

Attachment C16: Interview Recruitment Letter, Clinic Staff

[Date]

[Name]

[Address]

[Phone Number]

Dear [Name],

The Spina Bifida Association (SBA) and the Centers for Disease Control and Prevention (CDC) are interested in learning more about care coordination in spina bifida clinics. To accomplish this, we are inviting staff members from a small selected group of spina bifida clinics to share their experiences with care coordination.

Battelle Centers for Public Health Research and Evaluation has been contracted by CDC to conduct the data collection for this project. Your clinic director has provided us with a list of staff members who are familiar with care coordination and might be interested in participating in this project. The enclosed brochure provides information about the project. One of our staff members will soon be contacting you by phone or e-mail to invite you to participate.

Your participation would involve an in-person, one-on-one, informal interview regarding care coordination at your clinic. Topics of discussion will include the goals of care coordination as practiced at your clinic, the components and procedures of your care coordination activities, the role of care coordinators, and perceived clinic and patient/family satisfaction with care coordination services. The interview, which should take between 30 and 60 minutes, would be scheduled at your convenience during Battelle's visit to your clinic on **[days, dates]**. Your participation is voluntary, and any information that you may choose to provide will not be identified with your name or other identifying information. Information you may choose to provide will not be shared with your supervisor in an identifiable way.

Your participation is crucial to the success of this study. Thank you in advance for your interest in and assistance with this project. If you have any questions or would like further information, please contact me at 770-451-0882 x20.

Sincerely,

Jennifer Brustrom, Ph.D.

Battelle Project Director

Attachment C17: Interview Recruitment Flyer, Clinic Staff

Who:

The Centers for Disease Control and Prevention (CDC) has contracted with Battelle Centers for Public Health Research and Evaluation to conduct one-on-one interviews with staff members of this clinic. Battelle is a private non-profit research firm.

What:

We will conduct ½ to 1-hour interviews, using a standardized interview guide, with **selected staff** of this clinic. You will be encouraged to share your professional experience working with patients with spina bifida and their families and care coordination services.

Topics for discussion will include:

- The goals of care coordination as practiced here
- The components and procedures of your care coordination activities
- The role of care coordinators
- Perceived clinic and patient/family satisfaction with care coordination services

When/Where:

The Battelle study team will be at the clinic **[Day, Date] and [Day, Date]**. We invite you to schedule an interview session at your convenience during that period. Interviews will take place in the conference room.

Why:

Sharing your opinions and your clinic's experiences with care coordination will provide CDC with information that may be useful to other clinics, local organizations, and national organizations as they strive to improve services for individuals with spina bifida

How:

To schedule your interview, call Darcy Holtgrave, Battelle Project Coordinator, at 800-444-5234 ext. 109 or 314-339-5234 ext. 109.

Attachment C19: Interview Confirmation Letter, Clinic Staff

[DATE]

[Name]
[Address]
[City] [State]

Dear [Dr./Ms./Mr.] [Name]:

Thank you for agreeing to participate in an interview about coordinating care for individuals with spina bifida. Your thoughts and experiences as a health care provider are crucial to this study.

- You are scheduled to be interviewed on [DATE, TIME].
- The interview will take place at [Clinic location]

We will call you a few days before the interview to answer any questions you may have and to confirm your participation. Your participation is extremely important to CDC. If for any reason you will be unable to participate as scheduled, please contact me at 1-800-444-5234, ext. 109 so that we may reschedule you.

Sincerely,

Darcy Holtgrave
Battelle Project Coordinator

Attachment C20: Interview Consent Form, Clinic Staff

Flesch-Kincaid Grade Level: 12

The Spina Bifida Care Coordination Study Consent to Complete a Staff Interview

What is the purpose of this study?

The Spina Bifida Association (SBA) and the Centers for Disease Control and Prevention (CDC) are interested in learning the extent to which care coordination exists in spina bifida clinics and whether this function makes a difference for families and clinic staff. CDC has contracted with Battelle Centers for Public Health Research and Evaluation, a nonprofit research organization, to carry out a study to (1) examine the extent to which care coordination in spina bifida clinics is perceived as effective, (2) identify perceived barriers to providing care coordination in spina bifida clinics, and (3) identify potential best practices related to providing care coordination in spina bifida clinics.

Battelle will interview a small number of health care professionals (clinic directors and staff members) who provide care to patients with spina bifida and other services to them and their families. We believe that these individuals can provide valuable information and opinions about the clinic's care coordination functions. Battelle will also conduct focus groups with family members of patients with spina bifida to obtain information about care coordination from their perspectives.

What will I have to do if I am in this study?

You have been invited to take part in an informal interview because of your professional experience working with patients with spina bifida and their families and your familiarity with care coordination services. The interview will take between 30 – 60 minutes of your time. The interview will cover issues such as (1) the goals of care coordination in this clinic, (2) the components and procedures of care coordination in this clinic, (3) the role of the care coordinator(s), and (4) perceived clinic and patient/family satisfaction with care coordination services.

The interviews will be audio-recorded, and we will take detailed notes.

What are the risks to being in this study?

You may be uncomfortable talking about your professional experiences working with patients with spina bifida and their families.

What are the benefits to being in this study?

You will not benefit directly from being in the study. However, sharing your opinions and your clinic's experiences with care coordination will provide CDC with data that may be used to help other clinics, local organizations, and national organizations that strive to improve services for persons with spina bifida.

What about my privacy and the confidentiality of the information I provide?

All information gathered in this study will be kept private unless otherwise compelled by law. We will not include names or any personal identification in our notes or in any written reports. All data will be presented in the aggregate. We will permanently erase all audio recordings when the data collection is over.

Do I have to agree to be interviewed?

You are free to choose to participate in this study or not. If you do not want participate it will not affect you or your employment in this clinic in any way. In addition, if you do agree to participate you may refuse to answer any of the questions asked. You may stop the interview at any time.

Who do I speak to if I have questions about this study?

If you have any questions about this study, you may call the Battelle Project Coordinator, Darcy Holtgrave at 1-800-444-5234 ext. 109 or 314-993-5234 ext 109. You may also call any of the project team members if you have any questions or concerns. Contact information for project team members is on the next page.