

**The Crucial Role of Community Engagement in Public Health
Epidemiological Surveillance at the Community Level.**

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Abstract:

In the orchestration of health research endeavours, fostering connections within communities has evolved into a pivotal component. The precise role that community engagement should undertake in the realm of epidemiological and observational research remains elusive, given that a significant portion of this scientific exploration doesn't directly stem from community concerns and lacks an interventional essence. A beacon in this ambiguity is the National, An expansive longitudinal examination involving 50,000 people and their familial units. This study stands as an exemplar, offering a blueprint to inform the evolution of strategies for community engagement within the domain of epidemiologic research.

Keywords: Community, public health, blueprint, community-level, Evaluation.

Introduction:

The involvement of community members and organizations in the formulation and execution of research has assumed a pivotal role in biomedical, public health, and intervention research. Acknowledging and respecting the interests and values of community members, collaboration unfolds as a conduit for distinctive viewpoints and a wealth of information, seamlessly woven into the fabric of study design and implementation. This collaborative approach not only enriches the recruitment and retention of participants but also contributes to the production of results that are not only valid but imbued with profound meaning.¹

The evolution of incorporating communities into research practices is a response to perceived mistrust between communities and researchers. This paradigm shift aims to elevate the quality, relevance, and impact of research within the community.² This mistrust stems from genuine

concerns within communities, suspecting that researchers, albeit well-intentioned, might have treated them as mere laboratories. This suspicion arises from a historical lack of engagement in defining priorities, planning studies, or developing implementation strategies. There's a palpable concern among community members that researchers may prioritize personal and professional gains over the welfare of the communities under study or the broader society.

Current research studies adopt diverse approaches to community engagement. However, consensus on the most suitable method for involving communities in different types of research remains elusive. This uncertainty is particularly pronounced in large epidemiologic and observational studies devoid of an intervention component. Drawing insights from the National people study, this article scrutinizes the role of community engagement in epidemiological research, underscoring the vital necessity of involving communities at both national and local levels, even preceding the definition of local research sites.³

The National people's Study, a longitudinal observational inquiry encompassing 50000 individuals and their families across 50 diverse locations in India, exemplifies this approach. Participants will be recruited either before conception or during early childhood, with the study spanning until the individual reach at least 25 years of age.⁴ The study ambitiously explores the isolated and combined impacts of environmental exposures (chemical, biological, physical, psychosocial) and gene-environment interactions on pregnancy outcomes, child health and development, and precursors of adult diseases.⁵ The selection of study participants employs a probability sample representative of births in India, determined through a meticulous three-stage sampling design. This design, led by statisticians from the National Center for Health Statistics of the CDC, aims to ensure a representative and diverse cohort across the nation. The sampling strategy considers factors such as the average number of births, racial and ethnic demographics, and geographic characteristics in each primary sampling unit (PSU). Locations, corresponding to a single county or multiple adjacent counties in cases of low annual births, are chosen to capture the full spectrum of the India population. The second stage involves the delineation and selection of area segments within each PSU, including communities, school districts, census tracts, or other functionally defined neighborhoods. Finally, within each segment, households containing eligible women are identified and invited to participate. The National Children's Study is steered by a consortium of federal agency partners. the National Institute of Child Health and Human Development (NICHD), the National Institute of

Environmental Health Sciences (NIEHS) of the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC).⁶

The national community has played an indispensable role in endorsing this extensive multi-site study even before the meticulous process of site selection. The spotlight, however, shifted to local communities only post-site selection. Considering that each study site corresponds to a county or a cluster of counties, encompassing diverse communities within, the intricacies of community engagement manifest as a multifaceted challenge. Researchers grapple with the intricate task of precisely delineating communities within a single site.⁷

The term "community" carries inherent complexity, primarily stemming from the diversity and dynamic nature of human associations. Generally denoting populations sharing commonalities, such as culture, history, political authority, geographical localization, economic resources, or self-identification as a collective entity, the term necessitates careful definition in research contexts. Some groups exhibit cohesion, self-identifying as a distinct community, while others align along geographical boundaries or remain dispersed. Cultural or ethnic homogeneity characterizes certain groups, while others boast cultural or ethnic diversity. Alternatively, some groups coalesce around a specific physical or health condition. A persistent challenge lies in identifying pivotal community leaders capable of effectively representing the myriad views and perspectives inherent in this diverse landscape.⁸

Methodology: It is divided into four phases

Phase-I (Planning July 2008- July 2013)

Embarking on the planning phase, an exhaustive review of the literature laid the foundation for this expansive multi-faceted study. Drawing insights from past longitudinal epidemiological studies and contemporary literature on community-based participatory research, the study gleaned invaluable lessons. To encapsulate community perspectives, 33 focus groups convened, comprising healthcare providers, representatives from community organizations, and potential participants in the National Children's Study (NCS) – expectant mothers, teenage mothers, and couples attempting to conceive. These groups spanned diverse locales across India, including Mumbai, Pune, Nagpur, Thane, Nashik, Akola. Varying in geography, population density, and participant demographics (maternal age, socioeconomic status, and education), these focus groups materialized even before the identification of study sites.⁹

Examination of focus group transcripts unearthed pivotal recommendations related to community outreach, garnering community support, participant recruitment and retention, and the logistics of NCS visits and sampling. Strategies encompassed diverse communication channels, including radio, TV, bus ads, newspaper articles, websites. Recommendations extended to advertisements in healthcare facilities, schools, religious institutions, and community centres. Special emphasis was placed on engaging pregnant teens and teen mothers by reaching out to clinics and installing NCS mentors in schools. Some participants suggested aligning NCS visits with regular well-child visits to alleviate participant burden. Endorsement by primary care physicians was considered instrumental in enhancing study acceptability. Focus group participants emphasized the importance of consistent study staff, clear articulation of each visit's purpose, and flexibility in accommodating diverse beliefs and cultural concerns.

Continuous engagement was underscored through regular updates via newsletters or emails, fostering a sense of value in participants' contributions. Beyond study-related information, participants advocated for disseminating knowledge on health and environmental safety, lifestyle improvement, and addressing potential health risks unveiled by the study. The overarching goal was to empower families with knowledge of environmental exposures, creating a valuable resource for both families and communities.¹⁰

Enthusiasm for the study resonated across diverse focus groups. Some perceived participation as an honour, contributing to a process with the potential to impact individual and community health for generations. Others anticipated positive impacts on their own families, despite understanding the observational nature of the study. The resonance of epidemiologic work was acknowledged, provided it addressed relevant and significant concerns.

Preliminary steps included establishing the National Children's Study and 25 Working Groups, comprising experts from varied disciplines and lay communities. These entities, along with public assemblies, contributed to the development of a comprehensive Study Plan. Collaboration with over 35 national organizations. The study sought guidance from the Indian Health Service and the National Indian Health Board, showcasing a commitment to diverse perspectives.

Addressing potential trust barriers, the study heeded advice from academic nurses at the Various Indian Universities. The focus was on implementing trust-building activities at the local level, with an acknowledgment of historical issues of racism and discrimination.

Collaborative language development, protocol flexibility, appropriate incentives, and timely feedback were recommended as means to enhance trust within communities.

Post-identification of the 101 study sites, community profiles were meticulously crafted. These profiles offered a nuanced understanding of community dynamics, including statistics, political leadership, health departments, socioeconomics, demographics, housing, religion, geography, academic institutions, health systems, environmental health issues, and major media outlets. Armed with this insight, the National Children's Study engaged with communities, respecting unique cultural and regional nuances.¹¹

Phase II - Establishing Pilot Centers (pre-recruitment) (July 2008-Present)

The implementation strategy for this study commenced with the solicitation of "Vanguard" or pilot Centers in September 2008 across eight locations nationwide. The selection of Vanguard Centers followed a competitive process, assessing advanced clinical and epidemiologic research capabilities, adept data collection, and an unwavering commitment to data protection and privacy. The applicants were evaluated based on their history of engagement with local communities, identification of community networks, proposals for community needs assessments, and consideration of specific concerns expressed by local communities for inclusion in the study design. Each applicant was also tasked with formulating a plan for community engagement to bolster participant recruitment and retention. Contracts were awarded to seven Vanguard Centres in July 2011, initiating the development and execution of strategic plans for community needs assessment and engagement.¹²

Given the study's sampling strategy, which involved selecting representative segments within yet-to-be-defined counties, the Vanguard Centers grappled with the challenge of uncertainty regarding the precise communities to be chosen or the geographic areas from which participants would be recruited. Consequently, some centers developed general approaches to community engagement, while others awaited the delineation of actual segments to initiate the creation of community advisory structures. A Steering Committee, comprising principal investigators from each center, program office members, and interagency coordinating committee staff, was established shortly thereafter. Community representatives were later incorporated into this vital leadership group.

To sustain momentum and foster open communication with Vanguard communities, local celebration events were organized in each Vanguard location shortly after the award of contracts. These events, tailored to the unique circumstances of each community, provided an

opportunity for both celebration and the assertion that community engagement stands as a top priority in launching the study locally. Community representatives, local clinicians, elected officials, faith leaders, tribal representatives, parents, children, and educators were part of these events, with local media in attendance to disseminate information to the broader community.

Study planners developed a comprehensive framework to guide centers in formulating community engagement strategies. This framework delineates the various levels and strategies involved in recruitment, retention, and community engagement, emphasizing the importance of partnerships at the national, state, regional, and local levels. Recognizing the need for flexibility to address local community needs and concerns, the framework anticipates variation across sites. Involving communities in the design and execution of research is pivotal in addressing questions about community representation, voicing conflicting viewpoints, and selecting appropriate community partners. Influential individuals may emerge from community organizations, research institutions, social service agencies, places of worship, volunteer organizations, and/or local and state governments. Briefing sessions will serve as informative venues, capturing community concerns through discussions or brief surveys.¹³

In preparation for recruitment, slated to commence at the end of 2012, Vanguard Centres are encouraged to propose adjunct studies that complement the core study and address concerns voiced by local communities. The involvement of residents as research team members is anticipated, with roles encompassing outreach, recruitment, and integral participation. Community Advisory Boards, forums, focus groups, and discussions within Temple, churches, NGO, and community organizations will serve as avenues for consultation on various issues, including recruitment strategies, subject burden, unique cultural needs, and reporting research findings to communities. Facilitating community input aims to enhance awareness about the study and solicit valuable community feedback and concerns.

Phase III - Recruitment, Retention, and Data Acquisition (Scheduled to commence early 2013)

A pivotal determinant for the success of the study hinges on fostering one-on-one interactions and sustained relationships between participants and study staff. Local study centers are tasked with cultivating personal connections, emphasizing the participants' integral role and critical importance to the study's success. Staff members undergo training to embody respectfulness and provide transparent information about the study's expectations, ensuring potential

participants can make informed choices. This approach is envisaged not only to facilitate recruitment but also to enhance retention rates.

Given that numerous study visits will take place in participants' homes, the National Children's Study (NCS) aims for unparalleled flexibility in scheduling appointments, prioritizing the convenience of study participants and their families. The study is attuned to the intricate ethical considerations associated with conducting research within the home. Recommendations from the National Children's Study Federal Advisory Committee (NCSAC) draw from the insights of the National Research Council and Institute of Medicine, specifically the report titled "Ethical Considerations for Research on Housing-related Health Hazards Involving Children."

Recognizing that research in the home may unearth highly personal information, the study places a premium on safeguarding the privacy of participants and their families during home-based research. Simultaneously, researchers remain vigilant for any observations of behaviors, physical conditions, or family interactions that, while not pertinent to the study, may pose challenges to an individual's health and well-being. In instances where such observations indicate imminent danger or serious harm, researchers may bear legal and ethical obligations to intervene through appropriate authorities, ensuring the protection of the individual from harm.¹⁴

Phase IV - Analysis and Informing Communities (Expected time frame: 2011-2031) ¹⁵.

As the study progresses into Phase IV, spanning from 2011 to 2031, the anticipation is high among participants and communities to glean insights from the accumulated findings. The dissemination of aggregate findings will be a key facet, with information shared through newsletters, publications, and other channels to keep individual participants and communities abreast of the study's overarching outcomes. When scientifically valid and medically significant, participants will also be apprised of individual findings, accompanied by an educational component elucidating the meaning of the conveyed information. This process will involve the participation of personal physicians, contingent upon participants' consent.

However, findings of uncertain relevance, with the potential to cause undue alarm and be counterproductive to community health improvement, will not be shared with individual participants or communities. Striking a delicate balance, the study faces the challenge of developing communication strategies that effectively convey important aggregate findings to

communities while respecting the individual perspectives of participants. An essential consideration is the concept of sharing clinically useful information—utilizing aggregate data for specific purposes, such as enhancing health outcomes in both individuals and communities.

Moreover, the study bears the responsibility of devising methods that facilitate participants' comprehension and interpretation of the information shared. This underscores the commitment to ensuring that participants not only receive data but also grasp its significance, fostering an informed and engaged community throughout the course of the study.

Conclusions

The National Children's Study stands as a substantial longitudinal investigation poised to engage with diverse communities throughout India. The pivotal role of community engagement emerges as a cornerstone, integral to the study's enduring success. Prior to delineating specific communities, meticulous groundwork has involved the thoughtful inclusion of representatives from varied communities across the nation. Establishing familiarity with the community of interest, forging relationships with pertinent community figures, fostering transparent communication, and cultivating trust through a collaborative learning process are all foundational elements crucial for the triumph of this collaborative research endeavor.

As the seven Vanguard Centers initiate start-up activities at their respective sites nationwide, the subsequent phases of the study will be dedicated to the establishment and maintenance of community partnerships across the more than 101 study locations, drawing insights from the best practices gleaned from the Vanguard Centers. Despite the observational nature of the study, a steadfast commitment resonates in the endeavor to build trust with participants, their families, and their communities. This commitment manifests through active community participation in planning, the transparent communication of pertinent research findings to participants and families, and collaborative efforts to address issues of significance to communities based on the evidence amassed in the study.

In summary, the National Children's Study embarks on a journey marked by collaboration, community involvement, and the ethical dissemination of knowledge, reaffirming its dedication to fostering trust, understanding, and positive impact within the diverse fabric of communities across India.

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