

Attachment C2: Focus Group Recruitment Brochure

What about my privacy?

All of your comments will be kept private. Your specific comments will never be associated with your name. The report from the discussion group and the overall report for the study will only have information from the groups as a whole, not individuals.

What are the risks in this study?

You may feel uncomfortable talking about your personal experiences and opinions in a group situation.

What are the benefits in this study?

You will not benefit directly. However, sharing your experiences and opinions may be used to help improve services for patients with spina bifida and their families.

What is care coordination?

By "care coordination" we mean some kind of planning and organization for the care that a person with spina bifida receives.

Why is care coordination important for spina bifida?

Spina bifida can affect almost all parts of a person's life. A person with spina bifida often gets care or help from many different kinds of specialists. Planning and organization of care may help families. Care coordination may make patients and families feel more satisfied with the care they get.

What is the goal of this study?

The goal is to find out what families and clinic staff think about how well care coordination is provided in spina bifida clinics.

How can I sign up to take part in a discussion group?

Call Darcy Holtgrave, Battelle Project Coordinator, at 1-800-444-5234, extension 109

or

complete the response form and mail or fax it to Darcy.

How can I get more information about this study?

If you have any questions or concerns about this study, please do not hesitate to contact:

Jennifer Brustrom, Ph.D.
Battelle Project Director
Battelle Centers for Public Health Research and Evaluation
Telephone: 770-451-0882
Email: brustromj@battelle.org

or

Judy Thibadeau, M.N., R.N.
CDC Project Coordinator
McKing Consulting Corporation for
Division of Human Development and Disability
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention (CDC)
Telephone: 404-498-3559
Email: jthibadeau@cdc.gov

What will be done in this study?

There are ten clinics across the U.S. that will be part of this study. At each clinic, Battelle will talk with both families and clinic staff about care coordination. To talk with families, Battelle will hold a discussion group at each clinic. People who are asked to be in the discussion group will all be caregivers for a child with spina bifida. People who take part in the discussion group will be given \$40. Light refreshments will be provided at the discussion group.

If I decide to be in this study, what will I have to do?

If you are interested in being in this study, a project coordinator will call you. The coordinator will ask you a few questions to figure out if you are eligible. If you are eligible, you will be invited to take part in a discussion group. The discussion group will last about 2 hours. A coordinator will tell you where to go and what time to get there. There will be only one discussion group for your clinic.



The Spina Bifida Care Coordination Study

What is this study about?

This study is about how care coordination is provided at spina bifida clinics.

Who is doing this study?

Battelle Centers for Public Health Research and Evaluation is doing this study. Battelle is a non-profit private research organization. Battelle is partnering with the Spina Bifida Association (SBA) for this study. The National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC) is sponsoring this study.

CPHRE
Centers for Public Health Research and Evaluation
Battelle

What will the focus group be about?

The conversation will be about your experience and opinions as a caregiver for a child with spina bifida. There will be specific topics covered. The conversation will include topics like how you get different kinds of care, who helps you get that care, and how satisfied you are with this help.

Do I have to be in this study?

You are free to choose to be in this study or not. If you decide not to take part, it will not affect you, your child, or your child's care at this clinic or any other clinic. Nothing you say during the discussion group will have a negative result on your child's care.

If you decide to take part in the discussion group, you are free to stop being in the conversation at any time. You will not have to answer any questions you do not want to.

Attachment C3: Focus Group Recruitment Letter

/Date]

Dear Caregiver,

The Spina Bifida Association (SBA) and the Centers for Disease Control and Prevention (CDC) are interested in learning more about care coordination for individuals with spina bifida. We invite you to participate in a discussion group to talk about your experiences and opinions as a caregiver of a child with spina bifida at [clinic name].

- The discussion group will be held at on [date] from [time] to [time]
- Light refreshments will be served
- You will receive \$40 for your time

The discussion group will be organized by Battelle, a non-profit private research organization, and will include 8-10 caregivers of children with spina bifida. The discussion will include topics like how you get different kinds of medical care, who helps you get that care, how effective the help is, and how satisfied you are with this help.

We hope you will join us, because sharing your experiences and opinions may help improve services for patients with spina bifida and their families.

If you are willing to participate in the discussion group, please call Darcy Holtgrave, Battelle Project Coordinator, at 1-800-444-5234 ext 109 or complete the enclosed response form and mail or fax it to Darcy by [day, date]. Darcy's fax number and address are at the bottom of the form.

Thank you very much for your help with this project. If you have any questions or need more information, please contact Darcy at 800-444-5234, ext. 109 or 314-993-5234 ext 109.

Sincerely,

Jennifer Brustrom, Ph.D.
Battelle Project Director

