

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

Socioeconomic, Cultural, and Political Facilitators and Barriers to Access, Recruitment, and Retention in Orange County, California

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

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Title: Socioeconomic, Cultural, and Political Facilitators and Barriers to Access, Recruitment, and Retention in Orange County, California

Plan Control Number:

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: To conduct the National Children's Study effectively in Orange County, California, the Orange County Vanguard Center (OCVC) investigators and staff will need to successfully recruit and retain participants, who will represent very diverse socioeconomic, racial, and ethnic backgrounds. Engagement and recruitment in diverse communities will require strategic efforts based on individualized community characteristics. During sampling and listing, OCVC compiled segment characteristics that illustrate the diversity of the Orange County cohort for the NCS. A very brief overview of the segments is summarized below:

Characteristics of Participants by Segment, 2000 Census Data

Segment #	Segment Name	Eligible black, non-Hispanic females	Eligible Hispanic females	Eligible white, non-Hispanic females	Eligible other, non-Hispanic females	Estimated median housing unit value	Per capita income	Proportion of single family housing units
1	Rancho Santa Margarita	2%	13%	78%	7%	\$378,743	\$33,328	90%
2	Aliso Viejo	3%	14%	72%	11%	\$307,668	\$42,422	73%
3	Laguna Beach	3%	13%	77%	7%	\$444,646	\$54,428	51%
4	Irvine	0%	6%	38%	56%	\$370,000	\$43,114	99%
5	Costa Mesa	2%	20%	68%	10%	\$166,126	\$17,666	1%
6	Santa Ana East	0%	97%	2%	1%	\$155,523	\$8,058	16%
7	Santa Ana West	1%	80%	2%	17%	\$212,100	\$10,856	33%
8	Westminster	2%	15%	56%	28%	\$251,600	\$27,074	85%
9	Huntington Beach	1%	7%	76%	17%	\$318,378	\$32,696	99%
10	Garden Grove	2%	33%	43%	23%	\$193,048	\$16,765	98%
11	Tustin	2%	6%	63%	29%	\$350,646	\$45,443	73%
12	Anaheim East	3%	36%	43%	18%	\$241,560	\$21,255	87%
13	Anaheim West	7%	54%	29%	9%	\$215,400	\$11,714	13%
14	Fullerton	1%	11%	49%	39%	\$409,044	\$41,658	83%
15	Yorba Linda	2%	14%	77%	8%	\$217,184	\$31,508	55%

As this diversity illustrates, participants in the 15 segments are likely to have unique characteristics that will affect engagement, recruitment, and participation. Therefore, the purpose of this formative research study will be to identify the socioeconomic, cultural, and political facilitators and barriers to access, recruitment, and retention in Orange County, California. The information gathered will enable OCVC investigators and staff to develop strategies for each segment to maximize recruitment and ensure the highest possible retention rates. In addition to this study, the OCVC outreach team will be speaking with individuals and small groups in a less formal manner so that as much information as possible can be obtained to inform NCS efforts.

Use of Results: The information gathered will be used to:

- Identify recurrent themes that would explain the rate of participation and retention in diverse social and cultural groups
- Identify relationships between cultural beliefs, traditions and values, and facilitators of or barriers to participation

- Identify factors that might affect reliability and validity of information collected for the NCS
- Provide guidance and information to refine and modify research procedures for specific populations
- Identify specific engagement approaches for specific populations and segments
- Generate guidelines for recruiter selection and training –
 - o Identify desired characteristics for recruiters/enumerators for each segment
 - o Describe possible scenarios and recommend appropriate responses
- Generate segment-specific strategies for promotion and recruitment –
 - o Relate the NCS specifically to the identified key issues in the community
 - o Develop strong supporters at the grass-roots level in the community.

The data from interviews and focus groups will be used to design a written survey, which will also be reviewed by several key informants. This survey will be submitted for IRB and OMB review as a modification/new study prior to its use. The written survey will allow the collection of similar information from a greater number of participants and from participants in all 15 segments. The intent is to summarize the survey data for the county, specific areas adjacent to segments, and by participant characteristics such as socioeconomic status and race/ethnicity. OCVV investigators and staff will also examine cultural and ethnic differences, socioeconomic differences, and geographical differences.

Target Respondents: The target respondents for this research are women and their partners (for women who choose to identify and invite them) in the 15 segments described above. An effort is being made, as noted above, to ensure diversity in the recruitment and to obtain a representative sample. OCVV proposes to recruit 30 individuals for key informant interviews and 70 for focus groups (7 focus groups with about 10 participants in each). See Appendix B for a summary of the targeted individuals by segment area. Target respondents will be primarily women, although partners and family members will also participate in some areas. In several focus groups, men and women will be separated to encourage open discussion of issues affecting NCS participation and potential challenges in obtaining the full support of the family.

Potential NCS participants will not be specifically targeted, although it is possible that a participant in the formative research might become an NCS participant. Recruitment efforts will be focused on neighborhoods in the 15 segments, but do not include conducting pregnancy screening as part of this recruitment. Any woman with or without children will be invited to participate, and the participant’s partner (male or female) and other family members will be invited to participate as well.

Survey Administration: OCVV investigators and staff will begin by conducting key informant interviews with community-level individuals, with the goal of obtaining information and contacts for further focus group and survey research as well as developing NCS “champions” near segments. Individuals to be interviewed will be identified through a variety of sources, including recommendations from community leaders and various community programs or organizations. The Community Outreach coordinator and outreach specialists for the OCVV will be instrumental in identifying potential interviewees and have already developed an extensive network throughout the county. Some key informants have already been identified and are ready and willing to meet once the study has approval; additionally, many community leaders with whom OCVV staff has built a strong relationship through our community outreach efforts have offered their assistance in identifying key informants and focus group participants.

Additional recruitment efforts will include advertisement through school parent-teacher and other similar community and faith-based organizations. A concerted effort will be made to reach out to marginalized and harder to reach individuals by working closely with organizations that have successes in serving these populations. Some of these partner organizations are: WIC, which provides public assistance for mothers and children; Maternal Outreach Management System (MOMS), a community-based organization for underserved pregnant women; Orange County Asian Pacific Islander Community Association (OCAPICA); and Latino Health Access, an organization utilizing promotoras in underserved communities.

Survey Design: To develop and implement this formative study, a working group has been formed that includes our outreach specialist, hospital/birth visit coordinator, listing manager, study center coordinator, and several investigators who will ultimately be responsible for study implementation. This group will meet at least one time per week throughout the study. Together, the working group has developed strategies to

collect formative research data in each of the 15 segments. OCVC designed this study to use three strategies for data collection in order to provide the variance in sources and methods necessary to obtain valid and reliable results. Key informant interviews will be the first step in data collection and are described below. The use of key informants will help to identify potential focus group participants and OCVC investigators and staff will then implement focus groups in key geographical and demographic areas.

Key Informant Interviews. The objectives of the key informant interviews include: 1) to obtain further access into the community to facilitate focus group and survey research for this formative study (e.g., by obtaining referrals and recommended contacts), and 2) to obtain responses from key informants to the key questions addressed in this formative research study. Conducting interviews in a one-on-one setting will allow collection of perspectives from women similar to those who will be recruited for the NCS that OCVC might not obtain in a group setting or on a written survey. Potential key informants will be identified using recommendations from community partners and contacts and will be invited to participate in the formative research. Interviews will take place at a location convenient to the key informant, such as their home, office, or our study center. Interviews will also be scheduled at a time convenient to the key informant and may include evening and weekend hours. At the time of invitation and scheduling and again at the start of the interview, a study information sheet will be reviewed and verbal consent from the participants will be obtained. Interviews will last one hour and will be recorded and later transcribed. Interviewers will be OCVC staff and investigators. Interviews will be conducted in the primary language of the key informant. Key informants will also be asked to respond to a brief (5 minutes) demographic survey (Appendix C).

At the start of each interview and focus group, the interviewer or moderator will provide a brief overview of the NCS and the concept of “research.” OCVC has a standard script for the study overview that is written at the 6th grade comprehension level. The interviewer or moderator will also ask for and respond to questions that arise during and after the overview.

Focus Groups. With input from key informants, focus groups will be planned in segments and participants identified for those groups. OCVC has identified seven areas for focus group research, and in doing so, has selected areas that would be generally representative of the potential participants, in terms of socioeconomic, geographic, and racial/ethnic characteristics. Groups will be conducted in native languages (see Appendix B). The segments and planned focus groups for each segment are listed in Appendix B.

OCVC investigators and staff members will moderate the focus groups. All moderators will have a comprehensive understanding of the National Children’s Study and will be fluent in the languages in which the groups are conducted. Currently, our staff members represent diverse communities and speak the five languages we are most likely to encounter in our segments: English, Spanish, Vietnamese, Korean, and Chinese. At each group, the moderator will have one to two assistants, also fluent in the language of the group, who will assist the moderator and take notes. Focus groups will be audio recorded, and the notes and recordings will later be used to prepare complete transcriptions of the groups.

Prior to conducting focus groups, the moderators and assistants will complete targeted training provided by Elaine Vaughan, Ph.D., Research Professor, Department of Psychology and Social Behavior at UCI, who will serve as a consultant on this project. One of Dr. Vaughan’s areas of expertise is methodology for focus group and community research. The training will include strategies for conducting effective focus groups, including how to elicit involvement from members and how to respond in challenging situations or to challenging questions. Training for assistants will also address note-taking and transcription methods. Additional time will be spent reviewing neighborhood characteristics, specific to assigned areas, with moderators and assistants. Ideally, moderators will conduct groups in areas in which they have also been involved in key informant interviews. Moderators and assistants will fluently speak and write the language in which the groups are conducted.

Focus groups will be held in community locations, which will be identified through key informants and other community connections established by the outreach team. These locations may include: schools, libraries, community centers, and community based organization facilities. Meeting schedules will depend on the availability of the participants, including day, evening, and weekend meetings. Each focus group will last one and half hours and have eight to ten participants, and refreshments will be provided (coffee and pastries for morning or afternoon groups and a light dinner for evening groups). Onsite group childcare will be provided to facilitate participation, and trained childcare staff from another program at UCI will be used.

For at least one of the focus groups in each language, OCVC will intentionally recruit both mothers and fathers to participate, for a total of 12 participants for that particular focus group. During these groups, a breakout session will be conducted where a moderator will meet separately with fathers and mothers. Two moderators and two to four note-takers will be deployed for these groups.

Focus group discussions will be organized around two topics specific to recruitment and specific questions within each topic area (see below). [In a subsequent phase of the research, OCVC plans to collect more specific information on retention). At the start of the focus group, the moderator will review a study information sheet (Appendix D) with the participants and will ask for verbal consent to participate. In addition to participating in the recorded discussions, participants will be asked to complete a brief demographic survey (Appendix C). During focus groups, participants will be invited to sign up on a sign-up sheet to become part of a community advisory board. As in the informant interviews, the moderator will begin by providing an overview of the NCS, using the script provided (Appendix E), and will respond to questions about the study.

Data Collection Burden: A total of 170 hours of participant burden is being requested to conduct key informant interviews x 1 hour per interview and 7 focus groups of 10 participants x 2 hours per group.

Type of Respondents	Number of Respondents	Frequency of Response	Average Time per Response	Annual Hour Burden
Key Community Informants	30	1	1	30 hours
Potential Participant	70	1	2	140 hours
Totals	100			170 hours

IRB Approval: University of California-Irvine IRB approval was received on November 26, 2008. After the survey is developed, a new IRB and OMB proposal will be prepared prior to its use; thus, the current application is for permission to conduct key informant interviews and focus groups only.

Sensitive Questions: The survey instruments do not contain sensitive questions. The OMB format for asking race and ethnicity questions will be applied.

Remuneration: The targeted respondents of the focus group instruments will receive compensation in the amount of \$35, as well as childcare services while participating in the focus group and reimbursement of transportation costs traveling to and from the focus group location. Light refreshments will be served to the focus group participants during the study.

Appendices:

Appendix A: University of California-Irvine IRB Approval Memo

Appendix B: Summary of Methods and Segments

Appendix C: Anonymous Demographic Questionnaire

Appendix D: Study Information Sheet for Focus Groups

Appendix E: Focus Group Moderator Guide

Appendix F: Study Information Sheet for Key Informant Interviews

Appendix G: Recruitment Flyer for Focus Groups