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Community Engagement in Epidemiological Research

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Abstract

Objectives—Engaging communities has become a critical aspect of planning and implementing health research. The role community engagement should play in epidemiological and observational research remains unclear since much of this research is not directly generated by community concerns and is not interventional in nature. The National Children's Study (NCS), an observational longitudinal study of 100,000 children and their families, provides a model to help guide the development of community engagement strategies in epidemiologic research.

Methodology—This manuscript describes community engagement activities of the NCS during the planning phases of the study.

Results—There are many challenges of community engagement in epidemiologic research particularly before the actual research sites are determined. After communities of interest are designated many further issues must be resolved, including: defining the specific community, determining which residents or institutions represent the identified community, and developing trust and rapport through respectful engagement.

Conclusions—Community engagement is critical to the long-term success of any longitudinal epidemiologic study. A partnership with the community should be formed to ensure mutual respect and the establishment of an enduring relationship. Genuine community engagement offers the hope of enhancing recruitment, retention, and participant satisfaction.

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Keywords

community engagement; epidemiology; community-based participatory research; longitudinal studies

Introduction

Engaging community members and organizations in the development and implementation of research has become an important aspect of biomedical, public health and intervention research.¹ In addition to respecting the interests and values of community members, collaboration with communities can provide unique perspectives and a wealth of information that can be incorporated into the study design and implementation. This can consequently enhance recruitment and retention of participants and help produce valid and meaningful results.²

The practice of involving communities in research has developed over recent years both in response to a perceived mistrust between communities and researchers and in an effort to enhance research by improving the quality, relevance, and impact of research in the community.^{3,4} This mistrust has been generated by valid community concerns that perhaps well-intentioned research investigators have “used” communities as laboratories without engaging the community in defining priorities, planning studies, or developing implementation strategies.⁵ Community members have also voiced concerns that researchers may actually be more vested in personal and professional gain than in benefiting the communities they study or the larger society.^{6,7}

Research studies currently apply a broad range of approaches to community engagement.⁸ However, there is lack of consensus as to the appropriate method of involving communities for different types of research. This is particularly the case in large epidemiologic and observational studies that do not include an intervention component. This article uses the National Children's Study as a model to examine the role of community engagement in epidemiological research; focusing on the critical nature of engaging communities at the national and local levels even before local research sites are defined.

The National Children's Study is an observational longitudinal study of 100,000 children and their families from over 100 locations throughout the United States. Study participants will be recruited before conception or during early pregnancy and their children will be followed until at least 21 years of age. The study will examine the separate and combined effects of environmental exposures (chemical, biological, physical, psychosocial) as well as gene-environment interactions on pregnancy outcomes, child health and development, and precursors of adult disease.⁹ The study will recruit participants based on a probability sample representative of births in the United States. The sample for the study is determined by a three-stage sampling design implemented by statisticians from the National Center for Health Statistics of the CDC that provides a known probability for sampling units and individuals for inclusion in the study. The goal of this approach was to choose approximately 100 sites from across the country. Study locations, or sites, primary sampling units (PSUs), were chosen to achieve representation of all children born in the United States. The probability of selection of a specific location was based on the average number of births per year as well as racial, ethnic, and geographic characteristics in that PSU. This sampling strategy was determined after thoughtful evaluation of alternatives and broad consultation from experts in the field. In general, PSUs, or locations, correspond to a single county; however, for counties with small numbers of annual births, a location may consist of several adjacent counties. The second stage of the sampling design consists of delineation and selection of area segments within each PSU

comprised of communities, school districts, census tracts or other functionally defined neighborhoods. Finally, within each segment individual households containing eligible women will be identified and invited to participate. A consortium of federal agency partners leads the National Children's Study: the U.S. Department of Health and Human Services (including the National Institute of Child Health and Human Development [NICHD] and the National Institute of Environmental Health Sciences [NIEHS] of the National Institutes of Health [NIH], and the Centers for Disease Control and Prevention [CDC]) and the U.S. Environmental Protection Agency [EPA].^{10,11}

National Children's Study and Community Engagement

The National Children's Study is committed to working with communities in an effort to improve the health of America's children. Although observational in nature, the study recognizes the need to involve both the national and local communities in planning and implementation. A strict community-based participatory research approach is not possible for the National Children's Study because the US Congress determined the overall goals of the study in the Children's Health Act of 2000, and much of the planning for the study was completed prior to selecting individual communities.¹²

The national community has played an integral role in support of this large multi-site study prior to site selection. The local communities became visible only after the sites were selected. Since each site for the study represents a county or a group of counties, each site includes several communities. Community engagement can be quite complex, even within a single site due to the difficulty researchers have in defining communities. The term *community* generally refers to populations comprising persons who have, or are perceived to have, commonalities such as culture and history, legitimate political authority, geographical localization, economy and resources, or self-identification as a group. Because the word *community* is used in a variety of contexts and with different meanings, researchers seeking to engage a community need to define it carefully. Some groups are cohesive in the sense that they self-identify as a community. Some may be defined by geographical boundaries, while others may be physically dispersed. Other groups may be characterized by a common culture or ethnicity, while some groups may be culturally or ethnically diverse. Still others may be defined by a particular physical or health condition. A challenge is finding key community leaders that will best represent this multitude of community views and perspectives.¹³

The study envisions engaging communities by varying methods in each of its phases: Phase I-planning, Phase II-establishing pilot centers (pre- recruitment), Phase III-recruitment, retention, and data acquisition, and Phase IV-analysis and revealing information to communities. This manuscript will focus primarily on engaging the national community prior to the selection of local sites and the initial efforts to assure community involvement at the local level.

Phase I-Planning (October 2000-October 2005)

At the beginning of the planning phase, an extensive literature review enabled the study to draw upon the lessons learned from past longitudinal epidemiological studies and the current literature on community-based participatory research.^{11,14,15,16,17,18,19,20,21,22,23} In order to obtain community perspective, 41 focus groups of healthcare providers, community organization representatives, as well as potential NCS participants (expectant mothers, teenage mothers, couples trying to conceive) were convened from varying communities across the U.S. Multiple focus groups were conducted in locations representing all 9 of the U.S. regions including: Los Angeles, CA; Bellevue, WA; Sioux Falls, SD; Kansas City, MO; Chicago, IL; Burlington, VT; New York, NY; Philadelphia, PA; Research Triangle Park, NC; Farmer's Branch, TX; Albuquerque, NM. Focus group sites varied by geography and population density,

and participants varied by maternal age, socioeconomic status, and education. Each location had multiple focus groups of differing types, all assembled prior to the identification of study sites.²⁴

Analysis of focus group transcripts revealed many important recommendations concerning informing communities about the NCS, gaining the support of communities, recruitment and retention of participants, and NCS visits and sampling.²⁴ The focus groups recommended varying methods of communication in order to reach a broader audience (radio, TV, ads on buses, newspaper articles, websites, posters at Toys R Us®/Babies R Us®, etc.). Advertisements about the NCS could appear in doctors' offices, local schools, reputable organizations, places of worship, and community centers. Pregnant teens and teen mothers recommended sending NCS representatives to clinics where teens go to get health care, and installing NCS mentors in schools to provide information about the study.²⁴

Some focus group participants recommended coupling NCS visits with regular well-child visits, thereby decreasing the burden on participants and families. Endorsement of the study by a participant's primary care physician was thought to increase acceptability of the study as well. In general, focus group participants felt that consistency of study staff from one visit to the next and clear, concise articulation of what each visit entails will enable study participants to feel more comfortable with involvement in the study. A detailed description of the justification for each biologic and environmental sample as well as an explanation of the rationale for collecting samples will help resolve any ambiguity. Researchers should recognize diverse beliefs, apply study requirements flexibly, and adapt to unique cultural concerns.²⁴

Focus groups further recommended regular updates in the form of a newsletter or email in order to continually engage study participants and help participants realize the value of their contribution. Providing information to participants on health and environmental safety, ways to improve lifestyle and health, and how to deal with potential health risks uncovered by the study (e.g., diet plans for preventing obesity, ways to reduce asthma-causing factors within the home, environmental toxins in the home) will help families become more knowledgeable of environmental exposures and create a valuable resource for families and communities.²⁴

There was a general enthusiasm for the study among the various focus groups. Some groups see participation as an honor to be a part of a process that has the potential of affecting the health of individuals and their community for generations to come; others anticipate a positive impact for their own child and family even though it is understood that this is an observational study. Community members can appreciate the need for epidemiologic work if the issues under investigation are relevant and address important concerns.

Additional preliminary work included instituting a federally chartered Advisory Committee composed of scientists, clinicians, social scientists, community leaders, and ethicists, with a broad array of expertise from across the country. The National Children's Study Federal Advisory Committee (NCSAC) provides advice and recommendations to the study. In addition, a total of 21 Working Groups, including over 2000 representatives of the academic and lay communities from around the country, were created to facilitate the development of a Study Plan. These Working Groups created reports and implemented workshops that were critical in creating hypotheses, defining exposure assessment methods and developing outcome measures. In addition, the Community Outreach and Communications Working Group, Ethics Working Group, and the Health Disparities and Environmental Justice Working Group were invaluable in bringing the community perspective to the creation of the Study Plan.

Each year or two during the five year planning phase, hundreds of study investigators, academic leaders, members of lay organizations, and the public attended a large public assembly to discuss children's environmental health issues and provide feedback to study staff. Over 40

national organizations support the study, including: The American Academy of Pediatrics, March of Dimes, National Medical Association, American Chemistry Council, American Public Health Association, Learning Disabilities Association, and Children's Environmental Health Network. Consultations were sought from the Indian Health Service and the National Indian Health Board.

The NCS has also considered the potential impact of trust on study recruitment and retention, particularly within the African-American community. A literature review performed by academic nurses at the University of Mississippi advised the NCS on recruitment and retention strategies in minority communities.²⁵ The report focuses on issues of racism, discrimination, and a history of mistreatment that are major concerns within minority communities. The report identifies a lack of trust as one of the “most important barriers to participation.” and recommends that the NCS focus on trust-building activities at the local level since positive interactions can make even the most skeptical individuals and communities more receptive to participation. The report suggests that NCS researchers can build trust within the communities by collaboratively developing language in consent materials, allowing for some flexibility in the protocol, providing appropriate incentives for study participation, and giving timely feedback to participants regarding research results and findings. The report concludes that there is no one experience that dictates the African-American community's willingness to participate in research, but increasingly data support that among minority groups there is a strong desire to contribute to the greater good of society.²⁶ Trust can be enhanced if investigators and the research institutions can demonstrate a commitment to creating positive change in the interests of the population studied.²⁷

After the 105 sites for the study were identified, community profiles were created to obtain a better understanding of community dynamics and infrastructure. These profiles include basic information on community statistics, political leadership, health departments, socioeconomic, gender, race, and ethnic composition, housing, religion, geography, academic institutions, health systems, environmental health issues, and major media outlets. The community profiles have enabled the National Children's Study to pinpoint resources and collaborate with community leaders while being sensitive to unique cultural and regional issues.

Phase II- Establishing Pilot Centers (pre-recruitment) (September 2005-Present)

The strategy for implementation of the study included solicitation in November 2004 for the initial “Vanguard” or pilot Centers in eight locations throughout the country.²⁸ The Vanguard Centers were selected from a pool of applicants through a competitive process. These Centers successfully demonstrated advanced clinical and epidemiologic research and data collection capabilities, and a commitment to the protection and privacy of data. Entities submitting proposals were asked to describe past engagement with local communities, identify community networks, propose methods for community needs assessments, and consider community concerns and specific issues local communities might wish to be included in the study design. Each applicant was additionally asked to develop a plan for community engagement to support the recruitment and retention of participants. Seven Vanguard Centers were awarded contracts in September, 2005 and began immediately to create and implement strategic plans for community needs assessment and engagement in the study. Since the study sampling strategy involved the selection of representative segments within counties that were yet to be defined, the pilot centers were faced with the problem of not knowing exactly which communities would be chosen or even from which geographic areas participants would be recruited. Therefore, some Vanguard Centers chose to develop general approaches to community engagement while others awaited the delineation of actual segments to initiate the creation of community advisory structures. The Steering Committee was created shortly thereafter comprising principal investigators from each of the Centers, program office and interagency coordinating committee

staff. Steering Committee meetings offer a venue for communication, protocol finalization, and study policy development. Community representatives were added to this important leadership group shortly after formation.

To maintain momentum and an open flow of communication with the Vanguard communities, a local celebration event was held in each Vanguard location within a few weeks of the award of the Vanguard Center contracts. This allowed an opportunity for communities to celebrate their special role in the study and for the centers to make clear that community engagement is a top priority in launching the study locally. Each event was tailored to the circumstances of the respective community. One event was held at a local children's science museum, another at a large community hospital, and another at a local restaurant and meeting hall. Community representatives were part of the formal program of remarks; local clinicians, elected officials, faith leaders, tribal representatives, parents, children, and educators were represented at many events. In addition, local media were in attendance at most of the events to provide information to the broader community.

Study planners have developed a framework to assist centers in developing community engagement strategies.²⁹ This framework describes the multiple levels and strategies involved in recruitment and retention, and community engagement. The document focuses on engaging communities and developing partnerships at the national, state, regional, and local levels. It is anticipated that there will be some level of variation across sites in order to address local community needs and concerns. By involving communities in the design or conduct of research, researchers can resolve questions about who represents communities and their subgroups, how conflicting viewpoints in the community are voiced, and whether the process for selecting community partners is appropriate. The potential partners and key representatives from the community will vary from one community to the next. Influential individuals may emerge from but are not limited to community organizations, research institutions, social service agencies, places of worship, volunteer organizations, and/or local and state governments. A briefing session can inform interested community members about the study and be a valuable venue to exchange information. The study planners will aim to capture the concerns of the community at these briefings either through a discussion session or a brief survey.^{30,31,32} In preparation for recruitment, which is planned to begin at the end of 2007, the Vanguard Centers are encouraged to propose adjunct studies that will complement the core study to respond to concerns voiced by local communities.²⁸ The Vanguard Centers have developed a range of plans for the involvement of community members at the local level. It is anticipated that local residents will be hired as research team members and play important roles in outreach and recruitment.³³ Community Advisory Boards, community forums, focus groups, and discussions at churches and community organizations will assist each center to obtain consultation about a host of issues related to participation in this longitudinal study, including recruitment strategies, subject burden, unique cultural needs, and reporting research findings to communities. In addition, providing venues for community input will increase community awareness about the study and elicit community feedback and concerns.^{34,35,36,37}

Phase III- Recruitment, Retention, and Data Acquisition (Scheduled to commence early 2008)

An important factor to enhance the success of the study will be the one-on-one interactions and ongoing relationships between participants and study staff. Local study centers will build personal relationships between staff and participants, helping participants realize they are an essential part of the study and critically important to its success. Staff members will be trained to be respectful and offer truthful and candid information about what is involved in participating in the study, what is expected of participants, as well as accurate information about what the

study can and cannot offer participants, so that potential participants can make informed choices about participation. This approach will also hopefully improve retention rates.

Since many of the study visits will occur in the home, the NCS will be extremely flexible when arranging appointments to be convenient for the study participant and family. The NCS plans to be particularly aware of the complex ethical issues that may arise while conducting research within the home. The NCSAC has developed recommendations for the study based on the report of the National Research Council and Institute of Medicine entitled "Ethical Considerations for Research on Housing-related Health Hazards Involving Children."¹³ Since research conducted in the home may reveal very personal information, the study will assure that all research staff respect the privacy of participants and families while conducting research in the home. On the other hand, researchers may observe behaviors, physical conditions, or interactions between family members that are not relevant to the study yet are problematic to an individual's health and well being. If these observations suggest that a person is in imminent danger or serious harm, researchers may have legal and ethical obligations to intervene through appropriate authorities to protect that person from harm.¹³

Phase IV-Analysis and Informing Communities (Expected time frame: 2008-2029)

Participants and communities will be interested in learning about study findings. Aggregate findings will be shared with individual participants and communities through newsletters, publications, etc. Participants will be informed about individual findings when scientifically valid and medically important. In addition, participants will be educated on the meaning of the information transmitted. Personal physicians will be involved, with the permission of participants. Findings of uncertain relevance will not be shared with individual participants or communities since such information may be unduly alarming and counterproductive to improving the overall health of a community. A challenge for the study will be developing strategies that communicate important aggregate findings to communities, while respecting individual participants. Sharing information of clinical utility may be an important concept to consider; that is, the aggregate data should be used for a specific purpose such as improving health outcomes in individuals and communities. In addition, the study has an obligation to develop methods that help participants understand and interpret the meaning of this information.³⁸

Various communities will play a critical role in the data dissemination process. The community perspective can inform NCS researchers on ways to be sensitive to unique cultural and political issues and concerns within each community. Only by consulting communities will NCS planners become cognizant of the wide array of community views. The study Data and Safety Monitoring Board will review findings and determine the scientific validity and importance of data in order to assure that only valid and relevant information is revealed to participants and their communities. The Ethics Subcommittee of the Federal Advisory Committee will give advice about what should be told to individuals and communities. Community leaders may wish to know what aggregate data will be shared prior to dissemination. Although the local center will address the concerns of community leaders prior to dissemination, the study is committed to revealing valid and important findings to its communities.

Conclusions

The National Children's Study is a large longitudinal study that will interact with multiple communities across the United States. Community engagement is a critical aspect of the study and likely integral to its long-term success. Preparatory work, prior to defining the communities, has included thoughtful involvement of individuals representing diverse communities from throughout the U.S. Familiarity with the community of interest, building relationships with appropriate community representatives, clear communication, and

developing trust through a co-learning process are all prerequisites for attaining a successful collaborative research endeavor. As the seven Vanguard Centers engage in start-up activities across the country at their sites, subsequent implementation of the study will focus on developing and sustaining community partnerships at each of the more than 100 study locations from the best practices of the Vanguard Centers. Although observational in nature, the study is committed to building trust with participants, their families, and their communities by engaging the communities as active participants in planning, informing participants and families of relevant findings from the research, and helping communities to address the issues that are important to them based on the evidence amassed in the study.^{15-22, 33}

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