Collaboration of the Health IT Policy and Standards Committees

Public Health Task Force

February 8, 2017, 9:30 a.m. – 4:45 p.m. ET

Comment Submitted by the Association of State and Territorial Health Officials

Good morning, ladies and gentlemen. It is with great honor and privilege to be able to represent the Association of State and Territorial Health Officials (ASTHO) at this Public Health Task Force Hearing and to respond to questions posed to the public health community.

ASTHO is the national nonprofit organization representing public health agencies in the United States, the U.S. Territories and freely associated states, and the District of Columbia, and over 100,000 public health professionals these agencies employ. ASTHO members, the chief health officials of these jurisdictions, formulate and influence sound public health policy and ensure excellence in state-based public health practice. ASTHO's primary function is to track, evaluate, and advise members on the impact and formation of public or private health policy which may affect them and to provide them with guidance and technical assistance on improving the nation's health.

> **ASTHO's Vision is to support states in their work to assure** Healthy people thriving in a nation free of preventable illness and injury.
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> **ASTHO Mission** is to transform public health within states and territories to help members dramatically improve health and wellness.

With Centers for Disease Control and Prevention, ASTHO continues to work closely with state and territorial public health to assure their readiness and ability to prevent, respond and mitigate exposure to the Zika virus.

Zika virus is a mosquito-borne disease and is transmitted to humans primarily by the *Aedes aegypti* mosquito, the same mosquito that transmits dengue, yellow fever, and chikungunya viruses. CDC estimates that 80 percent of Zika cases are asymptomatic, resulting in a potential for missed cases in both men and women and therefore, the potential for increased transmission to women who are or may become pregnant.

This brief testimony is in response to the questions posed by the ONC's Public Health Task Force. While not a thorough landscape analysis or reflections of all state and territorial (S/T) responses to the questions, these comments will address three key areas:

1) The critical interest of S/T public health in collecting timely pregnancy status data.
2) State and Territorial Public Health current availability of pregnancy data
3) State and Territorial Public Health and Clinical Decision Support

The critical interest of S/T public health in collecting timely pregnancy status data.

The value of collecting pregnancy status and surveillance data is clear. Birth records, maternal perinatal death, and infant mortality are considered essential in documenting key aspects of population health. Timely collection of detailed pregnancy and birth data differs state to state. State public health departments must be resourced, however, with workforce and technology capabilities to optimally collect pregnancy data beyond what they collect now. As an example, regarding Pregnancy Status Monitoring and Evaluation, a question may be asked, "At what time in the pregnancy was pregnancy status clinically determined?". Maternal and fetal health relies on information about when pregnancy was determined. For some chronic or infectious diseases or conditions the time of pregnancy determination would have no relevance. In the instance of Zika, the determination of pregnancy can initiate a set of policy, responses and clinical actions that, when reported to state and territorial (S/T) public health, take place and offer additional knowledge for surveillance and data research.

Real time pregnancy status data is important to S/T public health departments to align resources for infectious disease notification and response in the instance of an outbreak. For prenatal care, especially in areas at greatest risk for Zika, this includes rural and designated provider shortage areas. Rural communities pose additional challenges where access to early prenatal care is critical but difficult. Mobilization of resources must be coordinated with local public health (PH); and in areas where local PH is similarly resource challenged, S/T public health may need to serve as the lead agency to develop the response policies, plans, monitoring and surveillance approaches while closely coordinating with their local public health partners and supporting organizations.

State and Territorial Public Health current availability of pregnancy data.

Public health develops strong partnerships and fosters effective data exchange relationships with health care systems for disease reporting. Zika presents both challenges and and opportunities for how to improve these reporting methods and processes. Health care and public health would greatly benefit from newer technologies for bidirectional electronic case reporting, where electronic health record (EHR) and public health entities can exchange data both timely and efficiently.

Simply, it would be helpful to know if a woman was pregnant or not. Currently our surveillance relies on delayed reporting of live births, fetal deaths, and maternal mortality. These data exclude women whose pregnancy did not end in a live birth, reported still birth, or maternal death. For example, maternal mortality case finding is challenging and women whose cause of death was not related to obstetric causes, who lack a link to the live birth or fetal death record or whose pregnancy status is unknown, are lost to surveillance. We can get some information from Medicaid claims, but that, too, is limited. Optimally, pregnancy claims should be linked to other data such as laboratory confirmation, ultrasound, and clinical exam details to provide a full picture of risk to both mother and fetus. There are no reliable pregnancy flags and our knowledge is retrospective. It would be useful for both surveillance and intervention practices to be able to identify pregnancy in real time or near real time.

Other information of use to state public health are:

- Is this the first pregnancy or what number
- Presence or absence and quality of prenatal care
- Immunization status
- Any prior pregnancy losses
- Maternal History – e.g.: hypertension, complications
- Post-partum plans
- Any prior or present member of WIC – prenatal and plans postnatal
- Partner notification in presence of Zika

Another request was for comment on how pregnancy status might be captured across the continuum. As noted above, pregnancy status is documented in real time in the health record through ICD10 codes, and the question of "if you are pregnant or may become pregnant" is standard. Still, public health might receive this information weeks or months later.

Current automated data has several layers: lab reporting, birth/stillbirth reporting and birth defects reporting. Zika status and pregnancy status are of interest in all these areas. We are working to add Zika exposure information to the HL7 birth and birth defects reporting, standards (reported by Michigan) but they are not there now.

Other areas where pregnancy information might be captured electronically could be at point of sale for pharmacy items, such as perinatal vitamins. These data sets, of course, may be very difficult to obtain due to significant privacy and security concerns for disclosing pharmacy histories of clients unrelated to pregnancy. Health care partners, such as pharmacies, value collaborating with public health on messaging to patients and the communities most affected by Zika. Communication and public messages on intention to become pregnant, the risk of becoming

pregnant while infected, having sex with or contact with other individuals who are infected at any point (perinatal exposures) and what the implications of these risks are must be coordinated and targeted by all public health and health care partners.

State and Territorial Public Health and Clinical Decision Support

Public health departments are challenged to keep pace with technological advances. Further, the proliferation of new data sources like the Electronic Health Record are usually unavailable to them. Only a few states have the ability to leverage the data opportunities to work more effectively with health care. Strategic approaches are essential. Fortunately, efforts toward improving data exchanges is a focus of the Centers for Disease Control and Prevention and S/T public health, and has been for at least the last 10 years. The direction of CDC under Public Health 3.0 provides a strategy for public health where informatics capability is necessary to ensure cross sector collaboration and improvements in population health. Efforts like the Public Health Community Platform, and the Digital Bridge initiative are important efforts to promote bidirectional data exchange with electronic health records, thus setting the stage for efficient, high quality and value-added data collection to improve public health. With these efforts health care, vendors and public health work together to assure direct "communication" with each other and progress toward case definitions to be used as standards. And in the case of Zika infection prevention and response, expanding these efforts to ensure that modules aligned with any Clinical Decision Support systems are available to S/T public health makes sense. Close coordination with the vendor community assures a better standardization and eliminates variability of data collection.

In general, decision support can be employed to support the pregnancy monitoring and tracking of each of the critical pieces of information deemed essential for public health to know. Monitoring and tracking of pregnancy status related to Zika must have clinical consensus on how to convert these knowledge elements into key performance indicators (KPIs). These KPIs ensure equity and optimal health care for all and can be tracked through effective forms of CDS that may, in some cases, be fully integrated with EHRs and public health as well as in other cases function as standalone decision aids.

The opportunities for Pregnancy Status Monitoring and Evaluation through Clinical Decision Support systems can be defined in two types of support, Provider based and Community based decision support valuable for public health.

- Provider-based Decision Support
  - Public health assisting with most recent clinical guidelines, standards of care, and evaluation protocols in the context of rapid policy changes on Zika
  - Clinical summaries of new evidence and recent care histories
  - Clinical monitoring and tracking reminder dashboards throughout patient continuum of care
- Community-based Decision Support
  - Community guidelines summaries made available to all health care providers
  - Providing a summary of community resources and public health agencies that might assist providers – especially those in rural areas
  - Protective/preventive measures information dissemination
  - Alerts and reminders on patient status via EHR and patient portals

Finally, S/T public health agencies and their leadership are strong advocates for these newer technologies, not simply for better access to data, but more to be able to ensure the health of their jurisdictions. Additional resources are essential. Partnerships with vendors and health care are essential. Assurance from all our federal, state and local leadership, that the gains within PH surveillance is not lost, is essential. One need only to speak with a health official who has been faced with the realization that one family within his or her state or territory has to experience the pain and suffering of having a child born with a Zika related birth defect, to know how critical these systems improvements are. We can and must do better, and enhancing our ability to prevent these occurrences is our collective responsibility.