

Attachment 9 - Reminder Phone Call Script

Hello, may I please speak with [PARTICIPANT FIRST NAME]?

IF NO, participant not available to speak:

I am calling on behalf of the Congenital Heart Survey To Recognize Outcomes, Needs, and well-being (CH STRONG) project conducted by <awardee>, the Centers for Disease Control and Prevention in partnership with March of Dimes, and we would like to get in touch with [PARTICIPANT FIRST NAME] or a parent or guardian if [PARTICIPANT FIRST NAME] is unable to use the phone. Is there a better phone number or better time to call?

RECORD IN DATABASE.

IF YES, participant available to speak:

Hello [PARTICIPANT FIRST NAME],

My name is [YOUR FIRST NAME] and I am calling on behalf of the Congenital Heart Survey To Recognize Outcomes, Needs, and well-being (CH STRONG) project conducted by <awardee>, and the Centers for Disease Control in partnership with March of Dimes. A few weeks ago, we sent you a <color> packet in the mail containing a brochure, survey and [ETC...] for CH STRONG. The purpose of the survey is to learn more about adults living with congenital heart defects. I am calling to confirm that you received our packet.

Have you received a packet in the mail from CH STRONG with a brochure and a survey?

IF NO, didn't receive packet:

May I confirm your current mailing address and email address?

IF YES, received packet:

Excellent. This call is just a reminder to complete the survey either online or on the paper copy at a time that is convenient for you. We expect that it should not take more than 20 minutes to complete the survey questions and we have included [INCENTIVE] to thank you for your time and participation. If you choose to complete the paper survey, we have also included a prepaid envelope so that the return mailing will be at no cost to you. We hope to receive your survey before [MONTH THAT DATA COLLECTION ENDS].

Do you have any questions for me at this time?

[ANSWER QUESTIONS OR MOVE TO NEXT PART]

Thank you for taking the time to speak with me. Your participation is valuable to us and will help improve our understanding of congenital heart defects. We look forward to receiving your survey. Have a great day.

Phone Script Stock Answers:

Q: Who are you?

A: My name is [NAME]. I work at <awardee site>. We conduct projects to learn more about birth defects, including congenital heart defects.

Q: What is CH STRONG?

A: CH STRONG stands for Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG. It is a project on congenital heart defects conducted by <awardee> and the Centers for Disease Control and Prevention in partnership with March of Dimes. We are asking thousands of U.S. adults born with a heart condition to complete a brief survey about their access to care and quality of life. The answers may help identify unmet needs of adults born with a heart condition and may also help families who have children with heart conditions plan for the future.

Q: What are congenital heart defects?

Congenital heart defects (CHDs) are conditions that are present at birth and can affect the way a baby's heart works. They are the most common type of birth defect. As medical care and treatment have advanced, infants with congenital heart defects are living longer and healthier lives through late adulthood.

Q: I don't think I have a CHD, but what if I do?

Our records indicate that [PARTICIPANT NAME] has been diagnosed with a congenital heart defect, but it is possible that we have contacted the wrong person. Can you please confirm the spelling of your name OR your first name, last name, and middle initial? Can you please confirm your date of birth?

If name and date of birth match: We believe you are the intended recipient of this survey so we would like to have your responses to the survey questions. Please proceed to fill out the survey to the best of your ability at a time that is most convenient for you.

If you'd like to learn more about congenital heart defects, we have a list of recommended websites that explain what congenital heart defects are, the different types of congenital heart defects, and resources for individuals seeking health care for their congenital heart defect. This list can be found on our website at www.CHSTRONG.org.

Q: Do I need to visit a doctor?

Individuals with congenital heart defects are encouraged to talk to a heart doctor (a cardiologist) to make the best possible choices for their health and to achieve the best care for their specific heart defects. If you do not

have a heart doctor, you can ask your regular doctor to provide you with the name of a heart doctor in your area.

If you'd like general information on the care and management of congenital heart defects, we have a list of recommended websites that explain what congenital heart defects are, the different types of congenital heart defects, and resources for individuals who are seeking health care for their congenital heart defect. This list can be found on our website at www.CHSTRONG.org.

Q: How did you get my (my child's) phone number?

A: We attempted to find current contact information on all individuals ages 18 to 45 years old identified as being born with a congenital heart defect in <awardee site>. Electronic databases and social media were used to find current contact information. Your/His/Her contact information was collected solely for this project and will not be shared with anyone but the staff conducting this project.

Q: Why are you calling my cell phone?

A: We call both landline and cell phone numbers. Many households no longer have landline phones. If we did not call cell phone numbers, we would not be able to reach individuals in all types of households.

Q: Why are you calling me?

A:

If PARTICIPANT – You were identified in our records as having a congenital heart defect so we sent you a CH STRONG survey packet in the mail. We are calling to confirm that you received it and to remind you to complete it at a time that is most convenient for you. We also wanted to provide you with an opportunity to ask questions about CH STRONG.

If PARENT - Your child was identified as having a congenital heart defect. We mailed a survey to him/her and are now trying to contact him/her to confirm it was received and to provide more information about CH STRONG if desired. We are hoping you can provide us with his/her current contact information.

Q: Why should I take part in the survey?

A: We need your help to better understand the experience of adults living with congenital heart defects. This survey asks questions about your access to care and quality of life, and your answers may help identify unmet needs of adults born with a heart condition. This information may also help families who have children with heart conditions plan for the future.

Q: How do I know this is a legitimate survey?

A: The surveys are conducted on behalf of <awardee>, March of Dimes, and the Centers for Disease Control and Prevention (CDC), and are authorized by the Public Health Service Act [42 U.S.C. 241]. The surveys provide important information about congenital heart defects. You can learn more about the survey at <website>.

Q: Will my answers be kept private?

A: Privacy is required by law. Names and all other personal identifying information will not be released. The information collected in the surveys will only be provided in summary reports.

Q: How long will it take?

A: We expect the survey to take you about 20 minutes, but the length of time may vary depending on which questions apply to you. Keep in mind that, regardless of whether you choose to complete the survey on paper or online, you can start at a time that is most convenient for you and can move through the survey at your own pace.

Q: Who uses this information?

A: <Awardee>, March of Dimes, and the Centers for Disease Control and Prevention will use the results of the study to help improve the health of adults living with congenital heart defects. We hope to identify unmet needs of adults born with a heart condition and help families who have children with heart conditions plan for the future. Reports from these surveys never contain any personal information and never identify who participated in the survey.

Q: How do I get the calls to stop?

A: While we hope you are able to help us with this important health project, we understand if you are unable to do so at this time. If you are certain that you do not want to receive further phone contact, I can add you to the “no-call” list. Would you like me to add you to the “no-call” list?

If yes: I have added you to the “no-call” list so you will not receive any more reminder phone calls from us. Though you will no longer receive reminder phone calls from us, you are still welcome to fill out and send in the survey at any time, and we would greatly appreciate receiving your responses in the mail or online. Thank you for taking the time to speak with me.

Q: Where do I get more information?

A: For more information, you can visit our website at www.CH STRONG.org