-based organizations, other public health agencies and even programs and groups within the department. And those different groups have different needs."

She says her team has discussed **differentiating between the need for direct access to raw data, cleaned datasets that can be shared or simply information that can be presented in dashboards**. "We've realized that just direct access to data sources doesn't necessarily meet the needs, because there's a lot of advanced expertise needed to pull that data, clean it and understand it."

Her team is starting to have these conversations with local health departments and tribal public health agencies, asking how the organization needs the data and what would be the most efficient way to access the data. "There is a lot of variability in capacity in those groups. **While some of those agencies may be able to pull data, manage that data and clean it on their own, there are many who just need access to information and not necessarily all of the data.** We're being careful that we don't develop solutions that don't actually meet the need," says Boulton.

Another challenge is aligning resources at the same time. She mentions that eCR has been a big push nationally. "We've brought on and built a large eCR team. But if it's not a priority for the hospitals, and they don't have the capacity and they don't have a particular interest, we're not going to be able to push those projects forward. Aligning resources and priorities at the same time is really challenging."

Data modernization activities

While EpiTrax is a success story, Boulton says "they have not solved everything," and data modernization is an ongoing process. She says different groups often try to solve the same problem, which may involve duplicate resources and solutions. Collaboration and communication can help solve that, and this is where Utah's data modernization efforts have been focused in the last two years.

Utah's Department of Health and the Department of Human Services merged in July of 2022, becoming the Department of Health and Human Services (DHHS). This merger presented the challenge of understanding how data modernization could work for the new joint organization. Nicole Yerkes, Utah's DMI Director, says, "We have a lot of modernization efforts happening with our public health systems, with our human services systems and some of the other agencies that are connected to the DHHS."

Nicole Yerkes

She says the agency is working to clearly define data modernization and what it means for DHHS. Through different forums that captured perspectives from across programs and positions, they have identified five core public health systems that they're working to modernize, while also acknowledging that modernization efforts are happening across the agency.

DMI Council

Yerkes says the creation of the Data Modernization Initiative (DMI) Council in 2023 helped set the foundation for moving forward with data modernization. It is the structure for all aspects of data modernization across Utah's public health system and provides reviews and recommendations for projects, priorities and implementation. The council is set up into three groups: executive, leadership and working collaborator tiers.

The **executive tier** consists of the executive-level leadership at DHHS, local health departments and tribal public health agencies. The group, which meets quarterly, helps support and guide prioritization of projects.

The **leadership level decides on projects that go to the executive level for sign-off**. The leadership tier meets monthly, and includes representatives from DHHS programs, local health departments and tribes. It also includes representatives from healthcare, Utah's health information exchange (UHIN), higher education and the One Utah Health Collaborative. Yerkes says the leadership tier helps drive discussions about different projects. They can also decide and develop work groups for projects. Yerkes adds, "The leadership level is really broad and encompasses all aspects of the public health system. And then they pull from their teams and their subject matter experts who are in that working collaborator level."

Working collaborator groups are more ad hoc in nature. Yerkes says, "When we need subject matter experts to come and really start to propel a project, we pull them in. And that's worked really well for us so far. We're half a year in, so I'm sure that there will be

Promising practices

- Consider open-source technology for user configurability and adaptability for different use cases.
- For shared systems and strategies, build trust through focused governance groups and documentation.
- Understand the different data needs of leaders, staff and partners–whether that's direct access to raw data, cleaned datasets that can be shared, or information that can be presented in dashboards.

adjustments that we make moving forward. But we feel really confident in the foundation that's been set."

An example of a working collaborative priority is to improve connectivity and data discrepancy issues between the local health departments and the Utah Statewide Immunization Information System (USIIS). A working group of informaticists from local health departments was created, and they examined their own local immunization processes, outlining particular pain points. The group also brought in members from the DHHS USIIS team to discuss modernization efforts that have already been made to the system and what the next priorities need to be. The group is currently meeting bi-weekly to create a plan on how they're going to address those pain points and priorities.

By early 2024, the DMI Council tiers were operating, with mission and vision statements for data modernization. Yerkes says they're in the implementation stage now, "ready to hit the ground running."

Factors in Utah's success

When asked what has helped Utah achieve its results, Boulton says the **leadership support has been critical**. "We can't do what we do without buy-in. Informatics can be expensive. Data modernization can be expensive. A lot of our goals involve fiscal responsibility, and in some cases, it's fiscal savings, right? But it's not cheap. Being able to have that buy-in, that support, really being able to integrate these initiatives into larger department strategies has been very helpful."

Support from leadership has been critical to Utah's success.

She also credits the **buy-in they've gained from end users**, especially through EpiTrax. "These are tools and processes that exist to make their lives better, to improve access to the data that they need, to allow them to focus on the stuff that they need to do and to let computers and electronics do the stuff that computers and electronics can do. And so, really having the end users engaged and supportive has been great as well."

Finally, she credits **national funding**. "It takes money, it takes support; it takes national directive and initiative. It requires public health and health care to work together. A national strategy and scope–and really the funding and support at the national level–is incredibly important."

Key takeaways

- Utah chose open-source technology to develop, maintain and host its disease surveillance system called EpiTrax.
- The benefits of EpiTrax include improved speed and convenience of data sharing, and user configurability that can adapt to changing surveillance needs. EpiTrax's features allow for automation and flexibility when receiving messages in different formats.
- Governance processes and user groups define roles and help drive the functionality and features of EpiTrax.
- Utah's Data Modernization Initiative (DMI) Council sets the foundation for data modernization and provides reviews and recommendations for projects, priorities and implementation.
- Leadership support, user buy-in and national funding have been instrumental to Utah's success.

Collaboration is an important component of Utah's data modernization efforts. Utah DHHS team members pictured here: Robert Herrera, Katie Zimmerman, Rachelle Boulton and Nicole Yerkes. Photo credit: Nick Sokoloff