DMI

Data Modernization INITIATIVE

Stories from the field

Partnerships

Communication strategies

Cross-agency data sharing

PARTNERING FOR ONE PUBLIC HEALTH

Utah, a land of diverse counties and tribes, says people must come first in data modernization

Utah is known for its rugged beauty and geographic diversity, and its population is as varied as its terrain. In a quest to modernize health data systems, the Utah Department of Health and Human Services (Utah DHHS) is working hard to bring diverse groups of people together. Each level of public health in Utah—state, local and tribal—brings unique perspectives, priorities and complexity to data sharing.

Collaborating between state and local levels

Sharing infectious disease data across partners is a classic public health challenge, but EpiTrax, Utah's disease surveillance system, has helped create a smooth relationship between the state and local health departments. (1) EpiTrax is used by the state health department, the 13 local health departments in Utah (representing 29 counties) and six tribal public health agencies. Kirk Benge, Health Officer at Utah's TriCounty Health Department says, "On the infectious disease side

Promising practices

- Implement communities of practice and touch-base meetings to help understand the different needs of local and tribal health departments, hospitals and clinics.
- When working with tribes, listen first. Be respectful of the tradition of who it is you're trying to serve or help.
- Be strategic when working with different priorities from local health departments (e.g., consider the time on the state side to make requested enhancements to a system, but also the value the local health department gains from those changes.)
- Shift the mindset that local health departments and tribal agencies are simply partners who sometimes participate in discussions —they should assist the state with prioritization, tools and evaluation for shared data systems.

Kirk Benge, Health Officer at Utah's TriCounty Health Department, and Nicole Yerkes, DMI Director at Utah DHHS, exchange ideas at the Healthy Communities Roadshow in Vernal, Utah. Photo credit: Nick Sokoloff

of things, working with the state is very good, because EpiTrax facilitates that. Having a shared database that each of us can see creates regular conversations. We still struggle in areas that don't have that shared database. When our information is siloed, there can sometimes be a push or pull about who owns data or who has access to that data."

In Utah, the state law is that the local health departments are the registrar of deaths and births and vital statistics. "Years ago, we came up with the shared vital records system, but unlike EpiTrax, we don't have query access to that system at the local level. Over time, it's shifted from us collecting vital records data in a local database and feeding it up to the state, to us inputting directly into a state vital records database. We have to ask permission to run a query to tell us what's happening in our area, and that's sometimes a little bit frustrating because we are one public health system, and I feel like I shouldn't have to ask permission to understand what's going on in my area."

Kirk Benge

He says Utah DHHS has been receptive to the issue but is also trying to balance the need to very closely protect and secure that data. "You run into that conflict if we want to protect and secure the data, but we also want those who need to access it to be able to access it. And it seems like there's always a little bit of a push and pull there about where the best line is."

On the state side, Utah DHHS has established governance processes and various groups such as the Data Modernization Initiative (DMI) Council and the EpiTrax Core Team to make sure they're recognizing the needs of the local health departments. The LHD Informatics Workgroup also links together the members of the 13 local health departments–some members are also part of the DMI Council.

Nicole Yerkes, DMI Director at the Utah DHHS, says there are many different considerations when working with local health departments. "With our local health departments, we have rural counties, urban counties, frontier counties [less than six people per square mile], we have some of our jurisdictions that are a single county; we have some that are multi-county. They have varying funding capacities and varying staff capacities. So all of these things we needed to take into consideration working with our local health departments."

Nicole Yerkes

Tribal partnerships

Utah is home to approximately 60,000 Native Americans, representing more than 50 tribal nations, with eight being federally recognized. (2)

Utah DHHS works directly with tribes through its American Indian/Alaska Native Health and Family Services (IHFS) tribal liaison. (4) Established in 2007,

Federally-recognized tribes possess certain inherent powers of self-government and entitlement to certain federal benefits, services and protections ... (3)


Jeremy Taylor

Utah was one of the first states to employ a dedicated liaison model for working with tribes. The IHFS develops strategies and policies to improve Indian Health in Utah. It also facilitates working relationships between Utah DHHS, tribal health programs, local health departments, other state agencies, and private provider sectors–cutting the bureaucracy for tribes. "This elevates tribes' public health concerns and honors the government-to-government relationship between state and tribe," says Jeremy Taylor, IHFS tribal liaison. During the COVID-19 pandemic, the state and tribes worked together to respond rapidly because "bridges were already built through the IHFS," says Taylor.

In addition, Utah DHHS hosts the Utah Indian Health Advisory Board and a monthly touchpoint meeting with tribal public health staff. Yerkes points out that tribes are sovereign nations and may work more closely with federal agencies versus the state. However, she says it's tribe-dependent—"[at the state level] there are some tribes we've had a consistent working relationship with and other tribes where we're still building a relationship."

In addition, some urban residents may be affiliated with a tribe, but they're not living on the reservation. "That adds complications compared to those that are living within reservation bounds. Also, our TECs [Tribal Epidemiology Centers] in our tribes span multiple states. The Navajo Nation in the corner of Utah is also in Arizona and New Mexico, so we need to work across states," says Yerkes.

Benge worked with tribes in a past position with the San Juan County health department and his current position in the TriCounty area (Daggett, Duchesne and Uintah counties). He says tribal connections are important, and, for a holistic view of the community, involve more than relying on the usual systems. Some counties might have a local tribal-owned and operated health center. In other cases, community members may go to an Indian Health Services (IHS) facility, which could be in different states—requiring coordination with neighboring states. "We have residents in the TriCounty area that, for them, it's more convenient to go to a facility in Colorado or Wyoming for treatment or diagnosis and those systems are non-EpiTrax. And so that's always a blind spot to us. We have to coordinate with those other state entities to better understand holistically what's actually happening in our communities."


The opening of the UNHS Monument Valley Community Health Center building expansion. Photo credit: Utah Navajo Health System (UNHS)


Shawn Begay

Shawn Begay is the Public Health Director for the Utah Navajo Health System (UNHS), which is governed by the Navajo Nation Department of Health. Like Benge, Begay believes EpiTrax naturally creates a helpful working relationship with the state. The communicable disease data shared in EpiTrax has been "a gateway for education and sets the interview process so patients get better care," says Begay. Through EpiTrax, Begay sees the cases for communicable diseases, such as sexually transmitted infections (STIs), tuberculosis (TB) or COVID-19, and can then assign the case to a UNHS nurse. Begay says "The nurse accepts the case, facilitates the investigation and educates the person in the community on how to get on a better track to health."

Begay also participates in the Utah Indian Health Advisory Board, hosted by DHHS. It's a forum for discussing changes to Medicare or other health laws and for discussing successes and challenges among tribes. In addition, Begay participates in a monthly touchpoint meeting for situational awareness of the infectious disease landscape in the state.

Begay says, "The state of Utah has been an excellent partner for education, grants, vaccines and personal protective equipment (PPE), among other things. So they've been listening to our needs, and have really looked out for any kind of federal dollars that would benefit our tribe or the tribes in Utah."


A solar groundbreaking event with the Ute tribe in Utah.
Photo credit: Nicole Yerkes

UNHS has many different governmental partners, from the state of Utah to federal institutions such as the IHS. UNHS works with IHS to refer patients when they need higher levels of care. When tribal members need to leave the reservation for specialized levels of care, such as oncology or cardiovascular care, "UNHS partners with IHS facilities to get these individuals the best care they can receive," says Begay. Additionally, UNHS and IHS worked together during the pandemic for resources, including education, PPE and coordination of care.

For a local-tribe relationship, Benge says the TriCounty area is making an effort to work more directly with the local Uintah-Ouray tribe. Their Board of Health recently amended their bylaws to create a seat on the Board of Health for a tribal representative. An issue that may come up, says Benge, is that people may not feel empowered to speak for the entire tribe. "That's really the issue that you face, making sure that you're connecting with somebody that is empowered, or they feel like they can speak for the tribe or make a decision. And that's where the real effort has to come in building personal relationships and being able to rely on each other."

Benge continues, "When you talk about tribes and reservations, we're really a shared community. We shop at the same stores; we go to the same gas stations; we go to the same schools. And that distinction of tribal or 'I live on-reservation or off-reservation' isn't in the forefront of many people's day-to-day lives."

Begay says there's truth in that statement, but also says the perspective can change when living on a reservation. "We shop at the same stores, we go to the same gas stations, that is true. We're able to see people who we associate with every single day. And when COVID hit us, it really did do a number to us [the Navajo Nation]. And so people that we used to see at the gas station, at the schools, at the stores, we didn't see around anymore, because a lot of them might have been sick from COVID, a lot of them might have perished from the disease."

During the COVID-19 pandemic, Begay says talking to people about how to protect themselves, especially the elderly, created a challenging reservation-specific issue. It required communicating the dangers of COVID-19

from English into Navajo. “There are really no words in Navajo that describe COVID. You just talk about a deadly cough. And so that [communications] issue, more or less, was applicable to the people that we served in the tribe.”

He continues: “So I think the mindset is different off the reservation and those living on the reservation. It just depends on your perspective.”

Clinical partnerships

Critical local partnerships are with hospitals’ infection preventionists and clinicians.

For Benge, critical partnerships at the local level are with local hospitals’ infection preventionists and clinicians. His team meets regularly with them to ensure information is captured correctly in EpiTrax. “For example, unbeknown to us, a hospital might change a billing code for a lab test, and that could sometimes break things at some level along the way. So we will have a coordination meeting with our local infection preventionists at the hospital, to double-check that we are seeing the same things.” He says they also connect with school nurses and local physicians to talk about what they’re seeing and if they have any concerns about illnesses in the community.

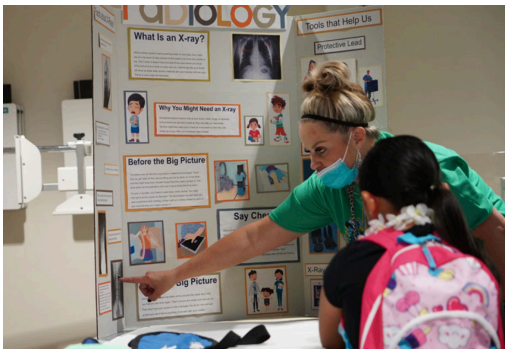
They strive for monthly touch-bases, but Benge notes the people who do disease investigations are touching base more frequently because sometimes they need additional information. He gives an example of a case of chlamydia or gonorrhea entering the system without a complete record, such as a missing phone number or invalid address. “Our disease investigator will call the infection preventionist that day to say, ‘Hey, what’s going on?’ It’s those personal connections and the trust that you build with those partners that makes the job better, quicker, faster, and helps us be able to solve issues quickly and easily.”

Working with different perspectives

Local health departments are interacting with the state, tribes, hospitals, clinics and the public at large. “Each relationship is a little bit different, but we’re all the same in the sense that everybody wants healthy communities. So we all start with that same premise; we’re all working toward improving health. But there is a nuance, I think, with understanding each and everybody’s roles in how they relay,” says Benge.

Benge continues, “For example, when working with a tribe, the tribe really wants to protect the health of their communities and the health of the people that live and work in their area or on the reservation or off the reservation. But the tribe is free to work directly with the state, they’re free to work with IHS or the feds or they’re free to work with us.

UNHS employs doctors, pharmacists, dentists and other medical staff, alongside traditional practitioners. These practitioners, or medicine men, might perform ceremonies before a patient undergoes treatment to put the patient at ease. “That sets us apart from health facilities off the reservation, that we recognize who our clientele is,” says Begay.



A radiology technician explains the use of X-rays during the UNHS Annual Teddy Bear Picnic. Photo credit: Utah Navajo Health System (UNHS)

Kirk Benge and Nicole Yerkes at the Healthy Communities Roadshow. Photo credit: Nick Sokoloff

And at the end of the day, they're going to work better with us if we build a solid relationship where they trust that what we are going to do is in the best interest of our community."

Listen first to understand what is important to tribes.

One way that health departments can build relationships with tribes is to "be respectful of traditional practices," says Begay. He advises listening first to understand what is important to tribes. "I think people have this understanding just to come in and do good. However, do they really take time to listen to the landscape of the people there? Or is it because Western medicine is the best, we have the answers? For some people, that could be the case, but for others, we've had ancestors who've lived here far beyond the settlers and some [of their descendants] practice traditional ways of healing. First and foremost, be respectful of the tradition of who it is that you're trying to serve or help."

Yerkes says having a shared data modernization strategy with so many different partners and perspectives can be challenging, but "we're really fortunate because we have a lot of people who are very excited about data modernization and want to be involved and see it succeed ... it's just been a matter of getting everyone to the table and deciding our strategy, our vision and what we're going to prioritize … making sure that everyone's voice is being heard." She adds it can be easy for the better-funded, higher-capacity organizations to take over and really push forward their priorities but it's important to "make sure that what we're doing is something that's for our entire public health system in Utah."

Yerkes says, "So a lot of different things go into consideration when we're working with these different parts of our public health system and how we're able to meet all of the needs as a unit. There are similarities in issues that have come up when it comes to data modernization, namely with data sharing. Some of the data sharing access issues that local health departments have been having, our tribes are having the same issues."

Technical priorities

On the technical side, a challenge can be working with different priorities. Rachelle Boulton, Health Informatics Program Manager, gives the example of a recent measles outbreak that was centralized in one local health jurisdiction. "There were some enhancements to EpiTrax that were totally doable and would help them to manage that outbreak. The challenge is nobody else needed that at the moment, right?"

Rachelle Boulton

She says her team tries to be strategic when responding to local health departments, such as adding enhancements that would be valuable to other situations in the future. A challenge is how much time and energy to devote to these kinds of changes: "We have to make the decision whether we pull people out of the work that they're currently doing, delay timelines, those sorts of things to reprioritize and get those things done. We want to meet those needs though, because if we really focus on centralized systems, it does take some power and control away from some of the local groups."

She adds: "And if we can't immediately address their needs, it does dilute the value to them. It's challenging and it's difficult to find that right place and that right balance with addressing everybody's needs, often we can't address them all at the same time."

One public health together

Yerkes says, "Data modernization in a public health sphere is unique because it's people first ... we're utilizing these systems and data, but it's for people." She adds that collaboration is important. "It's everyone working together to improve a system so that we all have better health outcomes and better access."

Boulton agrees, and says the mindset around partnerships should change. "Rooted in some core principles, we are shifting from the state-centric mindset that local health departments and the tribes are secondary partners. They are public health along

"[Local health departments and tribes] are public health along with the state health department."

with the state health department. They're not our customers. They're not a partner who sometimes participates—we are all public health altogether. And so they really do need to be at that table. They need to be assisting us [the state] with prioritization, with defining features or tools, and evaluation."

Going forward, Yerkes says funding and capacity have to be priorities. "And how can we leverage those that have more to lift up our smaller jurisdictions? We're only going to be able to move forward with everyone being there." Despite all the work at building partnerships, she recognizes there are areas where they need to know more about what's happening. "If it's a black void, then we can't address it. We need to ensure that everyone has a seat at the table."

Key takeaways

- Each level of public health in Utah—state, local and tribal—brings unique perspectives, priorities and complexity to data sharing.
- EpiTrax, Utah's disease surveillance system, has helped create a smooth relationship between the state and the 13 local health departments in Utah (representing 29 counties) and six tribal public health agencies that use it.
- Collaborative forums such as the Data Modernization Initiative (DMI) Council and the Utah Indian Health Advisory Board have helped the state listen to the needs of local and tribal health departments. The IHFS tribal liaison model also creates a direct link between the state and tribes.
- Critical partnerships at the local level are with local hospitals' infection preventionists and clinicians—monthly touch-bases help streamline communications.
- Because of the complexity of where tribal members may get care, data from the usual surveillance systems can't be relied on alone. To get a holistic view of all of Utah's communities, Utah's state, local and tribal health agencies continue to work on building relationships.

References

1. "Utah's open-source surveillance system paves the way for data modernization." Public Health Informatics Institute. https://phii.org/data-modernization-initiative/dmi-stories/utah- /

2. United States Census Bureau. https:https://data.census.gov/table/DECENNIALSF12010.PCT2?q=PCT2:%20AMERICAN%20INDIAN%20AND%20ALASKA%20NATIVE%20ALONE%20WITH%20ONE%20OR%20MORE%20TRIBES%20REPORTED%20FOR%20SELECTED%20TRIBES&g=040XX00US49

3. "Frequently Asked Questions about Native Americans." Office of Tribal Justice, U.S. Department of Justice. https://www.justice.gov/otj/about-native-americans#:~:text=What%20does%20the%20term%20'Federally,%22domestic%20dependent%20nation%22%20status

4. "American Indian/Alaska Native Health and Family Services (IHFS)." Utah Department of Health and Human Services. https://dhhs.utah.gov/ihfs/