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Years in the making, N.H. immunization registry hits snag during rulemaking

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New Hampshire was supposed to have a functioning vaccine registry by now. Such a system has been in the works, in one form or another, off and on for almost two decades.

Today, it remains the only state in the country without one. The latest attempt to get one up and running has run into opposition on several fronts – from vocal advocates for “vaccine choice” and those who question the extent to which the state plans to maintain records on those who don’t want to participate.

Picking up where an earlier push left off, last spring New Hampshire entered into a contract with an outside company to set up a registry and moved into the rulemaking phase of the project in the fall – to iron out the specifics of how the system would look in practice – with the intention of launching at the beginning of February.

But the discussion to finalize those rules was pushed back several times and, eventually, the New Hampshire Department of Health and Human Services withdrew the rules altogether – largely because of disputes over how people would choose to participate in the system and how their decisions would be recorded.

The department is looking to have the law that first established the registry amended to make the concept of “implied consent” more explicit. For now, neither the system’s supporters in the medical community nor its critics are satisfied with where things stand.

The concept of an immunization registry sounds relatively simple: It's a way to keep track of who has what vaccines, using a database that would allow these immunization histories to be communicated between medical providers.

In reality, the idea is proving to be more complicated. For New Hampshire, the development of a registry has exposed tensions between those in the medical community who say such a system would serve a valuable service to public health and communicable disease prevention, and critics who say such a system represents a potential overreach by the state.

Written into law, unfulfilled in reality

Plans for an immunization registry in New Hampshire date to at least 1998, when the state passed a law (<http://www.gencourt.state.nh.us/legislation/1998/SB0379.html>) to establish “a single repository of accurate, complete and current immunization records to aid, coordinate, and promote effective and cost-efficient disease prevention and control efforts.”

As outlined in the law (<http://www.gencourt.state.nh.us/rsa/html/X/141-C/141-C-20-f.htm>), the goals of the registry were threefold: to keep track of recommended immunizations; to “improve immunization rates” by tracking “overdue or upcoming” doses; and “control communicable diseases by assisting in the identification of individuals who require immediate immunization in the event of a disease outbreak.”

Health care providers are, under the law, barred from “discriminat(ing) in any way against a person solely because that person elects not to participate in the immunization registry.”

The registry, however, never got off the ground. There was an attempt to partner with Maine, but that also fell through. In recent years, the state revived its attempts to launch a new “immunization information system.”

In a 2011 request for information for the project (<http://www.admin.state.nh.us/purchasing/RFP%20DHHS%202014-008.pdf>), the state cites a federal push toward demonstration of “meaningful use” of electronic health records as one justification for establishing the system.

In April 2014, the executive council (http://sos.nh.gov/nhsos_content.aspx?id=8589934947) approved a five-year, \$1.35 million contract with the Arizona-based Scientific Technologies Corporation (<https://www.dropbox.com/s/etxcricl2mjxhuy/39A%20GC%20Agenda%20042314%20%282%29.pdf?dl=0><http://www.nvic.org/https://www.facebook.com/notes/national-vaccine-information-center/dear-new-hampshire-nvic-supporters-and-nvic-advocacy-team-members-action-alert/10152659315922931>) to set up the state's registry. The company has worked on statewide immunization systems for Maine, Washington, Wyoming and Arizona, among others.

According to an audio recording of the meeting, several executive councilors raised questions about the confidentiality protections that would be built into the system. Bureau of Public Health Systems, Policy and Performance Chief Marcella Bobinsky said the state would track who has access to the

registry – doctors, nurses and so on – and could track how a given user accesses the system.

A physician in one town would not be able to access individual information about someone who was not their patient, Bobinsky explained. Providers, patients and parents (if the patient is under 18) could choose not to participate in the system, she told the councilors. Other privacy safeguards will be built into the system, Bobinsky said in separate interviews.

From there, the state moved forward with the project. It held a public hearing in the spring, and prepared the guidelines on the registry for a September meeting of the Joint Legislative Committee on Administrative Rules. And that's when the plans stalled.

Debate over 'opt-out' approach, other rules

For this system to be most effective, Bobinsky and other supporters of the registry have said, it needs to be "opt-out" – in other words, all residents would be included unless they chose not to participate. A majority of the nation's immunization registries are opt-out rather than "opt-in."

In the rules put forward by the department in the fall, a person would need to complete a form to signal their decision not to participate in the registry. But here's where one of the points of contention also comes in: The state wanted to include those "opt-out" decisions as one of the "vaccination events" tracked by the registry.

This would mean, in theory, that the registry would still maintain a record of someone's decision to decline participation. Part of the reason for this, Bobinsky said, is that the system uses the personal information to block it from being transmitted at other points throughout the system. This, she said, will help the state to ensure that they are honoring someone's request to opt out.

One of those who spoke out against the department's plans for the immunization recordkeeping is Rep. Neal Kurk, a Republican from Weare who has established a reputation for defending personal privacy. His qualms have nothing to do with any kind of debate over the merits of vaccination – "those issues are not mine," he said.

Instead, he wants to make sure whatever system the state develops is "opt-out" in the strictest sense. Maintaining a record of someone's decision to opt out, he argues, violates the legislative intent of the original law on the registry, which reads: "No patient, or the patient's parent or guardian if the patient is a minor, shall be required to participate in the immunization registry."

Other opposition toward the registry has come from the National Vaccine Information Center (<http://www.nvic.org/>) – which describes itself as an "educational organization" promoting "vaccine safety and informed consent protections in the mass vaccination system" – and on a local level from Bedford resident Laura Condon.

Condon says her skepticism toward vaccines dates back decades. Within the last few years, she connected with the NVIC and now volunteers as its “advocacy director” for New Hampshire. She has been watching the development of the registry closely, submitting written comments on the rules and otherwise speaking out against the proposal.

In September – when the registry rules were supposed to go up for discussion – the NVIC posted two notes (<https://www.facebook.com/notes/national-vaccine-information-center/dear-new-hampshire-nvic-supporters-and-nvic-advocacy-team-members-action-alert/10152659315922931>) to its Facebook page encouraging its followers (<https://www.facebook.com/notes/national-vaccine-information-center/nh-please-use-share-this-important-information-to-object-to-the-propose-immunizat/10152661184477931>) to contact the legislators on the Joint Legislative Committee on Administrative Rules to voice opposition to the proposal. The notes outline more than a dozen objections to the rules – including a call to make the registry “opt-in” and to prohibit vaccine refusals from being recorded.

The NVIC also, in the notes, opposes sharing “even statistical information” with the New Hampshire Vaccine Association (<http://www.nhvaccine.org/>), which oversees the funding of the state’s vaccine purchasing program.

Condon harbors skepticism toward the registry on several fronts. On a personal level, she is concerned about the safety of vaccines. As for the registry, she is worried the state may use it to “harass” people who choose not to vaccinate either themselves or their children. Bobinsky, in response to this concern, said the state would not use the registry in this way.

“I think it states very clearly in the law that even if we have a registry, you are not compelled or required to receive vaccinations, and you shall not be discriminated against,” Bobinsky said.

Condon also believes this registry will be manipulated into a marketing tool, and that the information stored therein may somehow make its way back to pharmaceutical companies to help them turn a profit. The most recent version of the rules (<http://www.dhhs.nh.gov/oos/aru/documents/hep307fpannotated.pdf>), before they were withdrawn, added language that explicitly prohibited “release or use of patient identifiable medical information for the purpose of sales or market of services.”

“VaxNH shall not be used as a marketing information tool for pharmaceutical companies to direct marketing campaigns either through electronic means, phone, or mail,” the rules said.

Still, Condon remains unconvinced that this will protect against such information-sharing. And she remains unconvinced, generally speaking, of the need for a registry in the first place.

“My concern, again, is the need to know – the state is not a medical provider,” Condon said. “What is the state’s legitimate need to know my child or mine vaccination history?”

Medical providers defend need for registry

Those in New Hampshire's medical community have argued that the need is indeed there.

As pitched by Bobinsky and other health department officials, the system would, for example, make it easier for people to keep track of their immunization information if they switch doctors.

It would also, according to medical providers who support the project, be a major improvement over the fragmented and occasionally burdensome procedures currently being used to chart patients' vaccine histories. This would also make it easier for the state to distribute vaccines in the case of an outbreak either statewide or within a particular region, Bobinsky said.

New Hampshire has a "universal vaccine purchasing program," where it buys vaccines in bulk and offers them free of charge to all children in the state. (State law affords religious and medical exemptions.) The registry will allow the state to more efficiently manage its supply of vaccines, Bobinsky said.

After the rules were withdrawn, a group of doctors from Core Physicians – which has pediatrics practices in Exeter, Epping and Plaistow – sent a letter to the department (<https://www.dropbox.com/s/of01shps416rgza/Core%20Pediatrics%20Letter%20on%20VaxNH%2012-2014.pdf?dl=0>) expressing their frustration at the delays because of opposition to the "opt-out" approach. A copy of the letter was shared with the Monitor by Everett Lamm, a pediatrician who signed onto the document. Lamm was recognized by the state this year as a "Childhood Immunization Champion," and he participates in the New Hampshire Immunization Advisory Committee as well as the New Hampshire Vaccine Association.

"As licensed healthcare providers, we take privacy issues extremely seriously and deem it unreasonable for privacy advocates to stand on principle on this particular issue," the letter reads. "Please do not jeopardize the health of our children by refusing to share valuable, limited patient information with State public health officials through an 'opt-out' vaccine registry."

The doctors wrote that they "go to great lengths" to carefully administer and document immunizations, as well as to answer questions and to get "appropriate consent." The procedures currently available, the doctors wrote, can be burdensome and time-consuming.

To critics who question the safety of vaccines, the doctors write: "A comprehensive registry would provide even better opportunities to gather and track any potential detriments."

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