



After the Fact | The Invisible System Keeping Us Healthy

Originally aired Oct. 9, 2026

Total runtime: 00:16:48

TRANSCRIPT

Benny Martinez, host, “After the Fact” podcast: Hey, everyone. Welcome to “After the Fact.” For The Pew Charitable Trusts, I’m Benny Martinez.

Gabriela Domenzain, host, “After the Fact” podcast: And I’m Gabriela Domenzain.

Benny Martinez: So, Gabi, I’m reluctant to start this conversation because I know what the episode’s about, but what’s on the menu?

Gabriela Domenzain: So do you remember this past summer when we all were afraid of eating salads and produce because of the stomach issues it would cause?

Benny Martinez: I can’t forget that. My wife is a very salad-friendly eater, and she had to alter her diet altogether.

Gabriela Domenzain: What we were watching was a cyclospora outbreak. And what you didn’t know at the time was our public health data system was at work. And so, the better the system is, the more it protects everyone. But like any system, there are things that can be improved or updated.

Benny Martinez: Like what?

Gabriela Domenzain: So, for example, doctors’ offices log about a billion patients’ visits each year, and those visits generate a ton of data on disease and on treatment. So, during this outbreak, for example, we knew about it because people went to the doctor, and the doctor took tests because they had stomach issues, and they found out that it was cyclospora.

Benny Martinez: “Stomach issues.” Just putting it lightly.



Gabriela Domenzain: And there's a way to use the data that is gathered at doctors' offices better to help save lives and improve health outcomes.

So our team at Pew is working precisely on that. And I sat down with our colleague Maggie Arnesen, who works on Pew's public health data improvement team, to learn more about it.

Benny Martinez: I'm looking forward to that conversation, I think. But let's see what Maggie has to say.

Gabriela Domenzain: Maggie, welcome to "After the Fact." Thanks for being with us.

Margaret "Maggie" Arnesen, senior officer, public health data improvement project, The Pew Charitable Trusts: Thanks for having me.

Gabriela Domenzain: When I think of public health data, had you asked me six years ago, it would've been different. But now I think of stomach issues. Can you tell me what happened this summer that has to do with public health data collection and why we should care?

Maggie Arnesen: So we've been calling this "public health summer." So, we're recording this in August, and cyclosporiasis has been the buzzword this summer. So, since May, CDC's been reporting over 17,000 cases across the country of this foodborne parasite that is impacting people all over the place.

Gabriela Domenzain: So there's over 17,000 cases. And what's interesting is that we know this because specifically of the work that you do, right? So let's talk about public health data reporting. Why is it important? What is it?

Maggie Arnesen: So public health data reporting comes primarily from healthcare information.

So, when you go to the doctor, the doctor takes all your information, puts it in an electronic health record, and certain pieces of that information may be reportable to the public health authorities, so we call those reportable conditions.

Gabriela Domenzain: What makes a condition a reportable condition?

Maggie Arnesen: Some of these are pretty rare, you hope you don't see them, right? Like plague, tuberculosis, other things that are more common, COVID, RSV, norovirus, chickenpox. There's a whole list, but every state sets its own reportable



conditions list. And states have the legal authority to decide what is reported, who reports it—obviously, mostly healthcare. Sometimes it's childcare. Sometimes it's people who run hotels, people who work in transportation.

And if you are diagnosed or suspected with a reportable condition like cyclosporiasis, your doctor is going to notify the health department.

How this works in its full scope is the doctor's like, "Oh my gosh, I think that you may have a reportable condition." And they send you out for lab testing. And when that lab test comes back positive, that test gets reported to the health department, and then you become an official case. And so, once that case is created, either the state or local public health authorities start that case investigation.

That's a concept we're familiar with from COVID, trying to track down the individual, who they've been around, who may be exposed, trying to pinpoint the location or the cause.

Gabriela Domenzain: And some people might be worried about privacy issues, no? When you go to a doctor, you're expecting everything to be confidential, so how is that dealt with?

Maggie Arnesen: Yes. Most people are familiar with HIPAA, right? It's on all those forms you sign at the doctor. And that's set by the federal government, and that's kind of like this baseline that everyone operates under.

But states also have the ability to add their own levels of safeguards around health privacy on top of that, and that can vary from state to state. But each state, based on the concerns of their citizens and who's sharing that data and requesting it, again, can really set their own policy about that, which is great, gives them a lot of flexibility. It can also make exchanging data to another state or exchanging data from the state to the locals a little more difficult. So we do see barriers in how those policies may mismatch or hinder the exchange of information from other parties working in the health ecosystem.

Gabriela Domenzain: But they err on the side of privacy?

Maggie Arnesen: They do.

Gabriela Domenzain: Let's talk a little bit about when this all began. When did this all begin? When did we start sharing data?



Maggie Arnesen: So I know COVID is really when people started paying attention, but this has been going on since the 1870s, right? We're talking 150 years of health data collection. In the 1870s, doctors were mailing postcards to report information.

Gabriela Domenzain: Wow.

Maggie Arnesen: So this is a very long tradition. This is a very loaded phrase that gets debated in public health circles, but a lot of people say that when public health is working, no one pays attention. And when it's in the news, it's because there's a big crisis, but that doesn't mean it hasn't been working. In fact, it has been working because people aren't worried about what they're eating traditionally. They're not worried about is it safe to go in public? This, that, and the other thing.

Gabriela Domenzain: One of our incredible producers here, Julia, found a stat that 80% of the Centers for Disease Control [and Prevention]'s funding goes toward supporting state and local public health efforts. How does the mechanism work?

Maggie Arnesen: Essentially states have the legal ability to compel information to be reported to the state.

The federal government really doesn't have that. What the federal government does is they expend a huge amount of money, like you said, 80% of the budget, to support state and local health departments to conduct public health activities. Through that funding, they're able to incentivize states to share information, but legally, states are the ones that have the authority to compel the information and then states voluntarily share that with the federal government, with the CDC.

Gabriela Domenzain: So is there a major database somewhere? If I'm in Louisiana, and I get cyclosporiasis in Louisiana, how does it get communicated so that it's a macro number?

Maggie Arnesen: There's going to be a lot of variation here, but essentially each state kind of houses the data themselves, right? That data is then shared, or uploaded, to the federal government. And they are able to do big analysis, right? They're able to say, "Pennsylvania's rates are this," or "Utah's rates are this." And that's really critical in helping states see where they are compared to other states. So again, CDC gets this aggregate data, big buckets of anonymous data. States are the ones that kind of hold their residents' data.

Gabriela Domenzain: We've talked a lot about communicable diseases, but public health data encompasses way more categories. Talk to us a little bit about what other conditions we track.



Maggie Arnesen: Here at Pew, like on our project, we really have focused on these reportable conditions, which are generally infectious diseases. But public health has evolved over time. Now we talk about social determinants of health, now it's not just like, "Do you have measles?" It's we know where you live, where you work, your level of education, have you interacted with the criminal justice system—all of these different things impact your health, and in aggregate, they impact public health.

Gabriela Domenzain: Interesting.

Maggie Arnesen: And so, all these different kind of programs are generating data. That data already exists within government. And states are starting to really bring these different data streams together and say, "We actually have criminal justice information. We have social services. We have housing information. We have veteran status. We can start to aggregate this information and really start to drill down. We're realizing that this population who have experienced these factors are more likely to suffer from these conditions."

And then you can start to target those populations. You can be more effective with your interventions. You can identify who needs it and what will actually help. And if it's not working, you can see that too, and that's just as critical, right?

When states are facing, especially now, real resource constraints, being able to leverage data that already exists within government is more critical than ever. With these technological advancements, it's more possible than ever also.

Gabriela Domenzain: Talk to me about the challenges of gathering the data, making sure it's correct. Just a little bit about those challenges you're facing.

Maggie Arnesen: How many times are you in the doctor's office and they're faxing your information around, right? Fax is still the currency of health exchange.

Gabriela Domenzain: Wow.

Maggie Arnesen: Which is crazy. It's crazy, right?

Gabriela Domenzain: It's crazy. It's not digital?

Maggie Arnesen: Not completely.

Gabriela Domenzain: Wow.



Maggie Arnesen: We see that in current state policy, is that the acceptable methods of reporting are still these really manual methods.

Gabriela Domenzain: Wow.

Maggie Arnesen: So we know policy tends to lag practice. And so it tends to lag behind the technological advancements in the healthcare sector.

So when you're doing this manual reporting, right? When I'm filling out this form to say, "Oh, I think Maggie has this," right? And I'm filling this out by hand, and I'm in a hurry because I have a stack of these to do, and I'm the doctor, and I'm just trying to get to my next patient. And I get a phone number wrong, or I forgot to ask you your ethnicity, and I'm just going to make a guess based on what I think, or I don't actually have your address.

And then your office admin is like, "OK, well, I'm going to have, like, 30 more of these by the end of the day, so I'm just going to put them on a pile. Maybe I'll get to them by the end of the day. But maybe it'll be tomorrow. Oh, it's Friday afternoon, now we're not giving it to the health department until Monday, and I'm just going to send over this huge batch."

So, we're just seeing all these lags in the system, and it's not anyone's fault. People are busy.

Maggie Arnesen: But now laboratory reporting started to move towards more automation about 20 years ago. Generally, most big labs, you come in, they get an electronic order from the doctor, they run it through the system, they run the tests, and the result, positive or negative, is in an actual electronic system. And then that is generally electronically sent to the health department.

Gabriela Domenzain: OK.

Maggie Arnesen: Which is great. That was a massive innovation. And so states really heavily relied on labs to generate a lot of this public health data. They still do.

Right before COVID, a couple states were starting to pilot electronic case reporting. The lab is like, "Here's your name, here's your address, yes or no?" Making it easier for doctors to also report this information electronically, instead of filling out that form. Huge benefits for everyone, right?

Gabriela Domenzain: My parents were doctors. If anything that had to do with accuracy depended on reading their handwriting.



Maggie Arnesen: That's another thing! 100%, 100%. And we've done focus groups with doctors who say, "I like doing a voice recorder. I don't even want to have to write stuff out by hand." And again, it relieves the burden from providers to do what they're supposed to be doing, which is talk to you.

Unfortunately, this technology's expensive, right? It takes commitment for health systems, for hospitals, and now smaller providers to have electronic systems that can interface with the state. And so now we're seeing this challenge where everyone knows it's better, but the resource cost for small providers, for healthcare settings that are already under-resourced, it's very difficult to make that transition.

Gabriela Domenzain: Going back to the cyclosporiasis and COVID, Maggie, is the reason why we knew that these diseases were out there because of public health data reporting?

Maggie Arnesen: Yes. But if you don't have a condition, you may have language like, "Oh, you have unusual symptoms" or whatever, but you're relying on a provider to know that's reportable.

There are a lot of tools out there for doing what we see as passive data collection. We've talked about the specificity of your ZIP code, your contact information, for individual data. But population data is also critical, and so wastewater surveillance really started under COVID. It's being used in cyclosporiasis now, to kind of monitor infection levels in a community to see if they're increasing or not. It doesn't require anyone to report. It's anonymous information. Obviously, you have to belong to a municipal sewer system, so rural folks are left out of that equation.

But that's a really good way to kind of collect information. Another way is syndromic surveillance, which is anonymous data generated through folks who go to the emergency room.

Gabriela Domenzain: Now the phrase surveillance might sound scary, but it's a pretty straightforward public health tool. It helps medical experts more quickly identify an illness that is making a lot of people sick. And the sooner health officials know a potential outbreak is happening, the sooner they can do something about it.

Maggie Arnesen: Syndromic surveillance started after 9/11, really, when everyone was very concerned about bioterrorism. But syndromic surveillance is now used for heat-related incidents, climate change incidents, that allows the department to go through and look for just outliers. There's a lot of flexibility that states can use in these huge raw datasets to intervene early.



Gabriela Domenzain: So, Maggie, what concrete examples can you share from states that are making improvements in how they report data?

Maggie Arnesen: Some of the states that we worked with in the first phase of our project, we focused on using policy to drive change to electronic reporting. So Colorado made a requirement for labs to report using this electronic laboratory reporting. Utah made a requirement also for labs and became one of the first states to require electronic case reporting from providers, which is, like, a huge achievement.

Now, we also work in research in these topics around health data, and we are really focused on identifying examples of states doing this more innovative data work, recognizing that health exists across a spectrum, leveraging those different administrative datasets the government already houses.

I think one noteworthy one is in Massachusetts. And how this Massachusetts data warehouse came to be is that legislators were like, “We want numbers on this problem.” And the department said, “We got numbers here, and we got numbers here, but not for this problem.” And the legislature said, “Get some numbers.”

And so that was actually leverage for the department to launch this idea that had been percolating for a long time. How to bring in what we call cross-sector data: data from health, data from criminal justice, data from housing, workers’ compensation, all these different government datasets, and be able to really kind of put it together and match people across.

And it took them about 10 years. They started small, and they just kept adding different datasets. And it’s really the standout example of leveraging what already exists.

There were no additional burdens on folks to collect more information, it was just saying, “What can we use that we already have?” And they were able to pinpoint that folks, through workers’ comp, who had suffered a workplace injury were actually at more likelihood for developing substance use disorder later. And that’s so critical to be able to do intervention early.

Gabriela Domenzain: If all the best practices that we’ve talked about were implemented unanimously all around the country, how would that impact public health data?

Maggie Arnesen: There’s a lot of data gaps in these broad health questions. And this is where these advances in technology, we’ve talked about a little earlier for reporting reportable conditions, have a lot of promise for other types of data.



Imagine that for chronic disease. It's, like, the biggest part of the healthcare expenditures in this country. There's not really good data about it because just the amount of information that would need to be generated is just astronomical.

Now, using these kind of technological advancements we've talked about, where a system is automatically like, "Oh, you've been diagnosed with diabetes," and now that's generating an alert saying, "We've had 10 diabetes cases this week."

The potential to actually have accurate real-time information around chronic disease is incredibly promising. So leveraging the infrastructure that has been built for these reportable conditions, and being able to expand that to asthma, to diabetes, to heart disease. And being able to harness real-time data to do interventions early and to see if those interventions are working is just incredibly promising. And it's going to really have the ability to change kind of the public health landscape around data in the future.

Benny Martinez: Gabi, it's so interesting to hear Maggie talk about this because you don't really understand what goes into how, you know, health professionals track disease and really sort of peel back the curtains and see how that's all done.

Gabriela Domenzain: It's like a web, you know? It's a web of information. It depends on state cooperation; it depends on federal help as well. And the ability for a doctor from California's information to mesh with a doctor from Florida. That's this system that we're talking about which makes it possible for all of us to be safer.

Benny Martinez: All right. Thanks, everyone, for listening.

Gabriela Domenzain: And make sure you're subscribed to "After the Fact" wherever you get your podcasts to hear all of our latest episodes.

Benny Martinez: For The Pew Charitable Trusts, I'm Benny Martinez.

Gabriela Domenzain: And I'm Gabriela Domenzain. And this is "After the Fact."