

Attachment 6: CFS Patient Perspective Sampling Plan

Focus Groups

We plan to conduct four focus groups with 8-10 people in each focus group for a total of 32-40 participants. Focus group participants will be persons who have received a chronic fatigue syndrome (CFS) diagnosis by a physician. The age range for eligibility is 18-55 years. Fieldwork, a national marketing research company, will recruit the focus group participants and provide the facility for the focus groups.

Fieldwork has 12 locations in the United States with 16 focus groups facilities. Each site is specifically designed to conduct focus groups and includes up-to-date technology. For example, each site is capable of holding multiple focus groups, which can be either audio- or video-taped. Fieldwork also specializes in recruiting focus group participants. Recruiters are highly trained in ethics, security, and best practices. Fieldwork as an organization has experience with both the government and private sector.

The CFS focus groups will take place at Fieldwork facilities in Denver, Colorado (2 focus groups) and Orange County, California (2 focus groups). Fieldwork offices will also conduct recruiting for the focus groups in each location.

Fieldwork will use the flyer (Attachment 3) to recruit for the CFS focus groups from their internal database. Specifically, Fieldwork will use the flyer in an email for recruitment and has experience in this type of recruitment method, which consists of using email and social media (Facebook and Twitter). Using email (for Fieldwork internal database only) along with Facebook and Twitter (see below) to recruit people is now the standard in today's Internet age.

CDC has worked with Fieldwork to finalize a study screener (Attachment 5). This screener is only used once interested people have responded to recruitment methods and contacted Fieldwork about the CFS focus groups. The screener is needed to identify qualified participants and prevent habitual focus group participants from gaining access to the focus group (i.e. persons who participate in focus groups on a regular basis). The screener was adapted from a Fieldwork template to recruit CFS/ME patients.

Fieldwork will use the following sample plan to recruit 40 CFS participants:

- In order to seat 10 people in one focus group, 12 CFS participants will be recruited (20% over targeted number).
- Fieldwork will start with their internal databases to see if CFS is a flagged condition. If so, Fieldwork recruiters will contact those persons using the focus group flyer (Attachment 3) and administer the study screener (Attachment 5) to identify qualified participants.
- If CFS is not a flagged condition (for example, if the condition CFS is not a line item in the Fieldwork database and they have not done previous studies with CFS), Fieldwork will send out the focus group recruitment flyer via email to other persons in its database.

This sample would include persons who have self-identified as having a chronic medical condition that is associated with fatigue.

- If the first two recruitment methods do not result in fulfilling the sample, Fieldwork will contact physicians in its database. It will send the focus group recruitment flyer to physicians and ask them to inform patients about the focus groups. Physicians will not be asked to provide names to Fieldwork; instead, interested persons will be asked to contact Fieldwork directly and then given the focus group screener.
- Finally, if needed, Fieldwork will use its social media resources (Facebook and Twitter) to send out the focus group flyer. Interested persons will be asked to contact Fieldwork and then be given the focus group screener.

At no time will names of potential focus groups participants be provided to CDC. Additionally, once the number of focus group participants obtained (12 recruited persons for each focus group), Fieldwork will suspend recruitment.

Individual Interviews

CDC will be conducting 12 individual interviews in addition to the focus groups. Interviews are being conducted with CFS patients who are unable to physically leave their residence due to effects of the illness. These patients will be recruited through CFS patient organizations using the interview flyer (Attachment 4). CDC CFS Program works with different CFS patient groups and will give the Aspen Group, the contractor for the project, contact information for CFS patient organizations. Aspen will contact the patient group representatives and give them the interview recruitment flyer. The CFS patient organizations will reach out to potential interview participants and ask them to contact Aspen for information about the individual interviews. At no time will names of potential participants be provided to CDC. All persons interested in participating will call the Aspen Group to schedule an interview timeslot.