

Population-Based Surveillance of Congenital Heart Defects among Adolescents and Adults

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CDC and its grantees are making progress toward understanding the healthcare needs and outcomes among the growing population of older children and adults with heart defects. Learn more about their progress to date.

Background

- In 2012, CDC received funding from Congress to enhance and expand public health tracking to improve our understanding of congenital heart defects (CHDs) across the lifespan.
- With this funding, CDC is working with three grantees to begin a pilot project of population-based tracking of adolescents and adults with CHD. The grantees include the New York State Department of Health, Emory University, and the Massachusetts Department of Public Health.
- Population-based public health tracking is used by researchers to look at all of the people with a certain condition (like a CHD) who live in a specific area. This is being done so that researchers can better understand the survival, healthcare use, and longer-term outcomes of adolescents and adults living with CHDs.
- The three grantees collect and combine data from different areas and varying data sources within their states. All the data will be analyzed as a group, so any one person with a CHD cannot be identified.

	Emory University	Massachusetts	New York
Population	46 Counties	Statewide	11 Counties
Age range & special populations	11–64 years Pregnant women	11–64 years Pregnant women	11–21 years Pregnant women
Data sources	<ul style="list-style-type: none"> • Birth defects surveillance (for 5-county Metro Atlanta area) • Medicaid • Clinic/billing data • Vital records • Maternal mortality review 	<ul style="list-style-type: none"> • All payer claims database • Provider reporting • Vital records • Pregnancy to Early Life Longitudinal data • 	<ul style="list-style-type: none"> • Birth defects surveillance • Hospital discharge data • Clinic/billing data • Vital records •

Current Status of Adolescent/Adult Surveillance Pilot Projects

- Each grantee will use the same criteria to identify individuals with CHDs and is collecting the same types of data. This is helpful so that the data can be grouped together for analyses.
- The three grantees are in varying stages of data collection. To make sure data collection is going well, each grantee sends some test data to CDC. The first test was in September 2013 and it was successful.
- A group of representatives from CDC and each grantee meets regularly to discuss issues, such as how heart defects will be grouped together and how the data will be analyzed.
- An External Guidance Committee (EGC) has been established for the pilot project. It consists of sixteen members that represent medical and birth defects monitoring expertise, as well as key stakeholders and advocacy groups.
 - » The EGC's role is to provide input on the plans and progress of the project, as the three grantees identify and implement effective ways to conduct population-based monitoring among adolescents and adults with CHD.