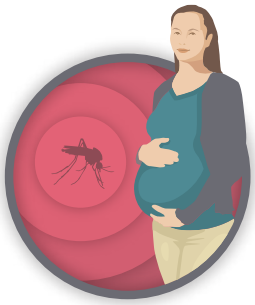
CDC's Response to **Zika**

US Zika Pregnancy Registry

Obstetric Healthcare Providers: How to Participate



Zika virus infection during pregnancy has been linked to adverse outcomes including pregnancy loss and microcephaly, absent or poorly developed brain structures, defects of the eye and impaired growth in fetuses and infants. Despite these observations, very little is known about the risks of Zika virus infection during pregnancy. Information about the timing, absolute risk, and spectrum of outcomes associated with Zika virus infection during pregnancy is needed to direct public health action related to Zika virus and guide testing, evaluation, and management.

US Zika Pregnancy Registry

To understand more about Zika virus infection, CDC established the US Zika Pregnancy Registry and is collaborating with state, tribal, local, and territorial health departments to collect information about pregnancy and infant outcomes among pregnant women with laboratory evidence of Zika virus infection and their infants. The data collected through this Registry will provide additional, more comprehensive information to complement notifiable disease case reporting and will be used to update recommendations for clinical care, to plan for services for pregnant women and families affected by Zika virus, and to improve prevention of Zika virus infection during pregnancy.

How to Participate

CDC and state, tribal, local, and territorial health departments request that healthcare providers participate in the US Zika Pregnancy Registry by:

1. Reporting information about pregnant women with laboratory evidence of Zika virus infection to their state, tribal, local, or territorial health department.
2. Collecting pertinent clinical information about pregnant women and their infants on the Pregnancy and Zika Virus Disease Surveillance forms.
3. Providing the information to state, tribal, local or territorial health departments or directly to CDC Registry staff if asked to do so by local health officials.
4. Notifying state, tribal, local, or territorial health department staff or CDC Registry staff of adverse events (e.g., spontaneous abortion, termination of pregnancy).

Who to Report to the Registry

Healthcare providers should report the requested information to the health department in accordance with applicable state, tribal, local and territorial laws. Those eligible for the registry include: 1) pregnant women in the United States with laboratory evidence of Zika virus infection (positive or equivocal test results, regardless of whether they have symptoms) and 2) periconceptionally, prenatally, or perinatally exposed infants born to these women, including infants with congenital Zika virus infection.

Healthcare providers practicing in Puerto Rico should report information to the Puerto Rico Zika Active Pregnancy Surveillance System (ZAPSS) rather than to the US Pregnancy Registry.*

*Puerto Rico has established a separate Zika Active Pregnancy Surveillance System (ZAPSS)

www.cdc.gov/zika

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COLORADO
Department of Public Health & Environment

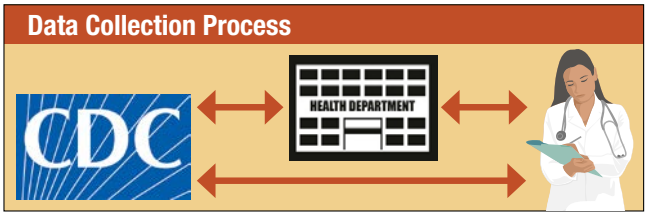
U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

How To Report to the Registry

- Healthcare providers should contact their state, tribal, local, or territorial health department to arrange for laboratory testing for Zika virus infection in pregnant women and infants who meet the clinical criteria for testing as outlined in the CDC guidelines.
- Healthcare providers can contact CDC (call CDC's Emergency Operations Center watch desk at 770-488-7100; email ZikaPregnancy@cdc.gov; or fax 404-718-2200) to discuss information on pregnant women with laboratory evidence of Zika virus infection. If healthcare providers contact CDC for clinical consultation, Registry staff will ensure that state, tribal, local, or territorial health departments are notified. CDC may also learn about pregnant women and infants with laboratory evidence of Zika virus infection through national surveillance of arboviral diseases.

How the Data are Collected

Depending on the preference of the state, tribal, local, or territorial health department, either health department staff or CDC Registry staff will contact healthcare providers caring for pregnant women and their infants for data collection.



Time points for data collection
Initial Identification
2nd and 3rd trimester
At delivery
Infant: Months 2, 6, and 12

CDC is requesting the collection of clinical information in identifiable form as a public health authority. As defined in the Health Insurance Portability and Accountability Act (HIPAA) and its implementing regulations, Standards for Privacy of Individually Identifiable Health Information (45 CFR § 164.501)] ("Privacy Rule"**), covered entities (e.g., healthcare providers) may disclose protected health information without patient authorization to a public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease (42 CFR 164.512). Data to be collected include clinical information pertaining to the pregnant woman's health, monitoring, and testing during pregnancy, results from evaluation and testing conducted at birth, and clinical/developmental information from the infant through the first year of life. As established in the HIPAA Privacy Rule (45 CFR 164.528), individuals have the right to request from covered entities (i.e., you, the healthcare provider) an accounting of the disclosures of their protected health information.

More Information about Zika

For more information, visit CDC's website www.cdc.gov/zika.

If families would like to speak to someone about a possible Zika virus infection or diagnosis during pregnancy, Mother to Baby experts are available to answer questions in English or Spanish by phone, text, or chat: www.MotherToBaby.org. The free and confidential service is available Monday - Friday from 8am - 5pm (local time).

CDC Guidance Materials

1. Update: Interim Guidelines for Health Care Providers Caring for Pregnant Women and Women of Reproductive Age with Possible Zika Virus Exposure – United States, 2016 (April 1, 2016) http://www.cdc.gov/mmwr/volumes/65/wr/mm6512e2.htm?s_cid=mm6512e2_w
2. Interim Guidelines for Healthcare Providers Caring for Infants and Children with Possible Zika Virus Infection – United States, February 2016 (Feb. 19, 2016) http://www.cdc.gov/mmwr/volumes/65/wr/mm6507e1.htm
3. Zika Virus: Collection and Submission of Fetal Tissues for Zika Virus Testing http://www.cdc.gov/zika/hc-providers/tissue-collection-submission.html
4. Collection and Submission of Body Fluids for Zika Virus Testing http://www.cdc.gov/zika/hc-providers/body-fluids-collection-submission.html