

Final Report National Children's Study Focus Groups

Prepared for:

**Danelle T. Lobdell, Ph.D.
U.S. Environmental Protection Agency
National Health and Environmental Effects Research Laboratory**

**Prepared by RTI International under contract 68-D-02-069:
Linda Dimitropoulos**

RTI Work Assignment Leader: Linda Dimitropoulos
RTI International
6110 Executive Boulevard, #420
Rockville, MD 20852
Telephone: (301) 230-4691
Fax: (301) 230-4647
E-mail: emarks@rti.org

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Final Report

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Prepared by:

Approved by:

Linda Dimitropoulos
RTI Work Assignment Leader

Jerry Rench
RTI Program Manager

RTI Project No. 08601.000.001.007

Prepared for:

EPA Work Assignment Manager: Danelle Lobdell

Attn: Ms. Frances Legg
U.S. Environmental Protection Agency
RTP-Procurement Oper. Div (D143-01)
4930 Old Page Road
Durham, NC 27709

Prepared by:

RTI Work Assignment Leader: Linda Dimitropoulos

RTI Contracting Officer: Don K. Enichen
Office of Research Contracts
Research Triangle Institute
P.O. Box 12194
Research Triangle Park, NC 27709-2194
Telephone: (919) 541-6634
Fax: (919) 541-8354
E-mail: enichen@rti.org

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1. Introduction

The primary objective of this work assignment was to develop a better understanding of the issues affecting the recruitment and retention of expectant parents and other selected stakeholders (parents, healthcare providers and community organizations) for the National Children's Study. The tasks undertaken to achieve this goal included reviewing and revising a moderator's guide; developing a site selection and recruitment plan; and conducting focused discussions with groups of stakeholders in areas across the United States and analyzing the data captured. The goal was to identify effective strategies and techniques that can be used to recruit and retain participants in the NCS.

The focus groups were conducted at 10 sites across the United States to gather insights from the following five stakeholder groups as described below:

- Expectant parents (10 groups)
- Parents of children without disabilities (2 groups: one with parents of children aged 3 to 5 and one with parents of children aged 6 to 11)
- Parents of children with disabilities (2 groups: one with parents of children aged 3 to 5 and one with parents of children aged 6 to 11)
- Health care providers (2 groups: one pediatric and one obstetric)
- Community organization representatives (2 groups)

This report includes a complete qualitative analysis on the data obtained from the focus groups and our recommendations for preferred strategies and techniques for recruiting and retaining expectant mothers into the NCS.

1.1 Distribution of the Stakeholders across the Groups

Group sessions were allocated across each of the five main NCS stakeholder groups. The largest number of sessions, 10 out of 18, was dedicated to exploring issues among groups of expectant mothers. Expectant parents were considered to represent the initial recruitment pool for the NCS.

Each of the 10 expectant parent focus groups was configured to take advantage of demographics that are believed to impact recruitment philosophies. Age, education, type of health care provider, geographic region and living area (rural, urban, suburban) are all factors thought to affect beliefs about recruitment and retention of expectant mothers. In addition, we were interested in getting the perspective of significant others, so one of the groups was comprised of expectant couples rather than just expectant mothers.

Since women who are 35 years or older may have different concerns than women who are younger than 35, we included one group comprised of expectant mothers over 35, and a second group comprised of expectant mothers under 35. To look for differences due to level of education, we included two groups comprised of expectant mothers with a high school education

or lower, and two groups comprised of expectant mothers with at least some postsecondary education. To provide for focused questioning regarding health care provider, three types of health care facilities were selected for special emphasis: a doctor's office, a health care clinic, and a maternal/fetal specialty clinic. Finally, the groups were distributed throughout urban, suburban and rural areas across the ten federal regions.

The next largest group consisted of groups of parents, to investigate issues of ongoing participation among members of an aging cohort. There were four groups of parents represented in the focus groups. Two of those groups were selected from a pool of parents of children with disabilities to gain insight into the particular concerns of that special group. The remaining two parent groups were recruited from a pool of parents of children without disabilities. In addition, there were two groups composed of health care professionals from either pediatric or obstetric practices. The purpose of recruiting the health care providers was to gain insight into the concerns of participating health care providers, who may be called upon to allocate some of their own time and the time of office staff to assist in the study. Finally, two groups were comprised of representatives of community organizations. Strong support from community organizations is thought to be instrumental in recruitment and retention of participants within a longitudinal study. These groups explored the concepts of community involvement and support. Two of the sites selected for the expectant mothers' groups also hosted groups comprised of the remaining four stakeholder groups.

1.2 Focus Group Procedure and Analysis Approach

Two study administrators were assigned to each of the focus groups. One was the moderator, whose responsibility was to guide each discussion group through each of the topics listed in the moderator's guide. The other was the note-taker, whose responsibility it was to record participant observations during the focus group session. A training session for the moderators and note-takers was held at RTI in Research Triangle Park.

Study administrators welcomed participants to the group and read through a scripted set of instructions. These instructions were designed to welcome participants to the group, introduce the moderator and note-taker to the group, review group ground-rules, and briefly describe the participant's task.

“What we are doing today is part of a project for the U.S. Environmental Protection Agency. This research will help us understand the best way to recruit and retain people like you in a large study of environmental health and safety risks to infants and children. The large study is called the National Children's Study, which we will refer to as the “NCS.”

The NCS plans to recruit about 100,000 children into the study. Observation will begin as early in pregnancy as possible, and children will be followed until at least age 21. This effort is being developed through collaboration between government and non-government agencies. This study will serve as a resource on the impacts of the environment and other factors on children and families, and will help answer questions that may arise in the future.”

Once group instructions were read, the participant's informed consent forms were distributed, signed, and returned to the study administrators.

The relevant focus group topics were presented to each of the stakeholder groups. The major areas for discussion across all stakeholder groups included generating interest, logistics of participation, and maintaining interest. The first part of the group was focused on gaining information about where people thought it best to hear about the NCS and what information they would want to be able to make a decision about whether or not to participate. The second part of the group focused on a potential schedule for participation as well as the reactions of the group to the collection of biologic samples including blood, urine, hair clippings, nail clippings, buccal cells, baby teeth, breast milk, meconium, placenta, and umbilical cord blood. All groups were presented a chart that described the following proposed tasks and schedule:

- During pregnancy: 1 home visit, 2 office visits.
- Year 1: 4 office visits
- Year 2: 2 office visits
- Years 3-6: 1 office visit
- Years 7-21: 1 office visit every other year.
- Home visits: every few years to collect samples of substances from your home, such as tap water or house dust samples.
- Each office visit will take about 1 hour.
- Provide some type of biologic samples, such as blood and urine, at each office visit.

Finally, the groups were asked to think about what would keep them interested in the NCS and whether they thought incentives would be appropriate in return for participation. All groups were shown a hand card that listed the following incentives for the group's considerations: coupons, gift certificates for infant supplies, school supplies, child photos, toys, children's clothing, postage stamps, donation to a charity in your name or electronic equipment such as a palm pilot, a beeper, or a cellular phone.

Note-takers recorded participant quotes, key points and themes in each question area, and made a tally of participant responses to key questions. Upon completion of the focus group interview, the note-taker and focus group moderator met to discuss the focus group interview session. The two discussed salient themes while the discussion group's input was still fresh in their minds, and reviewed the text of the note-taker's observations for accuracy. The note-taker then drafted a summary of the notes soon afterwards, and again reviewed the completed summary for accuracy. This process of tallying participants' answers to specific questions and distilling prevailing themes for each discussion group was the first level of data analysis.

The second level of analysis consisted of a note-based qualitative analysis with audiotaped backup of the note-taker data sheets.

1. Review note-taker data sheets from all sessions at one time;
2. Review note-taker data sheets from all focus group interview sessions in a question-by-question iterative method;
3. Compare primary themes identified by the moderator and note-taker for each question among interview groups;
4. Develop an integrating paragraph for each question, describing themes that were consistently discovered across focus group interviews;
5. Select key quotes that were typical of the primary themes identified.
6. Analyses are presented to focus group moderators and note-takers for review to ensure that themes were not over- or under-interpreted.

Analysts developed common rubrics for coding answers to individual questions. They went through each of the summaries to identify common themes, selected quotes that described those common themes, and tallied the frequency of responses to selected questions. After conducting a quantitative tally of answers to specific questions, analysts integrated findings into an overall synthesis of results.

2. Expectant Parent Groups

The characteristics of each of the expectant parent groups that were conducted are shown in **Table 1**.

Table 1. Sites Selected for the Expectant Parent Focus Groups

Group	Site	Government Region	Mother's Age	Mother's Education	Health Care Provider	Geography
P-1	Farmer's Branch, TX (Dallas area)	6	<35	Mixed	Mixed	Suburban
P-2	Philadelphia, PA	3	≥35	Mixed	Mixed	Urban
P-3	Sioux Falls, SD	8	mixed	≤ HSD	Mixed	Rural
P-4	St. Louis, MO	7	mixed	> HSD	Mixed	Suburban
P-5	Research Triangle Park, NC	4	mixed	Mixed	doctor's office	Suburban
P-6	Chicago, IL	5	mixed	Mixed	health clinic	Urban
P-7	Bellevue, WA (Seattle area)	10	mixed	Mixed	maternal or infant specialty clinic	Dependent on clinic
P-8	Los Angeles, CA	9	mixed	≤ HSD	Mixed	Urban
P-9*	Burlington, VT	1	mixed	> HSD	Mixed	Rural
P-10**	New York, NY	2	mixed	Mixed	Mixed	Urban

* Group P-9 includes five expectant parent "couples"

** Group P-10 is comprised of expectant parents who do not have health insurance and are considered a "hard to recruit" group.

2.1 Expectant Parent Group 1: Under 35 Years

Expectant parent group one was held in the Dallas, Texas area (EPA region 6). The recruitment criteria were that the participants be pregnant women, under 35 years of age, from mixed educational backgrounds who receive their health care from a variety of health care providers and who currently live in a suburban area. A national focus group firm that had a local office in this area recruited the participants. Facility staff recruited and screened participants by making telephone calls to potential participants selected from their proprietary database. Eleven participants were recruited but only three attended due to an ice storm in the region. All three group members were white.

2.1.1 Getting You Interested

The group members suggested that the doctor's office, newspapers, magazines and web sites as places that they might learn about the study. One woman suggested radio advertising but said that might be expensive. Another woman indicated that since she has been pregnant she watches a lot of TV commercials and suggested that may be a good way for women to learn about the study.

Regardless of the communication medium, the women agreed that they would want to know some key pieces of information before they would participate. For example,

- Would the child be tested?
- Would drugs be involved?
- Who is eligible and what would be expected?

The women also said that they expect to read the risks of participation in the fine print. The women also indicated that they would want to know if they had to travel to an office or a lab and they indicated that they did not want to travel too far from their home. One woman suggested that a packet of information be sent out to potential participants who call in response to an advertisement. That would allow for some private time to consider the information.

All of the women agreed that they would want to know exactly what was being done to their child and would want this to be totally private and confidential.

Initially all three women agreed that it would be equally important that the NCS directly improve the health of their child and contribute to science and overall public health, but after some discussion all three women agreed that the health of their child would be paramount. At this point one woman said that she didn't think she would participate in this study.

The group indicated that they would be excited about the prospect of college tuition at the very end of the study. They also suggested that there be a monetary incentive each year. In addition they would like to see progress reports and medical reports to see how their children were doing and what researchers were finding out.

The idea of a spokesperson or celebrity was not compelling, but the women indicated that they would like to speak with someone who had already participated in the study. Some of the women said that it would make them feel good to know that the research was benefiting their child as well as the health of the general public.

The women didn't think they would be more interested in participating in the NCS if they were pregnant, but they would be more concerned about what participation entailed. If they were pregnant at the time they were being recruited the women indicated that they would have to know a lot about the study before agreeing to participate. They would want to see statistics on diseases.

2.1.2 Time Commitment and Data Collection Activities

After presenting the women with the recommended list of office visits and types of specimens that might be collected at each visit, many of the women suggested that the visits be combined with the well-child checkups that they would have to attend. Otherwise, the women indicated it might be difficult to squeeze many visits into the first year schedule because there are so many well-child visits. After the child was older, it would be easier to accommodate the schedule. In addition they would like to see the same study employees each time rather than a strange new person each visit. The women did not think that the length of time required for each visit was an issue as long as they are compensated.

The women also said that if blood were to be taken from their children then they would prefer a finger stick rather than blood drawn from the arm. They agreed that children don't like to have their blood drawn from their arms.

All of the women indicated that it would not be a problem to complete a 20-minute questionnaire several times a year. They suggested 3 to 4 per year via Internet or e-mail. Ideally, they would like to complete the survey during the office visit or the home visit to collect samples with Internet or e-mail the second choice and telephone interview the third choice. They did not recommend a mail survey because they "have enough paperwork and it would get placed in the stack if it were mailed." They did indicate that an incentive would greatly increase the chances of getting the mail survey returned.

None of the women had an issue with someone coming to the home to collect water or house dust samples. They would like some notice before the person arrived. All thought that once or twice a year would not be a problem.

The group members had some concerns about the collection of biological samples especially baby teeth, breast milk and blood. One woman said that baby teeth have tremendous sentimental value and she would not be willing to part with them. Another member had concerns about breast milk since she does not plan on breastfeeding her child. She asked if she would be provided a pump to pump the milk. All of the group members had concerns about blood samples. One member said that the children have so much blood drawn from their regular visits additional draws would be too much. She also commented that her children are petrified of needles.

None of the group took issue with genetic testing as long as they got the results back, even if they indicated a genetic disorder. The women would also like tests to be done in the least invasive way possible.

All agreed that they would like to be contacted by telephone or by mail. They suggested using reminder postcards so that they could plan ahead better. In addition, all agreed to provide contact information including the name and number of relatives or friends but asked that they be given the chance to let them know that someone might be contacting them. One woman suggested that participants could send study directors a postcard when they move so that they would not need to give out contact information.

2.1.3 Keeping You Interested

The group did not like the list of suggested incentives. They thought that these items might be more appealing to a first time mom. They pointed out that women who already have children already have infant supplies and school supplies. The women also thought that the incentive list was geared toward low-income women and did not think that these incentives would appeal to women from middle and upper-middle class backgrounds. One woman said that electronic equipment might be nice but that a cable TV discount and Internet access are "not real incentives." They thought a combination of gifts and money would be appropriate. They really like the idea of college funds. One member also suggested that a good incentive would be a field trip for all adolescent participants.

All of the women thought they should be paid money for samples such as hair, urine or fingernails. One member suggested that a small incentive be paid for each office visit and then a large incentive at the end of the study. Another member suggested that the child be paid \$20 at each home visit. In addition to money, the group suggested non-monetary incentives such as summer camp, college funds, or field trips.

All of the women agreed that they would not feel coerced if they received any of the incentives discussed. In fact, the women commented that they would not even feel obligated if a "certain large sum of money" were offered. They all agreed that they could always refuse to participate.

The women indicated that they would like to receive medical results after every office visit. However, they recommended a newsletter be sent once a year to inform them of study news even though they admitted they may not read it. The newsletter should include results and statistics from their local area. The women all adamantly opposed the idea of attending local meetings.

The information that they would not want to receive includes other people's results or information. They would not want to know any statistics that did not pertain to their child and they would want the option to know about genetic testing. One woman indicated that she would want a follow-up if she were to learn that her child had a disease or problem.

2.2 Expectant Parent Group 2: Age 35 or Older

For the expectant parent group in Philadelphia, Pennsylvania (EPA region 3) the recruitment criteria were that the participant must be a pregnant woman who is 35 or more years of age and residing in an urban area. All participants were from mixed educational backgrounds and received their health care from a variety of health care providers. A national focus group firm with an office in the Philadelphia area recruited 11 participants and 9 attended. The firm made calls to people in their database and then used our screeners to determine eligibility. The group was comprised of seven whites, one African-American, and one Hispanic woman.

2.2.1 Getting You Interested

The first place that the group members recommended as a place where they would like to hear about the study was at their OB/GYN office. Other places the group recommended include the home school association, school association, other health care offices, and day care centers.

- “Can send information home [from the doctor’s office] and take time to read the information.”
- “You could call a number on a pamphlet.”

The group also thought that radio stations, TV commercials, and the Internet are good sources to hear about the study, but all group members agreed that mail and phone are not good sources of information.

- “Hang up on them.”
- “People throw out mail.”

The kind of information that group members were most interested in receiving was about any risks that might be posed to the child. They were also interested in how much time would be required and how confidentiality would be ensured.

- “Will my child be exposed to anything?”
- “Is the mother separated from the child?”
- “Do you have to stay the full 21 years?”

Group members all agreed that it would be equally important to them that the NCS directly improve the health of their child and that their participation would contribute to science and overall public health.

All of the group members agreed that incentives would make them excited about participation. They also indicated that other things that would be exciting would include:

- The potential benefit to the child
- Research results
- Possibly getting on TV

- A scholarship for the child

When probed about whether they would be excited about being in a national study, one person said, “Excited is not the right word.”

When probed about what they thought about a celebrity spokesperson, the group recommended someone who has pregnancy or motherhood experience. The only celebrity name that came up was Kelly Ripa. The group members did not like the idea of the Surgeon General as spokesperson.

- “I am pregnant.... Because I have a common bond to women who are pregnant, the spokesperson should also share that bond.”

The group was probed about whether they would be more interested or less interested because they were pregnant but all agreed that they would need more information on the study before they could make that decision. If they heard good things about the study, they might be interested.

- “Is there lots of testing? Needles?”

The group was probed further to find out how they felt about having a second child participate and they agreed that if everything went well with the first child, they would consider having a second child in the study. One person said that it would not be any harder having two children in the study than having one in it.

2.2.2 Time Commitment and Data Collection Activities

After reviewing the planned number of visits for years one through 21, the group members said that they would be able to deal with the visits, except perhaps the first year. But they also acknowledged that they would be at the pediatrician’s office a lot anyway. They agreed that collecting the study samples during a regular visit to the doctor was a good idea.

- “I’d be able to handle that.”
- “4 [visits] in the first year is a bit much.”
- “Do it during regular visits.”

The group members were very concerned about the details of blood and urine collection. They indicated that it would be important to know who would be taking the samples. All agreed that the children were afraid of needles. They did not want the study to take a test tube of blood from a newborn or put a catheter in to get a urine sample.

Most of the expectant parents in this group agreed that completing a 20-minute questionnaire would not be a problem. The group members preferred to receive the survey either by mail or e-mail rather than over the telephone. Completing the survey by e-mail or mail allows the group members to have control over when they complete the survey. It would be the most convenient method for this group.

Group members were also comfortable with the idea of someone coming to collect dust and tap water from their homes as long as they were given some notice and the collectors are on time. All agreed that one time a year was reasonable. Most agreed that every 3 months, or seasonally, would be acceptable.

- “Comfortable as long as they aren’t judgmental.”
- “Don’t want to sit and wait for someone to come.”

Most of the group members agreed that they would prefer to collect the samples themselves and then send them in or have someone come pick them up. They would like someone to come for the first collection to show them how to do it. The group agreed that they would be willing to collect home samples more often—once a month— if they could use the kit.

All the group members agreed that it would be a “nice incentive” if they were told the results of the dust and water test.

This group did not have a problem with providing any of the biologic samples on the list, except for a few group members who would want to keep baby teeth. They were very concerned about the logistics of taking some of the samples.

- “Is there a representative there during delivery?”
- “I would not want a stranger in the delivery room.”
- “How do they want the urine samples? “
- “Breast milk? If you’re not breastfeeding, how much will they want to pump?”

The question of genetic testing raised concerns about what was involved in the tests and what would happen after the results were interpreted.

- “Is it just a blood test? Is it continuous?”
- “Does your child have to go through more genetic testing if they find something wrong?”
- “Do you get kicked out of the study if something is wrong?”

The group members thought that genetic testing would be acceptable if the researchers were sensitive to how participants learned the results. All agreed that they would want a genetic counselor tell them the results of the testing. Some wanted this counseling to take place even before they were tested.

- “A genetic counselor tells you results not a random researcher from the study.”
- “Could you get a second opinion if they weren’t sure?”

There were mixed responses from the group about how they wanted to be contacted for appointments. Some of the expectant parents favored receiving a postcard or bulk mailing, while others would not trust the mail. All agreed that the telephone was not a good way to contact them and suggested that they contact the researchers instead.

All agreed that they would be willing to give the study a name of a relative or friend in case they moved. They suggested a phone number that they could call if they moved (an 800 number) or contacting the study through the doctor. There was some concern about finding and collecting data from children 18 to 21 because they may be away at college or even married.

2.2.3 Keeping You Interested

After reviewing the list of incentives, participants initially laughed. The group members recommended that the study provide scholarships, discounts on car insurance, savings bonds, percentage of tuition, or a fund for the child. They felt there should be a reward if people stay in the study until the end.

- “If you stay in then you get the money at the end.”
- “There must be something to keep you interested 21 years.”

The group members also thought that children should receive gifts or money every year. Some suggestions included gift certificates for younger children and electronic equipment for older children.

The group members vetoed the postage stamps, donations to charity, school supplies, and coupons for cable TV (unless they got it free.)

The group consensus was that the results of tests and of the study should be mandatory, not an incentive.

When probed further about whether any of the listed incentives were appropriate in return for the collection of biologic samples, all of the group members agreed that there were no appropriate incentives for biologic collection on this list that was presented to them. They would not give blood and urine in return for any of these incentives. Instead the consensus was that the study should give money.

- “[My incentive] is not on this list. Money always talks when time is involved.”
- “The Red Cross sometimes pays \$25 for people to donate blood and they can do what they want with the money.”

All of the group members agreed that participants should receive money. Most agreed that the money should start out as a smaller amount and build to a larger amount at the end of the study. There should be some type of incentive for each visit and something else for the end of the study. The members considered payment for memberships in a health or fitness club, swim lessons, ballet, and gymnastics classes would be good ideas. One group member suggested a fund for the child and another member recommended tuition money that would be available to the child at age 18.

- “Start off low, the longer you stay the more you get.”
- “Child should get it untaxed.”
- “Compensation for each visit.”

The amounts for the cash incentives suggested by group members included \$1,000 per year untaxed or \$5,000 to \$10,000 for all 21 years, depending on what is involved.

The group members all agreed that none of the gifts discussed would make them feel like they had to participate. The group raised the possibility that the study could go bankrupt and jeopardize the funds set aside for late payments to participants.

- “I would want stipulations, a contract that the government would not touch the money [for the child.]”
- “What if the study goes bankrupt after 10 years? Incentives should come every year to avoid study problems.”

This group recommended the use of a toll-free number and a newsletter as good ways to keep them informed. They would like to receive the newsletters quarterly that would include overall study results, information on the number of people in the study, a contact for address changes, reminders about visits, and a phone number to call to get the results of tests. The group thought that it would be difficult to attend local meetings but they also suggested socialization possibilities. “Have a picnic once a year. Families can meet.”

The group members said that there was nothing that they would not want to hear about. They said that they want the results of their child’s medical tests and overall study results. If the study could not interpret their test results, they would fall back on their doctor. If they could not get the results, they would feel “paranoid.”

2.3 Expectant Parent Group 3: Rural, HS or Less

For the expectant parent group in Sioux Falls, South Dakota (EPA region 8) the recruitment criteria were that the participants be expectant women living in a rural area who have a high school diploma or less (no college). Participants were of mixed age and type of health care provider. A local focus group firm recruited 11 participants and 9 attended. The recruiting agency called people in their database and then used our screeners to determine eligibility. The agency reported that it was very difficult to find women who had not received at least some post-secondary education. All nine participants were white.

2.3.1 Getting You Interested

The group suggested that the doctor's office and the hospital were good places to distribute information about the study. Both places present newly pregnant women with packets of information and medical paper work. The group also recommended Parents magazine as another frequent source of information as are newsletters and newspapers. The group indicated that a notice of the study sent by mail might be thrown out as junk mail. The group also agreed that they would be open to an investigator calling to talk about the study but only if they were notified ahead of time by a pamphlet from their healthcare provider. They would want to be sure it wasn't just another telemarketer. The group thought an information booth would be an unlikely place that they would find information about the study.

The kind of information the women would like to learn about through the above sources would include a description of the study that provided enough detail ‘upfront’ to make an informed decision. They were very concerned about how it would impact their family in terms of the timeline and eligibility. There was also consensus that it would be important to know about the risks and benefits associated with participation.

- “Would it be disruptive or something that will be simple?”
- “If it takes too much time may not want to do it.”
- “Most important: Pros and cons, what’s involved.”

Confidentiality and privacy were also a concern. They wanted to be assured that their data would be kept confidential and that their contact information would not be distributed to telemarketers.

- “...records would stay sealed.”
- “Name and number not given to every Tom, Dick and Harry...calling you or sending you stupid crap in the mail.”

There was consensus among group members that it would be more important that their participation in the NCS contribute to science and overall public health than to directly improve the health of their child.

- “It’s important to help somebody out not just my child.”
- “Don’t want it to be detrimental to my child.”

The group indicated that they would be excited about the prospect of participating in research that would help others medically. It is important to know that the information would be out there to benefit all children; to be making a contribution to the state. They also thought it would be exciting to be part of a large national study.

The group thought that the idea of a spokesperson or celebrity would be all right if the person was credible. The women indicated that a female celebrity with children would be good although they could not recommend anyone in particular. They also recommended that the person know something about kids and their health possibly a doctor or teacher or someone affiliated with children’s organizations. The person would have to be someone who is trusted and believable. They also mentioned that the doctor should be a natural doctor who prescribes herbs and oils and doesn’t use drugs for childbirth.

The group thought that they would be more interested in participating because they were pregnant. They agreed that child health did not become an issue for them until they became pregnant. No one indicated that they would be less interested in participating because they were pregnant. All agreed that they would be concerned about risks or how the study would affect their child. The group also agreed that the decision to enroll a second child would depend on what was involved with the first child.

2.3.2 Time Commitment and Data Collection Activities

After presenting the women with the recommended list of office and home visits and a general idea of the types of specimens that might be collected at each visit, the women asked what would happen during the visit. Some women had concerns that a small child may not be cooperative for an hour. Some of the other women thought the schedule would be okay and that quarterly visits during the first year was “not bad.”

- “As long as the child has something to do in that hour; two-year olds are busy bodies and they have to have something to do even if the doctor is just talking with the mother the child needs something to do.”

In addition to concerns about the young children, there were some concerns about teens and older children. The women thought that the study would lose some child participants when they became teenagers and that once the children turn 18 there is “nothing anyone can do.” One woman also suggested that when the older children lose interest, they might not answer the questions truthfully.

The group decided that with their busy schedules and because so many parents work full-time and the children are in daycare, office visits would be a burden and that they would prefer more home visits. They questioned whether an hour would be needed for a home visit but agreed that this would be more comfortable and convenient.

Some members of the group did not think that collecting biologic samples would be a problem as long as they received the results. Others wanted more information about what the samples would be used for and what would happen with the results. One woman opposed biologic samples and another indicated that urine would be okay but that she “doesn’t like needles.” Some members of the group thought that the children might be more relaxed if the samples were taken at home and that the children might cooperate better if the samples were taken at home. Other members said that the child will not like to go to the “doctor’s office if it becomes associated with the needles.”

The group thought that any survey they were required to complete should be completed by mail. They also wanted a clear definition of what was meant by “several times a year.” One woman thought it would be best if the survey replaced an office visit. Another suggested that the visit be shorter than one hour.

None of the women had an issue with someone coming to the home to collect water or house dust samples if they could get the results. They would like some notice before the person arrived. All thought that once or twice a year would not be a problem. They suggested a test for toxic mold and thought this was an interesting part of the study. The group did not like the idea of collecting the dust and water samples themselves. They would prefer if a qualified person came to the house. One woman suggested that it would reduce “the margin of error.”

The group members had few concerns about the collection of biological samples and indicated that if it would help others, then it would be okay. The samples that individual women said they would not be willing to provide include:

- Baby teeth
- Placenta
- Umbilical cord
- Meconium
- Breast milk

The group agreed that they would consider genetic testing as long as they got the results. However, if they could not get the results, they would not participate. The group members wanted to know the extent of testing, the methods that will be used and the specific plan for the testing. There were concerns about what the results would be used for and how they would be kept confidential.

All agreed that they would like to be contacted by mail because it is more reliable than telephone. “I might miss the call or not get the message.” One woman suggested e-mail. In addition, all agreed to provide contact information including the name and number of relatives or friends. They would also like a number to call the study team.

2.3.3 Keeping You Interested

The initial comment was “How much is this going to cost us?” The group added to the list of items recommended as incentives as follows:

- Coupons to the grocery, pharmacy, infant supplies, diapers, laundry detergent, formula, natural/alternative products.
- Gift certificates for baby photos, toys
- Donations to charity
- Electronic equipment for older children; if beepers or cell phones they need a plan to go with it.
- Cable TV discount so the children can be kept busy with cartoons.

Although they discussed the above incentives as appropriate for the planned tasks, all of the women agreed that they would want information about child health as well. “If you do a child study, you expect information about health.”

The group agreed that incentives would be appropriate for providing biologic samples but also felt strongly that the results and information would be important to learn and would be an incentive. Others mentioned that the incentive should have value but could be a donation to charity.

Since the group did not mention cash, they were probed as to whether cash would be an appropriate incentive. The response was that cash would be good but there would need to be

clear guidelines as to who gets the cash. “Would it be going to that person's child or overall children?” There was concern that the child’s money might get “squandered.” They agreed that some money should go toward the child and help the child and the family should be reimbursed for expenses and time. Some suggestions for the children’s money included:

- Starting a fund
- Stocks; bonds
- Savings accounts locked until age 18 when going to college

The group was reluctant to put a dollar amount on the incentive. When asked what amount would be appropriate for biologic samples, they responded that it would depend on what they learned from the test. The group reasoned that if they learned that something was wrong with their child, then they would be grateful for having the opportunity to have the testing done. The group also agreed that they would be grateful to learn that nothing was wrong with their child. The group echoed the same sentiments about the dust and water samples. They reasoned that these are tests that they would never have paid for and if they learn that there is something unhealthy about their home or water they would be grateful to have that knowledge.

- “I probably wouldn’t hire someone to clean my house or check my water. If something is wrong, I’m glad they found it and I know where it’s coming from...if three years down the road...if my kid is sick all of the time and I am sick all of the time...”
- “These are valuable things.”

All of the women agreed that they would not feel coerced if they received any of the incentives discussed. However, the group agreed that they might feel coerced if cash was involved but it depended on the amount.

- “If it is a huge amount or bigger amount, I’d hate for people to participate because they need that amount. I would rather it be a smaller amount and make up my own mind and be comfortable doing it.”

One woman said that money was not coercive.

The group said that they would like to be kept informed by mail because it is confidential. One woman indicated that there are “hackers on the net.” They recommended a newsletter be sent to inform them of the study on a monthly basis. All of the group members indicated that they would attend local meetings. The group also indicated that it would be all right to receive news by telephone and recommended a combination of mail and telephone.

The group said that they would like to receive medical test results after every visit, within a month. They also want to hear how far the research is progressing but they do not want to hear the same information repeatedly. The group would like to be informed of research progress every six months unless something new is learned which they want to hear immediately. Other information they would like to receive includes: new findings; publications based on the research;

and the status of the study. The group indicated that there was not any information that they would not want to know about even if the test results were not clinically interpretable at this time.

Overall this group was not very talkative. In the closing comments one group member asked if there would be psychological testing. She said that she had been in jail for a DWI and met some women who were doing hard drugs and had their children taken away and she thought it important to capture information about the social environment and state of mind of the children. There was also mention of being adopted and how the medical history is important. Finally, one woman had a concern about smoking during the first three months of pregnancy.

2.4 Expectant Parent Group 4: Suburban, HS or greater

Expectant parent group 4 was conducted in a suburb of St. Louis, Missouri (EPA region 7). The recruitment criteria were that the participants be expectant women who live in a suburban area and who have more than a high school degree (some college or post-secondary education). The participants were of mixed age and type of health care provider. A national focus group firm with a local office in St. Louis recruited participants by making calls to people in their database and using our screeners to determine eligibility. Eleven women were recruited and eight participants attended the session. All eight participants were white.

2.4.1 Getting You Interested

Group members were asked where they would like to hear about the NCS. Most of the group suggested the OB/GYN's office, pediatrician's office, day care centers, the school system, and Planned Parenthood. They also mentioned maternity stores, parenting magazine, and Babies R Us (their registry website) as good places to hear about information related to the NCS.

The group did not like the idea of a web site and they did not think that information in a magazine would be a trusted source of information. All agreed that an information booth or public transportation display would not be a good idea because not everyone uses public transportation. While a public service announcement or TV commercial would catch their eye, they did not think these were the best places to advertise. All agreed that they would throw away any information that was mailed to them especially if it was from a non-profit organization.

- “[I am] not sure I’d believe it if [it was] in a magazine.”
- “People throw those things away even though [they are] reputable sources.”

The kind of information that the group would like to receive about the study would include the risks, if any, to their babies. They wanted to know what was involved in the study, the effects on their child, and what would be required of the baby. Group members also wanted to know what benefits they would get out of their participation. In addition, the group wanted information about the timeline, eligibility criteria, location of testing, and confidentiality.

- “What do I have to do? What does my baby have to do?”
- “My concern is for the baby. What’s involved?”

The group was probed as to whether they thought it more important that the NCS directly improve the health of their child or that their participation contributes to science and overall public health. All group members agreed that the health of their child is paramount, but that the health of others is also important.

The group members offered a mixed response to the question about what would make them excited to participate. The group suggested benefits to the child, including physical tests and study issues they were concerned about would be exciting. They all agreed that it would be interesting to be part of a national study, but they would not necessarily be “excited.” Knowing someone in the study would not make a difference as to his or her decision to participate, but word of mouth is important.

- “Physical tests you can get early. Wow, we can get all this?”
- “Word of mouth feels safer.”

If there were a spokesperson for the study, the group thought that the best spokesperson would be a woman with experience being a mom. Someone who works with children might also be good. Most said it should not be a celebrity, unless she is a full-time mom. The only celebrity all agreed upon was Laura Bush. Other celebrities mentioned included Condoleeza Rice, Jane Seymour, Nikki Taylor, and Katie Couric. Some preferred that the spokesperson be someone local or regional, like a local newscaster.

- “Already a parent who has children.”
- “All American wholesome celebrity, someone who is a mom 24-7, with no nanny.”
- “Someone with a profession around children.”

The group was probed as to whether they would be more or less interested because they were pregnant. The group indicated that they might not want to participate during their first pregnancy, because there is a lot of stress. They wanted to know if they could change their mind about participation after the baby was born.

- “First pregnancy got a lot going on, stress with first child. Second child, bring it on. I’m more laid back.”

All agreed that having a second child participate would be acceptable if the experience with the first one was positive and if they could take care of the study activities with one visit instead of making separate visits for each child.

2.4.2 Time Commitment and Data Collection Activities

The group did not feel that the number of visits presented was unreasonable. But they did think that the number of visits the first year was a lot. They suggested the visits be

coordinated with regular doctor's visits. The length of the visit was acceptable to all of the group members. There was some discussion about whether they would prefer a home visit instead of an office visit. The child may be less stressed if the researcher came to the home. But the consensus was that an office visit was preferable to having a stranger come to your house.

- "You don't know who is coming to your house."

The group did not think it a problem to complete a 20-minute questionnaire four times a year. All agreed that e-mail or mail would be better than completing the interview by telephone. One person said that when you have children, 20 minutes is a lot of time on the telephone. The idea of replacing one visit with the survey was well received by everybody in the group. Time was a big concern for group members.

- If it replaced a home visit: "Yes, love that idea."
- "Four times a year not a big deal."

Group members indicated that home visits to collect dust and water samples would be acceptable.

- "I would want it to be a woman. I feel uncomfortable with men who come with a tag on."

Some group members thought that every three years was a good time frame. However, the group was willing to consider more frequent collections depending on the purpose of the sample collections. The group wanted to know the reason the study needed the tap water or dust and agreed that they might agree to collection once a year if it were important.

About half of the group liked the idea of collecting the samples themselves if they were sent a kit. The others thought it would be too much trouble.

- "Depends on how long it takes."
- "No worry about appointments."

The group members were probed about the collection of biologic samples and which types of samples they would be comfortable providing. The group agreed that they would not want to give placenta, meconium, or umbilical cord blood. They asked whether the placenta would be collected at the hospital.

- "Umbilical cord. What is it used for?"
- "Placenta. Who will be taking it? Weird."
- "I don't want an extra person in the delivery room."

The group members also agreed that they would not let their children provide baby teeth, first hair clippings, or blood.

- "Blood is a big deal."

The group was probed about how they felt about genetic testing. All members agreed to genetic testing and would want to receive the results, but were concerned about the possible negative effects.

- “I think it would be interesting.”
- “Very important.”
- “If something is wrong, I want to know.”
- “It could be harmful finding out about disease.”

The group members would like to schedule their next appointment when they were at the doctor’s office and then receive a postcard reminder or telephone message prior to the appointment. Mail was not seen as a good mode of contact and e-mail was not discussed.

- “[During] the first year’s [appointment] schedule the next [appointment] when you are at the doctor’s [office].”

Most of the expectant parents would feel comfortable providing the name of a friend or relative. They also suggested reminders on a website or a toll-free telephone number to call that would be listed in study updates or newsletters.

2.4.3 Keeping You Interested

The group was probed as to what kind of gift they thought would be appropriate to receive given the level of participation discussed. The group felt that the incentive should be larger the first year because there are so many visits.

- “Year 1 should be a big gift. Postage stamps for the first year would not work.”

Some of the group members did not like any of the gifts on the list. They suggested money for college or a U.S. savings bond.

- “Complete all 21 years and have a prize at the end.”
- “None of them [the incentives] are good.”

In addition the group recommended that the child should get an incentive as well. The group suggested an awards program or a catalogue from which the child could select a gift. They also noted the difficulty in getting older children gifts.

- “[Incentive] must be self-choice.”

The group was adamant that information on test and study results is not an incentive. This group expects to receive the results as part of the study-a condition for participation.

The group was probed as to whether any of the gifts discussed would be appropriate in return for the collection of biologic samples. The group agreed that the incentives for biologic samples should be larger than those recommended for the office visits. They did not mention what incentives would be appropriate.

- “Very personal things, body fluids.”

The group was probed further as to how they felt about receiving money for participating. The group members agreed that cash should be offered, especially at the end of the study, as a reward. Cash given in the beginning will draw people into the study. One person was concerned that if the study was too generous, “people will look at it in the wrong way.”

- “I deserve something from this study.”
- “[Money for the] end of the program is most important.”

One person said that cash would be used less for children, while another said that a child would like to receive money. Paying college age children in cash will motivate them to continue to participate.

- “Children would be excited to get \$5.00.”

Most of the expectant parents agreed that \$50 per visit would be a good amount. The entire group agreed that none of the gifts discussed would make them feel that they had to participate. The group also agreed that they would not participate for too small an incentive, such as \$20. However, the group members did consider that a larger incentive could be too costly for the study.

- “Incentive money for everyone would be difficult.”
- “Would be difficult to provide incentives for a wide range of people easily.”

The group was asked how they would like to stay informed about the study and they all agreed that a printed newsletter for the study would be a good idea. The newsletter could be put on a website.

This group also wanted the opportunity to contact others in the study and network. They suggested that there be a way to sign in on the Internet to contact others in the study and find out if anybody in their area was part of the study.

- “Sign in on a place on the Internet to get a hold of people.”
- “Know if anyone living 10-20 miles is part of the study.”

The group said that the decision about whether or not to attend a local meeting depended on the topic. If there were meetings for socialization, the group members said that they might be more willing to go to meet others. One group member suggested a trip to Disneyworld for participants.

In terms of personal test results, one group member said she would want to be notified by phone if the study found anything wrong with her child. Another group member said that she would prefer to get something in writing and a third person would rather meet one-on-one.

All participants in the group wanted child test results, genetic results, and home sample collection results, but they were concerned that the results be consistent, accurate, and reliable. If they could not interpret the results of the tests, they would not want them.

- “[If they could not get results] it would give you an ulcer.”

2.5 Expectant Parent Group 5: Suburban, Doctor's Office

Expectant parent group 5 was conducted in Research Triangle Park, North Carolina. The recruitment criteria were that participants be mixed in age and education, that they attend a doctor's office for their health care, and that they live in a suburban area. Staff recruited participants by calling doctor's offices and organizations that worked with pregnant women and children and asking if they would allow us to distribute flyers at their place of business or organization. Flyers were sent by mail, fax, e-mail, and in person. Some of the organizations contacted included doctors' offices, child care centers, YMCA, midwifery and pregnancy centers, La Leche League, the Durham Parks and Recreation Department, Healthy Start Academy, and the Boys and Girls Clubs. RTI staff recruited eleven people for the group and six participants attended. Attendance was lower than expected because of threatening weather. The group was comprised of six expectant mothers, three white and three African-American women.

2.5.1 Getting You Interested

The group suggested that children's magazines such as Carolina parent and Baby magazine would be good places to find information about the children's study. They also suggested the doctor's office, either Pediatric or OB-GYN as a reliable source of information. "I would trust the information if it came from my OB doctor." The group also thought that a TV news story about the study would be good but that radio advertising would be ineffective because it would be hard to write down the information. One group member also indicated that she would not respond to e-mail or letters since she "would think it is junk mail." Some additional suggestions include the Department of Social Services, Bus advertisements and the public library. One woman suggested setting up registration tables at baby stores.

The kind of information the women would like to learn about through the above sources would include:

- Study details
- Risks to the child
- Schedule of events
- Eligibility criteria ("I don't want to go through a hassle to find out I'm not eligible")
- Convenience and flexibility
- Benefits ("What would I get from the study?")
- All agreed that confidentiality and their child's privacy were a big concern.
- "I do not want my child's name published anywhere."

Three of the group members agreed that it would be more important to them that their participation contribute to overall "health of the entire population." Two of the group members said that they found it important for the NCS to improve the health of their children. One group

member felt that if her child had a specific disease, she would want the study to concentrate on her child.

The group indicated that they would be very excited about the prospect of participating in the NCS if they received incentives to do so. One woman said she was interested in something that would “clean up the environment and improve lives.” Another group member offered that she was interested in “the awareness that the study would bring.”

The group was mixed on the issue of using a celebrity endorser. One group member indicated that she didn’t trust celebrities. Another group member recommended someone like Doug Flutie because he has a child with a disability. The group also suggested the first lady, a parent or a medical doctor.

Three members of the group thought that they would be more interested in participating because they were pregnant. Two women said that they had other children so that being pregnant would not make them more interested in participating. One woman said that being pregnant didn't affect her interest in participation at all. Two women said they would have been interested even before they got pregnant; one woman said that she wasn't sure if she would have been interested before she got pregnant.

2.5.2 Time Commitment and Data Collection Activities

After presenting the women with the list of suggested office and home visits and providing a general idea of the types of specimens that might be collected at each visit, the group voiced concern about the number of visits and the retention of older children in the panel.

- "It's no way I could do four visits in one year. It would be overwhelming with the other things I have to do."
- "As the child gets older, how will you convince older children?"
- "The study would be more realistic if you stopped it at 18 years of age."

There was not much discussion about the taking of biologic samples but two women said that they would not allow their children to provide blood samples. One woman said that if it was "important for this study, I could do it." Another woman said that the collection of biologic samples "would have to be coordinated with my regular office visits." There was some discussion of the logistics--where will the samples be collected? How flexible are the researchers?" "I want the option of how samples will be collected." "I would have emotional distress; it is hard for me to see my child hurt." "I like home visits for convenience; I'd rather the person come to me.

The group didn’t think that completing a 20-minute survey was a problem but they disagreed about the mode of data collection. One woman preferred mail for privacy reasons. Another said that she would procrastinate with a mail survey and she preferred a telephone survey. The group raised the issue of privacy using the Internet. The group decided that they would like to complete a survey if it replaced one visit.

The group thought that it would not be a problem for someone to come to the house and collect water and dust samples. One group member indicated that she would prefer a female to a male coming over to her home. When asked if they would prefer to collect the samples themselves, some members of the group thought it would be convenient. One group member said that she preferred someone to come to the house and collect the samples so she wouldn't have to go to the post office and mail them herself. The main outcome of this discussion was that the women didn't object to the collection of the samples as long as it was done in a way that was convenient.

The group members had some concerns about the collection of biologic samples. One group member said that she was not comfortable at all with giving out biologic samples. Most of the women didn't like the idea of their child giving blood. They also agreed that they would not want meconium collected. This may have been a misunderstanding of what meconium is given this statement: "You are barely coherent to collect meconium." One group member said that she donated "a placenta to the hospital to help other children," so giving biologic samples as part of the study does not matter.

When asked how they felt about genetic testing, the women voiced concerns about what the tests would entail and wanted to know what risks the tests and procedures posed to the children. They were interested in knowing if they or their children had any genetic risk factors and they would like the results of genetic testing if there were few risks associated with the tests.

All agreed that they would like to be contacted by telephone or mail or through the doctor's office. One woman would like to have contact with a designated study staff member through e-mail and another woman said that she gets too much junk e-mail.

When asked if they would feel comfortable giving the name, address and phone number of a relative or friend as a contact, one woman said that she would be less inclined to do so at the outset of the study but more inclined later when she was more comfortable. One group member said that she would not give contact information for a friend or family member.

2.5.3 Keeping You Interested

After reading the list of proposed incentives one woman said that the list of items appeared to be aimed at first time mothers. They thought the incentive should be personal to the participant and expectant mothers should get options in the type of incentive they choose. The group liked the idea of coupons for clothing and school supplies. When asked if information about your health or your child's health would be an appropriate incentive the women all agreed that that information was expected regardless of the incentive.

A final comment was that an appropriate incentive would be to put money toward the children's college education. The women felt that the incentive would be a good motivator.

- "The more incentives you get, the more samples they will give."

- "The incentives should match the degree of the sample, i.e., more should be paid for placenta than urine, etc."

The women agreed that the incentives "should be given consistently in order to obtain samples."

The women all agreed that cash would be appropriate and that cash should be offered at every visit. The group agreed that they would not feel obligated to participate by receiving any of the incentives discussed; however, one woman indicated that if the incentives were too large she would "personally feel uncomfortable." Also, the women remarked that the only time they might feel guilty was if they were not adhering to the study's requirements.

The group suggested that one way they would like to be kept informed would be by having a web site or a newsletter delivered monthly or quarterly. The group members did not like the idea of local meetings because it would be more time the study was taking from their schedule. One woman agreed that communication by telephone would be okay. The group would like news about "enrollment, the study's evolution, preliminary findings, and findings that affect" their children. In addition, they would like news about test results of dust and water and information comparing geographic regions.

In terms of what information they do not want to hear about, the group agreed that it would depend on the person's interests. For example, a "person from the University of North Carolina might want research results but a person from the Department of Social Services might prefer to read something else.

2.6 Expectant Parent Group 6: Urban, Public Health Clinic

This focus group was conducted in the RTI offices in Chicago, Illinois (EPA region 5). The criteria for recruiting participants into this group required that participants be expectant mothers living in an urban area who received her health care from a public health clinic. Age and educational background was mixed. Participants were recruited by posting flyers in the offices of various community organizations, hospitals and health care clinics in Chicago. The women were screened to confirm that they were currently pregnant, living in the city of Chicago and that they received their medical care from a local health clinic. In total, eleven women were recruited to participate in the focus group. One of the women was found to be ineligible because she was under the age of 18 and could not legally consent to participate in the focus group. When she arrived for the focus group the moderator politely informed her that she was too young to participate, paid her the incentive and excused her from the group. Of the remaining, ten eligible women, a total of 8 women participated in the focus group. The group members were all African-American.

2.6.1 Getting You Interested

All the focus group members agreed that the best place to hear about the study would be at a medical clinic. They group felt that it was important to hear about the study from someone they could trust like their doctor. The group also suggested television commercials, parenting magazines, and posters on public transportation as good sources of information. The group said that they preferred to learn about the study by word of mouth or posted flyers in their neighborhoods. Other sources mentioned included social services and public aid offices, schools, and WIC offices.

The group did not recommend the use of newspaper advertisements or articles or information booths at the mall. Similarly the group did not want to receive the information by telephone and only three of the eight group members had access to e-mail.

- “Over the phone you would think it was a telemarketer...”
- “NO!” (to e-mail)

The kind of information that group members wanted to know before deciding to participate in the NCS include the purpose of the study and the risks and benefits to the child. All agreed that confidentiality was important.

- “What does it consist of?”
- “What do you need from me?”
- “Who is conducting it?”
- “Who is getting the results?”
- “How will it benefit my child?”
- “As long as it doesn’t do damage to you or your baby, it is ok.”

Group members agreed that contacts every other month would be acceptable. They wanted us to let them know about contacts in advance so that they could make plans.

The group was asked if they thought it was more important for the NCS to improve the health of their child or that their participation contributes to science and overall public health?

The group members had trouble understanding the question, but implied that improving the health of their child was more important than contributing to science. They wanted to know about their child’s health conditions and to get advice on health-related issues.

- “I don’t think research can improve the health of my child, but [it] can give you information on how you can do healthy things, advice...”
- “My son has asthma and I’m very curious to find out what’s going on with that.”

The group agreed that they would be excited to gain health information especially if it related to their specific concerns. Some of their concerns included asthma, hair loss, and ringworm.

The group said that it did not matter if they knew others in the study.

When asked if they thought using a celebrity spokesperson to disseminate information would be exciting, the consensus was that the best spokesperson would be someone who had relevant experience - someone family-centered, a mother, or a person with health knowledge, such as a nurse. Some thought a celebrity spokesperson was not a good idea. Others thought that a celebrity spokesperson would be good if they had something to say that participants could relate to, someone such as Brandy or Jada Pinkett-Smith.

- “Just don’t have someone there talking. Get someone with experience.”
- “A celebrity would just sell it to you”
- Danny Glover: “The fact that he’s saying something about it [anemia] would make me listen.”

Most of the group said that they would be more interested in participating because they are pregnant, as long as they were not experiencing problems.

- “It would mean a lot that I’m pregnant.”
- “I would do it unless I was having problems.”

One woman said she would be more cautious about participating when she was pregnant because she did not know what the study “would do with the samples.” I’d be a lot more cautious if pregnant.” “After the birth, the project could look at social and environmental factors.”

The women all agreed that if they had one child in the study, they would want the second child in the study also. “I wouldn’t want one to be left out—I’d want them all involved.”

2.6.2 Time Commitment and Data Collection Activities

No one in the group had a problem with the number of visits, except for the first year. They thought that there would be even more visits than those listed on the hand card. However, an important factor in how many visits would be reasonable was the distance the person would have to travel to the testing site.

- “I thought it would have been a lot more intensive.”
- “Four visits a year. I don’t think that’s bad.”
- “Well, the first year maybe [is too much], but the rest is all right.”
- “Depends on where the office is at.”

Most of the group members seemed uneasy about the sample collection. They thought that giving their breast milk and blood was too personal.

- “Breast milk, blood, etc. a little too personal.”
- “I ain’t crazy about giving blood.”

Some expressed distrust of the research process and the need for confidentiality. They, mentioned concern that their samples might be monitored for signs of drug use or that results of tests would be given to their insurance companies.

- “Feels like you are monitoring me to see if I’m doing anything wrong—drugs...”
- “[My] concern not about being personal, but concerned that they’ll be used for the right reasons, not for insurance...”

All of the group members said that completing the questionnaire would not be a problem. The group recommended a mail survey as the best way to deliver the questionnaire, because not everyone has e-mail and staying on the phone for a long time is difficult, especially for people who have children.

- “If it was by mail, ok, but I wouldn’t be on the phone for 20 minutes straight. I have 3 children.”
- “E-mail would not get to everyone. Mail is better.”

The group had mixed feelings about the collection of dust and water samples. Some people said the collections were fine, as long as they were used for a good purpose. Others said it was acceptable only if the sample collection would improve the home environment.

- “Only if you are going to do something to improve my environment.”
- “Depends on if it will help me.”

Some of the participants said that twice a year would be an acceptable number of times to have someone come to their homes and collect the samples, while others suggested every other year throughout the study.

The group was also mixed on the idea of performing the sample collections themselves. One woman said she would rather not do the collection herself.

- “You can’t depend on me collecting a sample.”

The group wanted to receive the test results. Most felt that if they did not get the results, there was no point in doing the testing. There were differing views about whether the study should do something to help them if the results of the testing showed that something was wrong. One woman suggested that the testing could help others over time, even if it did not help participants now.

- “If they don’t give you the results, it will be a waste of time.”
- “If you are taking a sample of my water and tell me something’s wrong, don’t check it if you’re not going to do something about it.”
- “I would go out and get bottled water if they told me.”

The group was asked how they would feel about their child providing biologic samples. Their first reaction of the group was that there were too many samples and that the samples were too personal. One said she would not be a guinea pig. Only one disagreed, initially saying that she could see that there would be different reasons for collecting different samples.

- “No, that’s too much. Nail, hair clippings, bowel movements. That just doesn’t seem right to me.”
- “I just think it is too much. The doctor doesn’t even ask for it.”
- “I know I wouldn’t let someone get all this stuff.
- “I’m not a guinea pig. [I] already go through healthy start, prenatal. They already check you for all the things you need to know.”

After the initial negative reaction, individual group members said they might give some of the samples. Blood and urine were the least offensive to them. They would have to know why the samples were needed and know that it is for a good purpose.

- “All but the first two (blood and urine) are turn offs. But if I felt it was a good purpose...”
- “If something poisonous shows up in your nail clippings, then I could understand it.”
- “I did the fish study in 97. They wanted a piece of placenta. I knew what they wanted and why.”

The group was opposed to genetic testing and did not want the results if testing occurred.

- “Absolutely not!”
- “Too much stuff going on in the world for that.”
- “[Knowing the results] would make me nervous.”
- “I don’t want the results. What if they say he’s a future killer, we want to study him more?”

When asked how they would like to be contacted for an appointment, five said mail was best, two preferred telephone, and one said e-mail.

- “Everybody don’t have a phone. Mail it to me or send someone to my door.”
- “Phone—it could get lost in the mail. Half my mail I don’t even read.”
- “E-mail...it takes me forever to get through my messages.”

The group was divided on whether or not they would want us to contact a friend or family member. Some suggested that the best way to contact them would be through a social agency or doctor.

- “No, my mom doesn’t like a lot of calls for me as it is. It wouldn’t make people in my family comfortable.”

2.6.3 Keeping You Interested

When asked what kind of gift would be appropriate for the level of participation discussed, the group suggested immediate rewards and also a long-term incentive. The incentives they liked were practical in nature.

They liked the idea of gift certificates for school supplies and for particular stores such as Kids R Us or a grocery store. They did not like coupons because you have to add your own money to them, while a gift certificate was already paid for. They liked very much the idea of receiving electronic equipment such as cell phones and pagers or a cable TV discount. However, these incentives appealed to them only if the study would pay the bills for service. They liked practical things such as bags of pampers, a case of milk, and cash. They also liked educational things for the child such as Dr. Seuss books and a set of encyclopedias. For long-term participation they mentioned a college fund, such as *Illinois First* where you can prepay for college, or savings bonds.

Some incentives they would not like to receive included coupons for toys or child photos which they already receive in the mail, postage stamps, and Web-TV, which they said they did not need.

The group did not believe that information on the health of the child is an incentive, but rather something they expect to receive.

When asked about whether they thought cash was appropriate, the group responded favorably however, one woman said that participation could not be equated with money. Two of the other group members wanted sizable amounts—a stipend or \$20,000 to \$30,000 over the course of the study. Yet another group member thought that those who participate just to receive cash would not stick with the study.

The group did not like the idea of receiving incentives in return for providing biologic samples. They said that they would feel like they were being bribed. There was an even stronger negative reaction to receiving money for biologic samples. Several people in the group responded negatively when asked specifically about receiving money for biologic samples, just as they had earlier when asked about receiving gifts for samples.

- “I’d be uncomfortable. I’d feel like I was being bribed.”
- “[It] heightens suspicion.”
- “I would feel like I am being used.”
- “You’d feel like you’re pimping your child.”
- “That syphilis study.” (Tuskegee)
- “We don’t want to sacrifice our children for humanity. We’re not martyrs.”

Upon further probing, some of the group said they liked the idea of receiving money for health needs. They mentioned paying for health insurance, dental visits, medical supplies that are not covered (e.g., special shoes), prescriptions, visits to the eye doctor, and braces for teeth.

The group said that receiving the incentives, either cash or gifts, would not make them feel coerced unless they had to “depend on the money to get by.” One noted that the money could be a temptation to some people who might come to depend on it and need it on a regular basis.

- “Only if I felt like I needed the money to pay my bills.”
- “No, it wouldn’t”
- “It is best not to tempt people.”
- “People will get dependent on the money. Whatever you do, make it consistent.”

The group said that public services announcements on radio and TV would help to keep them informed. They also suggested a health segment on the news. A few of the group members said they thought newsletters were a good idea and a few said they would go to a presentation or local meeting. Most preferred to hear about the results in other ways such as from the doctor. All members of the group said that they would like to receive information once a month. They were especially interested in learning their test results along with an explanation of what the results mean. They would also like to hear other results that might benefit their child, such as information on high blood pressure and sickle cell anemia.

The group was also interested in getting information on their local communities.

- “How high risk is my community?”
- “Which part of the study has more HIV? [If] when I saw where I live, it was lit up, made me want to read.”

When asked if there was information that they would not like to receive the group misinterpreted the statement to mean that information would be withheld from them.

- “How could you say that? You mean if everyone tested positive for something and you didn’t tell us?”
- “If something is wrong with me, I have to know.”

2.7 Expectant Parent Group 7: High-risk Pregnancy

Expectant parent group 7 was conducted in a suburb of Seattle, Washington (EPA region 10). The purpose of this group was to get the reaction of women who were experiencing a high-risk pregnancy. The recruitment criteria were that participants obtain their health care from a maternal/infant specialty clinic. All other demographic variables were mixed including type of living area (urban, suburban, rural) to accommodate participants who attended the specialty clinics. A national focus group firm with a facility in suburban Washington conducted the recruiting. Their usual data base approach to recruiting was supplemented by contacting clinics that met the criteria. The recruiting was difficult and slow. Twelve women who reported receiving care for high-risk pregnancy were recruited and nine attended the session. Two of the women canceled because they did not want to travel in the rain and one woman withdrew the week before because she went into labor. All nine women were white.

2.7.1 Getting You Interested

All group members agreed that the best place to learn about the study is at the doctor's office. The group members also suggested that midwives and childbirth classes could also be places to hear about the study, because you are "trusting and building a relationship with them as well." Overall, this group preferred to learn about the study by word of mouth from people they trusted.

- "Through a doctor's office. If the doctor knows and informs you of a study that you could possibly be part of that will be some of the best connections."
- "A doctor's office seems much more legitimate...A phone call could be a weird thing, even if they say they are the government, I don't believe them over the phone."
- "You feel trust with your doctor, rather than a cold call, it's personal."
- "If you are high risk...you are going in [to the doctor's office] more often than you would with a regular pregnancy, so there is more opportunity to have your questions answered—check in, find out more information before you make a commitment."

The group also recommended community or neighborhood newspapers, pregnancy magazines like *Fit Pregnancy*, and television. Some, however, did not think that newspapers were a good source. The group did not like the idea of letters or e-mail. They thought that they might throw letters away as junk mail or delete e-mail as spam. One suggestion was to send an e-mail that directed you to a web site where you could find more information.

- "[In a letter] it might sound interesting, but I don't know who these people are."

The group agreed that they would be nervous if someone called them about the study. However, they liked the idea of having a toll-free phone number to call for information. They wanted to initiate the interest and connection themselves.

The group members did not think that an information booth at the mall was a good idea but they suggested a booth at a children's fair as a possibility. The group also suggested enlisting the large baby store chains such as Toys R Us or Babies R Us.

- "Babies R Us—register when you are pregnant. A letter in a packet when you register. Option where you check to be contacted."

The group thought that a public transportation display might be helpful in that it could reach a more diverse population. They also mentioned schools that have a "Younger on the Way" program for older siblings, twins clubs, parenting classes, church, social service agencies, and shelters.

"Shelters—you want a more representative sample of the population...different classes and different ethnic groups."

The group members all agreed that they would need to know about the study before deciding whether to participate. This was very important. Some of the questions they would like answered include:

- What are they trying to learn?
- What is the goal?
- How is our contribution going to help further knowledge?
- What does it involve for the child--is it an interview or physical?
- What are the risks?
- Would this involve invasive procedures, trial drugs, physical or psychological testing?
- What are the benefits of participation?
- How much time the study would take per week and per day?
- What are the eligibility criteria?

Seven group members indicated that they would need to know the eligibility criteria up front so they won't make a telephone call if they are not eligible. Some group members also expressed an interest in knowing how many other people were participating and the size of the study. Confidentiality was very important. They wanted to be sure that their privacy was protected. The location of the testing was also important.

- "If it is an hour across the bridge every time for a weekly appointment that might be too much to do. You might have to have one on each side of the water."

Group members were probed about whether it would be more important that their participation in the NCS directly improve the health of their own child or that participation would contribute to science and overall public health? The group agreed that they did not expect the study to improve the health of their child. They did not think it would directly affect them while the study was going on, unless there was a negative effect.

When asked about the kind of things that would excite them about participating in the NCS, the group said that they would be excited about participating if it improved the lives of children and benefited humanity. The group members would also like to compare the results of their child's participation with national results. They would have to balance the effect on the family with how excited they were about the issues being addressed.

The group also said that if they were personally concerned about an issue that the study would address, they would be more interested in participating. For example, "If you have a niece with cancer, you will have more passion about research that deals with cancer." Other study issues that the group was concerned about included genetics and environment, the effects of pollution on urban versus rural environments, how ethnic groups react to the environment, and the environment and stress.

When asked if they would feel excited about participating in a large national study, the group members said that they would have to know more about the study before they would feel excited about participating in it. They also noted that if the study were too large, they would not feel special. Excitement would also depend on their level of involvement. They would want feedback along the way, including study results and the child's test results. Knowing someone who was participating would be a motivating factor for all of the expectant parents in this group. The group also agreed that it was exciting to know that the research would help others.

The group liked the idea of using a mother or a doctor as a spokesperson for the NCS. They did not think they could relate to someone who never had children. One person mentioned using a dad. All agreed that it would have to be someone who was invested in the research, not a celebrity spokesperson, who would not stick with the study. They did not like the idea of using Oprah because she does not have children, but said it could be a person who appeared on Oprah sharing a story. Other ideas were to use someone from an organization like the March of Dimes or a child telling a story, as in the Special Olympics.

Eight of the nine group members said that they would be more interested because they are pregnant. One person who had twins participated in a study before and the group agreed that the baby would come first and the study could not put the baby in jeopardy.

- “[I was] pregnant before with twins and I did extra studies. [But it] wasn't long term and wasn't 21 years. [I] would have to know more.”

The group felt that 21 years was a long time, but that once they commit to the study, they would stick with it. They would not want to “mess up the research.” But they would have to know what kind of time was required up front.

All agreed that before they were pregnant they probably would not have been interested in the study. They would be focusing on getting pregnant first, and on things like nutrition. One wanted to know what you would get out of the study if you were not pregnant. Another said that a lot could happen when you are thinking about having kids and you don't know where you will be in 5 years.

The group members all said that they would consider having a second child participate if the first child's experience was positive. All agreed that they would have to bring the other children along anyway. However, the office visits would have to be on the same day at the same time, because the group members do not want to make two trips.

2.7.2 Time Commitment and Data Collection Activities

All group members thought that a one-hour visit was too long and asked whether that included wait time. “Most doctor's visits don't last one hour.”

- “It will be challenging trying to get an 8-21 [year old] to go to the doctor for one hour...in that you committed them before they were born.”

The group members also thought that the number of visits in the first year was too many. The number would be acceptable if the visits could be coupled with the well-baby visits. All agreed that after the first two years, the visit schedule was minimal. Group members thought that reducing the number of visits to 1 time a year to age 6 and to every other year would be better. One person worried about how she would remember the visits for children ages 7 to 21 if they were every other year. They wanted the visits to be by appointment and at their doctor's office.

One member of the group shared her experience with a research study before.

- “[There were] tests involved with a research project. I wouldn’t have done it if they didn’t meet me at my doctor. I don’t have time to go to another place to get my blood drawn. So she just came there and right after my doctor appointment [in] 10 minutes she took my blood. I wouldn’t have done it any other way.”

All group members wanted more information before they would commit to biologic sample collection. One said she would want to know the procedures ahead of time and would have to be present at all times to give the child comfort. Some had no problem with sample collection, especially with less intrusive things like saliva, fingernails, and hair sample collection. Some were not sure about allowing blood and urine collection.

- “It is a scientific study... There is a purpose for that and that has value. [I have] not problem with that as long as I know the value outweighs the time commitment.”

The group members thought that completing a 20-minute questionnaire would not be a problem. However they preferred to complete the survey on the Internet rather than by mail.

- “Open up, click, click, click.”

The group would like the survey programmed so that if they were interrupted, they could go back to it later. Another option was to complete the questionnaire while they are waiting in the doctor's office. They would prefer something simple like multiple choice questions. The group also agreed that it would be good if the questionnaire replaced an office visit.

The group members thought home sample collection of dust and water was acceptable as long as they knew the “agenda” - what the collectors were doing and when the collectors were coming. One person compared it to carpet cleaning, where they give you a window of time when they will be there. They would want to see the results of the tap water and dust especially if there is something wrong, for example high lead or mold.

The group was probed to see how they would feel about collecting the samples themselves. While some preferred to collect the samples using a kit as long as they had clear instructions, others thought that the results would be more valid if someone from the study collected the samples. One person said that if someone came to the house, she would want to be there and would want to see identification.

- “I will wonder how valid the results will be from a wide range of persons, [with] education and cultural differences, may not understand the directions.”

- [Having someone come in would] lend more creditability, because some other participant may not send in their tap water. They may send in somebody else's water. If a representative comes to you...the data collected will be more valuable.”

When probed about how they felt about providing biologic samples, the group said that they would need more information about the sample collection, the use of the samples, and the effect of their collection on the family. None of the group members had any objections to the collection of hair, nail clippings, or urine. However, they all agreed that if placenta were collected, the study would have to work with the hospital or midwife. Most of the group would not want to provide placenta, meconium, umbilical cord blood, breast milk, or baby teeth. Umbilical cord blood is sometimes stored for potential use in the future. Placenta you might want to keep. One said she would collect meconium if she could just fold up a diaper and put it in a zip lock bag. The group members were reluctant to give breast milk. One woman said she would rather pump it herself using her own pump. The group agreed that baby teeth are kept for sentimental reasons.

When probed about their feeling toward genetic testing, most of the group agreed to allow genetic testing. One group member said that it would be important if they could learn something that would prevent another person from having a problem. Another group member thought that participation in the study would allow her to get more information than even her doctor could provide and if she could get the results she could have her questions answered right away.

Two group members said that they would not agree to genetic testing and one group member wasn't sure how she felt. All of the group members felt they needed more information, including the intended use of the information, a guarantee of confidentiality, and open communication. One person was afraid the study would sell their names or give them to the insurance companies.

At least 3 of the participants did not want the results. One said she would do the testing for the “betterment of society.” The study should give them the option of getting the results back. They suggested that the participant be allowed to check a box to indicate whether or not she wanted the results.

When asked how they would like to be contacted for an appointment, participants suggested a multidimensional approach that could include sending a letter, the schedule for the year, an e-mail reminder, and a phone reminder. Mail addresses may change, but some of the group members thought it would be best. Other group members thought that telephone was the best way to contact them about appointments because there is accountability and you are speaking to a real person. The call could be like a reminder call from the doctor or dentist's office. The group did not think e-mail would be good because e-mail addresses are more likely to change and sometimes messages do not get received.

The group members all agreed that they would give the study a contact name in case they moved. Group members also liked the idea of having a project website they could go to, enter a pin, and put in their new address information.

2.7.3 Keeping You Interested

The group was probed about the type of gift they would think appropriate to the level of participation that was discussed. All of the group members agreed that health information about the child should be “automatic.”

The group thought age-appropriate gifts would be good incentives for the children. For example, infant supplies early, then later a toy, and later when the child is older, cash. Most of the group thought that the child should receive a toy or book or something comparable each time they go for an office visit. One person thought that giving a little toy, like a toothbrush, would help to allay the child’s fears about coming again.

For long-term participation the group recommended larger, more substantial incentives, such as money for a college fund that would accrue interest or savings bonds. At least one group member thought this should replace the coupon or small gift and that contributions to the account should start when the child is an infant.

One group member did not think that anything on the list was appropriate. She thought that the items on the list were all things that she could get herself. Another said that nothing on the list would make her more inclined to participate because the thing that would convince her to participate was a personal connection.

- “If I saw the list ahead of time...I wouldn’t be interested in the study...things I can provide for my children...I expect that I would be turned off by the list.”

The group thought that gift certificates were better than coupons, but they did not really like either of the choices. “With a coupon you have to use your own money and may have no choice over the brand of item.” One person preferred to receive something she did not have to shop for, such as diapers, while another preferred a gift certificate to Toys R Us.

When asked if cash would be appropriate, one group member replied that her “child is intangible” and she could not assign an amount of money to her participation. Another group member felt that she would not want to receive anything. A third group member said that “time is money” and suggested that \$50 a visit may not be enough.

The group thought the incentives previously discussed were appropriate for the collection of biologic samples. One group member added that in another study in which she participated, she received additional ultrasounds that her insurance would not cover. The group thought that different families might need different things. Some families may not want compensation, but other families may need it. For families that cannot afford health care, four visits will be more than they usually get.

- “Provide a choice to families that some may say no they don’t want compensation...Others may say we really need what you can give us.”

When asked if they thought the NCS should use cash as an incentive, three of the group members immediately said that money was a good incentive, “a motivating factor.” All thought that a person “should get more money for more intrusive procedures.”

- “Get more in the beginning as the visits are more intrusive. If [they] are coming to get your dust it shouldn’t be as much as we get for child’s blood.”

Others said that they preferred the idea of the college fund or tax-free savings bond. One said she did not expect anything.

- “[It would be] Like you are hired...Information is really important. Free information that would cost you a lot of money to go to a doctor to find out. I will voluntarily commit to 21 years; otherwise, if I look at this...I would be suspicious of this. When I go to the doctor, I don’t expect a doctor/dentist to give my kids anything.”

When probed to find out if they felt that any of the gifts discussed would make them feel like they had no choice but to participate, the group said that too much money would make some of them suspicious. For example, “If the government was paying \$1,000 for a visit, a person would want to know why.” “Will there be some type of influence?” Others did not feel that any particular amount would make them feel they had to participate. One said she would participate for the information, not the money.

- “If I got \$100 from Toys R Us, [I would ask] why is Toys R Us giving me \$100? Are they getting some type of benefit or tax write-off?”

When asked how they would like to stay informed, the group said that e-mail, letter and/or printed newsletters were all good modes of communication. One wanted personal information throughout the study provided via a letter which would say ‘here are your test results,’ and a study website to put the results in perspective or get the bigger picture. Group members also mentioned Web chat rooms and a list serve and a toll-free number to call.

The group was divided on whether they would go to local meetings. For some the information would be a draw. If they missed the meeting, they would want to be sure they got the information another way. Others may be interested, but would not want these meetings to be mandatory. One group member said she would not attend because she would feel that the study took enough of her time. She “would rather use her valuable time to read something in half an hour, rather than go to an hour meeting.” The group also mentioned an annual study meeting, a conference, or a regional meeting.

The majority of the group wanted to receive study information quarterly or semi-annually. One person suggested a website where they could get information all the time. The group would want to receive study results, child test results, lessons learned, information about trends, and information on how results are being used. An interest was also expressed in knowing about collaboration with other groups and the sharing of information.

One group member thought that participants should have a choice about whether or not they wanted to receive test results. The all agreed that they would like to know that the research is continuing and they do not want to be “left in the dark,” even if the results cannot be interpreted at this time.

2.8 Expectant Parent Group 8: Urban, HS or Less

Expectant parent group 8 was conducted in Los Angeles California (EPA region 9). The recruitment criteria were that participants have a high school education or less (no college), be mixed in age and type of health provider, and live in an urban area. A national focus group firm with a facility in the Los Angeles area recruited participants by selecting names drawn from their database and screening them based on the selection criteria. Eleven participants were recruited and eight attended. The racial/ethnic composition of the group included one white, one African-American, five Hispanic, and one woman who identified herself as belonging to an “other” racial category.

2.8.1 Getting You Interested

Group members all agreed that the doctor’s office is the best place to hear about the NCS. One person said maybe a brochure in a doctor’s office would work. Other sources that might be good include the WIC office, the welfare office, a community organization or United Way.

The group also suggested that a parenting magazine would be a good source, but a newspaper would not because some people do not have time to read the newspaper. Television would be a good way to give information, but they would not want anything long and drawn out.

The group was divided on whether the mail was a preferred mode of communication. One person said she would toss it if it came in the mail. All eight group members have e-mail, but one said she would not give out her e-mail address and another said that she doesn’t respond to e-mail that might be spam.

The group members did not want to be called. The caller ID would come up on their phone as “unknown” and they would think it was a telemarketer. Group members also said that a booth at Baby Expo might work but a booth at the mall would not be a good idea. “It would take away from shopping.”

The group thought that an advertisement on the outside of the bus might reach them, but not an advertisement on the inside of the bus because none of the group members ride the bus.

The kind of information that the group would want to receive in order to make an informed decision includes:

- The purpose of the study
- The timeline

- What is expected
- Confidentiality
- Convenience of the testing site
- Risks and benefits

How often they would be contacted and confidentiality were the two most important issues to all the group members. The eligibility criterion was least important to this group. The group also wanted to know whether there would be testing and what the testing would be used for.

- [It would] depend on what it is...Is it clinical testing? What is the testing for?"
- "Will my child be anonymous?"
- "I don't want my child to be a guinea pig."

When probed about whether they felt it was more important that the NCS directly improve the health of their child or that their participation would contribute to science and overall public health, the group indicated that both were important. They did not think one was more important than the other.

- "One doesn't hold more weight than the other."

The group was asked to think about what would make them excited about participating and most of the group (6 of the 8 group members) agreed that it was the study issues that they would be concerned about. Some of the issues of concern include smog, asthma, and disposable diapers.

The group felt that they would need to know more about the study before they could be excited about being part of a national study. They didn't think that knowing someone who was participating would affect their decision to participate. All agreed that potential benefits to the child (or at least not hurting the child as part of the study) seemed more important to them than knowing the study would help others. Other benefits they mentioned were money and a scholarship for the child.

The group thought that the best spokesperson for the NCS would be a doctor or parent. They felt that the person would need to be able to answer questions and they didn't like the idea of using a celebrity or the Surgeon General. They preferred someone who has children and "understands."

- "Been where you are, currently pregnant, or have kids."
- "Not a celebrity. Most have nannies. They don't have the same concern."

When asked if they would be more likely to participate if they were pregnant, most group members said that they needed more information. If it would have to be safe for the mother and baby it would be okay. A couple of group members said they would be less interested in participating if they were pregnant. The others were not sure.

- “What is [the] involvement...disadvantages vs. advantages?”
- “How often getting tested...how much time?”
- “No kids, going to say no.”

The group all agreed that a second child could participate as long as the first child liked it and they (the parents) got the results.

2.8.2 Time Commitment and Data Collection Activities

The number of visits was acceptable to the group, but, when asked, 7 of the 8 said they would prefer it if the visits were reduced to 1 time a year to age 6 then every other year from 7 to 21. They were concerned that older kids may not want to be involved and thought the child should sign an assent form at age 14.

The length of the visits was acceptable to the group. One wanted to know if the hour included the wait in the doctor’s office, saying waiting can be difficult when you have a child with you.

- “Is that from in to out?”

Some of the group members were concerned about providing biologic samples. One said urine was ok, but another said collecting urine from a child is difficult. Another thought blood collection was acceptable. They did not want the sample collection to require any additional visits over those listed on the hand card. One group member preferred that someone come to the home to collect the samples, while another preferred the doctor’s office.

All group members agreed that they would complete the questionnaire and that inclusion of the questionnaire would not affect their participation in the study. They agreed that it would be better if the questionnaire replaced a visit. They did not want to do the survey over the phone. One preferred mail and three preferred Internet.

The group thought that home visits were okay, but they wanted more information. They were especially concerned about how often someone would come to the house and how long the home visit would be. Suggestions for the frequency of visits ranged from once a year to once every few years.

- “Ok, as long as not acting as a social worker.”
- “If sharing results [it] will be worth my time.”

Four of the group members said they would use the kit to collect the samples themselves. The others were not sure about this.

- “[I] don’t want to deal with doing it myself or contamination.”

There was a mix of feelings regarding having the children provide biologic samples. Two of the group members were generally willing to provide the biological specimens. Blood and urine were all right for some group members because they were used to giving these samples at

doctor's visits. The group did not mind the blood collection "as long as it was only an ounce or two." Some group members said that nails and hair were also acceptable. One was concerned with hair clippings because her babies are born bald. Some said meconium and placenta were okay because the hospital would just throw them away otherwise.

However, most of the group would not give meconium, placenta, and umbilical cord blood. They also did not see why anyone would give their breast milk. They did not want to give baby teeth because of their sentimental value, although one person said they would keep the first tooth and the study could have the rest.

- "Umbilical cord. Absolutely not!"
- "Breast milk...who will want to give their breast milk?"

When probed about genetic testing, some of the group members did not understand what genetic testing was and were concerned that it might be harmful, painful, or might affect the baby for a long time.

- "What is genetic testing?"
- "Would it affect you for a long time?"

Group members said they would only be interested if they could get the results and if it was confidential. They did not want the results to go to their insurance companies.

- "[If you] did testing and don't give results [I] will not participate at all."

The majority of the group members preferred mail contact. They also suggested phone calls for follow-up and reminders. Three participants said there would be no problem with providing the name of a relative or friend. The others preferred to keep study staff updated themselves. Some said that if they participated, they would keep us updated on their address. One said she would call us. Another suggested that we give them change of address cards to send in when they move.

2.8.3 Keeping You Interested

The group's initial reaction to the items on the list of incentives was negative. There was consensus that the list is small and uninteresting and the things on the list are not "meaningful."

- "The incentive [I want] is not mentioned, not on here [the list.]"
- "I don't like anything on the list."

Instead of the things on the list, they said they wanted money, a school scholarship, school vouchers, and an IRA that the child can not touch until later, or "something big." Group members especially liked the idea of the IRA and suggested something could be put into the account periodically. People should also get an incentive for each visit, but they did not say what they should receive.

The group did not like coupons, because there are so many out there already and because they had to spend their own money with the coupon. They assumed that the incentive would remain the same throughout the study and that it would not be relevant as the child ages. Some mentioned gift certificates for music CDs for teens and for Sears.

- “How long will they be an infant, what happens after [they are] an infant?”
- “So many coupons out for babies, kids, but you have to spend money.”

The group said that electronic equipment and Cable TV coupons were not good incentives because they can get cell phones and pagers free. Cable bills are high. Cable TV does not benefit the child.

All agreed that health information is something that they should get. It is not an incentive.

The group agreed that a small gift should be given to the child after each visit. The group was excited by the suggestion that the child be given a computer in return for the biologic samples, but they did not think that the study could afford to give computers to all 100,000 kids in the study.

All group members agreed that money was appropriate. They said “absolutely” to the question about payment of money for participation. The group thought that the amount of the incentive should increase with the number of samples collected. The group could not say how much would be a reasonable amount. They indicated that the amount would depend on the work involved in the study. To determine the appropriate amount, they would have to know more, especially about what would happen during the office visit. One said you could not put a price on it. Another said it should be nothing cheap and that \$25 or \$40 is nothing. When pressed for an amount, one said \$75 to \$100, two group members said \$100, and another said \$80 to \$100 per visit would be fair.

When asked if they would feel ‘coerced’ if they received any of the incentives discussed, most of the group said that they would not feel coerced. One said she “wanted to be coerced.” The only person who gave a dollar amount, said \$500 (a visit) would make her feel coerced.

The group agreed that the best way to keep them informed is through the doctor. During office visits they could get information and results. One suggested that there be a form that they sign to show that they understand the test results.

- “Send supplemental results from the study for the doctor to explain; if you have questions, [you] want to ask [the] doctor, not [the] study.”

The group also thought that a newsletter would be exciting and catch people’s attention. There was consensus that this would be a good way to inform people. There was also consensus that a toll-free number would be a good idea. They could call and ask a study investigator questions. It would be better than a meeting.

They liked the idea of being able to ask questions and get information on results but did not want to travel outside of their local areas to attend in-person meetings. Five group members said they would go to a meeting if it were local. All thought that mail was a better way to keep them informed than by telephone or e-mail. The group said that they would like to receive the results twice a year, but one said once a year would be sufficient. The group agreed that they would not want results more frequently.

The information that they most want to receive regularly is the results for their child's tests and the results of the study overall. Only one group member she would not want the test results if they could not be interpreted. Everyone else wanted all the information.

- “[I] want more of everything to feel safe.”

2.9 Expectant Parent Group 9: Rural, Couples, HS or Greater

Expectant parent group 9 was conducted in Burlington, Vermont (EPA region 1). The purpose of this group was to get the reactions of expectant couples. The recruitment criteria were that the participants be expectant parent couples with more than a high school education living in a rural area. The couples were of mixed age and type of health care provider. A local east coast focus groups firm with a facility in Burlington recruited 6 couples and 5 couples participated. The facility recruited participants by calling people in their database and screening them for eligibility using our screeners. All of the couples were white.

2.9.1 Getting you Interested

The group offered general ideas about places where they would be likely to hear or read about the NCS. There was a consensus that random telephone calls to the home to recruit would be annoying.

- Doctor's office
- Publish information in parenting magazines, on parenting websites and in local newspapers
- Childbirth preparation classes including breastfeeding and parenting classes (especially for first time parents)
- Parents with older children thought schools would be a good place to find information.

Overall, the couples expressed a need to be completely informed of the goals of the study and what is expected of them and their children before they would commit to participate. There was also a major concern about confidentiality and that the study tasks not interfere with their children's lives. The couples said safety was important and that they wanted assurances that the study would not disrupt their children's lives.

- “Parents expressed concern that participation be on their terms and not the terms of the researchers.”

- “Parents want clear expectations and statements of the goals of the study.”
- “Researchers must define “up-front” what the responsibilities will be so people know what they are committing to.”
- “The study must be well-planned and not make people uncomfortable.”

In terms of the timeline, all thought that contact once a year was “not too bad,” if there are few questions but they also thought it was important how they receive the questions. Some of the couples thought contact 2 to 3 times a year would be acceptable.

There was concern about whether they would be quoted in the press or on TV. The parents wanted “confidentiality” defined and they wanted to be sure that nothing would “come back to bite the children.”

The parents also asked:

- “What would be entailed?”
- “What of our children do we have to watch?”
- “Does the kid have to wear bandages or covers for chemical exposures?”
- “How will the data be obtained? Do we have to keep logs? Is it a physical?”
- “Do we have to draw blood?”

The couples were probed as to whether they would find it more important that the NCS directly improve the health of your child or that their participation would contribute to science and overall public health. There was consensus across couples that it would be more important to learn information that would help others.

The couples indicated that incentives would get them “excited” about participating and recommended money, a college fund, and just knowing that the study is benefiting the “greater good” as things that would make them excited to participate. However, all couples agreed that they wouldn’t mind participating if it “was not a huge invasion of privacy.”

In terms of being part of a large national study some of the couples thought that it would be enough to know that future generations would benefit from the study and that as the child got older, he or she would have the privilege of knowing that he or she was part of something very important.

All couples agreed that they would find comfort in knowing someone else in the study; however, they were cautious and asked about how that would impact the study.

- “Would having too many people who know each other in the study skew the results?”
- “Each experience should be unique; if you talk to others you would compare. The study should be more objective.”

When asked if it would help to have a celebrity endorsement, the couples had mixed feelings. Some said a celebrity would turn them off and others thought that it would be good if it were a respected professional in health or medicine.

- “Celebrities would turn me off; get someone with more clout.”
- “Not Sally Struthers.”
- “Nobody whining on TV about why we should participate.”
- “Surgeon General or someone respected.”

In additional comments about what would make them excited about participating, the couples recommended an online chat room.

- “I think an online community with members of the study would be beneficial.”
- “The online community would give us the security of knowing others are involved.”
- “You could still be anonymous in an online community.”

All couples felt that being pregnant would make them more interested in participating. However, there was some disagreement about whether recruitment should take place early in the pregnancy or later in the pregnancy.

- “Much more interested. Everything now is about your children.”
- “Now is a good time to get involved.”
- “Closer to the end of 9 months would be a good time to recruit; at the beginning parents are distracted.”
- “Earlier in pregnancy there is a lot of excitement.”
- “Contact people early in pregnancy.”

When asked if they would be interested in the study before they got pregnant, the couples all agreed that they would not be interested. All agreed that they were nervous before they were pregnant and early in the pregnancy because they were concerned if it would go well. They recommended sometime during pregnancy as the best time to recruit, and two couples recommended 4 to 6 months or after as the ideal time to begin the study.

When probed about whether they would be willing to have a second child participate if they already had one child in the study, the response was mixed.

- “If I were doing this study I would make it easy for the 2nd child to participate.”
- “If you have a second child 5 years later, are you in the study for 25 years?”
- “Are the requirements by age group?”
- “I’d be more likely to enroll the first child.”
- “Yes, what’s one more really?”
- “Yes, simultaneous involvement.”

- “Yes, neither kid would feel left out.”
- “Not sure the second time around would be worth it. Once you already experience labor you have a sense of what to expect. When you are pregnant the first time you are scared.”

2.9.2 Time Commitment and Data Collection Activities

All couples thought the information about office visits answered a lot of their questions. They agreed that this was not as invasive (in terms of their privacy) as they had imagined. All agreed that, if the visits were tied to their own health care provider, participation would be easy.

- “I don’t want to fly to Cleveland to give my samples.”
- “Will my doctor be willing to participate?”
- “Add study to child’s routine, i.e., during child’s visits for shots.”
- “Very do-able.” (All agreed)
- “You make four visits anyway in the first year.”
- “Very reasonable.”

When asked about their reaction to taking biological samples, the couples all agreed that taking blood from a child is hard to watch and it would make a difference if it were a finger stick or a blood draw.

When asked if they would consider making more visits if biological samples were not taken, all couples had questions about what the visits would entail. Their concern was for the child and what he or she would have to go through during a one-hour visit.

All couples agreed that:

- “All information about the doctor’s visits must be known in advance.”
- “Who’s part of the visit?”
- “Can the child leave the room?”
- “Will it be recorded?”
- All participants must “be very forthcoming.”

Initially all couples felt that completing a 20-minute questionnaire several times a year would be “very do-able” but they would like an option for how to complete the survey—“phone or in-person.” One couple thought 20 minutes was not reasonable. Three couples recommended specific frequencies:

- Twice a year.
- Every 4 to 6 months.
- Once every three months.

All agreed that they would be willing to replace an office visit with a survey because it is easier to schedule. All agreed that it would not make a difference in their decision to participate.

- “No. It is part of the study.”

The couples asked if there was a deadline for completing the surveys.

Four couples agreed that it would be fine if someone came to collect dust and water samples as long as it fit with their schedules and the same person did it each time. One couple thought this would be a nuisance. Recommended frequencies for sample collection include:

- “Every 3 months if they are quick.”
- “Every 6 months.”

When the option of self-collection was raised all couples were interested in collecting the samples themselves if all materials and instructions were provided. Their biggest concern is their schedule and collecting the samples themselves provides the flexibility all of the couples need.

- “No problem letting someone come [to the house], concern is about flexibility—the data collector must come when the participant wants them to.”
- “If the materials and simple clear instructions are provided with return envelopes, it would be easy to do and save the project some money too.”

The collection of biological samples was very controversial. All agreed that the collection of bloods was a “turnoff.” There was great concern about what the samples would be used for. It’s interesting that the couples did not ask what the samples would be “tested” for but rather “used” for. The couples also didn’t want the study to interfere with the birth experience.

- “The blood piece is a turnoff.”
- “What will everything be used for?”
- “Will everything be properly disposed of?”
- “Are they creating a DNA data base?”
- “What about human cloning?”

The group indicated that there would be some samples that they did not want to provide particularly if it meant that they would have to think about the study during childbirth as might be the case if samples of placenta and cord blood would be provided. One woman said that she thought breast milk was not something she would provide. Another woman said that she would not be comfortable providing samples of breast milk or placenta.

Some couples indicated that there were samples that they would not want their children to provide including umbilical cord blood or meconium. All couples agreed that they would not like to provide nail clippings. One couple indicated that they wanted to keep their child’s baby teeth. One mother indicated that she would rather give her blood than her baby’s blood. One couple suggested that if the parents collected urine samples from the children it might cut some of the time needed for office visits.

The group was probed as to whether they would agree to genetic testing which generated a lot of discussion concerning issues of privacy. There was concern about who would see the results. The couples weren't sure that they even wanted to know the results themselves. They did agree that privacy was a great concern. All indicated that they would need to know more about the plan for testing and that the details would have to be worked out. For example, they wanted to know how invasive the test would be. One couple said that genetic testing would be fine.

All agreed that they would need some flexibility in their schedules to perform the tasks required. They also agreed that time and date reminders would be necessary. Some couples recommended mail while others indicated that they get so much junk mail that it might get thrown out. If the notice was by mail it should be distinctive. Also, some couples thought a quick phone call would be fine but indicated that this could become bothersome if the calls were too frequent or too long.

One suggestion that received agreement was something they called the "dentist method." This approach involves sending a postcard two weeks prior to the date and then following-up with a telephone call one day before the task date. The couples also agreed that multiple methods might be best. One couple said that if they were paid they would not forget the dates.

The group was in agreement that providing contact information for a relative or friend would be fine. One couple said that the researchers might want to rely on another method of tracking them as well rather than relying on the participants to provide the contact info. They recommended checking the change of address at the post office and the Department of Motor vehicle registration.

2.9.3 Keeping You Interested

All agreed that an incentive would be required for continued participation and that the incentive somehow benefit the children. This group preferred cash incentives with additional gifts or gift certificates throughout the course of the study. All thought incentives would be appropriate in return for sample collection and there was consensus that the incentive payments be linked to the office visits. One couple suggested the money be placed in a fund like a Roth IRA. Others suggested that the money should be tax-free because it is a government study. There were suggestions that the money be placed in savings bonds or college funds for the children. However some couples thought that the incentives should be paid to the parents for the first few years and then later to the child because the child won't remember the incentives for the first few years. Another couple indicated that the child should receive the incentive all at once at age 21.

Although the group primarily focused on cash and gifts, the group mentioned study updates and reports of current results as also important incentives.

Some couples also indicated that they would like some choice of incentives. Some suggestions include:

- “Diapers.”
- “Food certificates.”
- “Coupons or gift certificates for children especially the first year.”
- “Cable or TV discount.”
- “Roth IRAs.”
- “Savings bonds and college funds.”

All couples agreed that the incentive should not be so large that the participants would feel that they must continue. They felt that gift certificates and coupons would not have that effect. All agreed that the incentive dollar amount should be fair for the time spent but should not be so large as to impact the child’s lifestyle. The amount that they felt was too large would be over \$500 per year or \$10,000 overall.

One couple asked what would happen when the child says that he or she does not want to participate any longer. Some couples indicated that it was the parent’s decision and the other couples weren’t sure what they would do.

The couples expressed concerns about having to drive to offices or labs to get results. They all indicated that their time is limited and they don’t want to spend much of their free time on study-related activities. The couples indicated that they would like to see a project website set up where they could receive e-mail and access to relevant information through links to journals and other relevant information. In addition the couples liked the idea of a newsletter written in laymen’s terms (and not scientific jargon) that informed them of trends and who’s involved in the study. Whatever the mode, the couples all indicated that they didn’t want to feel like they were in college all over again reading textbooks.

The group did not want to give up time to attend local meetings with presentations although one couple indicated that they would attend if the presenters were interesting. In lieu of meetings, the group suggested, and was very excited by, the idea of being able to communicate via e-mail with scientists and “bigwigs.” They indicated that it would be nice if this were possible even if only once or twice a year. The couples agreed that a meeting once every year or every five years would be okay.

Although the couples did not agree on any one specific type of information that they would not want to know about however, there was mixed reaction to finding out about local environmental exposures. Some couples indicated that they would want to know if there was something toxic in their area but some couples said that they would not want to know if the outcome was bad.

2.10 Expectant Parents Group 10: Women without Health Insurance

Expectant parent group 10 was conducted in New York City. The purpose of this group was to try to capture the thoughts and feelings of a group of expectant women who were defined as being “hard-to-recruit” for a study like the NCS. A decision was made to recruit a group of expectant women who represent the urban working poor; women who do not have health insurance of any type. Generally, this group falls through the cracks of the health care system because they work at unskilled jobs and do not have employer-provided health care but have achieved an income level that makes them ineligible for state or federal aid. Participants were also of mixed age and education. A local focus group firm recruited participants using their database as a primary resource. Staff recruited by telephone and screened potential participants using our screeners. As expected, the facility had difficulty recruiting people without health insurance. Contact with local health clinics and social service agencies reached more potential participants who were on Medicaid than those who were without insurance. The facility recruited 11 participants, but only 3 participated in the group. Of the eleven that were recruited, four women who were screened into the group were discovered to be under the age of 18 and had to be paid the incentive and sent home. The racial/ethnic composition of the group included one white, one African-American, and one Hispanic.

2.10.1 Getting You Interested

The group suggested that the doctor's office, clinic, hospital, or maternity stores as good places to distribute information about the study. They also recommended on-line sign up. Other media sources that were mentioned include billboards and parents magazines. The group said they were suspicious of e-mail and mail and would not like it if an investigator called them at home unless it was clear that the information came from their healthcare provider. The group did say that they would be suspicious of a telephone call especially if it seemed “invasive or scary.” “Wouldn’t like it; it would creep me out.”

All agreed that TV commercials and information booths would be good sources of information. The group indicated that they would prefer if they were in control of getting the information rather than having someone contact them.

The kind of information the women would like to learn about through the above sources would include:

- Who, what, where and why?
- What do you want from me?
- What are the risks?

All agreed that confidentiality and privacy were a big concern as was the location of the testing. One woman said that she would not want to go to another location or borough.

There was consensus among group members that it would be more important that their participation in the NCS contribute to science and overall public health than to directly improve the health of their child. Although one woman mentioned that she thought both would be important and suggested that perhaps she was being “selfish because she was without health insurance but would like to help others.” Another woman said that “initially she would be helping others but maybe her second child would benefit. The beginning of research is a helping task.”

The group indicated that they would not be very excited about the prospect of participating in research but considered the study issues important and it would be nice to participate in a large national study. One woman thought it would be nice to know someone else who was participating in the study and another woman said it wouldn't matter.

The group thought that the idea of a spokesperson or celebrity might get their attention but they would still need information. Suggestions for a spokesperson included:

- A celebrity who had children who could relate on some level.
- Normal person, a mom talking.
- Commercial with facts that touch upon disease and how they are different in a child's life
- An official, someone with some real facts and a name to back it up.

The group thought that they would be more interested in participating because they were pregnant. One woman indicated that she would not be interested if she was not pregnant and another indicated that she works with children and would likely be interested even if she was not pregnant. The group agreed that the decision to enroll a second child would depend on how “intrusive” the study was with the first child.

2.10.2 Time Commitment and Data Collection Activities

After presenting the women with the recommended list of office and home visits and a general idea of the types of specimens that might be collected at each visit, the women asked if the investigators would be checking the mother's health. The group thought that the time of the visits was fine if combined with their regular office visits for both themselves and their children. They agreed that 2 visits per year would be sufficient.

There was not much discussion about the taking of biologic samples but one woman commented that she did not like needles and another suggested that the mother receive some testing such as a cholesterol test as long as they were undergoing other tests.

“While you take blood you can help me if I help you; check my cholesterol.”

The other woman did not think that collecting biologic samples would be a problem as long as she received the results.

The group didn't think that completing a 20-minute survey was an issue. There was some discussion about the collection of dust and water samples. The women thought the water samples was understandable but they thought the dust collection was "a bit funny." They all agreed that it wouldn't be a problem if the collection was limited to twice a year. There were schedule and flexibility concerns about more frequent collections. Overall they were comfortable with the sample collection and agreed that if something were wrong they would want to know immediately. When asked if they would prefer to collect the samples themselves, they all agreed that it would depend on how complicated it would be and they would need a self-addressed stamped package. There was concern that they would do something incorrectly but all agreed that they could provide samples more frequently if they did it using a kit.

The group members had some concerns about the collection of biologic samples and indicated that they would only agree if doctors, not researchers, took the samples. The samples that individual women said they would not be willing to provide include:

- The whole list; they're all so personal
- Placenta and meconium
- Baby teeth
- Placenta

The group agreed that there would be little control over their samples once they were collected.

The group members were very concerned about the confidentiality issues surrounding genetic testing but did not appear to know much about what was entailed or what would be learned from genetic testing. All group members agreed that they oppose human cloning. The group was also concerned about the information and whether they would "get put on a list." One woman mentioned "the humiliation aspect—here are pictures of genetic mutations, very personal." They wanted to know who would get the information and what would happen to the information. They were very concerned about privacy and didn't want negative results to come back and cause problems for their children later in life.

- "How they get it. It is so extremely personal."
- "I'd need to know more about privacy aspect." [ALL AGREE]
- "Privacy aspect –make me comfortable I would like to know how it will affect child later on [in life]."

All group members agreed that they would like to be contacted by telephone or mail and they agreed that they would want to be contacted by the same person each time. All agreed that they would rather contact the study staff themselves rather than give contact information for friends and family. They suggested a project web site where they could enter information if they moved. They also suggested there be a project toll-free number to call if necessary.

2.10.3 Keeping You Interested

After reading the list of proposed incentives one woman said “I don’t see any money on here.” The members of the group added to the list of items recommended as incentives as follows:

- A gift certificate on the child’s birthday shows the child that you care.
- A gift certificate at Christmas
- Lifetime membership to Blockbuster
- Britta water filters

The group liked the idea of clothing and school supplies. Also coupons and gift certificates to buy whatever they like. The group did not think postage stamps or electronics (cell phones, pagers) would be good because they already own those items. A Cable TV discount was thought to be a good incentive because “the children can be kept busy with cartoons.” The group agreed that cable TV would be a good incentive because it is so expensive. Although they discussed the above incentives as appropriate, all of the women agreed that they would want information about their child’s health as well.

The group agreed that incentives would be appropriate for providing biologic samples. They recommended dental care, insurance, and discounts on braces.

When asked if cash would be appropriate, all agreed that “money walks and talks.” Additional comments included:

- “Money makes everything easier.”
- “Gift certificates are a close second; you can get what you want.”
- “Sometimes even if though you have cash you can’t make it.”
- “Money is always good.”

The group suggested that some amount be paid per visit. One suggestion was \$20 per visit. Another suggestion was a small amount to cover transportation and time.

- “It is voluntary and anything you get is a bonus.”

One woman said that she would want to be paid an amount equal to her hourly wage. The group agreed that they would look forward to receiving the incentive because it would help with the holidays and that they would like to put something away for the child.

All of the women agreed that they would not feel obligated because of the incentive and they said that they could not believe that anyone would feel obligated by the incentive. One woman said that she would feel uneasy about receiving electronics or cable TV. “Why would I get one brand over another?” “Am I being encouraged to get cable TV?”

The group suggested that one way they would like to be kept informed would be by having a toll-free number to call. All agreed that e-mail, a web site or a newsletter delivered

monthly or quarterly would also be a good idea. The group members indicated that they would find local meetings boring unless relevant to the area. They suggested that it might be interesting if the topic “was specific to the child’s age group.” Some topics they thought would be good are “childhood depression” or “signs about molestation.” The group agreed that they did not want to feel obligated to attend these meetings. The groups also agreed that communication by telephone would not be convenient or practical and they would rather have the information on paper. They would like to receive a newsletter once a month and new developments once a month. That way they can choose when to read the information. They would like to hear about how their participation “is relating to the study” and what accomplishments the study is achieving. In addition, they would like to hear about recruitment and how many women are in “year 1 versus year 5.” They would also like to have their children’s test results but they do not want to hear about anything that would make them “paranoid.” They would like test results if they were good or if they could do something about them. They do not want to hear about something if there is nothing that they can do about it. For example, they do not want to hear that “they can develop breast cancer” when there is nothing that can be done to prevent it.

The group said that they would like to receive medical test results after every visit, within a month. They also want to hear how far the research is progressing but they do not want to hear the same information repeatedly. The group would like to be informed of research progress every six months unless something new is learned which they want to hear immediately. Other information they would like to receive includes: new findings; publications based on the research; and the status of the study. The group indicated that there was not any information that they would not want to know about even if the test results were not clinically interpretable at this time.

3. Parents of Children with Disabilities

The parents of children with disabilities groups were conducted in Chicago and Research Triangle Park and included parents of disability children aged 3 to 5 and 6 to 11, respectively. The description of the groups and where they were conducted can be seen in **Table 2** below.

Table 2. Sites Selected for the Parents of Children with Disabilities Groups

Group	Site	Child's Age	Type of Practice	Geography
D-1	Chicago, IL	3-5	NA	<i>Urban</i>
D-2	<i>Research Triangle Park, NC</i>	<i>6-11</i>	<i>NA</i>	<i>Suburban</i>

3.1 Parents of Children with Disabilities Ages 3 To 5

This group was conducted at the RTI offices in Chicago, Illinois. The criteria for participation were that they be a parent of a child between the ages of 3 and 5 with a disability, either physical or mental, and currently residing in an urban area. Unlike the RTP parents of children with disabilities, this group proved to be very difficult to contact and the hardest to convince to participate in the focus group. The recruitment procedures were the same for both groups. Copies of the flyer advertising this session were sent out to and posted in the offices of several organizations including the March of Dimes, Easter Seals, Muscular Dystrophy Association, Catholic Charities, Children's Memorial Hospital, La Rabida Children's Hospital, and Shriner's Hospital. In addition, a staff member at the University of Illinois (of Chicago) Division of Specialized Care arranged to mail our flyers out to over 90 families from their mailing list. The mailing yielded a relatively small response. A few parents called to inquire about the focus group, but after learning that the incentive for participating was \$50, decided that it was not worth their time and effort given the cost of both parking in the downtown Chicago area and child care. A total of 7 parents were recruited to participate in the focus group and 3 parents attended. All three participants were African American.

3.1.1 Getting You Interested

Parents in this group agreed that the best place to hear or read about the NCS would be in a health clinic, hospital, or other health-related facility.

- "If you are trying to get 100,000 kids, prenatal clinics are best"
- "Hospitals that deal with handicapped kids – Shriners, UIC"

The group agreed that newspapers, magazines, and television newscasts were good places to hear about the study. They also liked the idea of hearing about the NCS through a national children's health organization.

- "[Television is] especially good."
- "[National children's health organizations] are all year around and people are always participating."

The group did not like the idea of learning about the NCS through e-mail, phone, or at an information booth.

- “I wouldn’t read an e-mail if I didn’t recognize the address.”
- “I tend to not give information on the phone.”
- “When people go to malls, they’re hardly paying attention to posters.”

The information that these parents thought was most important to know before contacting investigators includes confidentiality, risks and benefits. These topics proved to be most important for the parents in this group. Particularly, the parents were concerned about how their children might feel about confidentiality issues later in life. They did not feel totally comfortable speaking for their children in this regard. The group was concerned about the risks associated with participation and how they would relate to the expected benefits.

- “I don’t want everybody knowing about [the] disability.”
- “We don’t know how our children might feel – what their response would be.”
- “How would this benefit my child?”

Parents from this group agreed that overall public health would be their biggest motivation for participation. They were very interested in the ways that the study could help them or their children, but seemed to feel that was secondary.

- “Someone else can be helped, not only my child.”

The parents in this group felt that it was vital that the NCS share the same goals as the parents. Information on their children’s health and exposure to medical professionals were also mentioned as motivating factors.

- “If the goals matched my concerns then I’d be more interested.”
- “We can all sit down and come up with results to address diseases.”
- “For me, it would depend on if it is something I’m passionate about.”

The group felt that a spokesperson would need to be someone of high profile (an athlete or politician, perhaps), or someone in a position of influence, like the director of the project. They also thought it was important to include a spokesperson that has a child with disabilities, even if it is not a celebrity.

- “Before my son was born, the only celebrity I thought about concerning autism was Doug Flutie.”
- “Someone who has been through a situation with a handicap – they can survive and deal with life skills.”
- “President’s wife would reach people through TV, radio, and newspaper.”

Parents in this group said they would be more interested in participating because their child has a disability. They were concerned about the effect the study would have on their children, but felt that the effect would most likely be positive.

- “At 14, 15, 16, I’m concerned about the effect it would have on my child.”

Two parents felt they would not be interested until after becoming pregnant, and one felt she would have been interested even before becoming pregnant.

- “I wouldn’t be inclined to participate [before becoming pregnant]. Once the child was born and I knew he was disability, then yes.”
- “I got more involved with the school staff and teachers [after finding out my child was disability].”

When probed as to whether they would have a second child participate, two parents offered their opinions on this:

- “I can’t answer that – I’d have to give it serious thought. It would depend on how the first went”
- “I would say yes, if I already had one in the program. The children could learn from each other.”

3.1.2 Time Commitment and Data Collection Activities

Parents agreed that the number of visits planned for these children in the first year (8 office visits) would be too much. The length of the visits would be acceptable.

- “If they cut it down to maybe three, I’m good with that. Mom needs to get some rest.”
- “If some of the office visits could be made into home visits, that would make it much easier.”
- “Eight times? I wouldn’t be visiting my doctor that much.”

Parents expressed concern about the collection of biologic samples for children with disabilities. They were concerned that the child would develop a fear of the doctor’s office if biologic samples were drawn at each office visit and that it would be very difficult to convince children to continue.

- “I don’t like to see my child getting stuck to draw blood. Once every six months is enough for that.”
- “If you know they’re taking samples each time, you have to prepare your child for that. They’ll come to dread it.”
- “Trying to convince your four year old will be tough.”

When the group was asked to consider the age at which the children should sign the consent form themselves. The parents’ responded:

- “Ten years old”
- “High school”
- “Seventeen”

Parents said that completing a 20-minute questionnaire would be acceptable. One preferred e-mail and two preferred mail. They agreed that it would be preferred if the interview could replace a clinic visit.

- “Much, much better”

These parents said they would agree to have someone come to take home samples. Two would rather have a professional take the samples and one would be comfortable with a professional or with doing it with a kit. The group agreed that every few years was an acceptable frequency.

- “I want to know if there’s something in my pipes or if there’s something in my environment. It could be lead in the water.”
- “I like to know what’s in my water.”

The parents were shown the list of potential biologic samples and all parents agreed to provide biologic samples if possible. This group seemed concerned with baby teeth, although one parent had no problem giving these up.

- “That’s a lot of stuff!”
- “If it were spaced out it would be much easier.”
- “Blood – too much would be more than every six months – don’t want to scare the children.”

The parents had no problem with genetic testing, as long as the results were given to them. One parent would not agree to the testing if results were not given. Another parent would still participate.

- “If I wasn’t given results, I wouldn’t like it, but would still do it.”

The parents agreed that mail would be the best method of communication. They also thought phone contact would be appropriate.

The parents felt that providing the contact information for a friend or relative would not be a problem. One parent said it wouldn’t be necessary because she would provide the NCS with a forwarding address. Another suggestion was that the NCS ask for the contact information for the next of kin.

3.1.3 Keeping You Interested

Parents in this group had differing opinions about the best incentives for participation in the NCS. All parents seemed to like the idea of gift certificates for stores like Toys ‘R’ Us, Wal-Mart, or Rainbow Kids (clothing). They thought the most important factor was that the stores be close to their homes. The group was split on the ideas of child photos,

donations to charities, and Web TV (“would be nice, but personally I wouldn’t use it.”). One parent liked the idea of postage stamps, but the others disagreed. One parent liked the idea of cell phones and palm pilots.

- “Electronic equipment is always good.”

The parents added the idea of a trip or vacation as an incentive for participation in the NCS.

- “Weekend vacation or trip to Disney World”
- “Raffle for vacation”
- “Classes or tickets to events or ballgames”

The parents mentioned other alternative incentives, stressing that incentives should be for both parents and children:

- “Annual Christmas gift or special thank you”
- “Lottery for new bikes”
- “Access to other organizations, like the Make a Wish Foundation”
- Parents agreed that incentives should be offered when biologic samples are collected.
- “The more you ask for the more you’d want back.”

The parents agreed that money would be a good incentive. Recommended amounts ranged from \$50-\$100 per visit.

- “Money can always help – I see no problem [giving money]”
- “Cash can help you get something you really need.”

Parents were split on the issue of payment for biologic samples. One parent said she did not think money should be offered for urine, but it was appropriate for blood. Another said monetary incentives are appropriate and that “body fluid is body fluid.” One parent suggested that food be offered when biologic samples are provided, since the children may be weak afterwards.

When probed as to whether they would feel ‘coerced’ to participate if they received any of the discussed incentives and all agreed they would not feel coerced. “No amount is too much.” All parents in were in agreement on this point. They did not feel that there is an amount that would make participants feel they had no choice but to participate.

Parents found a variety of communication options acceptable. Specifically, they mentioned newsletters, meetings, and newspaper articles. The parents would be interested to hear about who is involved, what has been found, and how many participants have been retained.

Parents recommended project updates every six months, but expressed the concern that they would like test results immediately. They were interested to see how their area compares to other parts of the country on various health and environmental measures. The parents expressed

an interest in obtaining study results and including guidelines or tips on how to improve their immediate surroundings. Parents would want all test results, as long as they remain confidential. Parents agreed that they would want all results, even if they could not yet be applied to a standard.

The parents provided additional places at which they might be like to hear about the NCS and other organizations that may be interested in collaborating:

- “If you know someone who knows their children are going to come out with a particular illness, you can get them through clinics, doctors, and nurses.”
- “Colleges, medical colleges – good places to recruit”
- “Community organizations and the alderman’s office”
- “College of Associated Medical Science”
- “Social Services, Department of Public Health, WIC”
- “Church organizations”
- “Teen pregnancy workshops”
- “Rehabilitation and public services – Illinois Department of Human Services”

3.2 Parents of Children with Disabilities Ages 6 to 11

The focus group for parents of children with disabilities ages 6 to 11 years old was conducted in Research Triangle Park, North Carolina. The recruitment criteria were that the participants were parents of children between the ages of 6 and 11 who have a disability, physical or mental, and who are currently living in a suburban area. Only one parent per household was allowed to participate. RTI staff recruited for this group by distributing flyers to different groups that work with children with disabilities who then forwarded the information to parents. RTI contacted Durham Parks and Recreation, North Carolina Autism Society, Family Support Network of NC, NC Autism Society, Boys and Girls Clubs, the Lenox Baker Children’s Hospital, as well as a number of day care centers. Ten parents were recruited and 8 attended the session.

Five participants were white and three were African-American.

3.2.1 Getting You Interested

This group suggested OB/GYN and Health Department offices as the best places to advertise the NCS. Other suggestions for places to pick up information included:

- “Daycare”
- “Health Fair booth – family day”
- “Where moms hang out”
- “Pediatrician’s office – maybe simply on the back of the door”

The group also agreed that television would be a good place to hear about the NCS. The group was slightly less enthusiastic about radio. Newspapers were also seen as good sources.

- “PBS”
- “UNC TV”
- “I would use radio”
- “Won’t write it down if on the radio”

The group was split on whether they would respond to an e-mail message about the study, but most agreed that they would not respond to a letter in the mail or to an information booth at a mall.

- “Plain e-mails – no downloads”
- “I don’t go to the mall. More likely to be a scam.”

This group agreed that it would be vital to know the purposes of the study and what was expected of them before agreeing to participate.

The participants in this group seemed like they would be likely to agree to participate as long as they knew the risks associated with participation. They would want to be sure that their participation was for public good.

- “As long as you know it is helpful and knowledgeable.”

Parents were concerned with the length and location of appointments. They would want to know if special arrangements were necessary (something more involved than a regular doctor’s appointment). Transportation and child care were issues for some of the parents.

- “Will I have to take off work?”
- “Provide transportation”

Parents from this group agreed that it was important to them that the NCS contribute to science and overall public health. There was a short discussion of how children with disabilities participated in studies over the years and the impact that had on the health of their own children.

- “We’re all benefiting from previous studies, so we have to continue.”

The possibility of contributing to research on particular diseases and monetary incentives were mentioned as attractive benefits that would make the parents interested in participating. Networking with other parents was also mentioned as an interesting aspect of the study.

- “Help future generations.”
- “Similar disabilities group – bonding in the group will help people come back. The extended family feeling.”

Parents in this group were excited about the idea of participating in a large national study. They felt the national focus would result in helping people across the country.

- “[I’m] thrilled about this study!”

While no specific names were mentioned as suggestions for NCS spokespersons, several potential types were provided:

- “People who have children who have a disability – the football player who’s child has autism”
- “Behavioral psychologist/therapist catches my attention”
- “A spokesperson who has a disability child”
- “Professor of special education”

Parents in this group said they would be more interested in participating because their child has a disability. The group agreed that denial was their initial reaction to learning of their child's disability. Depending on when they are asked to participate, some parents "may want to run away from these issues." However, the group also agreed that they are in need of information and that the doctors are in need of information and they are open to ways to get that information.

- “We’re looking for an answer.”

Most parents said they would agree to have a second child participate in the study, depending on the age requirements. They may not agree, though, if they found the first child was “under a microscope.” The group also acknowledged that parents of children with other types of disabilities might think differently

3.1.2 Time Commitment and Data Collection Activities

This parents group placed a premium on flexibility and indicated that the study would have to work with each family individually because of the numerous activities that they are already committed to. The group agreed that the number of visits planned for these children in the first year (8 office visits) would be too much. They are already making many more visits to health care providers than parent so children without disabilities and would need to be provided some options for how they could participate without increasing their personal burden. The group agreed that there should be options to substitute home visits for office visits and that the visits should be combined with visits that they are already making. Some members of the group thought it would be an incentive to have in-home visits for the first year siting that new parents are often nervous and would welcome someone coming into their homes on occasion. Other parents emphasized the need to get out with the child once in a while and so would prefer office visits some of the time.

- “Year one – WOW!”
- “Home visits would be more convenient for new mothers”
- "I prefer to get out of the house."

Parents expressed concern about the collection of biologic samples for children with disabilities. Some parents were concerned about the blood draw. One group member who's child has a seizure disorder stated that her son already has his blood drawn frequently and it is very difficult. She did indicate that if the study would allow the blood sample to be drawn at the same time as a regular draw, then she would allow it. Some of the parents were concerned because

they know their child is fearful of needles and were concerned that they would develop a fear of the doctor's office if biologic samples were drawn at each office visit.

- “My son has to have blood drawn – No! It’s a nightmare.”
- “My child may not understand”

The group was asked at what age they thought that their child should be able to consent to participate in the study. Most of the group indicated that age 18 would be appropriate but offered that some of their children are severely disabled and it is likely that they will never be able to provide informed consent. Other parents indicated that it would be difficult to know when and at what age their child would be able to fully understand and provide consent. The group agreed that whether the child can provide consent should depend on the child's ability to comprehend the implications of participation rather than age. One group member indicated that for a typical child, age 12 might be the right age at which the child could provide informed consent. Another group member said that children under 18 should not be allowed to consent for themselves because they do not fully understand the long-term implications of the study. She noted that a child can be easily swayed by the immediacy of a birthday party or ball game and decide not to participate. She also indicated that parents should take into consideration the wishes of the child and decide if the child has a valid reason for wanting to discontinue the study.

When asked about how they would feel completing a 20-minute questionnaire, all said that would be acceptable. They noted that if they had made a commitment to the study they would complete all components of the study.

- “Something you’re dedicated to, you’re committed to.”

The group did recommend a variety of options for completing the survey. Some parents preferred a telephone interview so that they did not have the burden of having to mail anything. The parents also indicated that they preferred telephone interviews because they could fold laundry and perform other tasks while completing the survey. Other parents said that they would be more likely to complete an Internet survey. The parents expressed strong interest for completing a questionnaire if it replaced an office visit.

These parents said they would agree to have someone come to take home samples. The parents said that if a study team member came to collect samples, they would want the same agency or organization collecting the sample each time. They would want clear identification and credentials for the person who visited the home.

The group also indicated a preference to use a kit themselves because it would allow them some of the flexibility that they need in their schedules.

- “[I] don’t have to worry about making time for someone else to come.”

These parents would agree to provide biologic samples if possible. Most parents said that collecting biologic samples (specifically blood, urine, fingernails, and baby teeth) from their

children would be difficult because of the child's disability. The group also expressed a desire to have biologic samples collected less frequently.

- “Collecting blood with a finger poke is fine with me.”
- “Fingernails would be difficult – my son bites his down.”
- “[Collecting] baby teeth from autistic children is difficult – they swallow and spit them out. You might have incomplete gathering.”

These parents reported that genetic testing is something they have already experienced and would agree to do in the future. Parents said that they would want the test results. Their concerns centered on the confidentiality of the results. They feared that insurance companies would receive results that might affect future insurability or insurance premiums. One member of the group raised the issue that insurance companies may classify genetic disorders as pre-existing conditions and refuse to cover these disabilities.

- “Must be confidential.”
- “Confidentiality is very important.”
- “They must make it so that the results cannot even be subpoenaed.”

Parents expressed interest in a variety of options of being contacted: telephone, e-mail, and mail. Parents in this group suggested a computerized reminder telephone call 2 days prior to appointments.

All participants said they would feel comfortable providing the name and address of a friend or family member in the event that they moved.

- “Provide business card with phone number and website”
- “1 800 number or website to change address”
- “Must make it easy to contact study”

3.1.3 Keeping You Interested

Parents from this group felt that gifts and incentives were necessary for long-term participation in the study. Parents expressed a desire for gifts for both the child and parent. Most parents liked the idea of offering gift certificates. One recommendation was that participants earn points that could be redeemed from a gift catalog. Some ideas that were not on the list included college-education savings accounts/stipends or a general fund for the child. Electronic equipment (PDAs or Palm Pilots, touch screen computers, Internet access), and cellular phones were also seen as an attractive option.

The group was concerned about incentives over the course of the study. The general consensus was that gifts should be varied from year to year to keep participants interested.

- “Level of gift for every year you stay.”
- “Asking for 21 years is a lot.”

Parents agreed that incentives should be offered when biologic samples are collected. They noted that the amount and timing of the incentives would be essential to their success.

- “Money for child for blood drawn.”

The parents agreed that money would be a good incentive. A recommended amount was approximately \$50 per visit. Child care and transportation costs were mentioned as factors that influenced the amount of the incentive.

- “Blood – big bucks. \$40 might not get them into the office.”
- “Pay at all stages.”

The parents did not have an issue with money being too attractive to turn down for the NCS.

- “I don’t think there’s [enough] money in these studies.”

Parents preferred a website, and occasional meetings where the research team presents preliminary findings or project updates to the study participants. All agreed that multiple modes should be used.

- “Options are good.”
- “Have a prompt to check website.”

Parents recommended quarterly project updates. They didn’t feel that they needed information more frequently than this, but one parent did suggest that the NCS website be updated at least monthly.

- “There’s a point when you receive too much.”

Parents agreed that they would want updates on the recruiting process for the NCS. They also would want both objective test results and study findings. Parents also seemed interested in other resources such as references for further reading, environmental safety articles, or home remedies.

- “Citations, books, and other studies.”
- “Don’t take sides – just give information.”

Parents would want all test results, including genetic screening. Parents all agreed that they would want this.

- “Write it so a general person can understand it.”

Parents wanted test results, even if they can’t be clinically interpreted. Parents expressed a desire to receive genetic testing results even if they could not be interpreted at this time.

- “Over time things come out.”

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4. Parents of Children without Disabilities

The purpose of conducting focus groups with parents of children without disabilities is to learn about the concerns that the parents of older children may have as participants in the NCS. The groups of parents of non-disability children, 3 to 5 and 6 to 11 were conducted in Research Triangle Park, NC and Chicago, IL, respectively. The description of the groups and where they were conducted can be seen in **Table 3** below.

Table 3. Sites Selected for the Parents of Children without Disabilities Groups

Group	Site	Child's Age	Type of Practice	Geography
ND-1	Research Triangle Park, NC	3-5	NA	Suburban
ND-2	Chicago, IL	6-11	NA	Urban

4.1 Parents of Children without Disabilities ages 3 to 5

For the RTP group of parents of children without disabilities, the recruitment criteria were that the participants were parents of children ages 3 to 5 years who currently live in a suburban area. RTI recruited for this group by distributing flyers to groups that work with children who then forwarded the information to parents. The groups contacted included childcare centers, Durham Parks and Recreation Department, YMCA, Healthy Start Academy, and Boys and Girls Clubs. Ten parents were recruited and six parents attended the session. Two parents were white, three parents were African-American and one parent described herself as “other.”

4.1.2 Getting You Interested

Parents suggested many different places and formats in which to hear about the NCS. While individual participants came up with suggestions such as OB/GYN offices, day care centers, and churches, all agreed that a parents’ magazine would be appropriate. Specifically, the group agreed on *Carolina Parent Magazine*. The group did not specifically mention radio or television in either a positive or negative light. Many of the suggestions from the group focused on the placement of print materials in public places. The group indicated that directing these materials to the population to be recruited would contribute to a successful campaign.

- “children’s stores, Baby Gap”
- “bathrooms, changing rooms”
- “the park, the playground, bulletin boards”

In general, the focus group participants expressed the need to know the purpose of the NCS research and what was expected of them as research subjects. They need to know the time requirements, location of research activities, and their role in the process. All participants agreed that these were important factors to understanding before making contact with the investigators.

The privacy of health information was a key requirement for all participants.

Parents want to know they are helping others through their participation in the NCS.

- “Everyone likes to do something that better the world – dramatic results.”

The group emphasized the point that to be representative of the American people, the NCS should include all types of people. This appeared to be an important factor that would lead to their decision to contact investigators. Specifically, the group wanted to make sure that the Spanish speaking population would be included in the NCS.

- “Have a live person explain it in Spanish”
- “Latino credit union”

The group concurred that it was very important that their participation contribute to overall public health. In this group, the individual benefits seemed to be secondary.

- “Improvement for everybody, going to help our community”
- “Children would benefit, but ultimately grandchildren will be affected.”

The notion that participation in the NCS would have a positive impact on the participants’ community was mentioned by all as something that would create excitement. Knowing that participation led to improved health for others was mentioned as a major factor.

- “Me and my family have contributed to positive outcomes”
- “My children will make a difference.”

While a few participants indicated that personal recognition for participation would excite them, the majority of participants disagreed. Most believed that they would be excited to participate regardless of recognition.

The group agreed that an appropriate spokesperson would be someone who has a child and a passion for children’s health issues. The group believed that someone “knowledgeable in health and environment” would be appropriate. No specific suggestions for a spokesperson were offered.

The group was split concerning the notion that they would be willing to participate in the NCS before having children. Slightly more than half said they would be willing, but a few indicated that before having children, they were not as concerned with health issues.

- “[I was] not very concerned about environment, but now I am”

Parents generally agreed that they would be willing to have a second child participate depending on their experience with the first child. A good experience with the first child and as a study participant would make them more likely to allow a second child to participate.

4.1.3 Time Commitment and Data Collection Activities

The number of visits is fine, as long as they are convenient. In general, the parents agreed that the proposed number of visits per year is acceptable, as long as they are convenient and combined with regular office visits (if possible).

- “Piggyback with regular office visits.”
- “Make it convenient as possible.”

The parents raised concern about the collection of blood and urine. Specifically, the parents were concerned about whether blood could simply be collected by a finger prick, how much blood would be required from the draw, and how would baby urine be collected.

Parents generally would agree to completing a 20-minute questionnaire if it was administered by mail, or possibly e-mail/Internet. They would not complete a phone interview. Having one of the surveys replace a scheduled office visit did not seem to affect parent opinions.

- “No phone!”

Parents supported the collection of home samples. They did not find a schedule of every three years to be an inconvenience. Some parents preferred a sample collection kit to collect the samples themselves for reasons of convenience. Others would prefer someone coming to the home if they could collect samples on the weekend.

Parents, on the whole, seemed to indicate that they would agree to give some biologic samples, but perhaps not all of those mentioned. Their concerns centered on the ease with which some samples could be collected and the personal nature of other samples. Among those explicitly mentioned as easy to collect were hair and nail clippings, and cheek cells collected with a swab.

A couple of parents indicated that they like to keep baby teeth for sentimental reasons. Others said they would provide one, but not all baby teeth.

- “Teeth I couldn’t give.”
- “1 tooth is fine, a lot – no.”

Parents supported genetic testing as long as they are well informed about the procedure and convinced the procedures would not harm their children. Parents were very concerned about who would have access to the results of genetic testing. Parents would not agree to testing if insurance companies were given access to these data.

Parent opinions were mixed about the notion that they might not get the results of genetic testing. Two respondents indicated they would need to get the results of any test, while a few others were against this idea.

Parents in this group did not reach an agreement about the best contact method for making appointments. Several preferred options for contacting parents about appointments were mentioned by the group.

- “Postcard”
- “Reminder on voice-mail or e-mail”
- “Mail or phone”

The parents in this group would feel comfortable providing the name and address of a friend or family member in the event they moved. They also suggested sending out change-of-address reminders and holiday greeting cards.

- “Every 3, 4, 5 months – have you moved?”
- “Christmas cards [with] address change”

4.1.4 Keeping You Interested

Parents suggested that the best approach with incentives would incorporate many of the options listed. Several alternative incentives were also mentioned.

- “Health insurance... point system”
- “Box of diapers”
- “Coupons for clothes, books”
- “Gift certificate to gas or grocery”
- “Cash”

The group was nearly unanimous in their dislike for electronic equipment as incentives, although one participant expressed interest in a “coupon for Radio Shack.”

All parents agreed that the idea of a more long-term incentive that focused on the child would be an effective tool in keeping participants interested.

- “Gerber life insurance policy”
- “Education fund, \$25 a visit”

Parents were dividing on the idea of giving incentives for biologic samples. While some were turned off by the idea, others recommend cash incentives for every sample.

- “That’s just sick to me, incentive or no incentive.”
- “\$20-\$25 for each visit.”

In combination with the incentives previously mentioned, parents preferred an incremental payment – larger incentives as the child gets older. As for a specific amount, one parent suggested \$50 a visit.

- “We’re all for cash.”
- “\$50 reasonable for today’s 2 hours.”

Unless the amount was very large (\$300 - \$1,000), parents did not feel that incentives would be coercive. The group reiterated their concern that incentives be incremental.

- “You don’t want your dollar amount to be the bait.”
- “Don’t pay a huge sum up-front for participation.”

All participants agreed that they would like to see project updates take the form of periodic newsletters, a website, and a toll-free telephone number.

- “A 1-800 number for customer service questions.”
- “Hotline where you can speak to a real person”
- “Monthly newsletters with breakthroughs”
- “A way to retain and be constantly informed”

While most parents agreed that quarterly updates would be appropriate, one parent suggested that an annual update with project information would be sufficient.

- “Quarterly keeps me focused”

Parents were interested in obtaining personal and aggregate study results through a personalized newsletter or website. One parent also expressed interest in a bibliography and information about EPA resources.

- “Collective results by age group”
- “Break results up by age”

Parents were also interested in information on recruitment and retention in the NCS.

- “Research, downfalls, challenges of recruitment”

This group of parents expressed a concern for the “human interest” aspect of the NCS. They want all available study results, but in a way that is easy to understand.

- “Write it in plain English.”
- “Is it going to teach us something? Will it be beneficial to society?”

These parents would be interested in receiving results of medical, genetic and environmental testing.

4.2 Parents of Non-Disabled Children Ages 6 to 11

One group of parents of non-disabled children was conducted in Chicago. The parents were recruited by contacting several community organizations that work with children as well as some of the local pediatric health practices. These organizations included the Boys and Girls Club, Chicago Urban League, and Head Start. Each organization was asked to post a flyer advertising the focus group for parents of non-disabled children between the ages of six and eleven.

A total of 12 parents were recruited for the group. Two of the parents canceled on the day before the session and eight parents attended the focus group. Four participants were Hispanic and four participants were African-American.

4.2.1 Getting You Interested

This focus group offered many alternatives for places that would be appropriate to hear about the NCS. Most suggestions dealt with public places, like posters in public transportation or in clinics. Radio and television were also preferred to alternatives such as an information booth at a mall. TV and Radio commercials were most popular but attention to target audience is critical. The group suggested running them on different stations, with different types of programming, at different times of the day to ensure broadest possible coverage.

- “Magic Johnson HIV posters [in public transportation work well]”
- “Radio is a good idea, but ads should be on several major stations -- all genres (rock, rap, country, talk radio)”
- TV commercial must play twice a day [day and evening]”
- Shopping with kids is hectic enough and I wouldn’t take time to stop and talk about a study.”

The group expressed a desire in knowing as much as possible about the details of the study and the reasons behind collecting the various samples. They wanted to be informed up front about what was expected of them and their family and they wanted to understand all the risks and benefits (both individual and social) to be gained by participating in the study.

- “Location of testing and interview should be explained up-front.”

Some participants seemed very suspicious of government and that the EPA’s purpose in conducting this research.

- “EPA may be using kids as guinea pigs.”

The parents in this group expressed a concern about risks and benefits associated with the NCS. Risks and benefits must be clearly laid out and confidentiality assured before they would be comfortable signing on. Parents wanted to know what was expected of them and their child from the very beginning of the study.

- “Have all information up-front.”

This group felt it was important that the NCS both directly improve the health of their children and that their participation benefit public health overall. They wanted to know how the goals of the study fit into the “big picture” for society as a whole. Two participants felt that overall public health was a more important factor.

- “Show benefit for individuals and families and then explain how it benefits society”

Again, the group requested wanting to know as much as possible about the study before committing. A celebrity spokesperson could help but it would depend on their audience and their

perceived credibility (“Oprah doesn’t have kids”). There was a strong feeling that the use of incentives could help promote the study. Suspicion about trusting government surfaced again.

- “People are not trusting the government right now.”
- “Incentives – offer the family something. Let’s be real – something for something.”
- “[Need] more specific information – need to know what you’re getting yourself into”

The group was unsure if a spokesperson would be effective in promoting the NCS. If spokespersons were used, the group suggested using different spokespersons for different types of participants (“doctors,” “hip hop stars”).

For the most part, this group was in agreement that they would have been willing to participate before they were pregnant. One participant felt that she would have been too young and too scared at the time of her pregnancy to participate, but that she would do so at this point in time.

4.2.2 Time Commitment and Data Collection Activities

The group again expressed a desire to be completely informed about all aspects of the study before committing. As long as they understood what was expected of them and they felt they were making a worthwhile contribution to the health and well being of their child (and society as a whole) by participating in the study they would be open to any reasonable schedule.

- “During pregnancy – in-home visit is probably OK (although some people don’t want people in their house). The office visits will depend on the trimester of the pregnancy”
- “Year 1 - 4 visits is a lot because you already have so many visits during the first year [doctor’s appointments, etc.]”

Parents seemed open to biologic samples being taken in the home to reduce the number of office visits, but again required more information.

- “Parents need to know exactly why NCS needs another biological sample (especially after doctor already takes so many)”

The group did not want to be bothered by phone for this interview. They would prefer to receive a questionnaire in the mail and fill it out at their leisure. Group members suggested having the project give a quick reminder phone call to the home and then mailing the questionnaire.

- Five preferred mail.
- Two preferred Internet.
- One had no preference.

The group felt comfortable about having somebody else come to the house to collect the dust samples (to make sure it was done correctly). Their only request was that they be notified of

the results of such collection tasks – especially, if inspector found something hazardous in that particular sample. One participant suggested having the project staff work with the landlord to correct any problems discovered during the collection of samples.

- “Make an appointment first – don’t show up when I’m in my pajamas.”
- “If they find lead or asbestos or something – will they tell us or report it to the landlords – is something going to come out of it?”

The group felt comfortable with somebody collecting the dust samples but did not want to use a kit to collect the dust samples themselves.

The group felt that many of the biologic samples were pretty personal and outside of what they would expect a physician would collect. They felt they would need to be better informed about the reason for collecting each biologic sample and be fairly compensated for the sample before they could decide.

- “What is the purpose of each of these?”
- “This gets real personal. What’s in it for me? Even doctors don’t get this personal.”
- What’s in it for me and my baby?”

Some parents had sentimental reasons for keeping baby teeth. They also thought these would be hard to collect.

- “The tooth fairy takes those.”

Most parents had no complaints about genetic testing as long as they knew what was involved and were assured that it could be done safely. One mother said she would not have her baby subjected to injections for the study.

- “Genetic testing is OK as long as it’s safe”
- “No injections for my baby”

All parents agreed that they’d like to receive a quick phone call followed up by a letter reminding them of the appointment.

- Five participants looked favorably on phone as a method for this contact.
- Six participants looked favorably on mail as a method for this contact (including some who also looked favorably on phone).

The group did not seem to have a problem with providing a number of a relative or with contacting the project themselves if they moved, provided they felt good about participating in the study. If the study provides a benefit to the child or family then they may be more likely to notify the study of the address change.

- “You should provide a number for people to call if they move.”
- “Probably give my mother’s phone number – won’t change as often.”

4.2.3 Keeping You Interested

Gift certificates for clothing and/or college education were the most popular incentives mentioned. Parents wanted to help their children and themselves. A donation to a charity and postage stamps were the least popular. College bonds/certificates for child's future – that would be very inspiring to parents

- “Charity? – no, only if you're already rich”
- “Cable TV Discount – maybe, for how long (at least 3 months)”
- “Children's clothing is a good idea – helps child and parents.”
- “Incentives on yearly basis or at each visit”

Collecting biologic samples was perceived as more invasive than a simple interview. Parents suggested offering some other type of incentive, but gave no specific ideas.

- “Incentives based on age”

The group perceived cash as an acceptable form of incentive, but in general felt that it would be especially effective if coupled with other gifts (e.g., gift certificate for clothing). It was hard to determine the proper amount of money given the changing visit schedule the older the child got. Suggestions ranged from \$50 - \$100, but the group seemed unsure about how long the EPA could keep that up for 100,000 participants.

- “Money would be good – for some families it would be very important.”
- “Hourly wage”
- “Even if there is a lot of cash involved – you need to have additional types of incentives”

The group felt that monetary incentives would be appropriate given the amount of burden placed on the child and family.

- “No, nothing – maybe a million dollars.”

The participants would prefer either a phone call or a periodic presentation. Many thought the presentation might prove to be more informative because several people would have a chance to ask questions (that a certain individual may not have thought of).

- “Telephone call – you can also ask a real person questions”
- “Presentation – might be hard to work into everybody's schedule but it would be a good source of information”

During the early stages of the study the group agreed that info should be shared somewhere between every 3 – 6 months. A year without an update would be too long. However, as time went on, the participant grew older, and the number of visits decreased they felt that updates could occur less often (maybe 1 per year).

- “Every 6 months – I want an update of what's going on with my child's progress”

- “Every 3-4 months”
- “A year is too long to go without feedback – except maybe in later years when the required visits and other activities are already greatly reduced.”

The group wanted to receive both individual level feedback (how is my child?) as well as more global updates on the status of the study.

- “So you can make adjustments to lifestyle, etc. to improve your health”
- “Want updates on progress of the study – has it lead to any breakthroughs like new water filtration systems?”

Basically, the group wanted more info as opposed to less (even if there was no way to measure the findings against a scientific standard). Once they were committed to the study they expressed that they would be disappointed that if at some point EPA should decide to discontinue the study.

What other information would you not want to receive?

- “That I ain’t getting paid”
- “That the EPA is pulling the plug on the project,...after I’ve invested all this time”

5. Health Care Providers

The Health Care Provider groups were comprised of representatives from three categories:

- Physicians
- Nurses, nurse practitioners, and physician’s assistants
- Public health care workers

As described in **Table 4**, two groups of health care providers were included in this study—pediatric health care providers and obstetric health care providers. The group meeting in Chicago was comprised of health care providers who are involved in pediatric services. The focus group that was held in Research Triangle Park was comprised of obstetric and gynecological specialists as well as family practitioners that provide obstetric care.

Table 4. Sites Selected for the Health Care Provider Groups

Group	Site	Child’s Age	Type of Practice	Geography
HC-1	Chicago, IL	NA	Pediatric	<i>Mixed</i>
HC-2	<i>Research Triangle Park, NC</i>	NA	<i>OBGYN/Family Practice</i>	<i>Mixed</i>

5.1 Pediatric Health Care Providers

The group comprised of pediatric health care providers was conducted in the Chicago offices of RTI. Advance letters and flyers describing the purpose of the focus group were mailed out to pediatricians in several area hospitals and community health clinics including Children’s Memorial Hospital, Loyola Medical Center, University of Chicago Hospital, Erie Family Health Center, and the Clinic in Altgeld Gardens (a low-income housing project). Mailings were also sent to a handful of pediatricians with private practices whose names and addresses were listed on the American Medical Association’s (AMA) web site and recruiters also sent electronic versions of the advance letter and flyers to the e-mail accounts of members of the pediatric department at several area teaching hospitals. In addition, the recruiters contacted (via e-mail) the director of the Illinois Chapter of the American Academy of Pediatrics (ICAAP) who agreed to help spread the word about the upcoming focus groups by listing the recruiter’s name and phone number in their monthly electronic newsletter. This method proved quite successful and within a matter of days several physicians and nurses had contacted RTI wanting to learn more about the focus groups. Copies of the advance letter and flyer were then e-mailed or faxed to the interested health care providers. Many of these pediatricians also mentioned the focus group to their colleagues and news of the focus group was spread through word-of-mouth. Interest was very high amongst this group. All of the doctors and nurses who called were very eager to participate in the focus group. In fact, several had to be turned away because the session had already been filled. Overall, a total of 11 health care providers were recruited for the focus group and nine of them attended the session. Eight participants were white and one participant was African-American.

5.1.1 Getting You Interested

Group members said that the best place to read or hear about the NCS would be in a medical journal like the *Journal of the American Medical Association*, *Journal of Pediatrics*, *Pediatric RN*, or *RN magazine*. They also recommended that the study provide the information through a professional association like the American Association of Pediatrics or the National Organization for Pediatric Nurse Practitioners. They all agreed that the information should come from a trusted authority--a respected teaching/university-based medical research facility.

The health care providers also discussed places that potential participants might be hear or read about the study such as parenting magazines (i.e., *Chicago Parent*).

The group was interested in knowing what will be required from their practice and what will be required from the study participant.

- “What are the aims and goals of the study.”
- “[What about the] time commitment for participants and physicians.”
- “How much time is it going to take for the doctor? What is the physician’s commitment? Money and time are tied together.”

Providers mentioned concerns about the risks of the study, both to them as health care providers and to the participants. Issues such as how to go through the Institutional Review Boards (IRBs) were raised. The group agreed that IRB approval would be required from a number of individual institutions if the research team planned on using teaching/university-based institutions in the study. The group also raised confidentiality concerns.

- “[What are the] risks to patient.”
- “IRB approval process – you need an insider at each institution to really help campaign for the project and steer it through the IRB.”

Overall, the group suggested using a targeted approach to recruiting and enrollment. The group recommended that study staff discuss the benefits of participation with each individual study participant and with the health care providers to draw interest and encourage enrollment. The group pointed out that inner-city participants might be more interested in the study if the personal benefits they would receive from participation are emphasized during recruitment. The group though that recruitment of suburban participants should emphasize the benefits to science and the overall public health.

- “Individual benefits - inner city - versus global issues - suburban rich folks.”

To attract the interest of medical associations and research-oriented health care providers, the group recommended placing an emphasis on the potential findings of the study that will serve to benefit the overall public health.

- “Pitching the study to medical associations should promote global benefits and hypotheses.”

Participants noted the benefit to the individual of receiving health information by being part of the study should create excitement to participate.

- “Give results at least once a year or maybe every other year.”

When asked what they would find exciting about participation as a health care provider, the group indicated that being a part of a large national study linked to well-known and respected individuals and institutions would be VERY motivating.

- “Knowing the study investigator or institution would also increase excitement.”

The group recognized that study issues may vary depending on the population and or the physician's practice but all agreed that they would be more interested if the study related to issues they deal with in their practice.

- "More interested if it relates to personal issues for the physician (e.g., do you work with inner city kids – they deal with asthma, violence, malnutrition, obesity) everyday."

The group also thought that the opportunity to network with peers who are also involved would be exciting. The group noted that some institutions "advertise their participation in new research" as one of their selling points and that would be a benefit to the providers.

The Spokesperson recommended by the group should be a charismatic speaker or a medical authority (i.e., The U.S. Surgeon General).

5.1.2 Time Commitment and Data Collection Activities

The group was varied in their opinions as to the best way to promote the NCS and enroll participants into the study. The physicians were mainly concerned with disruption of patient flow and costs to the practice. Providers felt that physicians would not have the time to speak directly to patients about the study but that nurses might be able to spend more time with patients to discuss the study. The group thought that private practitioners in an affluent area might not be as willing to participate actively in recruitment as practitioners working in a teaching hospital or clinic. Actively participating in “community outreach activities” was not realistic for this group given their time constraints.

- “There is a cost to each physician’s practice – can you afford to spend an extra 5 minutes with every patient? It depends on the practice. Private practitioners in an affluent area might not be willing to do it, but in academic settings with more staff, it might be more feasible.”

In terms of actively promoting the NCS, providers expressed concerns about providing accurate information to patients and having the time to enroll patients by calling a toll-free telephone number. Most health care providers preferred that the patient contact the NCS study team directly if they were interested in participating.

- “It’s a time issue – does the provider have the time to make the patient understand everything or even learn everything about the study to be able to answer questions?”

- “Enroll via the toll-free phone number – only the physician needs to give them a phone number and tell them to call if they’re interested.”
- “I would not allow the study to directly contact patients.”

Health care providers would abstract or photocopy patient records, but reported that the NCS study team would need to provide financial assistance for these tasks. The providers who work in a local clinic indicated that a person would have to be hired to perform these tasks. The financial assistance could take the form of reimbursing the practice for the cost of a person already on the physician’s staff doing the work or by providing a research assistant to come in and perform the work.

- “[I would allow it] if EPA offered a \$15 incentive per chart and let the physician pick somebody from their staff to do it.”
- “Half-time nurse and half-time research expert – EPA would provide the funding.”

After reviewing the planned number of visits, the providers indicated that the number of planned visits seemed reasonable. Providers recommended that the visits occur during regularly scheduled well-child care visits to minimize the burden on patients and providers

- “Must be combined with standard well-child visits.”

The group did indicate that getting 30 minutes from primary physician would not be feasible. The more likely period would be fifteen minutes with the physician and the remaining time with a nurse or physician's assistant.

- “Nurse Practitioners have more time – could spend 30 minutes – but they might not be available for all 4 visits.”

Providers said that both the health care provider and patient would need to know what the biologic sample would be used for and what it wouldn’t be used for. Providers also mentioned that patients might be concerned that the placenta might be used for cloning.

- “Doctor would want to know exactly what was being screened for with each sample.”

Providers agreed that samples collected in the clinic could be gathered with regular biologic sample collection.

- “If you’re going to collect blood for the study, you should just try to take an extra tube during a visit in which the patient is already expecting the provider to draw a sample.”

Health care providers mentioned the challenge in collecting several of the biologic samples – placenta, umbilical cord blood, and meconium. Concerns about cloning were mentioned in relation to reservations about providing placenta. Breast milk was mentioned as a concern because mothers might be concerned that it could be tested for alcohol. Health care providers also felt that baby teeth would be difficult to collect from parents due to sentimental reasons.

- “Best bet is to couple the samples when they would typically be drawing samples anyways.”

Pediatricians were not comfortable with genetic testing because of the number of problems that could arise as a result of testing – interpreting results and paying for treatment if a genetic abnormality was found.

- “What is the EPA obligation to share the results?”
- “Would NOT want to interpret results.”
- “What if they discover there is a gene for Cystic Fibrosis? Might need a genetic counselor afterwards to interpret results.”
- “Testing for mutations would be more acceptable than testing for a specific gene (e.g., Parkinson’s).”

Providers felt that they could be involved in participant recruitment and data collection through medical records abstraction or biologic specimen collection. The collection of biologic samples was contingent on being collected during other regularly scheduled lab specimen collection and having specimen kits for the samples. Medical record photocopying or abstracting would need to be reimbursed by the NCS research team.

- “Amount of time spent would depend on if they were being reimbursed by the sponsor.” [EPA/NCS]

Providers stated that having extra (non-staff) personnel in the office could cause distraction and lead to a shortage of space.

- “Not enough room/space.”
- “Having extra people in the office.”

One group felt that the time commitment required by the study participants may cause appointments to run long, resulting in a patient flow problem.

- “Managing patient flow.”

5.1.3 Keeping You Interested

Providers preferred professional development incentives over office/medical supplies. Specifically, incentives included professional development items – journal subscriptions, membership in professional organizations, and medical conference funding.

- “Medical conference funding.”
- “Journal subscription or membership in professional organizations.”

Pediatricians recommended a monetary enrollment stipend and a per/patient reimbursement for time and effort depending on the demands placed on the practice. One specific recommendation was for the same reimbursement rate that insurance carriers provide for a 15-30 minute office visit

Providers agreed that the study should subsidize the labor cost involved in photocopying and abstracting. They also agreed that they preferred to have their staff do the tasks associated with the study.

- “We don’t want a gift – we want an extra set of hands.”

Pediatricians recommended newsletters and e-mail updates. Newsletters could be read by health care providers at their convenience. Some mentioned that a project website with study resources and updates would be useful. Pediatricians supported local meetings because they thought it would promote more exchange. Providers recommended quarterly updates.

- “Quarterly.”
- “No less than every 6 months.”

Providers mentioned that they would like updates on recruitment efforts, enrollment, and preliminary study findings. Health care providers mentioned included a toll-free help line to answer study-related questions.

- “800# help line for physicians who have questions during sample collection, recruitment, etc. It should serve as a support line to help practitioners.”
- “A real person to talk to.”

Providers reported being concerned about having test results that they couldn’t tell their patients about (i.e., genetic testing).

Providers agreed that the best way to communicate with their practice was through electronic mail and regular postal mail.

5.2 Obstetric and Gynecology Health Care Providers

The group of obstetric and gynecology health care providers was conducted in Research Triangle Park, NC. The recruitment requirement was that the health care provider work with obstetric patients. RTI staff recruited for this session by mailing advance letters to OB/GYN physicians who work in the RTP area. Staff also faxed flyers to local hospital OB/GYN units and met with office managers at different OB/GYN and Family Medicine facilities to distribute flyers to nurses, physician’s assistants, and nurse practitioners. Recruiting OB/GYN doctors in RTP was difficult compared to the ease with which we were able to recruit pediatricians in the Chicago area. One reason may be that the pediatricians are more interested in children’s health issues than are OB/GYN practitioners. It was not as difficult to recruit the nurses. Seven participants were recruited and five attended. Four of the group members were white and one was African-American.

5.2.1 Getting you Interested

The physician indicated that the best place to read or hear about the NCS would be in a medical journal such as *The American Journal of OB/GYN* and the *New England Journal of Medicine*). The nurses recommended going through a professional nursing association.

- Physician: “I read the New England Journal of Medicine because I know my patients will ask me about it. If I know they ask me, I will listen.”

Health care providers mentioned other sources that would bring the study to their attention. Opinions as to the best way of promoting the NCS included brochures and posters located in restrooms. Participants could read about the NCS and call a telephone number or access the NCS web site for more information. Others recommended a closed-circuit television advertisement system that had a video segment that described the study and provided NCS contact information.

Providers expressed interest in knowing what will be required both from them and from the study participant. Since the information was primarily for the purpose of attracting interest, detailed information might not be required until the practice makes contact with the research team for more information.

- “How much time is it going to take me? Is it something added to my job?”
- “What is going to be required of us?”
- “What types of questions will participants be asked?”

Providers mentioned concerns about the risks of the study, both to them as health care providers and to the participants.

- “What liability would it be for us? Are we going to be held responsible for the faults of the project?”
- “If the IRB from UNC is used, I would not have a problem with it. A respected name is important.”

The providers also expressed concern about retention over 21 years and indicated that if they were to recruit or convince participants, then they would have to be convinced first. The physician said that he would be convinced if he saw evidence of other studies that managed to retain participants. The non-physician health care providers emphasized that the entity conducting the study would have to be well respected. All agreed that approval by a respected Institutional Review Board (IRB) would carry a great deal of influence with local health care providers.

Benefits of the study focused both on personal/professional gain as well as the overall benefits to science. Health care providers wanted to know the objective of the study, what the research team was looking for.

- “What’s in it for me? Will I be recognized for my participation?”

Providers recommended discussing the benefits to the individual study participant and to the health care provider to draw interest and encourage enrollment. They also recommended emphasis on the benefits to overall public health to attract the interest of medical associations and research-oriented health care providers.

- “What is it going to do for my child? Then, how is my child’s participation going to help other children?”
- “Other children in the future will benefit from the study.”

When probed about what would generate “excitement” about participating, the group focused on incentives and benefits to individual participants as well as benefits to the health care providers involved. The group indicated that what the participant perceives as incentives and health benefits will vary based on their socioeconomic background.

- “There has to be an incentive to the provider.”

The physician also indicated that he would be excited if he knew the scientific plan and the goals of the study.

- “I want the details of the plan year by year.”

5.2.2 Time Commitment and Data Collection Activities

Health care providers reported general agreement with the notion of passively promoting the NCS to their patients. Again the group reiterated that the best way of promoting the NCS would include brochures and handouts as well as posters located in restrooms. Participants could read about the NCS and call a telephone number or access the NCS web site for more information. They also recommended a closed-circuit television advertisement system that had a video segment that described the study and provided NCS contact information.

When probed about how they would feel if they were asked to promote the NCS actively, providers expressed concerns about providing accurate information to patients and having the time to enroll patients. One nurse from a public health clinic indicated that the way that the clinic environment processes the intake of expectant women into their practice for prenatal care would rule out having the nurses conduct the enrollment. She explained that the first visit to the clinic for prenatal care is a group visit with perhaps ten patients and two nurses. She indicated that it would not be possible for the available staff to take on another role. She would like to see a representative from the study attend the intake sessions and provide all of the information to potential participants and answer their questions.

- “I don’t have enough time to explain the program. Initially, a researcher should deliver the information to the patient then a nurse could provide information.”

A nurse who works with a private physician offered that they enroll patients into studies all of the time and so that it would not be an issue for their type of practice. She indicated that the practice staff would attend a training session held by the study staff. During the training, the

health care providers would be provided with all study information and materials that detailed the objectives of the study, the risks, and the benefits.

- “Providers would need to be trained to develop a level of comfort. An in-service training would be good.”

The health care providers were asked about whether they would abstract or photocopy patient records. The nurses uniformly indicated that they would not photocopy because they are nurses and that should be someone else's job. The private practice nurse indicated that her practice has staff who would do that job. The nurse from the public health clinic said that she did not have staff and didn't want to get involved in that task. The physician noted that eventually all records would be electronic and there would be no need for copying or abstracting. A related concern that was raised focused on the U.S. Health Insurance Portability & Accountability Act (HIPAA) constraints on transmission of patient data.

In general, the health care providers preferred that the person doing the work be someone on their staff who could be trained on confidentiality and patient privacy issues rather than having members of the study team come into the office. The nurses indicated that having outsiders in the office was a terrible nuisance. The physician noted that he did not object to having study staff in the office but the nurses quickly pointed out that the physician is rarely the person who has to handle the additional staff in the office.

- “We would rather use someone from our office to handle this work.”

In addition, providers reported that the NCS study team would need to provide financial assistance for these tasks. Again, the number of patients recruited by each practice seemed to have an effect on the health care provider's willingness to actively promote the study.

Providers felt that the number of visits seemed appropriate. One recommendation was increasing the pre-natal visits to three (one per trimester), if nothing else to maintain interest in being a part of the research study. Another recommendation was for one visit per year for ages 3 to 6. They noted that due to the number of developmental milestones achieved in these years, the study team would need frequent contact to identify developmental disabilities.

- “The visits during pregnancy should be done during each trimester.”
- “Since children between the ages of 3 to 6 grow and develop rapidly, there should be one visit per year.”

Providers said that 30 minutes with the primary care physician would be too long. A nurse practitioner or physician assistant was recommended as someone who could assume the majority of the workload during these visits.

Providers recommended that the visits occur during regularly scheduled well-child care visits to minimize the burden on patients and providers.

Providers said that both the health care provider and patient would need to know what the biologic sample would be used for and what it wouldn't be used for. They also mentioned that patients might be concerned that the placenta might be used for cloning.

- “Have to know the purpose of collecting biologic samples – what’s being tested?”

Participants agreed that samples collected in the clinic could be gathered with regular biologic sample collection – piggybacked onto other regularly scheduled laboratory appointments. Kits could be provided to health care providers so that samples could be packaged and mailed to the study team for analysis.

Health care providers mentioned the challenge in collecting several of the biologic samples – placenta, umbilical cord blood, and meconium. The OB/GYN physician said that this wouldn’t be difficult but it would require that the patient have a kit with them upon admission for labor and delivery and that the hospital cooperate in collecting and shipping the samples. Some felt that mothers might be reluctant to provide breast milk either because they were not planning on breast-feeding or because breast milk production begins after the mother is released from the hospital. Health care providers also felt that baby teeth would be difficult to collect from parents due to sentimental reasons.

- “You could get a baggie that the maternity ward nursery places the baby’s first soiled diaper in and ship it off to the lab.”
- “Breast milk might be hard to get since the mother will be home by the time they’re producing milk and not colostrum. Also, some mothers may not want to produce breast milk or breast feed.”

Some of the family practice health care personnel (non-physicians) within the group were not comfortable with genetic testing because of the number of problems that could arise as a result of testing – interpreting results, paying for treatment if a genetic abnormality was found, the possible stigma related to having a genetic abnormality, and health and life insurability if results were disclosed to the insurance industry. The OB/GYN physician in the group seemed comfortable with genetic testing and genetic counseling and said that he routinely does this in his practice.

- “With genetic testing someone may be identified with a defect and labeled forever.”
- “I do genetic testing and counseling all the time in my practice.”

Providers felt that they could be involved in participant recruitment and data collection through medical records abstraction or biologic specimen collection. The collection of biologic samples was contingent on being collected during other regularly scheduled lab specimen collection and having specimen kits for the samples. Medical record photocopying or abstracting would need to be reimbursed by the NCS research team. Again, the number of patients recruited by each practice seemed to have an effect on the health care provider’s willingness to actively promote the study.

- “A low number of participants and we can do more, a high number of participants, we can do less.”

Several thought that if the task of being the office coordinator for the study came to one person, others would be envious. They felt that this could be mitigated by sharing the responsibility and reward and turning it into a team effort.

- “Employee griping.”
- “Jealousy of employees.”
- “Make it a group effort.”

5.2.3 Keeping You Interested

Providers preferred professional development incentives over office/medical supplies. Some recommended a laptop computer with a network card that could assist with data collection for the study while also expanding the capabilities of the office.

- “No tongue depressors or syringes.”
- “Staff could use a laptop computer with Internet access.”

Providers recommended a monetary enrollment stipend. Some recommended adding regularly occurring incentives that could be used for staff breakfast/luncheons, and a final monetary award for achieving their study quota. The added benefit for the periodic breakfast/luncheons was that it would benefit the entire staff, facilitating teambuilding rather than benefiting selected individuals.

- “Money is a benefit to the owner and staff. Money does move the world around.”

Providers recommended a per/patient reimbursement for time and effort depending on the demands placed on the practice. Specifically, an initial enrollment incentive, periodic incentives, and a concluding award for retaining their study quota.

- “We should be paid money per patient.”
- “Large money up front and at the end.”

Providers agreed that the study should subsidize the labor cost involved in photocopying and abstracting. They also agreed that they preferred to have their staff do the tasks associated with the study. Other recommendations included a new photocopier and paper, depending on the demands of the study.

- “We could charge a cost per patient.”
- “It depends on the numbers. Six patients a year and I’ll do it for nothing. I am interested in the study. A larger patient base – that’s different.”

Newsletters and e-mail updates were recommended modes of communication. Newsletters could be read by health care providers at their convenience. Some mentioned that a project website with study resources and updates would be useful. Health care providers in this group felt local meetings would work better for practice staff than for doctors, who have little time. Providers recommended quarterly updates.

- “I do not care about the meetings – e-mail works best for doctors.”

Providers mentioned that they would like updates on recruitment efforts, enrollment, and preliminary study findings.

- “The science of it would interest me.”
- “Updates on enrollment and ‘Are people interested’ interest me.”

Health care providers were interested in what worked and didn’t work in participant recruitment and enrollment.

Providers said that there is no information that they would not want to receive. They wanted all information on their patients.

- “I think we should receive everything.”
- “There is nothing I would not want to know.”

Practitioners agreed that the best way to communicate with their practice was through electronic mail and regular postal mail. Telephone contact, especially during peak business hours, was discouraged.

6. Representatives from Community Organizations

The fifth group of stakeholders includes representatives from organizations committed to public and community service. Strong support from community organizations is thought to be instrumental in the recruitment and retention of participants in a longitudinal study. Recognizing that the issues that are important to communities may vary by region, two focus groups were convened in different regions of the country to try to get a sense of these regional concerns. The groups were asked to represent their specific communities in discussions that explored the concepts of community involvement and support for the NCS.

Table 5 Sites selected for the Community Representative's Groups

Group	Site	Child's Age	Type of Practice	Geography
CR-1	Chicago, IL	NA	NA	<i>Mixed</i>
CR-2	<i>Research Triangle Park, NC</i>	NA	NA	<i>Mixed</i>

6.1 Representatives of Urban Midwest Community Organizations

This group was conducted in the Chicago offices of RTI. A number of community organizations serving women, children, and families (e.g., Chicago Urban League) were contacted about participating in the focus group. An attempt was also made to contact organizations that concentrate on environmental issues (e.g., Westside Health Authority). Wherever possible these organizations were targeted on the basis of their work within the community and the extent of their interactions with individuals who may also fall into one of the other groups of interest (pregnant women, children with disabilities, and/or children without disabilities). Some of the organizations that were contacted included the United Way, Catholic Charities, the Boys and Girls Clubs, the Illinois Parent Teacher Association, Voices for Illinois Children, Dreams for Kids, Head Start, the Jewish Children's Bureau and Improving Kids' Environment. Initial contact with the directors of many of the organizations was made via an advance letter that was mailed from the RTI Chicago office. The letters were followed by telephone calls from the recruiter who provided a brief overview of the focus group. Overall, a total of 11 people agreed to participate in the focus group and 9 of them attended the session. The group was comprised of 7 African-American and 2 Hispanic representatives of local urban community organizations.

6.1.1 Getting You Interested

Community representatives mentioned that church groups and other similarly trusted organizations would be good organizations to assist in recruiting participants into the NCS. In addition to religious organizations, a number of other recruiting sources were mentioned: day care centers, community/ recreation centers, volunteer centers, and other agencies that could disseminate study information (i.e., United Way, WIC Offices, The Urban League)

- “WIC offices – A lot of pregnant women with children up to 5 years old are there.”

Mode of communication varied and community representatives seemed to think a multi-mode communication approach would work best. Specifically, television commercials, public service announcements (PSAs), free newspapers, community newspapers, and billboards were mentioned. Of these sources, television commercials and PSAs received the most positive reaction.

- “Free newspapers.”
- “Community newspapers.”
- “PSAs – very good.”

All participants agreed that their organizations would need to know about the objectives of the study, what would be expected of the participants, potential risks and benefits, and confidentiality assurances.

- “My organization will want to know what the outcome is. How does it align with our goals?”
- “Some of the moms we service – they’ll have to really know what’s going on and what the end result will be. What they’ll get out of it.”
- “How personal are you going to be?” [Confidentiality concern]

Focus group interview participants reported that stakeholder groups and Community representatives could be identified by the subject matter of the study. Since this study involves environmental exposures and the health of children, environmental groups, children’s stakeholder groups that work with health risks, social services, health care facilities, schools, and social service network directories could be targeted.

- “For African-Americans and Hispanics – social services.”
- “Health care facilities.”
- “Different social service agencies – The Chicago Urban League.”

Funding for the organization was reported by participants as something that would make them excited to be involved.

“I’ve done research and I know that’s how we keep people coming back.”

Leaders said that supporting the objectives of their organization (e.g., children’s health, education, etc.) was very important.

“...congruence with the mission of the organization.”

The group members identified the following environmental and children’s health issues in their community:

- Lead poisoning.
- asthma
- obesity

- immunizations
- Drug use.

6.1.2 Ways Community Organizations Can Get Involved

Community representatives wanted to be informed partners with the research team. They emphasized the need be involved and well informed about the various aspects of the study. The Chicago group noted that their organizations could serve as a community liaison to the research team. Community representatives felt that their involvement would be important in fostering trust with study participants.

“You have doctors and scientists here...and your community here...and everyone goes over everyone’s heads, so you need someone in between.”

Participants agreed that it was essential that they know about all aspects of the study and be able to answer questions. Participants mentioned that workshops would be a good way to educate them on the various aspects of the study.

“In order for us to help you, we have to be experts too.”

Effective outreach campaigns might include trusted organizations such as The United Way, as well as the involvement of local churches and religious organizations.

“We’d go door to door and ask if we can sample for lead dust. For us to tell them about this particular study we would need to know what it is all about. We’d have no problem telling them about the NCS – they trust us.”

Participants noted that keeping study participants involved would be difficult because of the possible reluctance to provide biologic samples. Community representatives noted that parents have a good deal of control in keeping the child in the study into their pre-teen years, but beyond that, continued participation of the child will be a challenge.

“We have some females that by the time they’re 14, they’re moms!”

A second attrition-related issue focused on transient families or changes in family status. Families from these communities may be difficult to follow over time and seem pre-disposed to change their structure. A family may be recruited into the study, but upon marriage (in the case of single parents) or divorce and re-marriage, the male spouse may not support continued involvement in the study.

“At any point an ongoing relationship can break.”

The group had two concerns about biologic samples. The first was a general reluctance to provide biologic samples without a lot of assurances as to what the samples would be used for and what they wouldn’t be used for. The second concern was related to attrition due to a reluctance to continue to provide biologic samples once the study participant reached an age of assent.

“People will say, ‘What do you want?’ and ‘Why do you want it?’”

Community representatives mentioned the study must make it easy for the study participant to be involved. The protocol shouldn’t be intrusive or cause hardships. Biologic samples should be collected during regular office visits (e.g., during routine well-baby exams, school physicals, etc.).

Participants mentioned that the cost of the clinic visit and transportation to and from the clinic might be issues.

Community representatives believed that study participants would need a great deal of information prior to agreeing to provide biologic samples. Additionally, Community representatives thought that blood and urine samples would not be too difficult to obtain, but the remaining samples seemed much more problematic.

- “Some of them might be simple, urine maybe.”
- “Umbilical cord, meconium – that’s difficult to get.”
- “Breast-feeding is kind of a private thing ... may not want to give it up just for testing.”

Community representatives noted ethical concerns over the rights of the child. In the context of discussion of how members of their community would react to providing biologic samples, Community representatives believed that collecting these types of samples would be very difficult. The Chicago group mentioned the challenge of having pre-natal care provided by one health care provider and delivery of the baby by a different health care provider.

Community representatives emphasized that education of the community organizations was essential. They said that once education is provided to the community organization, community organizations could serve an intermediary role between the research team and community participants.

Community representatives felt that community organizations could serve as community advocates, presenting the needs of their community to local government once preliminary results are released by the research team.

- “The Chicago Urban League believes in community empowerment.”
- “There are advocacy things that can build support around the study, but what you are telling us is really vague.”

Community representatives mentioned that community organizations could help garner additional support for the study through outreach within their organization (e.g., large, national community organizations) or by community action boards. Community representatives used this opportunity to express concerns about the protection of human subjects. Participants from one group expressed concern that the children of their community would be “guinea pigs” for science.

- “Not like Tuskegee, be a guinea pig.”
- “Let the kids know they’re not guinea pigs.”

Community representatives mentioned the need for community organizations to feel comfortable with research project objectives and participant safeguards in order to participate.

- “Confidentiality would be the biggest issue ... the government is taking my kid’s urine. If he’s taking drugs, will the government arrest him?”
- “Safety of the children and families is the utmost.”

Community representatives raised concerns about the difficulty of maintaining a relationship and possible lack of interest in a long-term study. One group recommended periodic reports during the course of the study. The group seemed to feel that participants should receive some sort of intervention in the event that a health risk was uncovered.

- “I don’t think our organization would want to make a commitment to be in a 21-year survey – wouldn’t understand how they’d need to be involved over the whole course.”
- “I think 21 years is too long.”

Health issues that Community representatives felt should be included in the study were asthma, sickle cell, and genetic links to substance abuse.

6.1.3 Keeping You Interested

Community representatives felt that financial support to their organization would be necessary for long-term support of the NCS. Community representatives also felt that the research study would need to support the objectives of their organization. A flow of information from the research team to the community organizations that supported their stature and presented them in a positive light was also important.

- “If it is relevant to what my organization is doing, then it is a good partnership. If goals diverge, then we wouldn’t want to be involved.”

Community representatives felt that building trust was an important factor in their continued participation. An information flow from the research team to the community organizations would be a good way of building trust.

[What if continued participation helped to increase your access to relevant information on study-related issues?] “That would be a nice partnership to have that open communication. That would also build trust.”

Participants seemed to believe that a range of incentives would appeal to the varied needs and desires of their communities. Community representatives recommended providing study participants with a list of incentives that they could select from. Gift certificates for infant supplies were a popular incentive. Community representatives also felt that computers with Internet access would be well received. Also, study information and test results were not seen as an incentive. It was expected that participants would receive test results and health information during the course of the study. Incentives from the list that were not supported by participants were Internet access (of no use without a computer), postage stamps, and personal digital

assistants (PDAs or Palm Pilots). Incentives not on the list provided during the focus group interview recommended by Community representatives included college-education savings accounts/stipends, gift certificates for shopping (i.e., Wal-Mart, K-Mart, grocery stores), bus passes, cell phones (with service), and some kind of health care benefit (e.g., vision and/or dental care).

- “Mix it up, change it from year to year.”
- “Give them a computer with the Internet. The government throws away tons of computers.”
- “Grocery store gift certificates or Kmart and Wal-Mart.”
- “Give money to the child for education.”

Community representatives mentioned that an incentive would need to be given each time contact was made with the study participant.

- [Give the incentive] “...every visit, each time contacted.”

The group was probed as to whether they thought people would feel coerced to participate by the incentives discussed. The group agreed emphatically that coercion due to the incentive was not perceived as a concern by Community representatives.

- “People will drop out if they don’t want to participate.”

Community representatives agreed that they would like to see project updates take the form of periodic newsletters, a website with links to other organizations as well as project fact sheets, and occasional meetings where the research team presents preliminary findings or project updates to the community organizations.

- [Regarding a Website] “I can sit there and read everything I need to read.”

All participants felt that some sort of periodic information would be necessary – at least annually. Community representatives were split between wanting quarterly or annual reports. Several mentioned sending out updates regularly and when they were warranted (e.g., upon finding something that would be of interest to their community).

- “Every step of the way.”
- “Maybe a quarterly or yearly report.”

Community representatives mentioned that organizations would like to see preliminary results disseminated. The group reported that community organizations would benefit from hearing how results were affecting policy.

Community representatives endorsed community advisory boards where groups with competing goals could agree on common ground – the health and welfare of children.

- “Identify a common goal.”
- “It would be good to know how agencies from other areas operate.”

6.2 Representatives of Suburban Southeast Community Organizations

This group was conducted in Research Triangle Park, NC and was comprised of community representatives of organizations or agencies that work with families, children, or environmental issues that impact families and children. RTI recruiters contacted the North Carolina State Community Services Department, Durham Companions, Durham Public Schools, Durham Parks and Recreation, police department community policing program, a church, Public Allies, Environmental Federation of NC, Leaders for Environmental Justice, and the La Leche League. This was a high-interest group that was relatively easy to recruit. RTI recruited eleven participants. All eleven attended so two participants selected to be excused from participation. They were thanked, paid the incentive, and excused. The group was comprised of nine participants, two were white and seven were African-American.

6.2.1 Generating Interest in the Community

Community representatives mentioned that church groups and other similarly trusted organizations would be good organizations to assist in recruiting. In addition to religious organizations, a number of other recruiting sources were mentioned: day care centers, community/ recreation centers, volunteer centers, and other agencies that could disseminate study information (i.e., United Way). Television commercials, public service announcements (PSAs), free newspapers, and community newspapers. Of these sources, television commercials and PSAs received the most positive reaction.

Community representatives agreed that their organizations would need to know about the objectives of the study, what would be expected of the participants, potential risks and benefits, and confidentiality assurances.

- “How will participants benefit from the study.”
- “Parents and schools need to feel comfortable with the study.”

Focus group interview participants reported that stakeholder groups and Community representatives could be identified by the subject matter of the study. Since this study involves environmental exposures and the health of children, environmental groups, children’s stakeholder groups that work with health risks, social services, health care facilities, schools, and social service network directories could be targeted.

Funding for the organization was reported by Community representatives as something that would make them excited to be involved. Recognizing community organizations that are involved and emphasizing the importance of their role in the success of the research project would make them excited. They would want the community organizations that help to be cast in a positive light. It would be important also to ensure that the study does not negatively affect their organization’s standing among its clients, constituency, or community.

The group identified the following as environmental issues in their Community:

- Air quality

- Lead poisoning
- Poor water quality due to agricultural run-off
- Cigarette smoke

Health issues of concern for Community representatives included:

- Asthma
- Obesity
- Diabetes

6.2.2 Ways Community Organizations Can Get Involved

Community representatives wanted to be informed partners with the research team. They emphasized the need to be involved and well informed about the various aspects of the study. Community representatives focused on being part of the study design and planning phase. This was crucial for any subsequent involvement. It would create a sense of “ownership” that would allow them to go into their communities and endorse the project. Community representatives felt that their involvement would be important in fostering trust with study participants.

- “Planning done without the input of community organizations will produce resistance.”

Community representatives agreed that it was essential that they know about all aspects of the study and be able to answer questions. Participants mentioned that workshops would be a good way to educate them on the various aspects of the study.

- “I am uncomfortable at this time because I do not know enough about the project.”

Effective outreach campaigns might include trusted organizations such as The United Way, as well as the involvement of local churches and religious organizations.

- “The church is the best place to recruit participants. People trust their churches.”
- “To feel comfortable, there has to be a certain level of trust between the community organization and the EPA.”

Community representatives noted that study participants might be reluctant to provide biologic samples whether for legal reasons (e.g., drug use) or sexual behavior reasons. Biologic samples should be collected during regular office visits (e.g., during routine well-baby exams, school physicals, etc.).

- “The study shouldn’t be intrusive or cause hardships.”
- “Samples should be collected during regular office visits. Do not add extra office visits.”

Community representatives mentioned that the cost of the clinic visit and transportation to and from the clinic might be issues. Community representatives also believed that study

participants would need a great deal of information prior to agreeing to provide biologic samples. Additionally, Community representatives thought that blood and urine samples would not be too difficult to obtain, but the remaining samples seemed much more problematic.

- “Clear information about how the findings will be used.”
- “Breast milk, placenta, umbilical cord blood, and meconium” [will be difficult to obtain]

Community representatives expressed reservations founded in research ethics about providing biologic samples. One group noted the rights of the child, while another group mentioned the need to have biologic information safeguarded.

- “Information must be safeguarded.”

In the context of discussion of how members of their community would react to providing biologic samples, Community representatives believed that collecting these types of samples would be very difficult. The participants mentioned that some people within their community might be reluctant to provide biologic samples because of lifestyle issues, such as substance abuse.

Community representatives emphasized that education of the community organizations was essential. They said that once education is provided to the community organization, they could serve an intermediary role between the research team and community participants. This group expressed reluctance to discuss the specifics of the research study with participants but did feel that they could play a role connecting participants with the research team.

Community representatives felt that community organizations could serve as community advocates, presenting the needs of their community to local government once preliminary results are released by the research team.

Community representatives mentioned that community organizations could help garner additional support for the study through outreach within their organization (e.g., large, national community organizations) or by community action boards.

Community representatives used this opportunity to express concerns about the protection of human subjects - the need for clear and consistent information for the community groups.

- “Expectations of community organizations need to be clear.”

Community representatives mentioned the need for community organizations to feel comfortable with research project objectives and participant safeguards in order to participate.

- “Let people know why samples are collected and people would need to know the purpose.”
- [Holding up the list of biologic samples] “I can’t explain this to my boss.”

Community representatives raised concerns about the difficulty of maintaining a relationship and possible lack of interest in a long-term study. One group recommended periodic

reports during the course of the study. Community representatives also seemed to feel that participants should receive some sort of intervention in the event that a health risk was uncovered.

- “I think 21 years is too long.”
- “Periodic reports providing interventions would help build support.”

6.2.3 Keeping You Interested

Community representatives felt that financial support to their organization would be necessary for long-term support of the NCS.

Community representatives felt that the research study would need to support the objectives of their organization. A flow of information from the research team to the community organizations that supported their stature and presented them in a positive light was also important.

Community representatives felt that building trust was an important factor in their continued participation. One group mentioned that an information flow from the research team to the community organizations would be a good way of building trust. The other group said that not only would they like to work with a single research organization, but they would like the same person serving as a liaison between the research team and the community organization.

- “I want to talk to the same person through the course of this study ... a personal relationship.”

Participants seemed to believe that a range of incentives would appeal to the varied needs and desires of their communities. Community representatives recommended providing study participants with a list of incentives that they could select from. Popular incentives from the list presented to the group included gift certificates for infant supplies, money, savings bonds, calling cards, and youth activities (e.g., museum trips, tickets to sporting events, educational trips). Also, study information and test results were not seen as an incentive. It was expected that participants would receive test results and health information during the course of the study. One incentive from the list that was expanded was “school supplies.” One group felt that expanding the definition of school supplies to include school tuition or college education expenses would be well received. Incentives from the list that were not supported by participants were Internet access (of no use without a computer), postage stamps, and personal digital assistants (PDAs or Palm Pilots). Incentives recommended that were not on the original list provided included college-education savings accounts/stipends, gift certificates for shopping (i.e., Wal-Mart, K-Mart, grocery stores), and bus passes.

Community representatives mentioned that an incentive would need to be given each time contact was made with the study participant.

- “Money consistency shows appreciation.”
- “The amount of the money is not as important as the consistency.”

The group did not think that community members would find the incentives discussed coercive.

- “No – none of these incentives.”

Community representatives agreed that they would like to see project updates take the form of periodic newsletters, and occasional meetings where the research team presents preliminary findings or project updates to the community organizations.

All participants felt that some sort of periodic information would be necessary – at least annually. Community representatives were split between wanting quarterly or annual reports. Several mentioned sending out updates regularly and when they were warranted (e.g., upon finding something that would be of interest to their community).

- “The dissemination of information should be driven by the information. Do not send out unimportant information.”

Community representatives said that community organizations would like to see preliminary results disseminated. Community organizations would benefit from hearing how results were affecting policy. Community representatives thought information about project successes and challenges would be valuable.

Community representatives endorsed community advisory boards where groups with competing goals could agree on common ground – the health and welfare of children.

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7. Expectant Parent Group Comparisons

One of the objectives of this focus group project was to assess differences that might exist between the groups with respect to recruiting and retaining participants in the NCS. In the following sections, we compare the expectant parent groups across demographics that are believed to impact beliefs about recruitment and retention. Age, education, type of health care provider, type of living area (rural, urban, suburban) and geographic region are all factors thought to affect beliefs about recruitment and retention of expectant mothers. Comparisons are provided for age, education, type of health care provider, urbanicity, and geographic region. Caution should be exercised when interpreting these comparisons because the variables of interest are frequently confounded by other variables.

7.1 Expectant Parents Age 35 and over and Age 35 and younger

There are a number of reasons to assume that expectant parents who are younger than age 35 (Group 1) may have differing concerns about participating in the NCS than expectant parents who are age 35 or older (Group 2). Below we explore a comparison between the two age groups.

7.1.1 Getting You Interested

Both groups thought it best to learn about the study through their health care provider but the younger women also thought magazines, radio and TV were good sources, although there was some concern about the expense to the study. The older women thought that other good places to hear about the NCS were the Home Schooling Association, other health care offices and day care centers. The older women offered that telephone and mail were not a good medium for communicating information about the study.

In terms of the kind of information the women expect before making a decision to participate, the older women wanted to know about risks to the child, the kind of time commitment expected and how confidentiality would be insured. The younger group also expressed concerns about the child's participation and said that they wanted to know what kind of drugs or tests were involved and what the eligibility criteria were. The younger women expressed more cynicism and said that they expected to find the risks "written in the fine print." Both groups agreed that they would have to know exactly what was involved and how privacy would be insured.

The older women thought that it was equally important that their participation benefit the child and contribute to science and overall public health. The younger women initially started their discussion holding the same view but then decided that they would be more interested in the benefits to their child's health than the contribution to science.

Both groups felt that incentives would make them "excited" about participating in the NCS. The younger group preferred college tuition, annual stipends, medical reports on their

children and study results. The older group mentioned benefits to the child, benefit to research, possibly being on TV and a scholarship for the child as things that would make them excited.

The younger group did not find the idea of a celebrity spokesperson as compelling and would rather to speak to someone who has participated and has first hand knowledge of the study. The older group recommended a spokesperson that has pregnancy or motherhood experience. The only celebrity they mentioned was Kelly Ripa, a co-host from a popular morning TV talk show. The older women did not think someone like the surgeon general should be used.

The younger group did not think that they would be more interested in participating because they are pregnant; in fact they indicated that they would be more concerned about what participation entailed. The older women indicated that they would need more information about the study before they could make that decision. Neither group had an issue with a second child participating as long as things went well with the first child.

7.1.2 Time Commitment and Data Collection Activities

The groups agreed that the schedule for the first year was the most difficult but that if the visits could be combined with the well-child checkups that they already had to schedule, that it would work out. Both groups were concerned about whether blood would be taken. The younger women thought a finger stick would be okay but both groups thought blood draws would be a problem and the older women indicated that they would not allow the infants to be catheterized for urine samples.

The groups also agreed that a 20-minute questionnaire would not be a problem and both groups would like to complete the survey by e-mail or Internet. The older women also would prefer to complete the survey by mail rather than by telephone. The younger women said that they were absolutely opposed to a mail survey saying that it would get thrown out or stacked away somewhere and not get completed. This group suggested that it would be most convenient to complete the survey during the office or home visit.

The groups did not have a problem with someone coming to the house to take dust and water samples as long as the appointments were scheduled in advance. The younger women thought once or twice a year would be okay. The older women thought that once a year was good but that every three months or seasonally would be acceptable. The older women would prefer to collect the samples themselves as long as they were trained. They agreed that they could collect the samples as often as once a month if they could use the kits. The older women also thought that the results of these tests would be a nice “incentive.”

The younger women had some concerns about providing biologic samples particularly baby teeth, breast milk, and blood. The older women were more comfortable with providing biologic samples with the exception of baby teeth and there was some concern about the logistics of collecting some of the samples such as placenta, infant urine, and breast milk.

Both groups thought genetic testing would be acceptable. The younger group wanted to have the results and wanted the test to be minimally invasive. The older women were mostly concerned about how the tests would be performed and what would happen with the results. This group was particularly concerned about how they would learn the results and recommended genetic counseling be offered.

There were mixed views from the older group on how they would like to be contacted for an appointment. Some favored a postcard reminder but others did not trust the mail and suggested that they be allowed to contact researchers for an appointment. The older group also did not want to provide contact information for relatives but rather wanted to contact researchers if they moved. The younger group recommended telephone or postcard reminders for regular appointments and would provide contact information for their friends and relatives. This group also recommended that they be allowed to send a change of address post card to researchers.

7.1.3 Keeping You Interested

Neither group liked the initial list of incentives provided and preferred to receive a combination of gifts and money and really liked the idea of a college fund. The older women said that they expect to receive the results of testing and that this was not an incentive. Both groups felt that they should be paid money for providing biologic samples. In addition neither group said that they would feel coerced to participate by receiving any of the incentives that were discussed including cash, college funds, trips, summer camp, and health club memberships. The older group discussed the possibility that the project could go “bankrupt” and they were concerned about losing any funds that were setup for the children.

Both groups would like to receive a newsletter containing results of the study and local area issues. The younger women suggested sending it out once a year but acknowledged that they would not always read it. The older women recommended quarterly newsletters. Neither group wanted to attend local meetings but the older women recommended a ‘once a year’ social event like a picnic.

7.2 Expectant Parents: Type of Health Care Provider

To learn more about whether expectant parents who received their health care from different sources held differing beliefs about participating in the NCS, we recruited three expectant parent groups based on whether they received their health care from a private physician's office, a public health clinic or a maternal or fetal health specialist or high-risk specialty clinic.

7.2.1 Getting you Interested

All three groups said that they would like to learn about the study from their doctor's office and emphasized the trusted relationship they had with their doctor. The clinic group also mentioned social service office as a good place to advertise the study.

Similarly, all three groups wanted to know details about the study before agreeing to participate. The doctor's office group emphasized risks, schedule, privacy, and eligibility. They did not want to waste time learning about a study for which they were not eligible. The clinic group wanted information about what was required, who is conducting the study and who gets the results. The high-risk group wanted information about the goals of the study and their contribution would further our knowledge of the issues followed by the risks and benefits of participation.

The groups varied as to whether it was more important for their participation to benefit their child or contribute to science. The doctor's office group was split on the issue while the clinic group was adamant that the study benefit their child. The high-risk group did not expect the study to contribute specifically to their child's health but rather benefit them indirectly in the future.

The groups also varied on what would make them excited about participating. The doctor's office group said that they would be excited if they received incentives with only two group members stating that it would be exciting if they helped to clean up the environment or bring greater awareness of environmental issues. The clinic group said that they would be excited to about the idea of gaining health information especially if it related to personal concerns that they may have about asthma, hair loss, or ringworm. The high-risk group also mentioned that it would be exciting to learn something that addressed personal concerns such as cancer in the family, but they also said that they would be excited about participating if the study improved the lives of children and benefited humanity.

The doctor's office group said that they did not trust celebrities but would recommend a well-known person if they were credible. For example, they recommended Doug Flutie, former football player and father of an autistic child. The clinic group felt similarly and recommended, Brandy, a pop singer who just went through a highly publicized normal pregnancy and Jada Pinkett-Smith, actress and mother. The high-risk group felt that the spokesperson should be a mother or a doctor, someone who has children.

The women in the doctor's office group were mixed on whether they felt that being pregnant at the time they learned of the NCS would affect their interest in participating. Three member's of that group said they would be more interested if pregnant, two of them said that they would be interested even if they were not pregnant and one said that being pregnant would not affect her interest at all. The women in the clinic group said that they would be more interested in participating if they were pregnant as long as they were not having problems. The high-risk group all agreed that they would not have been interested prior to becoming pregnant because they would be focusing on getting pregnant and nutrition. All groups agreed that having a second child participate would depend on how well it went with the first child.

7.2.2 Time Commitment and Data Collection Activities

The doctor's office group thought that the number of visits in the first year was too many and the high-risk group thought an hour was too long but if the visits were combined with well-baby visits, then the number of visits was acceptable. The clinic group felt that the schedule was acceptable.

The groups were mixed on the collection of biologic samples. The doctor's office group had two members who were opposed to blood samples but the general concern was logistics of the sample collection, that samples be collected by a responsible party such as the doctor and that the child was comfortable. The clinic groups were clearly uneasy about the sample collection and objected to breast milk and blood samples. They expressed concern about whether the samples would be tested for drugs or sent to an insurance company. The high-risk group wanted more information about the procedures and the time commitment involved before making a decision.

All three groups felt that the questionnaire would not be a problem. The doctor's office group preferred to complete it by mail or telephone. They did not trust the Internet citing privacy concerns. The clinic group recommended mail because everyone does not have e-mail access and the high-risk group preferred an Internet survey that can be programmed to save so that if they are interrupted they can return to it.

The group had mixed feelings about the collection of dust and water samples. All three groups thought that it would be acceptable to have someone come to collect the samples but some had concerns about the process. The doctor's office group asked that a female collector come to the house because they were uncomfortable with letting a strange male into the house. The clinic group thought the sample collection would be acceptable if they were used for a good purpose and improved the home environment. The high-risk group thought the collection acceptable if they knew the purpose of the tests, the schedule of collection, and the test results. All three groups were unsure about doing the collections themselves citing their fear that they would introduce error into the study.

There was some misunderstanding about the types of biologic samples that might be collected and a general feeling that more information would be needed before people would give consent to provide these samples. The doctor's office group was concerned about blood and meconium. The clinic group said that the samples made them feel like guinea pigs and found that blood and urine were the least offensive samples on the list. The high-risk group said that they wouldn't have a problem with hair, nails, or urine. They were concerned about the logistics of taking the placenta and would not provide placenta, meconium, umbilical cord blood, breast milk or baby teeth.

The groups also expressed mixed feelings about genetic testing. The doctor's office group was concerned about logistics but would want the results. The clinic group was opposed to genetic testing and did not want the results even if the tests were conducted. The high-risk group was the most divided and concerned. Most thought they would agree to genetic testing but

two women opposed the tests and one was undecided. There were concerns about the results and who would get the results. One person expressed concern that the results would be provided to insurance companies. Three participants said that they would not want the results even if the tests were conducted.

The doctor's office group would like to hear about their appointments by mail or by telephone but the clinic group preferred mail reminders because everyone may not have a telephone. The high-risk group preferred a multi-dimensional approach that includes an annual calendar, an e-mail reminder, and a telephone reminder. The doctor's office group and the clinic group did not want to provide contact information for friends or relatives but the high-risk group said that they would provide contact information. This group also recommended a project website where people could go to update their personal information.

7.2.3 Keeping you Interested

The groups agreed that incentives would be appropriate in return for participation and all agreed that the results of their tests were not an incentive but rather were expected. All three groups thought cash would be acceptable except in return for biologic samples. The clinic group said that they would feel like they were being bribed and they would be suspicious if the study offered money for samples. However, they did like the idea of receiving money for health needs such as insurance, dental visits, medical supplies that are not covered, prescription and visits to the eye doctor. The majority of the high-risk women also objected to money for samples with one member citing that she could not assign a dollar amount to her child. Yet, another woman said that time is money and \$50 a visit might not be enough. All three groups said that they would not feel coerced by any of the incentives discussed. The doctor's group said that the only time they would feel uneasy about taking money would be if they did not adhere to the study requirements. The clinic group said they would not feel coerced unless they had come to depend on the money. The high-risk group said that if the payments were too high they might feel uncomfortable such as if they were paid \$1000 per visit. The group also mentioned that if they received a gift certificate for \$100 from a specific store they would be curious about the motives of the store.

The doctor's office group said that they would like to stay abreast of study issues through a website or newsletter, but they did not want to attend local meetings. The clinic group suggested public service announcements on radio and TV and a newsletter. They said that they might attend a local meeting. The high-risk group recommended e-mail or newsletters but they were divided on the concept of local meetings. Some group members thought that the study would already take enough of their personal time.

7.3 Expectant Parents: Level of Education

Participants were drawn from two education levels--less than or equal to high school or some post-secondary education to try to learn whether expectant parents who have different levels of education also have different concerns about participating in the NCS. Two groups were comprised of expectant parents who achieved no more than a high school education (Groups 3 and 8) and two groups were drawn from expectant parents who had received some post-secondary education (Groups 4 and 9). However, because level of education was not fully crossed with the type of living area as shown in **Table 6** below, the comparison between the two levels of education will be made within the rural type of living area. This section looks at the comparison of the lower education and the higher education groups respectively. Both groups are rural.

Table 6. Education by Type of Living Area (Urbanicity)

Level of Education	Rural	Urban	Suburban
HS or less	Group 3	Group 8	No group
Greater than HS	Group 9	No group	Group 4

7.3.1 Getting You Interested

Both of the higher-education group and the lower education group indicated that they would like to learn about a study like the NCS from their doctor's office and recommended parenting magazines as a good source of information as well. The groups were both very concerned that they learn enough information to make a decision about participation and shared concerns about how the study activities might disrupt their lives. They also wanted to be assured of privacy and confidentiality.

The two groups also agreed that it was more important that their participation contribute to science and the overall public health than their individual child's health. The two groups differed somewhat on what would make them excited about participating in the NCS. The lower education group said that being involved in research that benefited medical science would be exciting as would being part of a large national study. The higher education group agreed and said that it is exciting to know that the study is benefiting "the greater good" and that when their children are older they will have the privilege of saying that they were part of something very important. Although the groups agreed to some extent about what would make them excited about participation, the higher education group added that they would find money and possibly a college fund exciting as well.

When asked how they would feel about knowing others in the study, the higher education group noted that it would be nice to know someone else in the study but questioned whether having too many people who knew each other in the same study would skew the results. The lower education group said that knowing someone else in the study did not matter.

The higher education groups was “turned off” by the idea of a celebrity spokesperson. The lower education group wanted someone “credible” but didn’t mind if the spokesperson was a celebrity.

Both groups felt they would be more interested in participating if they were pregnant than if they were not pregnant.

7.3.2 Time Commitment and Data Collection Tasks

Both groups initially thought the office visit schedule was acceptable. The lower education group was concerned about keeping small children occupied for a one-hour visit. This group decided they would prefer home visits since it would address the issue of keeping the children occupied and fit better with their busy schedules. The rural higher education group was concerned with schedule and logistics and reducing disruption in their lives.

Both groups agreed that the survey would not be a problem with the lower education group preferring to complete it by mail and the higher education group preferring a telephone or in-person interview. Both groups liked the idea of the survey replacing an office visit.

The groups differed in their reaction to the collection of dust and water samples. The lower education group found it acceptable for someone to come and collect samples as long as proper notice was provided. The group did not like the idea of collecting the samples themselves using a kit because they were worried about the quality of the samples. The higher education group had mixed feelings about someone coming to the house to collect dust and water samples. Most of the group agreed that it would be acceptable if the collection was done on a convenient schedule and by the same person every time. The rest of the group thought it would be a “nuisance.” The group very much liked the idea of collecting the samples themselves using a kit.

The lower education group was more comfortable with the idea of providing biologic samples than the higher education group, but agreed that they would need more information. The samples they would not be willing to provide include baby teeth, placenta, umbilical cord blood, meconium, and breast milk. The higher education group agreed that the collection of bloods was a “turn off.” There was great concern about what the samples would be “used for” and concern about the government compiling a DNA database. The members of the higher education group varied on what they would not provide but the list included placenta, cord blood, meconium, breast milk, nails, and baby teeth.

The lower education group said that genetic testing would be acceptable if they received the results. The higher education group was more skeptical and concerned about privacy issues. Several members of the group were not sure if they would even want the results of the tests.

The lower education group preferred to be contacted by mail for appointments because they felt that it is more reliable than telephone. Most members of the group agreed to provide contact information for friends or relatives. The higher education group agreed that they needed some flexibility in their scheduling and would require time and date reminders. They

recommended that mail notifications be distinctive so that they are not mistaken for junk mail. Some group members said that a quick phone call would be fine but that it would be bothersome if they started getting calls from the study. The higher education group also would agree to provide contact information and suggested that study staff use Department of Motor vehicle records or some additional method of tracking people as well.

7.3.4 Keeping You Interested

Both groups suggested that incentives should be provided throughout the course of the study and at the end of the study. The lower education group expressed concern about how much the study would cost and whether the study could afford incentives for everyone. The lower education group discussed non-monetary incentives and had to be prompted to consider money as an incentive. They were reluctant to suggest a dollar amount and had concerns about who would get the money (parent or child). When asked about receiving cash for biologic samples, the group had mixed feelings and said it would depend on the outcome of the testing. They reasoned that if the test revealed something treatable that they would not otherwise have known about, then the test would be reward enough in itself. Although, the higher education group focused primarily on cash and gifts, both groups agreed that test results were a nice benefit.

All groups wanted to stay informed of study activities and results. The rural lower education group prefers to be kept informed via mail because they feel it is more secure than the Internet. They would like test results by mail after every visit. The lower education group would also attend local meetings. The higher education group was concerned about having to drive to various locations to get information and indicated that they did not want to spend all of their free time on study activities. They recommended a web site where they could receive e-mail with links to journals and other relevant information. This group did not want to attend local meetings.

The lower education group indicated that they would want to receive all test results even if they were not interpretable at this time. The higher education group expressed some reservations about information they might learn. There was mixed reaction to finding out about local area environmental exposures—some group members would want to know and others would prefer not to know about toxic exposures, “especially if they were bad.”

7.4 Expectant Parents: Urban, Rural, and Suburban

The expectant parents' groups were drawn from urban, suburban, or rural areas to examine whether expectant parents who live in different areas have different thoughts and ideas about participation in the NCS. It is important to note that the comparisons across these living areas are potentially confounded by other group selection characteristics such as age, education and type of healthcare provider (See **Table 1** for the distribution of participant characteristics by group).

The data from the four urban groups, three suburban groups and two rural groups were reviewed to see if there was agreement on any of the discussion topic areas within the specific

categories of living areas. Then the data were reviewed across the types of living areas to see if there were differences that could be attributed to living in one of the three areas. **Table 7** summarizes the responses to the major discussion topics by the three types of living areas.

7.4.1 Getting you Interested

There are many areas of agreement across the types of living areas. For example, all groups thought it best to get information about the NCS from their doctor or clinic. However, the urban and suburban groups did not want to receive mail notices about the study. Both groups said that they throw the information away. The urban groups also added that they did not want to receive telephone calls about the study either. The rural groups were not bothered by either approach.

All of the groups thought that a spokesperson for the study needs to be someone who has experience with children, such as a parent. They did not think a celebrity was necessarily appropriate because they are not credible. Another area of complete agreement was if they would consider enrolling a second child in the NCS. All groups said that if the first child's experience were good then they would like to include the second child. All of the groups also thought the suggested number of visits to the doctor were reasonable if combined with well-child visits.

Table 7. Discussion Topic by Type of Living Area

Discussion Topic	Urban	Suburban	Rural
Place to Learn about NCS	Doctor's Office No Phone calls No Mail	Doctor's Office No Mail	<i>Doctor's Office</i>
Information Desired	Risks	Risks	<i>Privacy and Confidentiality</i>
Individual Benefits v. Contribute to Science	Mixed	Benefit Child	<i>Contribute to Science</i>
Excited to Participate	Mixed	Incentives	<i>Contribution to the Greater good*</i>
Celebrity Spokesperson	Someone credible, a parent	Someone credible, a parent	<i>Someone credible, a parent</i>
More or Less Interested because Pregnant	Would need more Information	Not more or less interested; concerned	<i>Definitely more interested</i>
Enroll 2 nd Child	No problem	No problem	<i>No problem</i>
Number and Length of Visits	Reasonable/Combine with well-child visits	Reasonable/Combine with well-child visits	<i>Reasonable/Combine with well-child visits</i>
20-Minute Survey	Okay by mail or e-mail	Okay by e-mail	<i>mail/phone, in-person*</i>
Dust and Water Collections	Okay Would perform collections w/kit	Okay if a woman did the collection	<i>Mixed *</i> <i>(Low-Ed group would not collect samples. High-Ed group would collect the samples)</i>
Biologic Samples	Too many, too personal	Objected, Confused about purpose and logistics	<i>Mixed</i>
Genetic Testing	Mixed*	Okay Wants results if negative outcome can be prevented	<i>Mixed*</i>
Contact for Appointments	Mail/Phone	Appointment w/doctor mail and phone reminders	<i>Mail</i>
Contact information for friend or relative	Would provide/ Would call 800 Number	Call 800 number or web site	<i>Would provide/call 800 number or send post card</i>
Incentives	Yes	Yes	<i>Yes</i>
Stay Informed	Newsletter Local meetings no	Newsletter Local Meetings-maybe chat room	<i>Newsletter Local Meetings-mixed (Low-Ed group-yes High-Ed group-no)</i>
<i>Information wanted/not wanted</i>	<i>Personal results* Research Progress Area Issues/ (one group did not want results that were not interpretable)</i>	<i>Personal results only/ mixed</i>	<i>Personal results regardless/High-Ed group did not want to hear about local area toxic exposures*</i>

*Responses appear to be moderated by another variable

There are also some topics on which the groups clearly differed by type of living area. For example, when discussing what type of information they would want to have before they made a decision to participate in the NCS, the urban and suburban groups both emphasized knowing the risks to their children while the rural group emphasized knowing how their privacy and confidentiality would be maintained. There were also differences in the groups' responses to whether they thought it more important for their participation to directly benefit the health of their child or make a contribution to science and overall public health. The responses from the urban groups seemed to be moderated by another variable, possibly socio-economic status or education. The older women group (35 and older) responded that both were equally important. The urban women who received their health care from the clinic said it was more important that their child directly benefit and the urban uninsured women thought it more important to contribute to science. The suburban groups all agreed that it was more important to benefit their child and the rural groups all agreed that it was more important to contribute to science. Similarly when the groups discussed what would make them excited about participating, the urban women were mixed once again, with the over 35 group citing incentives, the clinic group citing study issues like smog, asthma and disposable diapers and the uninsured group citing obtaining health information as exciting. The rural group cited benefiting the "greater good" as the most exciting part about participating with the rural higher education group adding that incentives would be exciting too. There were also differences on the topic of whether they would be more or less interested in participating because they were pregnant. The urban groups said they needed more information, the suburban groups said that they would not be more or less interested but they would be concerned about participating while pregnant and the rural groups agreed that they would definitely be more interested.

7.4.2 Time Commitment and Data Collection Activities

The groups also differed on the preferred mode of completing the survey. Both the urban and suburban groups said that they would prefer mail or e-mail but the rural groups said that they preferred either mail or telephone and the rural higher education group added that they preferred telephone or in-person interviews.

The groups' response to the issue of dust and water samples was varied. The groups were asked to discuss whether they would object to having someone come to their home to perform dust and water sample collection. They were also asked if they would prefer to use a kit to perform the collections themselves. The urban and suburban groups were okay with the in-home collections. The urban group also said that they would like to collect the samples themselves. The suburban group asked that the data collector be a woman because they had concerns about letting a strange man in the house and they did not want to collect the samples themselves because they might make an error. The rural groups differed in that the lower education group thought it would be okay if someone came out to collect samples as long as they were provided proper notice and they did not like the idea of collecting the samples themselves citing it as too much "trouble." The higher education group was divided on the issue of in-home collections with

half of the group saying it was acceptable as long as it was scheduled, but the other half of the group thought the in-home collections would be a "nuisance." This group did, however, say that they would like to do the collections themselves.

The collection of biologic samples was quite controversial and it became evident across groups that there is not a good understanding of the logistics or purpose of the collection of these samples. The urban group was overwhelmed by the list of samples and said that there were too many and that they were too personal. The suburban groups objected to the collection of the samples and expressed some confusion about the logistics and purpose of the collection. For example, there were concerns about whether a project staff person would have to be in the delivery room to collect the placenta. The rural groups also were divided. The lower education group indicated that they would be willing but needed more information. The higher education group was more concerned about what the samples would be used for. There was discussion of the government developing a DNA database.

There was a mixed response across the groups about genetic testing and again this appears to be an area where people have little knowledge of what genetic testing is, how it is performed and what is learned from the test results. The Urban over 35 group was the most knowledgeable about this topic and suggested that the testing might be acceptable if genetic counseling was provided. The suburban group indicated that they would not want to receive results that gave them information about illnesses or diseases that they could not prevent. For example, one woman said that she did not want to know if she were a candidate for breast cancer if there was nothing that she could do to prevent it. The rural groups were concerned about privacy and they were not sure that they wanted to know the results.

The groups wanted to be contacted about appointments by mail and telephone. Both the urban and rural groups said that they would provide contact information for a friend or relative but that they also wanted the option of informing study staff if they moved by calling a toll-free number or sending a postcard. The suburban group did not want to provide contact information but agreed to let study staff know if they moved.

7.4.3 Keeping You Interested

All groups thought that incentives (both monetary and non-monetary) were appropriate, but the level of incentive appears to vary by socio-economic status. All groups thought that a newsletter was appropriate to keep them updated on study issues. The suburban groups also recommended a web site or chat room for participants.

The groups differed on the kind of information, if any they did not want to receive. All agreed that they wanted personal results. However, one of the urban groups did not want results that were not interpretable. The rural groups wanted all of the results of any tests, even if they are uninterpretable at this time. However, the rural higher education group expressed concerns about what they might learn and said that they do not want to learn about local area toxic exposures.

7.5 Expectant Parents by Geographic Region

It is reasonable to assume that there may be regional differences in the kinds of issues that are important to expectant parents. To evaluate whether there are differences by geographic region, a comparison was made of expectant parent groups across major geographic regions. The ten federal regions were clustered into five geographic regions-West, Midwest, Southwest, Southeast and East. **Table 8** shows the distribution of expectant parent groups across these geographic clusters. The west region is comprised of the groups from Seattle and Los Angeles. The Midwest includes the groups from Sioux Falls, Chicago and St. Louis. The Southwest includes Dallas and the Southeast includes the RTP group. The East region is comprised of the NYC, Philadelphia and Burlington groups.

Looking across the major topic areas, there does not appear to be much difference by geographic region. Where there is variation it appears to be attributable to socioeconomic factors such as education or type of living area. For example, the rural groups are more likely to indicate that it is more important for the NCS to benefit the greater good than their individual child and they are more likely to indicate that they would be excited by the opportunity to participate in research that helps others. The only exception is when the rural group is also a higher education group, in which case the group cites the “greater good” plus an incentive much like the suburban groups who tend to indicate that what would make them excited about participating is an incentive.

Table 8: Expectant Parent Groups by Geographic Region

Discussion Topic	West Regions 9, 10 Groups 7, 8 (suburban, urban, mixed age, ≥35 mixed education mixed and specialist hcp)	Midwest Regions 5, 7, 8 Groups 3, 4, 6 (rural, suburban, urban, mixed age, ≤HS and ≥HS)	Southwest Region 6 Group 1 (suburban, <35, mixed education, mixed hcp)	Southeast Region 4 Group 5 (suburban, mixed age and education, doctor's office)	East Regions 1, 2, 3 Groups 2, 9, 10 (rural, urban, mixed age and hcp, mixed education and <HS)
Place to Learn about NCS	Doctor's office No email or mail (spam and junk mail) No telephone	Doctor's office or clinic No mail No telephone	Doctor's office	Magazines Doctor's office	Doctor's Office
Information Desired	Goals, risks, benefits, eligibility criteria (LA), confidentiality and convenience of the test site	Goals, risks and benefits	Would the child be tested? Would drugs be involved? Eligibility	Study details Risks and benefits Schedule Eligibility Convenience and flexibility	Goals Risk Confidentiality
Individual Benefits v. Contribute to Science	Mixed	Mixed Rural—benefits others Urban, suburban benefit child	Child's health	Majority—benefits others	Rural and Urban NYC- Benefits others Urban Philadelphia- equally important
Excited to Participate	Benefits to the health of children Study issues: smog, asthma, and disposable diapers	Mixed Rural—research that helps others, national study Urban, suburban—learn about personal health issues such as asthma, ringworm, and hair loss.	College fund	Incentives	Rural and Urban Philadelphia—Incentives Urban NYC—study issues, large national study
Celebrity Spokesperson	Doctor or parent	A mom or a nurse	Someone who had participated	Someone credible, a parent Doug Flutie	Rural--Someone credible, a parent Urban—a celebrity who is a parent.
More or Less Interested because Pregnant	LA group mixed Seattle group more interested	Mixed Suburban—not during first pregnancy	More interested but concerned	Mixed Would need more Information	Rural and urban NYC—more interested Urban Philadelphia—more information

Table 8: Expectant Parent Groups by Geographic Region (Continued)

West Regions 9, 10 Groups 7, 8 (suburban, urban, mixed age, ≥35 mixed education mixed and specialist hcp)	Midwest Regions 5, 7, 8 Groups 3, 4, 6 (rural, suburban, urban, mixed age, ≤HS and ≥HS)	Southwest Region 6 Group 1 (suburban, <35, mixed education, mixed hcp)	Southeast Region 4 Group 5 (suburban, mixed age and education, doctor's office)	East Regions 1, 2, 3 Groups 2, 9, 10 (rural, urban, mixed age and hcp, mixed education and <HS)	
Enroll 2 nd Child	No problem	If all goes well with the first child	No comment	No comment	Mixed—depends on how it goes with first child.
Number and Length of Visits	Reduce to one time a year to age 6 and every other year from age 7 and older	Mixed Rural preferred home visits to office visits	Reasonable/Combine with well-child visits	Overwhelming the first year How do you keep older children interested?	Reasonable/Combine with well-child visits
20-Minute Survey	Okay by Internet	Okay by mail or e-mail No telephone	Okay Internet or e-mail	Mail Telephone	Okay by e-mail or mail Rural—telephone or in-person.
Dust and Water Collections	Okay—if they know the schedule. Mixed on using the kit (might contaminate; introduce error)	Mixed Urban—Okay if it will improve the home environment	Okay No comment on self-collection w/kits	Okay if a woman did the collection Mixed on whether they would perform collections w/kit	Okay Will collect with a kit.
Biologic Samples	Okay for urine and blood. Most would not provide meconium, placenta, cord blood, baby teeth, or breast milk	Okay for urine and blood	No baby teeth, breast milk or blood	Confused	Mixed Concerned about logistics
Genetic Testing	Seattle – Okay but wanted more information LA—did not understand; concern about pain	Rural—Okay if they received the results Suburban—Okay Urban—No	Okay—wants results	Concerned about the risks of the tests but curious about test results	Concerned about confidentiality, purpose and logistics.
Contact for Appointments	Mixed but most prefer mail with a telephone reminder	Rural—mail Suburban—Doctor's office with a telephone reminder Urban—Mail	Telephone or mail	Telephone or mail	Mixed mail/telephone Appointment w/doctor mail and phone reminders

Table 8: Expectant Parent Groups by Geographic Region (Continued)

West Regions 9, 10 Groups 7, 8 (suburban, urban, mixed age, ≥35 mixed education mixed and specialist hcp)	Midwest Regions 5, 7, 8 Groups 3, 4, 6 (rural, suburban, urban, mixed age, ≤HS and ≥HS)	Southwest Region 6 Group 1 (suburban, <35, mixed education, mixed hcp)	Southeast Region 4 Group 5 (suburban, mixed age and education, doctor's office)	East Regions 1, 2, 3 Groups 2, 9, 10 (rural, urban, mixed age and hcp, mixed education and <HS)	
Contact information for friend or relative	Okay, but prefer to contact study with address change info via a website and PIN	Rural, suburban— Okay but would also like a toll-free number Urban—through the doctor	Would provide/call 800 number or send post card	Mixed, reluctant	Mixed w/NYC not wanting to provide a contact number Call 800 number or web site
Incentives	Yes Nothing on the list	Yes	Yes	Yes	Yes
Stay Informed	e-mail, newsletter, doctor's office	Newsletter Local meetings Socialize with other participants Internet chat	Newsletter No local meetings	Web site or newsletter No local meetings	Toll-free number Newsletter No local meetings Maybe a picnic for participants
Information wanted/not wanted	Test results, study results, progress, lessons learned	Test results, study results		Depends on the individual	Personal results only/ mixed

HCP = Health Care Provider

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8. Parents Groups

8.1 Children with and without Disabilities

It is likely that parents of children with disabilities have different concerns about participating in the NCS than parents of children without disabilities. Two groups of parents of children with disabilities and two groups of parents of children without disabilities were conducted to try to understand the differing concerns of these two groups of parents. For the sake of convenience, we will refer to these groups as the “disability” and “non-disability” groups. Caution should be exercised in interpreting these comparisons, because the groups were also distinguished by urbanicity and children’s age.

8.1.1 Getting You Interested

All four groups said that health care providers or clinics were good sources of information about the NCS. However, the two disability groups emphasized that these sources were the best sources of information, while the non-disability groups listed health care providers among a number of different sources. The disability groups mentioned hospitals with handicapped children and rehabilitation services as good sources, as well. Both the disability and non-disability groups said that day care centers and churches were also good sources of information. The urban disability group also listed community organizations, the alderman’s office, social services, public health, teen pregnancy workshops, and national children’s health organizations as other places to hear about the study. The non-disability groups added parent’s magazines and placement of print materials in public places as ways to advertise the study. Groups did not think use of a mall would be fruitful and only one non-disability group thought that ads on public transportation would catch the eye. The disability groups favored transmission of information via television and newspaper, while the non-disability groups favored television and radio. The groups were mixed on the format of information sharing (e.g., email, letter, or phone.)

The disability and non-disability groups would need more information in order to make a commitment to the study. The disability groups were initially concerned with the risks of the study to the child, while the non-disability groups were initially concerned with the purpose of the study and what would be expected. One (suburban) disability group and both non-disability groups said the location of the appointments would be important, with the disability group bringing up the issue of transportation. All but the suburban disability group brought up the need for privacy and confidentiality. The two non-disability groups differed from each other in their focus on helping others and having a representative study (suburban) and suspicion of the government (urban.)

Both disability groups and one non-disability group (suburban) thought that contribution to science and overall public health was more important than direct benefit to their child. The other non-disability group said the two were equally important. One disability group (suburban)

noted that their children had participated in studies in the past and discussed the impact that had on the child's health.

The disability groups listed more concrete things relating to health as things that would excite them about participating, while the non-disability groups were less concrete. Things that would excite the disability groups were information on children's health, research on particular diseases, exposure to the medical profession, networking with other parents of children with disabilities, and "issues they are passionate about." One group was excited about being in a large national study. "[I'm] thrilled about this study!" The suburban non-disability group was excited by the positive impact the study could have on their community and improved health for others, while the urban non-disability group said they needed more information and incentives to participate, and expressed distrust of the government. (One disability group also mentioned incentives.)

Three of the four groups thought a spokesperson could be effective in promoting the study. Only the urban non-disability group was skeptical. According to them, it would depend on the audience and the spokesperson's credibility and different spokespersons would be appropriate for different audiences (e.g., doctors, hip hop stars.) The disability groups agreed that the best spokesperson would be someone who has a disability child, whether or not this was a celebrity, or a person who has a handicap, a professional in special education or a behavioral psychologist. The suburban non-disability group agreed that it should be a person who has a child. They also said that a person with a passion for children's health issues or knowledge of health and environment would also be a good spokesperson. The named individuals included the President's wife and Doug Flutie.

The disability groups were asked if they would be more interested in participating in the study because their child has a disability, while the non-disability groups were asked whether they would have participated before they had children. Parents in both disability groups were more interested in participating because their child has a disability. "We're looking for an answer." The non-disability groups were not unanimous in their responses. The suburban group was split, with some saying that before they had children they would have had less interest in health and environment issues, and most of the people in the urban group saying that they would have participated before they became pregnant. All the groups said that they would consider having a second child participate in the study if the first child's experience was good.

8.1.2 Time Commitment and Data Collection Activities

The number of office visits that are planned for the study is 8 visits the first year for disability children and 4 visits for non-disability children. Both disability groups felt that there were too many visits the first year and liked the idea of substituting some home visits for the office visits. Although one of the non-disability groups said 4 visits were too many, the focus in the non-disability groups was on understanding the project (urban group) and logistics or convenience (suburban). None of the groups had any problem with the length of the visits.

All of the groups thought that completion of a 20-minute survey was acceptable. The disability groups liked the idea of having the survey replace an office visit. Three groups were split between telephone and Internet as modes of survey data collection, while the last group (urban non-disability) had a consensus that mail was best, with a reminder phone call.

All four groups said collection of tap water and dust in their homes by a study member was acceptable. Scheduling by appointment and assurance of identification and credentials for the visiting sample collector were issues and groups wanted the test results. Two groups – the urban disability and the suburban non-disability—were mixed as to whether they would prefer a study representative to collect the samples or collect them themselves. The suburban disability group wanted to use the kit to collect the samples themselves, while the urban non-disability group wanted a professional to come to the house.

All the groups agreed that they would be willing to provide at least some of the biological samples. None of the groups would give up baby teeth, at least the first tooth, for sentimental reasons. The disability groups expressed concern about the blood sample, thought the samples should be collected less frequently, and noted that collection of samples from children with disabilities can be difficult. Both non-disability groups had reservations because of the personal nature of the samples. The suburban non-disability group was concerned with the procedures for collecting the blood and urine, but said they could give hair, nails, and cheek cells. The urban non-disability group would need to know the purpose for each sample and would need compensation for giving these samples.

The disability groups would agree to participate in genetic testing and some group members said that this is something that they have already experienced. The non-disability groups would agree if they knew what was involved in the testing and were assured that the procedures would be safe for the baby. All the groups wanted the results of the tests, and two groups (one disability and one non-disability) mentioned concerns with confidentiality, especially not wanting insurance companies to know the results.

All the groups were mixed in their responses to the question about the best mode to contact them about appointments and there was no difference between the disability and non-disability groups. Disability and non-disability groups mentioned mail, phone and email.

Both the disability and non-disability groups would be willing to provide a name and address of a friend or relative to be contacted in case they moved. One of the non-disability groups (urban), however, would only give out the names if they felt comfortable with their participation in the study. The disability groups mentioned handing out business cards with a study phone number on them or having an 800 number or website that they could use to update their information. A non-disability group suggested mailing of a Christmas card to participants and having a request for address change included.

8.1.3 Keeping You Interested

All of the disability and non-disability groups thought that incentives were important to promote participation in the study and suggested an array of types of incentives. All the groups felt that there should be incentives for both children and parents and three groups liked the idea of both immediate and long-term incentives. All liked gift certificates for places like Toys R Us and Wal-Mart or for clothing, food, or gas. The urban disability group wanted to be able to use the gift certificates in local stores. Other more immediate incentives mentioned by the disability groups were electronic equipment, tickets to event, money for classes, vacations, a lottery for a new bicycle, and Christmas gifts. Similarly, the non-disability groups mentioned diapers and coupons for clothes or books. Three of the groups wanted long-term incentives also and suggested things like health insurance, college education, and general funds for the child. (The urban disability group was the only one that did not mention these incentives.) Group members were generally not keen on stamps, photos, Web TV or donations to charity. One disability group and one non-disability group were split on whether incentives should be offered for sample collection, while the other two groups favored incentives for biological samples. In the suburban non-disability group some were turned off by the idea of payment for biological specimens. Disability groups thought that incentives should vary over the years depending on the age of the child and that people should be given bigger incentives the more that was asked of them. Non-disability groups thought that incentives should get bigger as the child ages and that both non-cash and cash incentives should be given. All the groups liked the idea of receiving cash incentives and suggested an amount of \$50 to \$100 per visit. The urban disability group also suggested that the child be given food after the sample collection because he may feel weak. None of the groups thought that payment of incentives would make them feel that they had to participate.

All of the groups suggested use of multiple modes to keep them informed of the study. One disability group suggested use of a website and occasional meetings, while the other group liked newsletters and newspaper articles in addition to meetings. The non-disability groups mentioned websites, newsletters, a toll free number to call, meetings, or a telephone call from a study representative. The disability and non-disability groups wanted study updates either quarterly or semi-annually.

Both the disability and non-disability groups wanted test results for their child and overall study results. The disability groups would like information on study recruitment and retention, comparative findings for different communities so that their child's tests could be put into a context, articles about health and environmental safety, and a bibliography of relevant books. The non-disability groups would like information on their child with suggestions on how to improve their child's lifestyle or health, bibliography, and information on EPA resources. Three of the groups (both disability and one non-disability) said they would want the results of genetic tests even if they could not be interpreted. (The other group did not discuss this.) The urban non-

disability group would not like to hear that they were not getting paid or that the EPA was “pulling the plug” on the project after they invested time in it.

8.2 Younger Children and Older Children

Child age was also used to define the parent groups. Because it is likely that parents of younger children will have different concerns about participating in the NCS than parents of older children, four groups that differed on children’s age were conducted. Two groups were comprised of parents of children ages 3 to 5 years and two groups were comprised of parents of children ages 6 to 11. Caution should be exercised in interpreting the children’s age comparisons because these groups also differed on two other demographic variables—disability/non-disability and urbanicity (urban and suburban).

8.2.1 Getting You Interested

The 3 to 5 and 6 to 11 groups agreed that hearing about the NCS from a health provider, (OB/GYN or pediatric), health department, clinic, or hospital would be best. One 3 to 5 group also mentioned a national children’s health organization and one 6 to 11 group mentioned a booth at a health fair. Other sources mentioned by the 3 to 5 group included day care, church, a parents magazine, and placement of print advertising in public places, while those mentioned by the 6 to 11 groups also mentioned day care and posters on public transportation and in clinics. One 3 to 5 group thought multiple media would be appropriate to carry the message about NCS (e.g., newspapers, magazines, and television.) They did not like the idea of email, phone, or a booth at a mall. (The other 3 to 5 group did not address this issue.) The 6 to 11 groups liked television as a medium, were split on email and radio, and did not like mail or booths at a mall.

All the groups needed to know more about the study and its purpose, what is expected of them, and the risks and benefits before committing to participate in it. Both 3 to 5 groups and one 6 to 11 group also expressed the need for confidentiality and privacy of study results. Three groups (one 3 to 5 and both 6 to 11) wanted information on the time requirements and location of testing. One 3 to 5 group wanted to know that the research would help other people, that the study would be representative, and that it include the Hispanic population. One 6 to 11 group expressed distrust of research and wanted to know why each type of sample was collected.

Both 3 to 5 groups and one of the 6 to 11 groups were more concerned that the research should contribute to science and overall public health than that it directly benefit their child. The other 6 to 11 group thought that overall public health and their child’s benefit were equally important. One 3 to 5 group said that the research should focus on disease and help the community. Members of one 6 to 11 group noted that their disabled children had experience participating in research.

The 3 to 5 and 6 to 11 groups differed somewhat in what would excite them about the study. The 3 to 5 groups listed the positive impact on their community, improving health for others, information on their children’s health, shared goals, and exposure to medical professionals

as things that would excite them. The 6 to 11 groups mentioned research on particular diseases, incentives, networking with other parents of children with disabilities, and being part of a large national study.

Three of the groups said that a spokesperson should have a child (or disabled child), while the other group of parents of 6 to 11 year olds was skeptical that a celebrity spokesperson would be effective. That group thought that if spokespersons were used, they should have different spokespersons for different audiences. The 3 to 5 group also said the spokesperson should have a “passion” for children’s health issues, be knowledgeable about health and the environment, have a handicap (disabled group), or be someone who is high profile (the President’s wife or Doug Flutie, who has a disabled child.) The other (disabled) 6 to 11 group suggested behavioral psychologists or professors of special education as good spokespersons.

One 3 to 5 group would be more interested in participating in the NCS because their child has a disability. The other 3 to 5 group was slightly more likely to participate before they became pregnant. The 6 to 11 groups followed the same pattern, with the disabled 6 to 11 group more interested in participating because their child has a disability and the other group being willing to participate before they were pregnant.

All the groups were willing to have a second child participate if the first child had a good experience. One 3 to 5 group thought that the children could even learn from each other. One 6 to 11 group was somewhat hesitant, saying that it would depend on the age of the child and that they would not want their child put under a microscope.

8.2.2 Time Commitment and Data Collection Activities

One of the 3 to 5 groups and both 6 to 11 groups thought the number of visits the first year was too much. This was especially the case for the disabled 3 to 5 and 6 to 11 groups who would be required to have 8 visits, as opposed to 4 visits for the non-disabled, the first year. They wanted to replace some of the office visits with home visits. None of the groups had a problem with the length of the visits. One 3 to 5 group said the schedule was acceptable as long as the visits were convenient and could be piggybacked on regular child doctor’s visits. One 6 to 11 group said they would need to be fully informed, understand what is expected, and see that the study makes a worthwhile contribution to their child and to society. Then they would be open to any reasonable schedule. One 3 to 5 and one 6 to 11 group expressed concerns about the biological sample collection and wanted to know how samples would be collected and how much would be collected, and said that many visits would make children fearful of the doctor’s office.

All of the groups thought that completion of a 20-minute survey would be acceptable. One 3 to 5 group and one 6 to 11 group said they would like to see the survey replace an office visit. The 3 to 5 groups favored doing the survey by mail or e-mail but did not want to do it over the phone. The 6 to 11 groups were split between wanting telephone or Internet and mail. Those preferring mail said they could do the survey at their leisure and not be bothered by the phone.

All of the groups agreed that they would allow someone to come to the home to collect dust and tap water samples. Both the 3 to 5 groups had mixed responses on whether they preferred someone coming to the house or collecting the samples themselves with a kit. The 6 to 11 groups were split on this. One 6 to 11 group wanted a professional to take the samples in order “to do it correctly,” while the other group preferred collecting the samples themselves with a kit, which they thought would be more convenient. One 6 to 11 group thought that the collector must be from the same organization each time and must have identification and credentials. The other 6 to 11 group wanted the results, especially if they showed hazardous substances, and wanted the study to work with the landlord to correct the problem.

All of the groups were willing to provide at least some of the samples, with the general exception of baby teeth, which they wanted to keep for sentimental reasons. Two groups, one 3 to 5 and one 6 to 11, had reservations about giving samples that were so “personal.” Two groups (disabled 3 to 5 and 6 to 11) thought that the number of samples, especially blood, was too much. “That’s a lot of stuff!” “That’s outside what the doctor usually collects.” One 3 to 5 group wanted the sample collection spread out more and did not think that blood should be collected from the baby more than once every 6 months. The other 3 to 5 group said they were willing to give hair, nails, and cheek cells. One 6 to 11 group said that collection of these samples from disabled children would be difficult. The other 6 to 11 group wanted a reason for the collection of each type of sample and needed to be compensated. “What’s in it for me and my baby?”

The 3 to 5 and 6 to 11 groups agreed that they were willing to have genetic testing. They needed to be well informed, assured that the testing would not hurt the child, and given the results, which must be confidential. They would not want the insurance company to get the results. One 3 to 5 group was mixed on whether they would undergo the testing if they could not get the results. One 6 to 11 group (disabled) said they had already had genetic testing.

There was a mix of responses to a question about the best way to contact them for appointments. Two groups, one 3 to 5 and one 6 to 11, thought that mail and phone were the best ways to contact them. The other groups had a mix of responses that included mail, phone, email, voice mail, a postcard, and a computerized reminder call.

Three groups (both 3 to 5 and one 6 to 11) reported that they would not have a problem giving the study a name, address, and phone number for a friend or relative who could be contacted in case they moved. The other 6 to 11 group indicated that if they felt good about participating in the study and saw some benefit to the child, they would be more likely to give a contact name. The 3 to 5 groups suggested that the study routinely collect information on the next of kin, send change of address reminders, or send holiday greeting cards with change of address requests. Some group members said they would contact the study on their own and did not need reminders. The 6 to 11 groups suggested that the study provide a 1-800 number that people could call, hand out a business card with a number to call, or use a study website. They said it was important to make it easy to contact the study.

8.2.3 Keeping You Interested

The 3 to 5 and 6 to 11 groups agreed that incentives were important to gaining their participation and keeping them interested. They also agreed that there should be incentives for both parents and children and that some incentives should be more immediate while others were long-term. All the groups thought gift certificates (for gas, groceries, toys, clothes) were a good incentive. The 3 to 5 group said it was important that the gift certificates be for local stores in their community. Least popular were postage stamps and donations to charity, followed by web TV and child photos. Other short-term incentives mentioned by the 3 to 5 groups included coupons for books and clothes, a box of diapers, an annual Christmas gift, a vacation, tickets to ballgames, money for classes, and a lottery for a new bicycle. The 6 to 11 groups liked electronic equipment and also suggested that people accumulate points that they could use to select a gift they wanted from a gift catalogue. In addition to these more immediate incentives, one 3 to 5 group and both 6 to 11 groups thought there should be something more substantial for the children, such as a college education fund, life insurance, or a general fund of money. One 3 to 5 group did not mention long-term incentives.

Three groups (one 3 to 5 group and both 6 to 11 groups) thought there should be incentives for biological samples, while the other 3 to 5 group was split, with some members “turned off” by the idea of paying for samples. Incentives should increase the more samples you ask for, according to one 3 to 5 group. One 6 to 11 group thought that because collecting the biological samples was more invasive than doing a survey, the incentive should be larger, but it did not specify what that incentive should be.

All groups thought cash was a good incentive. “We’re all for cash.” The 3 to 5 groups said that with cash you could get something you really need and that the cash amount should increase as the child ages. The 6 to 11 groups thought that cash incentives should be combined with non-cash incentives and that child care and transportation should be factored in to the amount that is appropriate. It was especially important to pay for the blood samples. The 3 to 5 and 6 to 11 groups agreed that the cash incentive should be \$50 to \$100 per visit. None of the groups thought that a certain amount of cash would be coercive, unless it was \$300-1,000 per visit or a million dollars for the study.

Asking how the group members would like to be kept informed elicited a variety of responses. Both 3 to 5 groups suggested newsletters, one liked websites and a toll free number, and the other liked presentations and newspaper articles. The 6 to 11 groups suggested phone, presentations, and a study website. Those who wanted phone contact liked the idea of talking with a real person about the study. Presentations would be good forums for asking questions, but might be difficult to fit in their schedules. All groups agreed that contacts to keep them informed should take place quarterly or semi-annually.

The 3 to 5 and 6 to 11 groups all wanted the study results and individual test results, and three groups (both 3 to 5 groups and one 6 to 11 group) also wanted information on study recruitment and retention. All the groups wanted some types of other information. The 3 to 5

groups wanted bibliography, tips on how to improve their surroundings, and lists of EPA resources. The 6 to 11 groups wanted reading suggestions, information on environmental safety and home remedies, and guidelines on how they could adjust their lifestyle and improve their health. Three of the groups said they wanted genetic and other test results even if they could not be interpreted. The fourth group (6 to 11) did not address this issue. The 3 to 5 groups made some additional comments on this topic. They suggested that there be a way to get personalized results via newsletter or website and that there be a way to compare individual test results with results in other parts of the country. They also said that results must be easy to understand and that test results must be confidential.

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9. Health Care Providers: Obstetric and Pediatric

There was a high-level of agreement between the obstetric and pediatric health care providers. Health care providers agreed that the best place to read about the NCS is in a reputable medical journal. Both groups also agreed that it is important to know what would be expected of them and their practice.

Both groups expressed concerns about providing accurate information to patients and having the time to enroll patients. Most health care providers preferred that the patient contact the NCS study team directly if they were interested in participating.

Both groups indicated that they would be willing to abstract or photocopy patient records if compensated for the staff time required. A related concern that was raised focused on the U.S. Health Insurance Portability & Accountability Act (HIPAA) constraints on transmission of patient data.

All health care providers felt that the number of visits seemed appropriate. The OB/GYNs recommended increasing the pre-natal visits to three (one per trimester) but both groups recommended that the visits occur during regularly scheduled well-child care visits to minimize the burden on patients and providers. Both groups also agreed that the health care provider and patient would need to know what the biologic samples would be used for and what it wouldn't be used for. They also mentioned that patients might be concerned that the placenta might be used for cloning. All health care providers mentioned the challenge in collecting several of the biologic samples – placenta, umbilical cord blood, and meconium. Similarly, all had concerns about genetic testing because of the number of problems that could arise as a result of testing. Providers prefer professional development incentives over office/medical supplies and both groups recommended a monetary enrollment stipend. They recommended a per/patient reimbursement for time and effort depending on the demands placed on the practice.

Newsletters and e-mail updates were recommended modes of communication. Practitioners agreed that the best way to communicate with their practice was through electronic mail and regular postal mail.

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10. Community Representatives

There were many similarities between these two groups. Both groups recommended churches and community centers as a good place to learn about the NCS. Similarly, both groups agreed that they would need to know the objectives of the study before agreeing to get involved and they both reported that funding for their respective organizations would make them excited about being involved. Both groups reported obesity, asthma and lead poisoning as environmental concerns. The Chicago group also mentioned drug use and immunizations. The RTP group added air quality, cigarette smoke, water quality, and diabetes as concerns.

The Chicago group wanted to get involved by serving as a community liaison between participants and the study team. The RTP group preferred to get involved in the planning and design phase. Both groups felt their participation would foster trust with the study participants.

Both groups thought that participants would be reluctant to provide biologic samples. The RTP group cited drug-testing or sexual behavior as possible concerns. The Chicago group cited concerns that the participants might have about what the samples would be used for. In addition, they felt that once children reached an age of assent, they would no longer be willing to provide samples. Both groups thought that if the study were to succeed it would have to make participation simple. The RTP group mentioned transportation to and from the clinic and other associated costs as hardships. The Chicago group indicated that participants would need a great deal of information before being comfortable with the notion of providing biologic samples.

Both groups raised issues regarding the protection of human subjects. The Chicago group went so far as to mention Tuskegee indicating that there is still some mistrust of the research community at least as represented by this group of urban community representatives.

Both groups felt that community groups should act as advocates presenting the needs of their community to local government once preliminary results are announced. In addition, they felt that the community could support the project by educating community members.

The community representatives agreed that funding for their organizations would keep them interested in the long-term. They also agreed that study participants should receive a variety of short-term and long-term incentives to maintain participation.

Finally, both groups agreed that they would like periodic updates via newsletters and meetings at which results are presented. In addition, the Chicago group suggested that a web-site would be nice so that they can stay apprised of new study information.

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11. Summary and Recommendations

To successfully recruit and retain 100,000 participants in the NCS, researchers will need to have a complete understanding of the issues that affect the stakeholders' motivation and ability to participate in the study. There is an extensive literature on the social psychology of persuasion that indicates that there are two routes to persuasion: the central route and the peripheral route (Eagly & Chaiken, 1993). Attitudes formed through the central route are the result of extensive evaluation of the information presented and are therefore more predictive of future behavior and more resistant to change. Attitudes formed through the peripheral route are generally formed quickly based on cues in the environment rather than on extensive issue-relevant thought. Attitudes formed through this route are generally subject to change and are not predictive of behavior. The major approach to recruitment of participants in the NCS will need to include an informational campaign that addresses the issues identified by the focus groups as important for each of the stakeholder groups.

This summary of results will review the major issues discussed by the stakeholder groups and discuss the implications for gaining and maintaining the commitment of the major stakeholders. Overall, expectant and current parents, community leaders, and health care providers were consistent in their responses to the questions presented to them. In addition, all of the stakeholders agreed that the study was important and they appeared to be motivated to carefully consider the information provided in order to make an informed decision about whether they would get involved in a study of this type and magnitude. However, before asking for a commitment from the stakeholders, the NCS will need to establish credibility by providing evidence that it is a viable study that has the commitment of the agencies involved and the financial support to follow through with that commitment.

All of the groups agreed that the best way to get them involved in the NCS is to provide complete information about the goals of the study and the details of the role each stakeholder is expected to play. The informational campaign should address the common themes that have emerged across groups. For example, all groups indicated that they would need to have answers to the following questions before agreeing to get involved with the NCS:

- What agencies and organizations are sponsoring the study?
- What are the primary goals and objectives of the study?
- What are the eligibility criteria for participation?
- What is expected from the stakeholder?
- What are the potential risks and benefits for the stakeholder?

To persuade stakeholders to make a commitment to get involved in the NCS, the informational campaign will need to go beyond addressing the major themes that are of concern to all groups and target specific issues that are of concern to each stakeholder group. For example, the information provided to the health care providers should emphasize that the research team is aware of the burdens that the study may impose on their practice. The messages will need

to address issues specific to the type of practice where the health care provider works. For example, health care providers who work in the public health clinics clearly indicated that they were understaffed and that they would not be able to take on additional tasks. Providers who work in private practice indicated that they have enough staff but those staff would have to be paid for the extra time. Nurses clearly did not want to be relegated to performing clerical tasks. Providers who work in a research-oriented practice indicated that they often participate in studies and were not as concerned about staffing or disruptions. The information provided to each of these health care provider subgroups should clearly emphasize that the study team has considered the potential burdens that the study may place on each particular provider's practice and is prepared to offer specific plans to alleviate those burdens.

Similarly, community leaders expressed concern that the goals of the study be consistent with the mission of their organization. Therefore, the information provided to the community groups should be tailored to emphasize how the goals of the study fit in with the overall concerns of the group. For example, organizations that are concerned with the behavioral issues common to children diagnosed with Attention Deficit Disorder (ADD) may find research questions that are aimed at learning more about the relationship between environmental exposures and ADD very relevant to the organizations' goals.

The informational campaign directed at parents should emphasize how their rights and the confidentiality of their data will be safeguarded. Emphasis should also be placed on the individual benefits of participation and how their participation will help enhance children's health overall. Nearly every focus group conducted with expectant parents or current parents said that the research team should emphasize the benefits both to the individual and overall public health, while several others said that supporting the overall public health was most important. Only one focus group said that the benefits to the individual should be emphasized. When probed to make a choice between societal or individual benefit, a second group began to convert their response to the benefit of the individual.

Persuading parents to agree to the collection of biologic samples or genetic testing will require educating them about the purposes of the sample collections or tests and providing the details of the protocol for collecting the sample or administering the test. Some of the groups demonstrated very little knowledge or experience with providing biologic samples or with genetic testing. In addition, concerns were raised about issues such as cloning and DNA databases. These kinds of fears will need to be addressed by educating the potential participants.

Once the stakeholders have committed to participate, the challenge will become how to keep them interested. Expectant and current parents, health care providers, and community leaders all agree that periodic newsletters and a frequently updated website would be the best ways to keep them interested in the NCS. Parents want information in easy-to-understand, non-scientific terms, while health care providers want a provider-specific newsletter and website where they can receive information and contact the NCS team.

Parents of children with disabilities cited a clear desire to contribute to a greater understanding of the overall public health. Parents cited a tradition or history of parents volunteering their children to participate in health studies for the common goal of identifying causes and treatments for future generations of children.

One possible confound to this question is the potential socially desirable component of the question. Although expectant parent and current parent focus group respondents may not be intentionally altering their responses, there may be a strong cultural expectation that people should participate in activities that help others (i.e., altruism) and this may be stronger for some segments of society than others (i.e., rural populations or those from higher socio-economic status groups).

When asked about what would make them “excited” about participating in the NCS, most parent groups said that the individual benefits were primary with the exception of the rural groups which both thought that being part of a national study that would benefit the greater good was very exciting. Incentives and compensation were mentioned as leading motivators along with the receipt of health benefits associated with being part of a long-term health study. Being part of a large, national study was exciting for community leaders and health care providers who see their involvement as aligned with their mission of advocacy and excellence in medicine, respectively.

When discussing potential spokespeople to represent the NCS, all participants recommended spokespersons with whom they could identify children’s health issues – a well-known parent (mother mentioned specifically by some groups) or children’s advocate who has credibility on health and wellness issues. Frequently mentioned potential spokespersons included First Lady Mrs. Laura Bush. Community leaders added Bill Cosby because of his history of children’s advocacy and his respect among African-American communities. Additional factors that may strengthen Bill Cosby as a spokesperson may include his doctoral degree in education and his identification with health and wellness because of long-running acting roles he has played on television.

Most parents said that they were somewhat more interested in participating because they are expectant parents or they would have participated when they were pregnant. Parents of children with disabilities said that they were more interested in the study because they are parents of a child with a disability. They cite a strong desire to contribute to the overall understanding of disabilities among children.

Most participants from the expectant parent and parents of children without disabilities group felt the number of visits was acceptable. The parents of children with disabilities felt that the proposed number of visits was too high. These parents recommended that the study provide plenty of options for participating for example offering to replace the additional office visits with home visits if necessary.

All stakeholder groups (including health care provider and community leader groups) felt that convenience was a key to participation both for parents and health care providers. All groups recommended coordinating study office visits and biologic sample collection with regularly occurring office visits (i.e., well-baby visits both pre- and post-natal, immunization visits, school physicals, and sports physicals).

The duration of the office visits did not seem to be a problem for the groups involved. Current parents reported concerns about keeping the participating child occupied for an entire hour and the possibility of bringing all of their children to the physician's office for the participating child's office visit. Health care providers said that the majority of that time would be used by a nurse practitioner or physician's assistant rather than with the physician.

Collecting biologic samples was problematic in terms of the types of samples collected and convenience in collecting the samples. Most parents were reluctant to provide at least some of the samples proposed in the focus group interview. Only urine specimens and hair clippings met little resistance. Parents were rather mixed on allowing the children to provide blood samples. Some parents expressed concern that the children would be frightened and one group expressed concern about attempting a venous blood draw on a small child and suggested that a finger stick would be preferable. Parents recommended biologic sample collection during regularly scheduled office visits. Health care providers also supported this approach saying that this practice is not unusual and would be relatively easy to implement.

Another problem with collecting biologic samples was raised by the parents of children with disabilities. Parents in both groups raised concerns about the availability of the biologic specimen (e.g., fingernails not available because the child compulsively chews fingernails off) or the extreme difficulty in obtaining the sample due to the disability (getting a child with sensory integration disorders to endure finger-pricks in order to provide blood samples).

All parent groups said that completing a 20-minute survey would be acceptable. Where a preference was expressed, mail-surveys were preferred and Internet surveys were reported as an acceptable alternative. Most of the expectant parents discouraged the use of telephone for the

surveys. A mixed-mode design with a mail-out survey with an Internet option seems to meet a broad range of desires for survey participation.

All parent groups agreed to provide access to their homes for home sample collection. Most parent groups said it was important that the data collection team call in advance to establish an appointment to visit the home, that the appointment be in reasonable time increments (e.g., “not between noon and 5 p.m.”), on days convenient to the study participant (e.g., available on weekends and evenings), have clear identification, and be the same agency or data collectors through the course of the study. Many parents would agree to collect home samples using a kit provided that there was individual training or very clear written instructions. Some parents did object to using the kits to collect water and dust samples citing concern about getting it right. Very few parents indicated that it would be inconvenient to use the kits. Nearly all parent groups expressed an interest in receiving the results of home testing. Most groups said that they would want to know the results of home testing so they could take action if the environmental exposure appeared to be dangerous. Providing test results may be problematic in that study participants would change their home and environment thus changing their exposures. It may be that the study team provides respondents with home test results that are not too scientific or detailed yet convey the appropriate information.

Most parents generally supported the notion of collecting biologic samples and would agree to provide some of the less personal samples without much difficulty. Parents seemed reluctant to provide more personal samples such as placenta and umbilical cord blood, possibly out of unspecified concerns about scientific impropriety (e.g., human cloning or creation of a DNA databank).

Parents were also concerned about providing meconium but may have been reacting to the personal nature of the sample. After some discussion, most parents would agree to provide this sample. Health Care Providers said collecting this would not be a problem – since mother and child are still in the hospital at the time that the meconium is produced. The nursery nurse could enclose the first diaper in a bag and send it to the research team.

Health care providers said that collecting placenta, umbilical cord blood, and meconium would not be difficult and could be handled by the hospital that hosts the study participant for labor and delivery. The study participant could bring a biologic sample bag with them to the hospital or have a tag that identifies them as a study participant and alerts the local labor and delivery staff that specific biologic samples must be collected.

Samples that parents said they would not provide included baby teeth and breast milk. Parents noted sentimental reasons for not wanting to provide baby teeth, although one group of parents recommended that the parents could keep the first tooth and the study team could have the next tooth. Parents of children with disabilities cited baby teeth as a biologic sample that may not be available since some children swallow or spit out (and don’t retain) their baby teeth. Providing breast milk was a concern primarily because not every mother chooses to breastfeed.

Again, participants seemed surprised by the personal nature of the biologic samples presented for discussion.

All parents and community leaders said that study participants would need detailed information about what samples are required, why they are required – what questions these specific samples can answer, what the sample will be tested for, what the sample will not be tested for, and what will happen to the sample once testing is complete (e.g., long-term storage, destruction, etc.). As mentioned earlier, concerns about research ethics, safeguarding privacy and confidentiality, and protecting the rights of participants were topics of discussion for most groups.

Most of the parents said they would agree to genetic testing for themselves and the child participating in the study. Parents said that the research team would need a clear discussion of confidentiality and a rigorous set of procedures in place to safeguard the genetic test results. When asked if they would want a copy of test results, some parents insisted on receiving results while other parents did not want to have information they might not be able to do anything about. One parent group recommended asking parents whether they wanted results provided to them or not.

Health care providers seemed divided on the issue of having genetic test results. One group had only one OB/GYN physician and four other non-physician health care professionals, while the other group consisted of four pediatricians and five non-physician health care professionals. While the majority of the group had concerns about receiving genetic test results, the OB/GYN physician said that he routinely receives, interprets, and counsels patients on genetic test results. The group of pediatric health care workers did not want to interpret the results for patients.

A potential concern centers on the generalizability of opinions for the health care provider group. Groups recruited for the study were pediatricians in one health care provider group and OB/GYNs and other health professionals in the second group. Since genetic counseling often occurs as part of family planning and many of the biologic samples would be collected upon delivery, having a broader representation of OB/GYN doctors would be desirable. For these focus group interviews, there was only one OB/GYN in the focus group interview because two other OB/GYNs that agreed to be in the focus group interview were called away on a medical emergency. The one OB/GYN who participated in the focus groups expressed a great deal of interest in research and was familiar with research protocols used to collect biologic samples in other studies. The opinions of participants in these groups may not generalize to other health care providers, especially those who do not have a strong interest in research or operate their practice with a strong business-model philosophy. These health care providers may be the most difficult persons to enlist help from and maintain interest. Additional focus group interviews of health care providers who may be reluctant study partners – similar to a survey non-response bias study – would provide valuable information for the study team.

All parent groups said that they would prefer to be contacted for appointments by mail (letter or postcard), clearly marked as coming from the NCS research team (so it does not get set

aside with lower priority mail items). They want a telephone reminder several days prior to the appointment.

All parent groups said that they would agree to provide a point of contact in the event they moved or changed telephone numbers. All groups recommended processes whereby study participants could easily provide their own change of address information – website, toll-free telephone numbers, postcard reminders to send in change of address information, and other study information mailed at least annually (e.g., holiday cards) to engage participants in changing their address, if necessary.

The conversations about the appropriate use of incentives were consistent in that all groups thought the use of incentives was appropriate and no one thought that any of the incentives discussed were coercive. However, care needs to be taken when deciding what is appropriate to offer as an incentive. Most parents believed that monetary incentives would work, but a strategy would need to be developed so that people were not doing the study “just for the money.” The psychological literature indicates that an incentive that is too large will induce compliance with the task at hand but will not lead to long-term commitment (Eagly & Chaiken, 1993). An incentive should be perceived to be a bonus or a reward for the performance of a positive behavior but not payment for services rendered. The difficulty lies in choosing an incentive that will be viewed as a reward to all groups. Some of the suburban groups rejected every incentive that was presented on the list of potential incentives while other groups thought that some of the listed items would be acceptable. The goal will be to achieve a balanced incentive plan that will appeal to all groups without tilting the scales such that any one group feels that they are complying with the study to obtain the incentive.

An issue that was raised in several groups was an equitable incentive amount relative to a participant’s current financial stature. Some said the incentive wouldn’t be coercive unless they needed the incentive for their daily needs. In fact, what some perceive as a seemingly small incentive could be a sizable incentive to others and be coercive. A combination of cash incentives plus costs and some other long-term investment incentive (e.g., college savings plan or paid medical/dental insurance) seems like a strategy that will meet participant short and long-term needs while also not being coercive.

To achieve long-term commitment to the NCS, participants will need to be intrinsically motivated to participate in the study because of the belief that participation is a worthwhile and important activity. Participants who are merely behaving out of compliance will be less committed to the overall study and will be more likely to discontinue their participation.

Health care providers recommended professional development or practice development items such as a laptop computer that could be linked to an existing office network, journal subscriptions, membership in professional organizations, and medical conference funding. Office and medical supplies did not appeal to health care providers.

Community leaders said that funding for their organizations, the degree of alignment between the NCS and their organization's mission, and the opportunity to build credibility and demonstrate advocacy among their constituency are important incentives for their support and participation.

Parents and community leaders agreed that they would like to receive a paper newsletter on a quarterly or bi-annual schedule that described recruitment process, project successes, lessons learned, preliminary results, information for participants (e.g., change of address information), and references for further reading on environmental exposures and children's health issues. Parents also recommended that the NCS project website be continually updated with current information and include links to resources to understand biologic, genetic, or home test results.

Health care providers recommended a similar approach with one form for parents-participants and another newsletter specifically for providers. Information in the provider newsletter would focus on the areas mentioned for the parent-participant newsletter with additional information on project coordination and data collection issues (e.g., toll-free help line for physicians, frequently asked question or FAQs for physicians, biologic sample kits, record abstracting information, data collection points of contact for the NCS, etc.)

Most parent groups wanted to receive all of the information learned from the study and from their individual tests. Nearly all parent groups expressed interest in receiving biologic, genetic, and home test results – even if the results could not be interpreted at this time or if it could not be applied to a meaningful standard. Some groups wanted to have the option not to receive test results. Health care providers were divided with one group wanting all information possible for their patients whereas another group did not want information that they could not relay to their patients.

12. Recommendations for Future Focus Groups

A general sense of mistrust of research and researchers surfaced among some of the African-American and Hispanic participants in the focus groups. Conducting a series of focus group interviews that examine cultural issues is recommended. Groups could consist of urban and rural White, African-American, and Hispanic female parents (with some male parent groups) in various geographic regions. To facilitate trust in the focus group team, moderators should be of the same racial/ethnic background as the participants. The Hispanic groups should be facilitated by a Spanish-speaking moderator and assistant-moderator. Questions should focus on identifying barriers to participating in medical research and developing strategies to facilitate participation in the NCS.

Since all groups suggested that the recruitment of pregnant women into the study should be through their health care provider, it will be important to conduct another group of OB/GYN physicians. Since few OB/GYNs were available for focus groups, additional data may confirm results found in the current study and explore biologic sample data collection and willingness to participate for practitioners who use more of a business model. In order to ensure an adequate number of OB/GYNs, several focus group interviews could be conducted in conjunction with a large national professional conference (e.g., American College of Obstetricians & Gynecologists and American Academy of Pediatrics). Questions asked should focus on the logistics for recruiting pregnant women through their health care provider, factors that would encourage recruiting, data and sample collection, receiving and interpreting study participant test results (including genetic testing) and incentives for hard-to-reach OB/GYNs and pediatricians.

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References

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