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Community Outreach and Engagement to Prepare for Household Recruitment of National Children’s Study Participants in a Rural Setting

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Abstract

Context—The National Children’s Study (NCS) is a longitudinal study of environmental influences on children’s health. Recruitment of a representative birth cohort that will be followed until 21 years of age requires unique approaches across the nationwide study communities.

Purpose—To describe community outreach and engagement in preparation for household recruitment of women of childbearing age at a rural-classified NCS location that includes 4 adjacent Northern Plains counties spanning 2,500 square miles.

Methods—Outreach and engagement methods focused on rural community characteristics. The team established an advisory council, conducted outreach meetings with agencies and groups, participated in local events, and collaborated with stakeholders. Study awareness was raised using radio announcements, local television stories, and widespread distribution of print materials through churches, businesses and childcare centers. Impact evaluation examined the number of stakeholder events by type. Outcome evaluation examined the number of households contacted for recruitment, numbers of age-eligible women who completed the screening, and exploration of whether women had heard about the study.

Findings—Over 300 outreach events occurred, ranging from tribal council meetings to parade entries. Recruitment outcomes were as follows: (a) 80% of 14,700 non-vacant households were reached for potential recruitment, (b) screening interviews were conducted with 89% of the 5,800 age-eligible women identified; (c) 53% of women who completed the screening had heard about the study.

Conclusions—Outreach targeted to rural communities facilitated strong recruitment outcomes. Collaboration with the cooperative extension service was a unique rural asset that facilitated relevant activities. Participant retention is an ongoing priority.

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Keywords

observational study; outreach; recruitment; rural; women

The National Children's Study (NCS) will examine the effects of the environment on the health and development of 100,000 children.¹ Environment is broadly defined to include a number of natural and man-made issues, such as biological agents, chemical and social factors, physical surroundings, behavioral influences, genetics, cultural and family influences, and geographic locations. This unprecedented epidemiological study was designed to include a nationally representative birth cohort that will be followed from preconception, pregnancy, or birth, until 21 years of age. Initial plans were to recruit women of childbearing age from sampling segments within 105 study locations to ensure that the NCS birth cohort reflects the diverse ethnic, racial, economic, religious, geographic, and social groups within the United States (US). The first 7 NCS sites, designated as "Vanguard Centers" were selected to evaluate a pilot study protocol which employed door-to-door household recruitment of women of childbearing age starting in 2009. These Vanguard Centers included: Duplin County, North Carolina; Montgomery County, Pennsylvania; Orange County, California; Queens County, New York; Salt Lake County, Utah; Waukesha County, Wisconsin; and a 4-county site that includes Brookings County, South Dakota; and Yellow Medicine, Pipestone, and Lincoln Counties in Minnesota (hereby referred to as the BYPL site). An additional 30 study locations began enrolling participants using alternative recruitment methods in 2010. Optimizing household recruitment of age-eligible (ie, 18- to 49-year-old) women required unique approaches across the initial 7 NCS locations. The purpose of this manuscript is to describe community outreach and engagement leading up to active household recruitment of women of childbearing age at the BYPL site.

Communities where the NCS will take place are highly diverse. For example, one of the original 7 Vanguard Centers is Queens County, New York, a highly immigrant, metropolitan-classified study site with about 2.3 million people who reside in a 109-square-mile (mi²) area.² The population density exceeds 20,000 people/mi². The 4 counties of the BYPL site are rural-classified based on population data from the US Census Bureau and county-level criteria as defined by the US Office of Management and Budget.³ There are roughly 55,000 people who reside in the 2,500 mi² BYPL site, resulting in a population density of about 20 people/mi².² Under the original NCS protocol, household recruitment of women of childbearing age was planned within randomly selected sampling segments located in each of the 7 Vanguard sites. The sampling plan was designed to enroll approximately 250 births per year at each initial site over a 5-year period. The enrollment goal of 250 births per year comprises < 1% of the annual births in Queens⁴ and about 42% of the annual births in the BYPL site (based on 2000 to 2004 birth data). The low population density of the BYPL site meant that 7 of 11 original sampling segments (which were identified to yield between 45 and 65 births per year) were included in the initial recruitment plan. Geographically far-reaching community outreach was essential for the BYPL site because of the number of dispersed households in the sampling area.

LITERATURE REVIEW

Community outreach activities include communication about the NCS to groups, organizations, and residents of specific communities.⁵ Community engagement is a process of working collaboratively with study communities to build relationships and secure long-term support and endorsement of the study from potential participants and the agencies that serve them.^{5,6} Prior research findings informed the outreach and engagement approaches that were developed to maximize the household recruitment of women of childbearing age

for the BYPL site. Face-to-face interaction was superior to media and print materials in terms of recruitment and retention of healthy, community-based women for the Midlife Women's Health Study.⁷ Ethnically diverse women were drawn to the study when it was endorsed by their churches, their children's schools, or other trusted agencies. Community encounters with data collectors and investigators who could answer their questions about the study was appealing to participants. In a synthesis report of how to recruit diverse women as research participants, 3 relevant factors were identified: awareness, acceptance, and access.⁸ Awareness is facilitated through personal contact of potential participants with study recruiters. Acceptability is garnered through messages of support disseminated by community leaders and local media. Accessibility is achieved by reducing participation barriers and through provision of incentives. Face-to-face approaches that were community-based and supported by community leaders were incorporated into the BYPL plan.

Successful approaches to improving enrollment of women and children in public health or assistance programs are relevant to NCS recruitment and retention. Collaboration with trusted and established community-based organizations is vital.⁹⁻¹² Such organizations include faith-based services, education, human and public services, and others. Examples are early childhood education programs like Head Start, primary schools, daycare centers, children's museums, park and recreation programs, libraries, churches, tribal groups, and county fairs.¹³ The BYPL approach to outreach and engagement focused on the unique community-based organizations located in study communities.

METHODS

Recruitment Objectives

Outreach and engagement methods employed locally relevant strategies to raise awareness of the NCS and build relationships with BYPL communities. The recruitment objectives derived from a strong outreach and engagement plan were to: (a) make contact with all eligible households during the door-to-door recruitment, (b) maximize the number of screening evaluations completed by women of childbearing age, and (c) identify that women who completed the screening had previously heard about the study.

Outreach and Engagement Training and Protocol for the BYPL Site

All members of the BYPL study team who served in roles other than administrative support participated in outreach activities. The team approach included 2 to 4 people attending each meeting or event, with one person identified as the facilitator. One team member was responsible for making arrangements, completing a post-event evaluation, sending a thank you letter, adding the information to an outreach database, and following-up on post-event issues. Training for staff members with diverse educational backgrounds prepared them for work in rural communities. Content for the training was derived in part from a guide for community health promotion.¹⁴ Staff members explored the physical layout of study communities and identified relevant organizations and gathering places for women of childbearing age. Outreach staff visited local businesses and identified community stakeholders for future outreach activities.

Population Characteristics of the BYPL Site

Staff development also focused on the characteristics of the population that resides in the 4 counties, including subpopulations with unique sociocultural backgrounds and restrictions on outreach or recruitment. Ninety-three percent or more of the residents within the BYPL counties identify their race as white.² Diverse subpopulations reside in the counties, including American Indians, a growing Hispanic population, and Hutterites. Characteristics of these populations influenced outreach and engagement methods. Each is described.

The current communities of the BYPL site were established in the 1800s when a large influx of immigrants took place, many from Germany and Scandinavia, as well as other Northern European countries.¹⁵ Expansion of the railroad and the US Homestead Act attracted immigrants to the area mainly for farming, but also for business opportunities. The contemporary small towns that characterize the BYPL counties are more diverse than the original settlements, but the economy remains highly agricultural and most communities retain some ethnic traditions of the settlers. Annual community events were opportunities for far-reaching outreach and engagement prior to recruitment. Examples include county fairs, community parades and ethnic heritage days. For example, Aebleskiver Days is an annual summer event that celebrates the Danish heritage of many people living in the Tyler, Minnesota, area.

The land area of the BYPL site was home to tribes of the Dakota Sioux Nation prior to the influx of immigrant settlers.¹⁶ The 4-county area includes one 746-acre site located in Yellow Medicine County that was returned to the tribe by the federal government in 1938, eventually becoming the Upper Sioux Community. American Indians also reside outside of the Upper Sioux Community and are dispersed throughout the 4 counties. Building long-term and trusted relationships with the American Indian community was a priority. Communication with the tribal council of the Upper Sioux Community guided the study team on the locally relevant practices for recruiting and retaining the American Indian population throughout the BYPL counties. These best practices included participation of a respected community member in the advisory council and study team participation at annual community events.

The Hutterite Brethren are similar to the more well-known Anabaptist groups (eg, Amish and Mennonites) in their primary language (German) and their cultural beliefs.¹⁷ Hutterites reside on self-sufficient rural colonies; however, they use modern technology in their farming operations and are diversifying their economic base to include manufacturing. Members of the study team previously collaborated with the Hutterite communities within the BYPL site. The team relied upon these relationships in order to work within the hierarchical social structure to raise awareness of the study, and to plan recruitment approaches if any of the several colonies within the 4 BYPL counties were eligible for inclusion.

The Hispanic population residing in rural areas of the US grew by 44.6% between 2000 and 2010, faster than any other racial or ethnic minority.¹⁵ This demographic shift also took place in the BYPL counties. For example, in Pipestone County, Minnesota, the Hispanic population grew from 0.7% in 2000 to 3.7% in 2010, while Brookings County, South Dakota, changed from 0.9% to 2.0% during the same time period.² Growth in Hispanic residents is largely due to employment opportunities in area meat processing plants and large dairy industries.¹⁵ The team capitalized on the experience of local public health, social service, and health care agencies to advise on study communication and recruitment strategies to reach the Hispanic population. Spanish-speaking staff members were hired and Spanish language outreach materials were disseminated at places of employment, churches, and community service agencies.

Community Stakeholder Identification, Outreach, and Engagement

Stakeholders were defined as community leaders who understand the BYPL site and have long-term commitments to the communities. Stakeholders were leaders in government, community organizations, the target population, and the health system (both acute care and public health programs that serve women and children). A summary table that lists the stakeholders and corresponding roles in support of the NCS is provided as Table 1. Initial outreach capitalized on existing relationships that were built through prior research projects

and through the educational and service affiliations of South Dakota State University (SDSU) as a rural land-grant university. Stakeholders identified relationship-building strategies that would facilitate household recruitment and long-term retention. They helped to anticipate potential stumbling blocks to study implementation and ways to overcome them. Recommendations to raise awareness and educate community members about the study were selected based upon their potential to reach the largest and most diverse audiences through local programs and events. Stakeholders suggested community advisory council (CAC) participants who could facilitate study implementation. Council members represented each county and had related experience with rural outreach and access to diverse populations. The CAC was formally established about one year prior to recruitment.

Law enforcement leaders were important stakeholders to inform about the future presence of research personnel and study vehicles in communities. These leaders advised the study team on rural safety issues, including how to prepare for seasonal weather hazards, animal safety (such as vicious dogs), and personal safety of staff members in rural areas.

The study team capitalized on a strong affiliation with the county-based Cooperative Extension Service (CES). The CES is an agency of the United States Department of Agriculture, and it was created in 1914 as part of federal legislation focused on bringing research to local people.¹⁸ A land-grant university in every state leads the CES, including SDSU in South Dakota. Extension agents advised on venues and opportunities to expose rural families, especially women of childbearing age, to information about the study. Agents also provided guidance on how to identify occupied rural housing units for recruitment, and they guided the team on rural travel challenges such as unmaintained roads.

Awareness of the NCS throughout the greater health care community was promoted through publications, displays, and presentations at nursing and medical association meetings. Informing local hospital and clinic leaders about the NCS was critical due to their role in implementation of the research protocol and in conveying a positive message about the NCS to patients. Initial meetings with health system leaders were followed by focused meetings with nursing units, laboratory managers, ultrasound/x-ray managers, and medical records personnel. This outreach facilitated contractual agreements for research services and defined plans for research approval. Outreach to direct care providers was challenging due to their primary focus on patient care. Hospital nurse managers and clinic managers advised the team on ways to inform these groups about the study. Relationship building with health care stakeholders that were new to research with the SDSU study center took place over time and required numerous contacts to garner study support.

Collaboration with public health and social service agencies provided insight into the specific outreach and engagement activities that would reach young families, women of childbearing age, and fathers of young children. Agency leaders identified local media and community services as the most successful approaches. These stakeholders recommended the federal Women, Infants and Children (WIC) program to facilitate getting the word out about the study to potential participants who may be hard to reach through other approaches. Social service agencies identified family focused activities where study personnel could engage with families. Daycare centers, home-based childcare providers, and local school districts were stakeholders that offered ways to reach young families. Some churches also assisted in these efforts by posting free announcements in weekly church bulletins.

Use of print and broadcast media began with introductory articles published in local newspapers and interviews of study personnel by local radio and television stations. Newsletters published by community organizations included short articles about the study or brief advertisements indicating that recruiters would be in the community soon. Both

nationally and locally designed posters and flyers were placed in clinics, chiropractor offices, dental offices, and retail stores. An easy to recognize and co-branded logo that included a familiar image of SDSU along with the standard NCS logo was used. Paid and free advertising was obtained with local radio spots and public service announcements. Billboards were posted on highly traveled roads within the counties. The advertisements announced that recruitment would begin soon and encouraged participation.

Major employers, community groups, and local businesses invited staff members to share study information. Examples of community groups were the Lions clubs and Rotary clubs that provided an opportunity to speak about the study at their regularly scheduled meetings.

Grassroots efforts focused on strategies to reach large numbers of people. This was accomplished through parade entries, mobile NCS displays, and a listserv. A study entry in local parades included a decorated vehicle, helium balloons, and NCS staff members distributing promotional items. A table-top display was developed for use at health fairs and community events. To engage families, children's activities were developed to accompany the mobile display. A large NCS display rotates through community venues. The display includes an interactive playhouse with play food and pictures of culturally diverse meals enjoyed by families. A quarterly online newsletter is sent to members of the BYPL listserv. The newsletter provides study updates and reviews recent outreach.

RESULTS

Results of BYPL outreach and engagement were evaluated for both impact and outcome. Impact evaluation examined the type and number of stakeholder activities that occurred up to the launch of household recruitment. For purposes of non-disclosure, numbers in this report have been rounded per NCS guidelines. Table 1 includes a column that summarizes the number of stakeholder meetings or outreach events that took place. Over 300 different stakeholder meetings or events occurred, and promotional materials were distributed to ~400 local businesses. Health care outreach accounted for over 33% of the total number of meetings and events (~100). Grassroots partner organizations were the sponsors of annual community events where the NCS staff participated with a parade entry, table-top display, or children's activities.

Measurement of the recruitment outcomes achieved from the outreach and engagement plan was facilitated by data that were collected on the number of housing units eligible for recruitment, and how many of those units were reached for potential recruitment. Lists of all dwelling units within the sampling segments were developed using 350 hours of staff time and requiring 12,500 miles of travel to complete over an 8-week period.¹⁹ There were 16,000 household units identified in the sampling segments. Each household was mailed an informational letter about the study that also informed residents about door-to-door recruitment. Recruitment outcomes examined how many of these households were enumerated (defined as the act of approaching the household, speaking with 1 household member, and requesting identification of other household members, especially 18- to 49-year-old women). Outcome data also explored the number of age-eligible women who agreed to complete the baseline pregnancy screening interview, and whether these women had previously heard about the study.

Of the 16,000 household units in the BYPL sampling segments, 1,300 were identified as vacant, leaving 14,700 units available for recruitment. Of these available households, 80% were reached for potential recruitment. There were 5,800 eligible women identified between ages 18 and 49 years, and screening interviews were conducted with 89% of them. A total of 53% of the women with complete screening data had heard about the study prior to the

household visit. Women were asked to report all of the ways they had heard about the study (Table 2). Fifty-two percent of the women heard about the study through the letter received in the weeks prior to household recruitment. Thirty-nine percent cited interpersonal sources of study information, and this communication was with a friend or acquaintance (20%), family member (7%), someone else in the community (7%), a physician, or another health care provider (4%). Twenty-five percent of women reported hearing about the study through promotional approaches that used the media (18%), billboards (5%), and the Internet (2%). Twenty percent reported hearing about the study through other sources such as local parades, county fairs, children's carnivals, and other community events.

DISCUSSION AND CONCLUSIONS

Outreach and engagement team members developed relationships with community members through their consistent presence at local events and study activities. This type of long-term commitment and personal recognition of research personnel is critical to building trust, and sometimes reducing historical mistrust, in long-term studies of children's environmental health.²⁰ The team approach also provided an opportunity for mentoring new staff in outreach activities.

The most frequently cited way that women heard about the study was the informational letter mailed to the home prior to household recruitment. Thirty-nine percent of the women who heard about the study reported some type of interpersonal interaction as the source of information. The mailed informational letter was applied across all households, while the interpersonal communication was a result of exposure across multiple different approaches to getting the word out about the study. Site-specific interpersonal efforts, grassroots outreach, and media-driven communication were meant to enhance recruitment and long-term retention, which will be explored in future studies. Social media strategies were not approved for use by the NCS program office at the time of household recruitment. Currently, social media sources like Facebook, Twitter and Study Center websites are used for community outreach and to showcase NCS activities. Social media strategies are currently under development for long-term retention of participants.

Outreach and engagement required a significant investment of staff travel time in this 2,500 mi² rural Northern Plains site. In contrast, Orange County California is one of the original NCS Vanguard Centers where the size of the sampling segments is much smaller, but the area has highly diverse race-ethnicity, sociodemographics, and physical geography, requiring outreach and engagement approaches tailored to that site. Orange County reported that 30% of the women who completed the household screening had heard about the study,²¹ compared to 53% from the BYPL site. The mailed study letter and input from a community advisory group were the uniformly applied approaches to outreach and engagement at each of the 7 original Vanguard Centers. A greater percentage of women of childbearing age who reside in less densely population study sites are potentially eligible for recruitment compared to women who reside in densely populated sites like Orange County. Far-reaching grassroots outreach through parades and other community events is a feasible approach to raising study awareness and inviting women to inquire about potential participation in rural areas. Such approaches would reach many more ineligible women in densely populated areas.

Outreach staff members should anticipate study delays when conveying information about a national study that is just getting underway. The Vanguard Centers experienced several delays that required changes in the timeline for recruitment, protocol approval, and local employment opportunities. Maintaining a positive image of the study and conveying optimism about the eventual launch of the study was essential.

Preparation for study recruitment requires a generous and realistic timeline that prioritizes outreach and engagement activities. For the BYPL site, the outreach with state and local government and tribal leaders was priority, followed by health care organizations and providers, which required the most time. Rural health facilities commonly have limited research experience and infrastructure.²² The relationship and capacity building with rural health facilities led to very supportive collaboration with these agencies. One to 2 years of effort prior to active recruitment is recommended, especially when working with rural health facilities or in other areas where there is a potential for research mistrust.

Outreach and engagement with NCS participants and study communities will be a dynamic and evolving effort. Outreach in new housing developments and among new residents in eligible segments is needed in a multi-year recruitment plan. Maintaining a presence at annual community events that take place across the small towns located in rural sites is important in keeping the community involved and aware of the study. Including community volunteers to assist with games at annual NCS carnivals and other outreach programs has numerous benefits. The partnerships engage community members in study activities and keep the NCS in the local media. Carnivals for families also serve as a recruitment tool since the event is promoted throughout the community.

Because the NCS birth cohort will be retained as participants until young adulthood (21 years of age), retention planning is underway. Approaches are focused on meaningful incentives, newsletters, greeting cards, and follow-up phone calls. To develop an expectation for long-term contact, names and contact information of relatives and others who could help to locate participants were requested at enrollment. Community stakeholders are provided annual study updates. Overall goals of the updates are to retain study support and to inform stakeholders of study developments and results.

Successful implementation of the NCS requires community-based efforts. Rural communities where the study takes place should capitalize upon the assets in these environments when planning outreach and engagement efforts. These assets include the cooperative extension service as well as the unique events associated with rural and ethnic heritage, including parades, county fairs, and other annual events that occur in study communities.

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TABLE 1

Outreach and Engagement Stakeholders, Roles, and Impact Evaluation

| Stakeholders | Role of Stakeholder in the NCS | Impact Evaluation |
|---|---|--|
| Government: state, county, city, tribal, law enforcement | <ul style="list-style-type: none"> Identify locally relevant outreach and engagement strategies Identify ways to translate and communicate findings Learn about and plan responses to safety issues Access birth data to create sample segments (state) | <ul style="list-style-type: none"> Meetings with government/tribal officials (n = 21) Meetings with law enforcement (n = 6) |
| Hospitals, clinics, and health care systems | <ul style="list-style-type: none"> Aid in recruitment Collaborate in protocol implementation Inform of study and role in data collection Establish formal agreements related to the study Identify ways to translate and communicate findings | <ul style="list-style-type: none"> Meetings with health system, clinic and hospital staff (n = 106). |
| Cooperative extension services, public health and Women, Infants and Children programs | <ul style="list-style-type: none"> Strategize approaches to enhance recruitment and retention Identify referral resources and procedures Identify ways to translate and communicate findings | Meetings to inform and to seek assistance with recruitment (n = 17) |
| Social service agencies | <ul style="list-style-type: none"> Access certified childcare programs for outreach Identify referral resources and procedures Strategize approaches to recruitment and retention | <ul style="list-style-type: none"> Meetings to inform and to seek assistance with recruitment (n = 7) |
| Daycare programs, child care providers, and schools Churches, Non-profit and service organizations | <ul style="list-style-type: none"> Recruitment Outreach to potentially eligible families Identify approaches to share research findings Outreach to enhance recruitment Raise awareness of the NCS Identify approaches to share research findings | <ul style="list-style-type: none"> Meetings with childcare services and school administrators or boards (n = 24) Meetings with church leaders (n = 16) |
| Media partners: print and broadcast | <ul style="list-style-type: none"> Recruitment Translate and communicate research findings | <ul style="list-style-type: none"> Media outlet meetings (n = 39) Television or radio interviews (n = 9) |
| Major employers, businesses, and community groups | <ul style="list-style-type: none"> Outreach to enhance recruitment Identify ways to translate and communicate findings | <ul style="list-style-type: none"> Employer and community group meetings (n = 27) Venue for promotional materials distribution (n = 379) |

| Stakeholders | Role of Stakeholder in the NCS | Impact Evaluation |
|---------------------------|---|--|
| Other grassroots partners | <ul style="list-style-type: none">• Outreach to enhance recruitment• Relationship building | <ul style="list-style-type: none">• Participation in community parades and events (n = 74) |

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TABLE 2

Reported Ways That Women Heard About the NCS

| Response Category | Percent |
|-----------------------------------|----------------|
| Letter in the mail | 52% |
| Friend or acquaintance | 20% |
| Family member | 7% |
| Someone in the community | 7% |
| Physician or health care provider | 4% |
| Media | 18% |
| Billboard | 5% |
| Internet | 2% |
| Other | 20% |