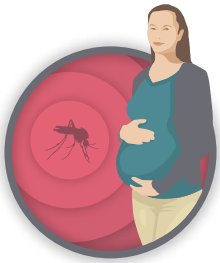
CDC's Response to **Zika**

US Zika Pregnancy Registry

Health Departments: How to Participate



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

US Zika Pregnancy Registry

CDC established the US Zika Pregnancy Registry and is collaborating with state, tribal, local, and territorial health departments to collect and share information about Zika virus infection during pregnancy. The data collected through this Registry will 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.

Reasons to Participate

Reporting to the US Zika Pregnancy Registry will allow aggregate data to inform public health efforts at the local level as well as broader recommendations. Some states have already implemented enhanced surveillance for pregnant women and infants. The US Zika Pregnancy Registry staff can help by notifying states and territories of laboratory evidence of Zika virus infection among pregnant women that come to Registry staff's attention when healthcare providers contact CDC for clinical consultation. Registry staff are also available to help with follow-up data collection, if requested.

How to Participate

State, tribal, local, and territorial health departments can participate in the US Zika Pregnancy Registry by

- Identifying pregnant women and infants eligible for Zika virus testing in accordance with State or CDC guidelines.
- Coordinating testing at a State Public Health Laboratory or CDC for those eligible.
- Reporting information about 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 information about periconceptionally, prenatally, or perinatally exposed infants born to these women, including infants with congenital Zika virus infection
- Collecting enhanced surveillance data about pregnant women and their infants who are eligible.
- Working with CDC to determine state-specific methods for collecting and sharing data.

Who is Eligible to be in the Registry

- Pregnant women in the United States[1] with laboratory evidence of Zika virus infection (positive or equivocal test results, regardless of whether they have symptoms) and periconceptionally, prenatally, or perinatally exposed infants born to these women.
- Infants with laboratory evidence of congenital Zika virus infection (positive or equivocal test results, regardless of whether they have symptoms) and their mothers.

www.cdc.gov/zika

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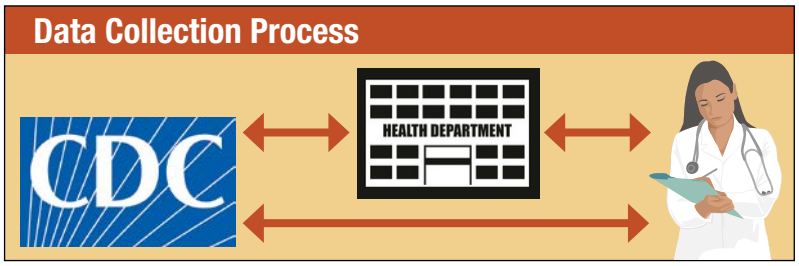
COLORADO
Department of Public Health & Environment

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

How to Collect the Data

Various methods (e.g., medical record abstraction, telephone consultation) can be used to collect surveillance information for the Registry. Depending on preference and capacity of the state, tribal, local, or territorial health department, staff may choose to follow up with healthcare providers or ask CDC Registry staff to follow-up.



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

Health departments may obtain data collection forms by emailing the Zika pregnancy email address (ZikaPregnancy@cdc.gov). In addition, a shared website for State Zika Coordinators and Registry staff and a secure file transfer protocol (FTP) site has been established. CDC staff will also provide health departments with forms when Registry eligible women and their infants are identified through laboratory testing at CDC. Data to be collected include clinical information pertaining to the pregnant woman and the infant through the first year of life.

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). As established in the HIPAA Privacy Rule (45 CFR 164.528), individuals have the right to request from covered entities (i.e., the healthcare provider) an accounting of the disclosures of their protected health information.***The identity of people in the Registry will be kept private and secured.** US Zika Pregnancy Registry data will be transferred and stored in accordance with the highest security standards for confidential records.

How to Report Registry Data Securely to CDC

CDC Registry staff have identified State Zika Coordinators to tailor data collection, reporting, and sharing of information in accordance with the specifications of each state. Health department staff can submit information to CDC Registry staff by

- Electronic data transfer through FTP (e.g. CSV, Excel, Access, Word, PDF files)
- Encrypted email to ZikaPregnancy@cdc.gov
- Secure fax at 404-718-2200
- Telephone report (Call 770-488-7100)
- Electronic data transfer through CDC's Secure Access Management Services (SAMS)

[1] Puerto Rico is establishing a separate Zika Active Pregnancy Surveillance System (ZAPSS) to collect information on eligible cases in the Commonwealth of Puerto Rico.

Thank you for your interest and participation in the US Zika Pregnancy Registry

More Information about Zika

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

If families would like to speak to someone about a possible Zika virus 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).