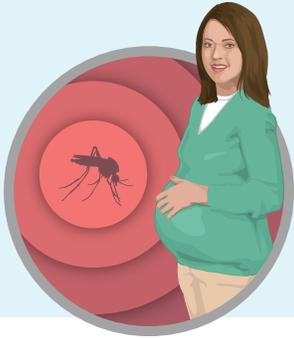


# US ZIKA PREGNANCY REGISTRY

## Health Departments: 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. 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. All states and territories are now participating in the US Zika Pregnancy Registry to conduct enhanced surveillance.

## 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 and infants who meet the eligibility criteria shown below.
- 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 and US territories (with the exception of Puerto Rico) with laboratory evidence of possible Zika virus infection (regardless of whether they have symptoms) and periconceptionally, prenatally, or perinatally exposed infants born to these women.
- Infants with laboratory evidence of possible congenital Zika virus infection (regardless of whether they have symptoms) and their mothers.

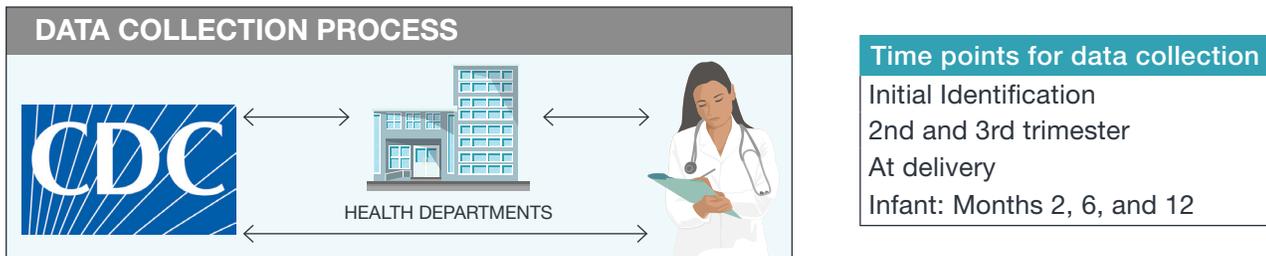
[www.cdc.gov/zika](http://www.cdc.gov/zika)



**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.



Health departments may obtain data collection forms by emailing the Zika pregnancy email address ([ZikaPregnancy@cdc.gov](mailto: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. Data to be collected include clinical information pertaining to the pregnant woman and the infant through the first year of life. CDC staff will provide Health Departments with paper and PDF-fillable US Zika Pregnancy Registry forms and database support for local electronic data entry.

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.

You may wish to use the fact sheet for [pregnant women](#) to let your patients know how their information is being used. This fact sheet also contains information on the Assurance of Confidentiality that CDC has obtained. The Assurance is a formal confidentiality protection authorized under Section 308 (d) of the Public Service Act. Under this Assurance, identifiable information about your patient and the care you provide can only be used to better understand Zika virus infection during pregnancy and its outcomes. CDC cannot share it with anyone without your permission and your patient's permission, even if an official of the court, the government or law requests it.

## 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 CDC's Secure Access Management Services (SAMS)
- Electronic data transfer through FTP (e.g. CSV, Excel, Access, Word, PDF files)
- Secure fax at 404-718-1013
- Telephone report (Call 770-488-7100)

<sup>1</sup> 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](http://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, email, or chat: [www.MotherToBaby.org](http://www.MotherToBaby.org).

The free and confidential service is available Monday - Friday from 8am - 5pm (local time).