

**House Public Health Committee
Regarding Interim Charge #2
Testimony by Gary Floyd, MD, Chair, TMA Council on Legislation
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Purpose of Health Registries and Benefits

Health registries are critical tools for medicine and good public health. Some of the benefits health registries provide include:

- Determine the incidence of a disease,
- Evaluate disease trends,
- Identify populations at high risk, and
- Make available data for deeper research.

Successful registries are developed by a broad base of stakeholders and are part of a secure connected registry system. Because registries provide important data to maintain and improve the health of our communities, it's critical that registries are well-populated, current, and updated as needed.

Physicians know the critical role registries play, along with many others, who are responsible for data reporting. Physicians and their patients benefit when a registry fulfills the public health intent to understand and reduce disease and/or cause of illness.

Physicians want to ensure that the right registries exist and that they benefit Texas, and will work within the state's public health system and private systems as technology evolves.

Challenges in Partnership

There are challenges that prevent robust health registries in Texas. Health registries are a partnership between physicians and their patients and the state. This partnership requires balance in roles and commitment.

Physician' challenges: Barriers exist on the physician side of this public health partnership that affect well-managed registries in Texas. These barriers deal with the difficulty in reporting. Today, physicians report to a variety of state registries, which range from immunization, newborn hearing screening, and birth defects, to the electronic death registration system. And rather than having a single sign-on system between registries, where a Texas physician could use one name and password to get into the system, it is much more fragmented. Each registry may have different procedures and web-based systems, and require different passwords and PINs.

Sometimes it's often difficult for physicians to enroll and regularly submit information to a registry. Health registries often use different software and as a result are not integrated with each

other. In addition, they typically are not sophisticated enough to connect with new electronic health record (EHR) systems. That can mean, depending on the size of the physician's office, one or more staff members who input immunization data into the registry manually, when all of the immunization data already exists in our electronic medical records. That translates to increased cost to physicians and to the health care system.

Patient and state-side of the partnership must understand and ensure there is a purpose for collecting timely and useable data. The data, while secure, must also be accessible when needed to benefit the state and its citizens. The state has the responsibility to ensure that registries are maintained to meet the new privacy standards, communication, and the flow of business.

The strength of the data also depends on the management of the information. A strong public health registry has data that is accessible and useable, and that can inform physicians or public health officials about trends or incidence.

Good example: The Texas Cancer Registry is one of the largest in the country and is a good example of a registry system striving not only to collect the highest quality data, but use and share the data with the ultimate goal of improving cancer prevention and treatment.

Researchers request cancer registry data hundreds of times each year. This data, which follows national guidelines for security and privacy, can lead to significant advances in our understanding of cancer.

Here are a few examples of how Texas cancer data was used last year:

- Texas data was part of a 45-state analysis in the *Journal of the American Academy of Dermatology* of trends and survival rates of melanoma.
- Texas data was part of a study published in the *Journal of the American Medical Association* demonstrating a higher rate of cancer among a range of organ transplant recipients associated with immunosuppression during the transplant. Previous studies only focused on kidney transplants.

Partnership for Patients and Parents

One of the registries most familiar to physicians is ImmTrac, the statewide immunization registry. ImmTrac's technology is outdated and not compatible with a growing number of EHR systems used in physician offices. In most cases, immunization data is entered manually. There is no system that automatically downloads the data from the EHRs.

If we cannot hire additional staff to input immunization records, one option we have is to fax or mail our records to the Department of State Health Services (DSHS). DSHS staff then enters the data. There are a couple of problems with this system. It creates a lag time, so others, including school officials and other health care professionals, don't know the child was immunized. This can create the potential for duplicate entries, since they do not have the child or family member with them to scrutinize the record if questions arise.

ImmTrac can have a tremendous benefit for a patient. Once a patient consents to ImmTrac, he or she no longer has to keep a paper copy—the immunization history is maintained electronically for the patient to access, regardless if they switch physicians or move across the state. To ensure we truly benefit our patients and prevent giving duplicate shots, we must recognize the mobility of our patients.

The relevance to emergency preparedness was highlighted in 2005 when many people from New Orleans were evacuated to Houston during Hurricane Katrina. Because Louisiana had electronic data on vaccination records they could share electronically with public health officials in our state, many duplicate, costly vaccinations were avoided and sparse resources were conserved in a crisis.

However, issues remain with the accessibility and life of data within ImmTrac. DSHS is now destroying immunization data of 19-year-olds who have not been contacted by the department to determine whether they would like their records maintained. Such a process was legislated in 2009 so consent could be gathered before records in ImmTrac were permanently destroyed, thereby creating a lifelong registry. I think we would all recognize that few college-age teens are going to be concerned with their medical records until a point in life they really need them. State policy should support successful lifespan registries, including ImmTrac, by allowing patients and parents to provide or withdraw consent throughout their lifespan.

Additionally, ImmTrac data should be usable. A parent of a child headed to kindergarten last fall told me they wanted the ability to evaluate schools based on the safety of the student population. They understood the risk involved by placing their child among other children who are not vaccinated. While we would not suggest disclosing the identity of individuals who choose not to vaccinate their children, certainly it is fair and just to give parents the liberty of knowing how many children in their prospective school have not been vaccinated. The right to protect your child exists on both sides of that question. Parents, and ultimately patients, should be empowered to make the best decisions for their own health care.

Strength of Data

The strength of a registry depends on the information and the quality of information that goes into the registry.

Conclusion

In medicine, we continue to integrate technology to better track our patient's history, ensure accuracy, store records securely, and use records to improve patient safety or deliver higher quality. TMA surveys indicate almost 50 percent of Texas physicians use an EHR and that number is expected to climb to 60 percent by 2014. Physicians not utilizing an EHR will be penalized beginning in 2015, which adds to the adoption urgency among physicians.

We urge you to prioritize funding for DSHS to give the adequate resources to integrate better technology to ensure the same guarantees for public health information. We believe that public health works. We believe that access to and the utilization of public health data is a critical foundation of any efficient and affordable health care system.

For a successful partnership that achieves better public health and quality patient outcomes, and lowers the cost of health care in Texas, we need to depend on an up-to-date and secure system of registries. In addition to existing registries, opportunities will certainly expand for additional registries, and we urge you to use a broad-based stakeholder group to optimize privacy, security, efficiency, and effectiveness. To use resources most efficiently and effectively, this may require careful consideration of what data is actually necessary to collect, and what data we are willing to invest in with limited resources.