

Participant Information Sheet

Congenital Heart Survey To Recognize Outcomes, Needs, and wellbeinG of KIDS (CHSTRONG-KIDS)

RESPONSIBLE ORGANIZATIONS:

Massachusetts Department of Public Health, Boston University School of Public Health, Minnesota Department of Health, and National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC).

PURPOSE:

People born with heart conditions are living longer because of better care. However, little is known about the daily life of children born with heart conditions. Thus, the Metropolitan Atlanta Congenital Defects Program and the CDC are asking parents or caregivers of children born with a heart condition to complete a brief survey. This survey asks questions about your child's access to care and quality of life as well as your needs and experiences as their caregiver. Your answers may help identify unmet needs of children born with heart conditions and their caregivers. This information may also help families who have children with heart conditions plan for the future.

PROCEDURES:

Completing the survey is up to you. Nothing will happen if you decide not to complete the survey. If you decide to take part in this survey, complete the survey and mail it back in the postage paid envelope or you can scan the provided QR code to complete the survey online. We will take your return of the completed survey as your consent to be part of this project. The survey will take about 20 minutes, but the exact time depends on your answers. It would be helpful if you completed the entire survey. However, you can refuse to answer any question and you can stop at any time.

RISKS:

There are no known risks to you for completing the survey. If you do not want to answer a question, you do not have to. All personal information (name, date of birth, address, and email address) will be kept private and stored separately from your other survey answers.

BENEFITS:

There is no benefit to you for completing the survey, but your answers are important to children born with heart conditions and their families. The survey information may help identify unmet needs of children born with heart conditions and their caregivers. Additionally, this information may help families of children born with heart conditions plan for the future. We will share what we learn at meetings and through reports. We will never share information that could identify you.

CONFIDENTIALITY:

We are contacting parents or caregivers of children who were born with a heart condition. On the survey, we ask for your email address if you are interested in receiving project updates in the future. You may decline to be re-contacted now or at any time in the future.

All of the answers you provide will be kept private to the extent allowed under federal laws [Privacy Act of 1974 (5 U.S.C. § 552a)]. These laws do not prevent the project staff from reporting information needed for evaluating or auditing the project.

We will assign your survey a number. Only certain project staff will have access to your name and address information. None of your answers to survey questions will be linked to your name or address. If you choose to provide your email address on the survey, we will store your email address separately from the rest of your survey responses. In reports, your answers will be combined with the answers from everyone else that took part in the survey.

All of the completed surveys will be kept at the CDC in locked cabinets in locked rooms with limited access by the project staff. All the computer files will be kept on a secure, password-protected server.

COSTS/COMPENSATION:

We know your time is valuable. As a thank you, we included a \$5.00 gift card for you in this survey packet. Please keep the gift card, whether or not you complete the survey. If you choose to return your completed survey via mail or complete it online, we will send you another gift card worth \$20.00 to thank you for the additional time and effort.

RIGHT TO REFUSE OR WITHDRAW:

Your participation in this survey is up to you. Nothing will happen if you decide not to take part. You can refuse to answer any questions and you can stop at any time. If at any time you would like to have your survey answers destroyed or removed from the project, please call [site phone number] or email [site email].

If you have any questions, please contact:

The CHSTRONG-KIDS Project Manager
[site email] or [site phone number]

If you have questions about your rights as a participant in this project, please call the CDC's Office of the Deputy Associate Director for Science at 1-800-584-8814. Leave a message including your name, phone number, and refer to Project ID 0900f3eb81e181e3, and someone will call you back as soon as possible.