

**CAREGIVER FOR YOUTH INFORMED CONSENT FORM
FOR FOCUS GROUPS**

**TITLE OF INFORMATION COLLECTION: Asthma Control Initiative
Communication Messaging and Materials
Development**

Sponsor: The Centers for Disease Control and Prevention's
(CDC) Air Pollution and Respiratory Health Branch
(APRHB)

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You are being asked permission for your child to take part in this study because your child is aged 12–18 and has asthma. After reading this form, which explains the research, you may decide if you would like your child to participate in the study or not. Your child's participation is voluntary. If you decide to allow him or her to start the study and then change your mind, your child may withdraw at any time. If you allow your child to participate, he or she may choose not to participate and can withdraw at any time.

You may ask the research team questions about the study at any time. They will explain anything you do not understand.

You must sign this form before your child can take part in the study. If you would like a copy for your records, you may request a copy from the research team.

About This Study

Fors Marsh Group (FMG) is a research company contracted by the Centers for Disease Control and Prevention (CDC) to investigate youth's reactions to and their understanding of asthma management. We plan to conduct focus groups with youth across the country. During the focus group, which will last about 90 minutes, your child will be asked to share his or her thoughts about asthma management.

There will be an onsite research staff observing the focus group in a separate room. The focus group will be audio-recorded and transcribed for study-related purposes, but no personally identifiable information will be tied to your child or made available to researchers.

Study Benefits

There is no direct benefit to your child. Your child's feedback will help us to decide how asthma management interventions can be improved.

Incentive

Your child will receive an incentive of \$45 as a token of appreciation for his or her participation, and you will be provided an incentive of \$30 as a token of appreciation to help with costs associated with transporting your child to the facility for the focus group. Your child will receive the incentive for his or her time even if he or she chooses not to answer some of the questions during the discussion.

Anticipated Risks

FMG will be very careful to allow only members of the research team to see your child's information. Despite all of our best efforts, there is a small risk that others might find out what your child says in the focus group. In the case of a breach of confidentiality, appropriate steps will be taken to notify participants. Remember that your child can stop participating in this study at any time.

Because this is a group session, participants might share private thoughts that they do not want shared with others outside of the group. We ask that your child respects everyone's privacy and not share what is discussed with people outside of the group. We will ask the other group members to do the same thing.

If you or your child has any questions about this research study, you may call Sarah Evans of Fors Marsh Group at 571-858-3757.

Privacy

Everything your child says during the focus group can be heard by the research team.

The focus group will be audio-recorded and transcribed for note-taking purposes. By signing this form, you consent to allowing your child to be audio-recorded during the focus group.

Your child's identity will not be linked to any of his or her responses. This means that no one outside of the research team will be able to link what your child has said back to him or her. Everything your child shares will be kept private to the extent allowed by law. Therefore, we will not share anything your child provides with anyone outside of the study unless it is required to protect him or her or if required by law. However, if he or she shows a direct threat of harm to him- or herself or others, we have the right to take action out of concern for your child and concern for others.

All information we collect—including anything your child says in the focus group, information collected during screening, audio files, and transcripts—will be stored on a password-protected computer and/or in locked cabinets that only the research team can access. We will collect some personal information from your child, such as his or her age, gender, and race, but this information will only be used for eligibility and scheduling purposes. After three years, all collected data will be destroyed by securely shredding documents or permanently deleting electronic information.

Results from this study may appear in professional journals or at scientific conferences. No individual participants will be identified or linked to the results. We

will not disclose your child's identity in any report or presentation. Results also may be used in future research or shared with other researchers. Other researchers will not have your child's name or any identifying information.

Participation and Withdrawal

Participation in this study is voluntary. Your child may withdraw at any time by contacting Sarah Evans of Fors Marsh Group at pi@forsmarshgroup.com or 571-858-3757.

Your child does not have to answer any question that he or she does not want to answer. Your child will receive the incentive for his or her time in the interview even if he or she chooses not to answer some questions.

We advise you to keep a copy of this consent form for future reference. If you would like a copy for your records, you may request a copy from the research team.

If you have any questions or complaints about your child's rights as a research subject, please contact the [CDC IRB] at [email].

Consent - Please complete and sign.

I, _____, have read this form and agree to allow my child to

[PRINT NAME]

participate in this study.

[SIGNATURE]

[DATE]