

**National Institute of Health
National Institute of Child Health and Human Development**

Investigating small group information meetings as a community engagement strategy to encourage Latina/o and undocumented worker participation in the National Children's Study – Duplin County NC

**Request for OMB Clearance of Data Collection Instruments
under NIH/NICHD Generic Clearance # 0925-0590**

NICHD Division: Program Office, National Children's Study
Contact Name: Dr. Ken Schoendorf
Contact Phone: 301-594-1302
Contact Email: Schoendk@mail.nih.gov

Title: Investigating small group information meetings as a community engagement strategy to encourage Latina/o and undocumented worker participation in the National Children's Study – Duplin County NC

OMB Number: 0925-0590

Expiration Date: 06/30/2011

Program Title: Formative Research and Pilot Methodology Studies for the National Children's Study

Program Goals: Studies performed under this program are designed to improve data collection within the National Children's Study. Projects under this Generic Clearance will include projects designed to:

- improve Community Engagement at Study Locations, thus improving participant recruitment and retention
- inform methods of engaging Community-level health and medical providers, resulting in improved participant recruitment and retention
- test technologic methods of interaction with participants (e.g., Interactive Voice Recognition) to decrease respondent burden, improve participant satisfaction, and decrease cost

Purpose of the Survey: The purpose of the research is to investigate whether conducting small group information meetings about the National Children's Study as a community engagement strategy will encourage the participation of Latina/o and undocumented workers in the National Children's Study. Through this research, the NIH and contract institutions will gain insight from potential study participants on the following:

- Determine whether holding small group meetings about the NCS in the target communities is an effective community engagement strategy for new immigrant Latina/o and undocumented communities.
- Assess the perception of the NCS within the selected populations.
- Evaluate whether small group meetings are an effective recruitment strategy within male and female subgroups and within two specific subgroups of the Latina/o population by area of origin – Mexican and Central American immigrants to North Carolina (North Carolina is experiencing an influx of “new immigrants” to the U.S.).

Use of Results: The proposed research will directly inform community engagement and recruitment strategies in Duplin County, one of the NCS Vanguard Locations. A large fraction of births in the county are to Latino parents (39% of 2007 births), and we anticipate many are undocumented immigrants. The proposed research will also aid the NIH, the Coordinating Center, and NCS sites where there are significant immigrant populations in the development of community engagement activities and recruitment strategies that are relevant to and effective in Latino immigrant and undocumented communities. The results will help

advance the development and use of customized messages and strategies to enhance study involvement across diverse demographic groups within NCS communities. This work will also produce a focus group protocol that will provide feedback on the NCS.

Each transcript will be read to determine if themes develop from responses to research questions. We will also look for similarities and/or differences in responses from the various ethnic and age sub-groups included in this research to determine if there is a need for customized messages and strategies. The aim of the research study is to further engage the Latino/sub-populations within Duplin County in an attempt to ensure their representation in enumeration for the NCS.

Target Respondents: The target respondents are specific subgroups within the Latino community in Duplin County: males as well as females, immigrants from Central America and Mexico, grandparents and parents. The following are the potential NCS participants who will be recruited for this formative research:

- Mexican men and women who are new immigrants and possibly undocumented
- Central American men and women who are new immigrant and possibly undocumented
Mexican and Central American grandmothers and grandfathers

Survey Administration: NCS Duplin County staff members have developed an in-depth list of stakeholders and key informants at the segment level within the county. In each of these segments, key informants will provide information about potential participants. Specifically, we have identified Hispanic churches, places of business, gathering places and other key places and people with inroads into new immigrant communities. Participants will be invited one-on-one by one of the identified stakeholders/key informants to the focus group meetings. The meetings will be hosted by a trusted representative within the Latino/a community (pastor/pastor’s wife or a Latino/a business owner) and focus groups will be held at churches, in businesses and other places where the Latino/a community is already familiar and feels a degree of safety and comfort.

Survey Design: Ten focus groups will be conducted to test and obtain feedback on the use of small group meetings to encourage recruitment for the NCS within specific difficult to engage sub-populations of Duplin County’s Latina/o community. Data will be collected by bi-lingual research staff hired in Duplin County. They will be trained in focus group collection techniques by the NCS-UNC research team under the leadership of PI, Barbara Entwisle, who has conducted focus groups among many groups, including in international settings. Ten focus groups will be held in three Duplin County sample segments: two of the segments have a high concentration of Latina/o residents and the other segment is the most rural segment with an industrial farm largely populated with Latino workers. The research design procedures will be submitted to the UNC Institutional Review Board before any work is conducted.

Segment	Ethnic group	Gender	Relationship to participant
Segment 1 two groups	Mexican	Female	Potential participant
Segment 1 two groups	Mexican	Male	Potential participant
Segment 2 two groups	Central American	Female	Potential participant
Segment 2 two groups	Central American	Male	Potential participant
Segment 3 two groups	Mexican and Central American	Female	Parent/grandparent of potential participant

Three staff members from the NCS Duplin County project will attend each session. One bi-lingual moderator will lead the focus groups and a bi-lingual transcriber will take notes. The Duplin County Project Manager, Deborah Bailey, or a community outreach staff member will be on-hand to aid in the arrangements. She will only sit in the interview room if participants are comfortable with her participation.

A Moderator Guide has been developed that the moderator will use to guide the discussion. An English-language copy of the Focus Group Moderator Guide is included as Appendix D, and a Spanish-language copy of the Focus Group Moderator Guide is included as Appendix E.

The following are specific activities for the focus groups:

1. Response to the invitations to participate in the focus groups will provide preliminary data on the willingness of the Latina/o population in Duplin County to participate in small group meetings. The focus group approach will mimic the small group meetings that we envision employing to spread the word about the study in the community. These “house parties” or informal small-group meetings have been used by political candidates to get the message out about their platforms and positions. Right before and during study recruitment, we envision using small-group meetings to get the word out about the NCS and allow potential participants to ask questions or react to information about the study in a trusted place. This proposed research is to evaluate whether we can get individuals in the community to attend such a meeting, to get their reaction to vignettes, and to gauge whether such meetings would increase the likelihood of their participating in the NCS.
2. The focus groups will allow us to obtain feedback on the small-group strategy and get specific suggestions about how it might be improved. The focus groups will be conducted separately with female and male potential participants. Because there are distinct communities involving migrants from different places of origin, separate groups will be held for migrants from Central America and migrants from Mexico. An additional focus group will be conducted with the parents of potential participants in recognition of the role and influence of elders and members of multi-generational households within new immigrant and undocumented Latina/o communities.
3. After focus groups have concluded, notes will be translated and transcribed. A summary report of findings will be written and presented to the research team to inform recruitment and data collection. A summary report will be presented to the Duplin County Community Advisory Group to solicit further suggestions on ways to improve recruitment and retention.

Data Collection Burden: A total of 160 hours of participant burden is being requested to conduct 10 focus groups of 8 participants x 2 hours per group.

Type of respondent	# of respondents	Frequency of response	Average time per response	Annual hourly burden
Potential participant	64	1	2	128
Parent or grandparent of potential participant	16	1	2	32
Total	80			160

IRB Approval: The protocols for the focus groups have been submitted to the UNC-Institutional Review Board for approval as a modification to our current IRB approval for the NCS in Duplin County. We have requested and received a waiver of written informed consent because we do not plan to re-contact any of the participants, and the only thing linking the person participating to the activity would be his or her signature on a consent form. Correspondence indicating IRB approval is included as Appendix A.

Sensitive Questions: The focus group Moderator Guide does not contain sensitive questions. However, this work does involve a vulnerable population. Information will be collected to identify individuals to invite. After the focus group occurs, those documents will be destroyed. As indicated above, no names will be collected on consent forms. Even though we will emphasize to all participants that comments made by others during the focus group session should be kept confidential, they will be told and the consent will

reflect that it is possible that participants may repeat comments outside of the group at some time in the future. They will be encouraged to be as honest and open as possible, but remain aware of our limits in protecting confidentiality.

Remuneration: A dinner will be served during each focus group. As indicated above, we anticipate using small-group meetings as part of our recruitment strategy, and we do not anticipate providing any payment to participants in those meetings. To make this effort replicate that model as closely as possible, we will provide dinner (or another meal), but no additional incentive to participate.

Appendices:

Appendix A – University of North Carolina Institutional Review Board Approval Memo for Formative Research

Appendix B – Focus Group Recruitment Guide (English version)

Appendix C – Focus Group Recruitment Guide (Spanish version)

Appendix D – Focus Group Moderator Guide (English version)

Appendix E – Focus Group Moderator Guide (Spanish version)