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Testimony Before the Policy and Standards Federal Advisory Committees on Health Information Technology

Panel 1: Public Health Departments

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Thank you for the opportunity to speak before you today on behalf of the Commonwealth of Massachusetts. Capturing pregnancy-related information in electronic health records to support response activities has broad appeal across public health. Today I will speak specifically with regard to its applicability for infectious diseases. My comments will be limited to the specific questions focused on public health need or response.

Zika virus is the driver for initiating this discussion, and the public health need to identify infection early in pregnancy is critical and has been clearly documented and cited. I would like to state for the record that there are many additional infectious diseases posing serious threats to women and children's health where public health and clinical intervention are necessary. Rapid identification of pregnancy status prioritizes follow up activities, improves surveillance and ultimately prevents further spread of disease.

These diseases include, but are not limited to:

- **Hepatitis B virus**, where there is an opportunity to prevent perinatal transmission through administration of immune globulin and vaccination beginning at birth
- **Syphilis**, where early intervention during pregnancy prevents serious congenital disease or death
- **Chlamydia** and **gonorrhea**, where prioritization of follow up on pregnant women with these infections can prevent pneumonia and other illness in newborns
- **HIV**, where early identification and treatment can reduce the risk of perinatal transmission

- **Hepatitis C virus**, where ensuring appropriate laboratory testing of the baby after birth to inform appropriate medical care
- **Influenza virus**, where vaccination can be prioritized for pregnant women, generally more at risk for severe illness
- **TB disease** and **LTB infection**, where medications may be contraindicated for pregnant women and their fetus

With regard to the specific question before the panel regarding what core pregnancy information public health needs to know my response is two-fold.

First, regardless of what data elements are collected, there must be guided policy that ensures these data are captured via coded and standardized value sets, to the extent possible. This will support more accurate data collection and reporting, and enable public health to automatically triage and respond to the vast amounts of information reported to surveillance and case management systems.

Second, in terms of specific data variables, at a minimum, public health needs to know whether an infected woman is currently pregnant and if so, her estimated date of delivery. These variables may be captured as "yes/no/unknown" and "date" fields respectively.

Additional important data elements and corresponding coded values may include:

- current gestational age (as a number with weeks or months as a unit) and associated date
- # of fetuses (as a number)
- complications, prenatal diagnosis, abnormal ultrasounds- this information is particularly relevant for Zika virus, syphilis, and rubella infections. However, these data elements or findings may not be fully portrayed as coded values.
- pregnancy outcome (coded) and date
- current treatment for the infection of concern (standardized medication and dosage) and corresponding date
- exposure date

In terms of when pregnancy-related information should be collected, it is dependent on the type of infection under investigation. For example, with Zika virus, public health needs to know whether the woman was pregnant at the time of exposure, her estimated delivery date, and ultrasound results. For hepatitis B and other chronic infections, we need to know laboratory test results for every pregnancy. For diseases such as syphilis, the earlier public health knows about infection during pregnancy and can intervene, the more likely a positive outcome for the baby; accurately capturing when the mother was exposed and whether treatment was given is critical.

Public health should establish the business rules for relevant infections to provide EHR vendors for clinical decision support activities. Furthermore, collection of pregnancy information should

not just be focused on collection and storage within the EHR but across the continuum of care. In the current environment, public health is often taking action based on receipt of the laboratory test information alone. Having pregnancy information consistently present with laboratory test results is critical for prioritizing resources and conducting interventions and follow up. Laboratory testing by large commercial laboratories, hospital laboratories and other testing facilities should capture pregnancy information and provide this information to public health.

With regard to where pregnancy information is captured electronically, my only comments are that in my experience, it is highly variable and not collected in a standardized manner. There is clearly a need for a recommendation standardizing how these data should be structured.

Pregnancy information is critical for public health investigations, vaccination recommendation determinations and prescription prescribing practices. To streamline engagements between providers and public health it is important to consider both reducing the burden of reporting on clinicians and the timeliness of reporting. To the extent possible, data must be collected in structured formats following national standards. I would recommend the model currently employed by the Digital Bridge whereby, for example, public health was charged with developing consensus upon a minimum set of data elements to be included in the initial electronic case report. Public health and our partners should agree to what and how these pregnancy-related data elements may be standardized for inclusion in the EHR. Receipt of these data allows public health to prioritize resources and act accordingly to reduce morbidity and mortality.

As we have seen in recent emerging public health threats, there are often rapidly changing recommendations and significant confusion in the provider community to understand testing practices and other public health follow up activities. The current process of providing letters and guidance documents rely on clinicians reading, understanding, and transferring knowledge to apply the new guidelines. Educating the clinical care community is critical and challenging. Automated tools that may rapidly be deployed for clinical decision support may help alleviate such confusion. The need to quickly disseminate public health information to EHRs may most appropriately be done from a centralized platform such as the Digital Bridge.

For more routine interventions, best practice alerts would also be useful. A positive pregnancy result may prompt the clinician to ask questions about travel history, vaccinations, or information about sexual partners.

In summary, accurate and timely access to pregnancy-related information is a critical component of public health response. As we move further towards full implementation of electronic health records and development of a platform to support public health reporting, articulating the minimal key variables and values, and standardizing their format will facilitate actionable public health information.