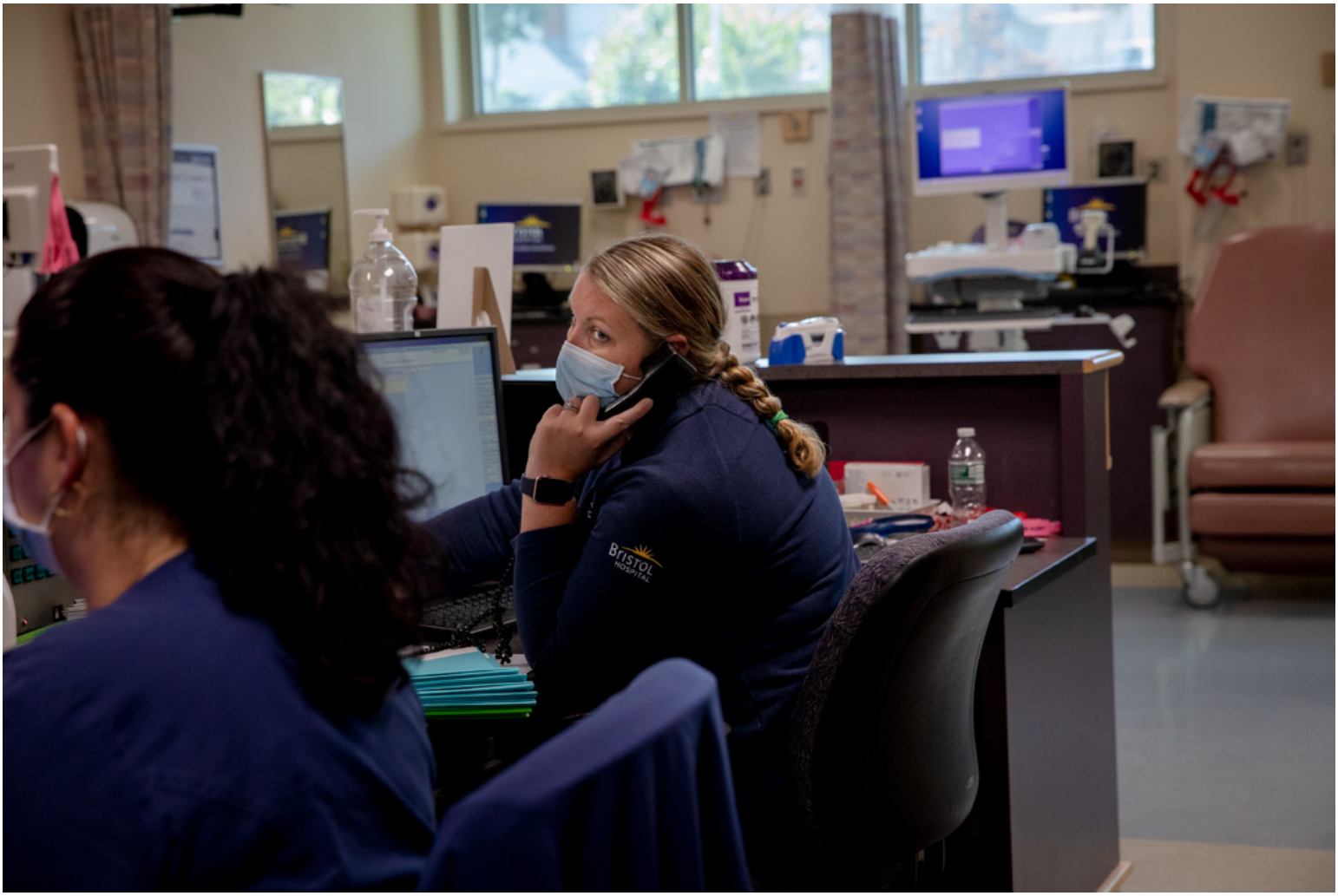


As pandemic wears on, Connecticut prepares to launch its long-awaited health information exchange

Kristin Levine, a registered nurse, calls a patient from Bristol Hospital. Connecticut is one of the few states that don't have a broad health information exchange, a singular place where every practitioner involved in a patient's care can access medical records. Connecticut is preparing to launch one this fall. | photo by: Yehyun Kim :: ctmirror.org

COVID-19, HEALTH :: **by JENNA CARLESSO** | **OCTOBER 15, 2020**

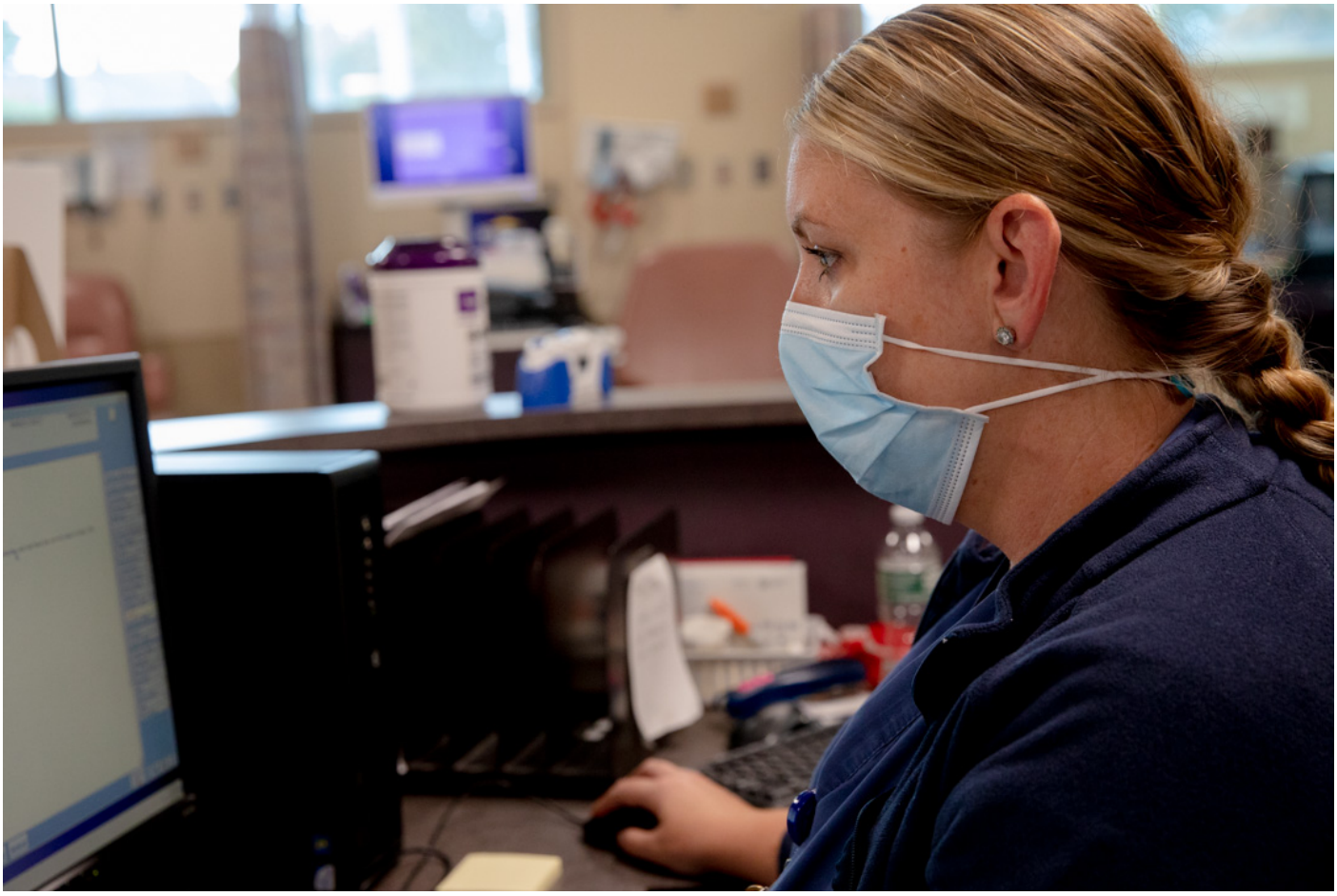
This fall, after more than a decade of false starts, shifting plans and millions of dollars spent, Connecticut will launch its statewide health information exchange, a single repository of medical data that can be accessed by any provider involved in a patient's care.

The long-anticipated system is arriving at a critical time: the need for up-to-the-minute, robust patient information has become more pressing as COVID-19 continues its grisly march through the state. The exchange is designed to reduce duplicative services, prevent medical errors and improve care.

But even as the move is regarded as an important step forward, leaders of the most recent push to form the network have been frustrated with the pace of progress. Three previous attempts collapsed in failure, leaving Connecticut without an all-inclusive data sharing system when the pandemic hit last winter.

Meanwhile, other states have used their information exchanges, known as HIEs, to trace outbreaks in nursing homes, to identify COVID-19 hotspots in communities, to analyze data on race and ethnicity and to help agencies, like public health departments and regional health districts, access more extensive patient information in the midst of an emergency.

“I just wonder how many people could have been saved, had we had this up and running,” said Allan Hackney, Connecticut’s health information technology officer, who is in charge of the latest effort to create an HIE here. “How many health care workers could have avoided burnout if we had this data? I get very frustrated.”



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Levine checks a patient’s information before calling to confirm an appointment.

During a medical seminar over the summer, Hackney watched as his counterparts in Rhode Island and Maine dazzled with demonstrations of real-time COVID-19 data.

“They were showing live graphs of information on what’s happening with COVID in counties and towns, by zip code, by age,” he recalled. “Then we get to Connecticut – and yes, we have some reporting we’re pretty happy with – but the data is coming in whenever it comes in, and the robustness of it is not even in the ballpark of what I saw from Maine and Rhode Island. They’ve had HIEs for a long, long time.”

The exchange will allow health practitioners to get fuller patient medical histories. If a woman receives a coronavirus test at a physician's office in New Haven and walks into an emergency room in Putnam a week later, the hospital doctors could view her results, along with any underlying conditions she may have. The system gathers data from physician practices, laboratories, hospitals, radiology offices and community organizations, giving providers a comprehensive look at a patient's background.

> *I just wonder how many people could have been saved, had we had this up and running."*
>
> — Allan Hackney, state health information technology officer

Information about immunizations and advanced directives, which have taken on fresh significance during the pandemic, are also expected to be included in Connecticut's HIE.

"We've had to piece together public data, private data, data from the Connecticut Hospital Association, and other information to understand what's going on," said Max Reiss, a spokesman for Gov. Ned Lamont. "Tools like this prevent that time from being wasted. It would have been easier … to have something like this in place seven months ago."

Since coronavirus took hold in the state, Hackney has pondered how things might have been different if officials had managed to get the system online sooner. More than 4,500 people have died of COVID-19 here.

The network is expected to launch in November.

"Connecticut would have been in a lot better place if we had an operating HIE," Hackney said. "It kills me that we're in this situation."

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Allan Hackney, Connecticut's health information technology officer, poses for a portrait. Hackney is in charge of overseeing efforts to build and launch the statewide health information exchange.

'We were made for a time like this'

Connecticut is one of the last states in the nation to launch a broad health information exchange.

Some states have a single network that serves all residents. Others, like Texas and California, have several regional HIEs that cover different pockets of the state. And a handful have started the networks but run into problems, forcing them to dissolve the systems and start over.

With the ability to aggregate data, HIEs have played a key role in disaster response efforts during floods, fires and hurricanes. Since COVID-19 moved into the country, the systems are being used to support contact tracing, track trends and direct resources.

"There's one example in Oklahoma, where by looking at zip code data, they were able to identify a particular nursing home where there was an outbreak. And by working with the nursing home, they identified the person who brought COVID-19 into the home," said Tom Reavis, a spokesman for the Strategic Health Information Exchange Collaborative, a trade association representing about 80 HIEs nationwide. "They gave valuable information for public health."

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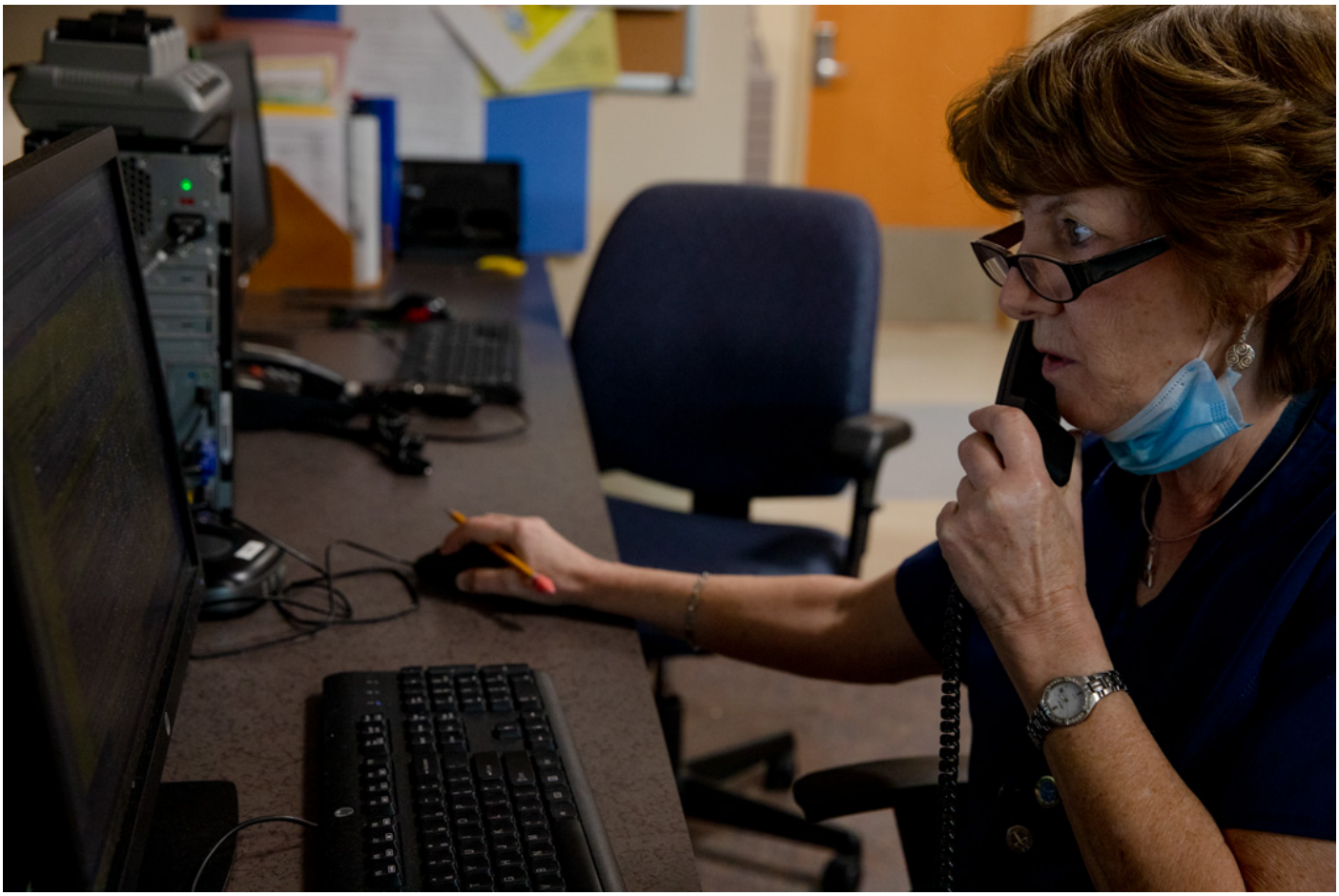
>
> — Max Reiss, governor's spokesman

At least three information exchanges – in Nebraska, Pennsylvania and Oklahoma – created dashboards during the pandemic that corral COVID-19 data from across the state into one place.

"A Pennsylvania HIE, KeyHIE, has a dashboard where you literally can see, county by county, hour by hour, what the situation is looking like there," Reavis said.

Indiana's HIE worked with the state and Indiana University to form a new initiative that shares information on social determinants of health, such as food access and housing stability, with researchers and health care providers who are dealing with COVID-19.

An HIE in Tallahassee, Fla., developed a system allowing practitioners to view medical records from health plans, hospitals, urgent clinics, public health departments and other entities across the state.



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Laurie Grady, a registered nurse, talks to a patient from Bristol Hospital.

In Delaware, which launched the country's first statewide health information exchange in 2007, HIE officials are working with state agencies to fill in gaps in patient data.

"When somebody has gone to, let's say, one of these pop-up testing sites at a Walgreens or some other location, they don't always fill out their information clearly," said Randall Farmer, chief operating officer of the Delaware Health Information Network. "They don't always include all the information that would be helpful from a public health standpoint. So our governor's office came to us and asked: Can you guys help enrich some of this missing information?"

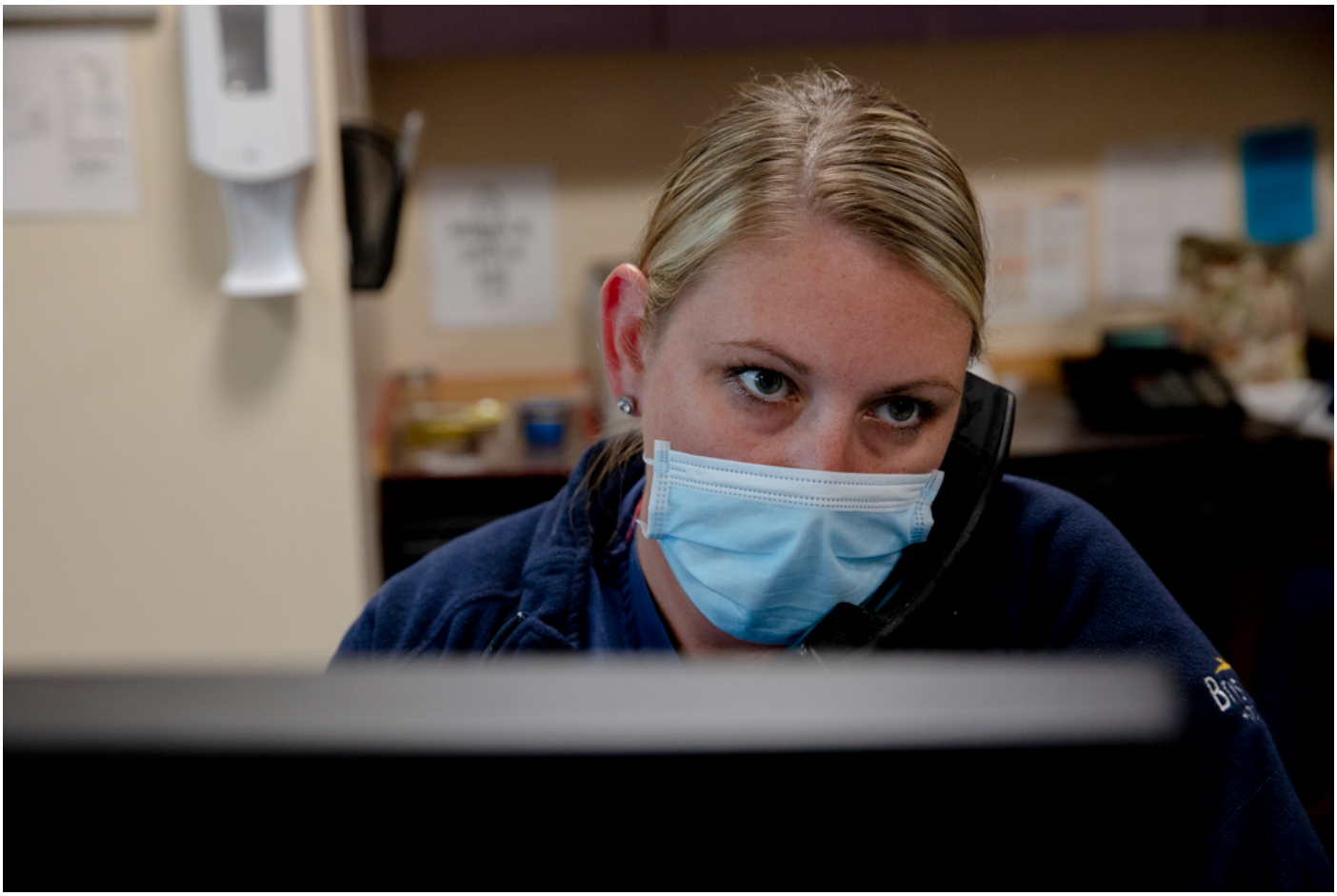
"If somebody forgot to put in their ethnicity, and we have that information from a previous record on a patient, we're able to enrich that so the state can see if there's a disparate impact on a particular community," he said.

Nevada's HIE has a similar strategy with some of the regional health districts. The districts gather information on reportable diseases and conduct syndromic surveillance, a method of analyzing data to detect or anticipate an outbreak.

“When the pandemic hit, they realized they didn’t have much information on the COVID-positive patients and what their comorbidities and other issues were,” said Michael Gagnon, executive director of HealtHIE Nevada, a nonprofit organization that runs the statewide health information exchange.“So they were having a hard time figuring out, did this person really die of COVID? Or did COVID just exacerbate something else, but they died of a heart attack?”

The HIE helped supplement hospital data that the health districts already obtained with information from a patient’s primary care physician, lab results and other records.

“They were thrilled, because they didn’t have this kind of clinical information on their patients to do statistical monitoring and all their analytics,” Gagnon said. “They were flying blind a little bit.”



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Levine talks to a patient. Proponents of Connecticut’s HIE say it could have saved more lives and helped prevent health worker burnout during the first seven months of the pandemic.

Having robust patient data has been crucial. Since the pandemic began, several HIEs are coordinating directly with public health officials, providers and laboratories to boost awareness of cases and community transmission. They are also analyzing patient information to track the disease’s progression.

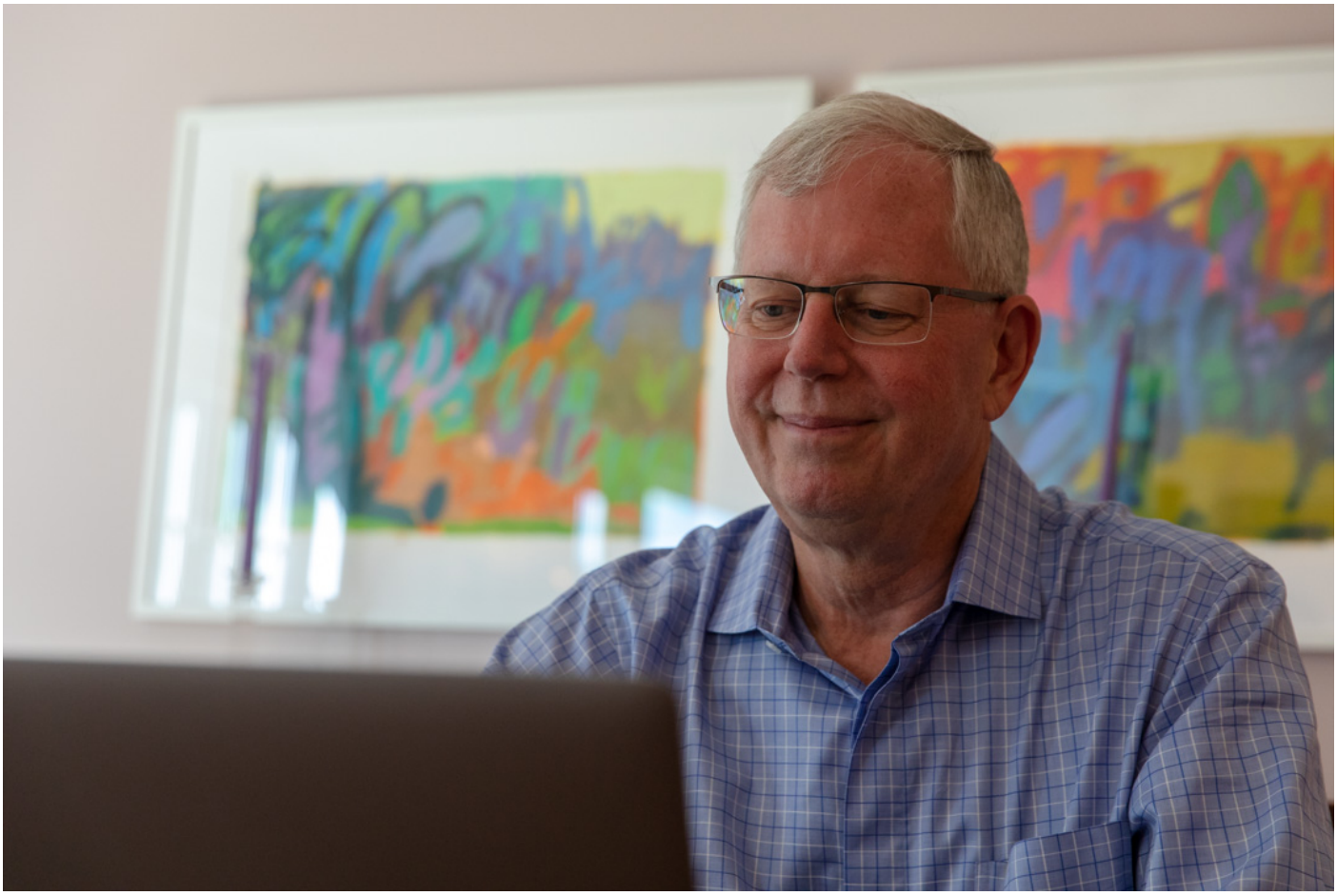
“Right now, in public health reporting, it’s episodic data – how many COVID tests were done, how many positive results came back, how many people are staying in ICU beds. But it’s not patient-identified information, so it doesn’t give you any sense of trajectory,” said Dr. Donald Rucker, national coordinator for health information technology. “You’re not able to see

how patients do over a time span – what's the amount of time between somebody testing positive and then developing some immunity, what's the rate that people get re-infected, or what's the time course of going from a nursing home to a hospital. For that, you need to be able – in a privacy-protected way – to follow patients over time."

Longitudinal health records – patients' medical records spanning the course of their lifetimes – that are included in HIEs make analyzing those developments easier.

Swift access to patient information also reduces the burden on the provider. It can be time consuming for a specialist, for example, to track down X-rays, lab results or records of an emergency room visit from practitioners in different networks. HIEs have helped cut through some of those cumbersome steps – an especially useful tool during a public health emergency.

"This is the power of HIEs. We were made for a time like this," said Kelly Hoover Thompson, chief executive officer of the Strategic Health Information Exchange Collaborative. "I've been watching Connecticut for a while, and there's such a missed opportunity there."



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Hackney participates in an online meeting while working from home.

Preparing to launch

Before its latest effort, Connecticut made three unsuccessful attempts to form a statewide health information exchange.

The first bid started in 2007 with a plan to build a network for Medicaid patients. But most physicians had not yet switched to electronic health records, so the state's medical professionals weren't ready for it.

A second attempt in 2011 – through the Department of Public Health and a quasi-public group called the Health Information Technology Exchange CT (HITE-CT) – got off to a stronger start but was mired in a legal battle and later folded. HITE-CT had developed no means of generating income and no one was interested in the product it contracted with an outside vendor to create. The vendor filed claims for millions in unpaid invoices and sued for non-compliance of the contract. HITE-CT dissolved in 2014, but the state was still responsible for paying off more than $7 million it owed on a loan.

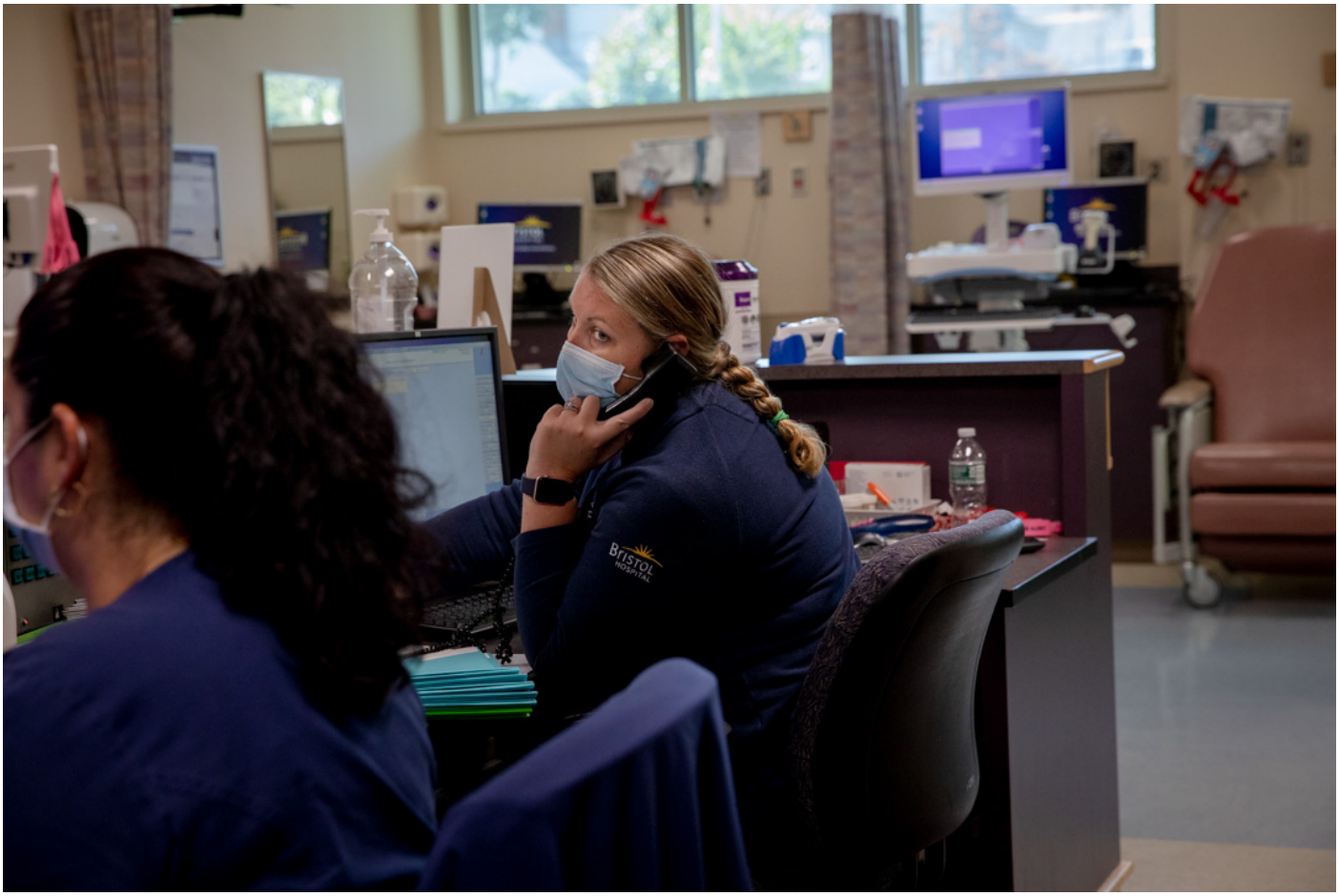
The third venture was overseen by the Department of Social Services and lasted 10 months, beginning in 2016. That effort also centered on Medicaid-based initiatives, while larger plans for a statewide HIE were left for those who spearheaded the fourth – and most recent – attempt in 2017. That was when Hackney, Connecticut's health information technology officer, started his work.

> *"I've been watching Connecticut for a while, and there's such a missed opportunity there."*
>
> **— Kelly Hoover Thompson, CEO Strategic Health Information Exchange Collaborative**

But before Hackney even began, the state had spent at least $18 million on projects that failed to produce an HIE. For the last three years, Hackney has focused on engaging stakeholders and the public, working with an advisory group and tackling priorities one at a time. The latest effort is being overseen by the nonprofit Health Information Alliance.

In May, Connecticut's exchange, named Connie, signed its first client – CTHealthLink – a network run by the Connecticut State Medical Society that serves a series of physician practices. Legal agreements with other health systems are in the works. Hackney originally had envisioned going live in March or April, but the pandemic caused delays.

With so many different health networks already operating their own electronic records systems, bringing everyone together is expected to take time. The larger networks, like Hartford HealthCare and Yale New Haven Health, will pull in many practices and patients at once. But some systems are more complicated. One physician network in Connecticut runs more than 50 different electronic medical records systems across 200 doctors' offices. Integrating those is trickier, Hackney said.



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Connecticut is one of the few states that still don't have a broad health information exchange, a singular place where every practitioner involved in a patient's care can access medical records.

Health care practitioners are required to participate in the HIE. By law, hospitals and laboratories have one year to sign up once the exchange is deemed operational. Other providers have two years. The state has set up a secure email system so medical personnel who don't have access to the right technology can communicate with the HIE until the infrastructure is in place. Funding is available for providers who need help connecting to the exchange.

Hackney said it could take two to three years to get everyone fully on board.

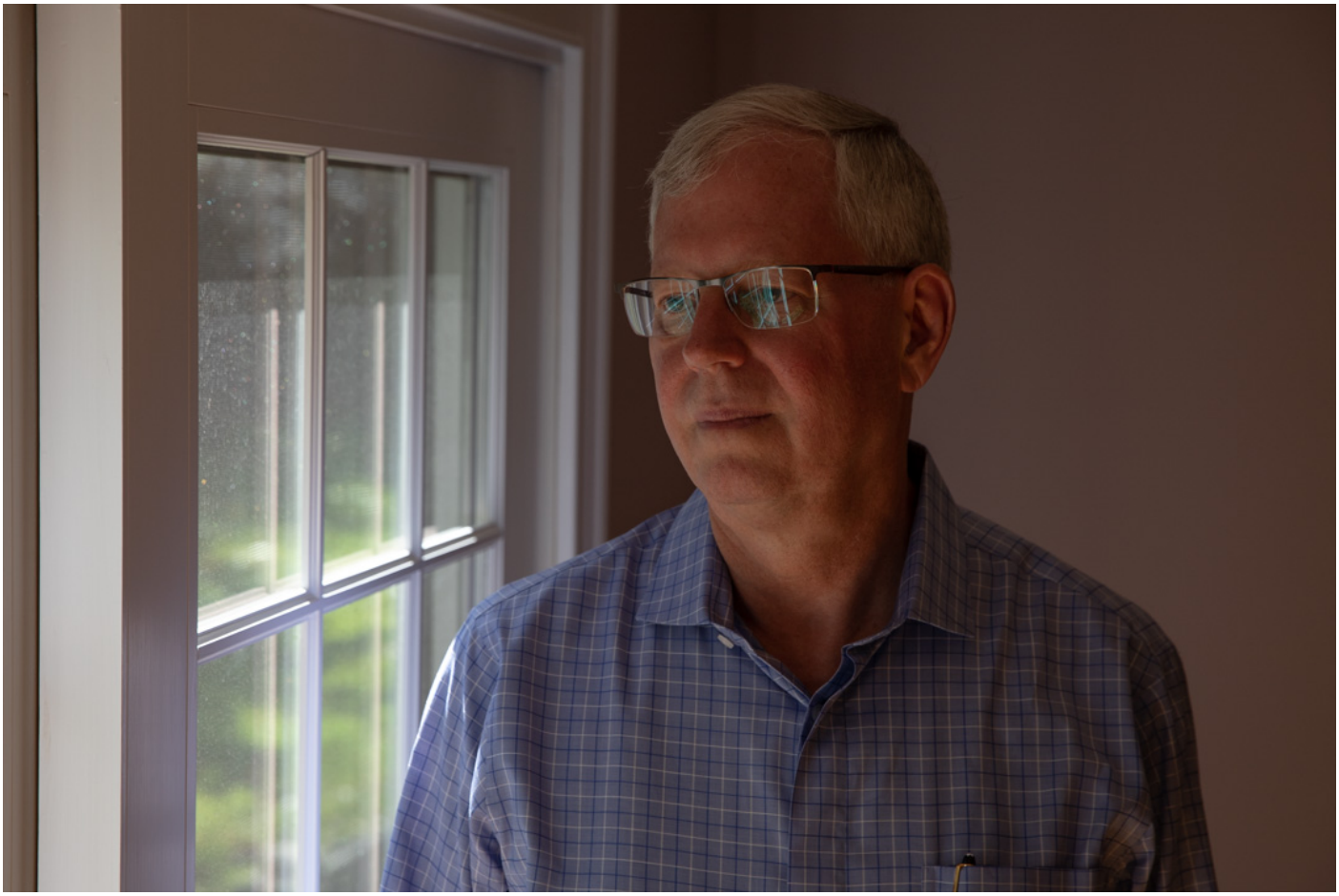
About $48 million has been set aside for the project, with 10% of that covered by the state and federal funds making up the rest. Officials estimated that just over $20 million has been spent so far. HIE organizers are required to use the remainder of the federal money by September 2021.

Hackney and others must come up with a way to sustain the system beyond next year. Along with additional federal support, they expect to pursue private sector contributions.

The state is still crafting rules about privacy. Many HIEs have a so-called "opt-out" system, meaning patient data will be shared across the network unless a patient opts out. Only a handful of HIEs still have an "opt-in" system, in which data can't be shared unless a patient consents. Leaders of health information exchanges say the opt-in policies are time consuming and unnecessary, since 95% or more of patients in those states end up opting in.

Hackney said Connecticut's Office of Health Strategy is working on a policy that would follow the opt-out system. It will be subject to a regulatory process.

As the launch approaches, several providers said they are looking forward to the broader exchange of information.



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"Connecticut would have been in a lot better place if we had an operating HIE," Hackney said. "It kills me that we're in this situation."

John Brady, vice president and chief financial officer for the Connecticut Hospital Association, said the state's acute care hospitals already have been coordinating with one another to share resources and report information daily during the pandemic, but the HIE will allow more providers to access patient data.

The association has its own electronic records system, PatientPing, which provides notifications of where a patient has been seen and what the primary diagnosis was at the time. But the system lacks complete provider notes, tests and labs, and doesn't communicate with all medical providers in the state.

"There is robust data exchange and sharing capabilities on the part of hospitals in Connecticut already," Brady said. "We think the HIE can and should focus on getting the providers connected who are not currently involved or who don't have the ability to exchange data. That will help facilitate telehealth and coordinate care."

The HIE is also expected to assist state agencies in pinpointing hotspots across zip codes and neighborhoods.

"Right now with the pandemic, we are working with the Department of Public Health to look at where the hotspots are according to the data they collect," said Kimberly Martone, deputy director of the Office of Health Strategy. "But the data is very limited. When we look at the number of hospital beds in a certain area, we're able to see increases in the average length of stay, along with discharge data. But ideally, you want to be able to look at the specific populations in an area and the needs of that population. What diseases – especially chronic diseases – are in that area that we could address?"

In the early days of the most recent push to form an HIE, organizers were met with resistance and frustration. Years of failure around the initiative had fueled deep skepticism among some providers.

Part of the project's success was winning back that support, Hackney said.

"When I think back to where I started, we went to do outreach and it was, 'What the heck is the state doing? Why did you let this stuff linger?' People were angry," he said. "Now they have come around. They're motivated. They want this thing to work."

Jenna Carlesso is CT Mirror's Health Reporter, focusing on health access, affordability, quality, equity and disparities, social determinants of health, health system planning, infrastructure, processes, information systems, and other health policy. Before joining CT Mirror Jenna was a reporter at The Hartford Courant for 10 years, where she consistently won statewide and regional awards. Jenna has a Master of Science degree in Interactive Media from Quinnipiac University and a Bachelor or Arts degree in Journalism from Grand Valley State University.

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