

Focus Groups Among Adults with or Caring for Individuals with Congenital Heart Defects (CHD), Muscular Dystrophy (MD), and Spina Bifida (SB).

Request for OMB approval of a New Information Collection

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Supporting Statement B

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The data collection will not involve any statistical methods and no statistical generalizations will be made beyond the particular respondents.

1. Respondent Universe and Sampling Methods

To participate in the focus groups, participants must meet the following primary inclusion criteria:

- Be eighteen (18) years of age or older
- Be diagnosed with one (1) or more of the following birth defects or developmental disabilities OR care for a person with one of the following conditions
 - Congenital Heart Defects (CHD)
 - Muscular Dystrophy (MD)
 - Spina Bifida (SB)
- Live within the United States
- Have the ability to speak and read with proficiency in English

Potential participant pools for each condition will be developed using the following strategy:

- For the CHD focus groups, the contractor KRC Research will use the CDC-provided list of individuals who had previously participated in CH STRONG and agreed to be recontacted. KRC will use the CDC-provided list and publicly available records to trace each potential participant provided on CDC's CHD list to confirm their contact information and vital status. This list will form the basis for CHD focus group participation.
- For the MD and SB focus groups, the contractor KRC Research will begin by using pre-recruited panelists from their recruitment partners. These participants will have already opted into extensively maintained lists of people who are open to participating in focus groups. However, given the relative rarity and challenges of MD and SB, KRC Research expects to supplement that panel by finding additional participants (as described in the bullet below).
- In cooperation with recruitment partners, KRC will also conduct a targeted recruitment effort based on reaching individuals diagnosed with MD or SB and their caregivers through trusted sources like care groups, advocacy associations, online condition community groups, and influencers in their communities. KRC will collaborate with an internal analytics team to identify locations where condition-specific conversations are occurring. KRC recruiting partners will then use that list of locations to reach these communities and recruit individuals who may meet

participation criteria, screen them to ensure they are qualified, and invite them to the participant pool. As word of mouth is one of the best ways obtain participation from hard-to-reach audiences, KRC also plans to partner with owners of the online support groups, bloggers, podcasters, and others to promote the recruitment effort. From those recruited into the participant pool, KRC will employ snowball recruiting to source additional individuals from within their communities.

Of the individuals identified from these efforts, KRC will direct a recruitment partner to distribute, via phone call, traditional mail, or electronic mail, an invitation to be screened as the first step to joining our participant pool (Attachments 1, 2, 8, 9, 10, 11, 19, 20, 21, 22). When an individual receives the invitation to screen, they will complete a screening questionnaire (Attachments 3, 12, 23) online or via a phone in a call with a staff member from one of KRC's recruitment partners. Individuals will be qualified based on their responses to the screening questionnaire and the recruitment quotas set for recruitment.

Within the parameters of the defined focus group compositions, participants will be selected to maximize variability across regions in the US, urbanicity, gender, race, ethnicity, employment status, and educational attainment.

Selected participants will be invited to confirm their interest and availability in participating (Attachments 4, 13, 24). Once confirmed, a confirmation message will be sent to the participants with logistical information, as well as the date and time of the focus group (Attachments 5, 14, 15, 25, 26). To incentivize participation in line with market research recruitment standards for this audience, focus group participants will be offered \$75 as a token of appreciation for their time. If, at the time of invitation, the participant declines to participate, a replacement participant will be selected from the pool of eligible participants.

2. Procedures for the Collection of Information

Upon the completion of tracking and tracing the individuals included on the CDC-provided CHD list, KRC will compile and return said list with updated contact information and vital status.

After completing screening, forty-six (46) focus groups will be conducted that will last no more than ninety (90) minutes each. Prior to each focus group, participants will be required to sign and date a consent form that outlines the details about the focus group, such as privacy and incentive (Attachment 30). Participants will be sent the form electronically and required to sign it electronically. Project records will be maintained in accordance with the federal record retention requirements. Additionally, at the start of each focus group, respondents are given a brief verbal reminder of the consent form details.

Data will be collected by the CDC communications research contractor, KRC Research. Focus groups will be conducted over the internet with a professional moderator who will guide a real-time discussion but will also allow the direction of the discussion to take its own course. For online focus groups, participants will share aloud or type on screen, and all other participants will be able to hear and read the conversation. Participants may be physically located in different parts of the country within one group.

Trained moderators from the contracted firm KRC Research will conduct all focus groups as well as oversee recruitment and screening. The moderator will use a semi-structured discussion guide for all focus groups (Attachments 6, 16, 27). The questions in the guide will explore the individuals' experiences, barriers, and facilitators related to their or their care recipient's respective condition and clinical care.

Focus groups will be audio recorded to capture the content of the discussion. Recordings will be transcribed for analytic purposes in support of the development of a report. Field notes will be taken during the interviews to capture key quotes or expressions. No recordings or transcripts with personally identifiable information will be shared outside of the KRC Research team conducting and analyzing the focus groups.

3. Methods to Maximize Response Rates and Deal with No Response

To ensure high participation rates, we will periodically recontact scheduled participants leading up to their focus group date to ensure that they are still interested and available. If a potential participant declines, we will quickly find a suitable replacement from the pool of approved participants. As mentioned earlier, this pool of approved participants will intentionally be larger than the minimum number needed to recruit the focus groups in order to ensure there will be a sufficient number of recruits to pull from for each focus group.

By design, all potential participants in these focus groups will be drawn from a panel of individuals who have opted in to participate. To maximize and encourage response, the screening questionnaire (Attachments 3, 12, 23) is intentionally designed to collect only the minimum amount of information needed to determine the qualifications of participants, and quotas for several demographic variables are "loose," meaning that there is no exact number of individuals who must be recruited with certain criteria. (For example, recruiting "up to 4" urban residents, rather than "exactly 4.") This may reduce the number of individuals who will be screened.

It is sometimes the case that participants do not sign in on time for their focus group, either for unexpected personal reasons, forgetfulness, or other reasons. To minimize the instances of this occurring, respondents are given several days' advance notice of the focus group and are sent reminder emails the day before and day of the focus group. Over-recruitment for a focus group is also utilized in case not all participants arrive to attend the group.

At the beginning of each focus group, participants will be reminded that their participation is voluntary, they do not need to answer any question that they are not comfortable answering.

4. Tests of Procedures or Methods to be undertaken

Test emails of communications to participants will be sent by KRC Research or their partners ahead of sending any large distribution. Screening processes will be tested by KRC Research to ensure they are functional, accessible, and reliable prior to participant invitation to be screened. Video conferencing platforms to be utilized for the focus groups will be tested and validated by KRC Research prior to the

focus groups. KRC Research will study and conduct a trial-run of the focus group discussion guides prior to conducting the focus groups.

5. Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data

The following individuals are working under contract with CDC and have been consulted throughout the development and design of this data collection. These individuals will lead the interviews once the package is approved.

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