Community Engagement and Methods for Conducting Longitudinal Birth Cohort Studies: Lessons Learned from the NIEHS/EPA Children's Centers

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Introduction

Many complex issues impact children's health, including the communities in which they live. Significant community involvement in research has been shown to be highly important, especially for working with marginalized communities that typically have not been included in making decisions about research and interventions in their own communities.

A variety of methods and logistical complications are anticipated for carrying out a study with the scope and complexity of the National Children's Study. In addition to community outreach and engagement, other important issues include ethics, outcome and exposure assessments, data and specimen management systems, and communication of results.

Two papers commissioned by the National Children's Study focus on some of these issues – one on community-based participatory research (CBPR): (*Israel et al., 2005*), and another on methodologic and logistic issues in conducting longitudinal birth cohort studies (*Eskenazi et al., 2005*). They were published as part of a mini-monograph, "Lessons Learned from the NIEHS/EPA Centers for Children's Environmental Health and Disease Prevention Research," in the October 2005 issue of *Environmental Health Perspectives*. Highlights of these papers are presented in this poster.

References:

Eskenazi B, et al., 2005. **Methodologic and Logistic Issues in Conducting Longitudinal Birth Cohort Studies: Lessons Learned from the NIEHS/EPA Centers for Children's Environmental Health and Disease Prevention Research.** *Environmental Health Perspectives*, 113:1419–1429. doi:10.1289/ehp.7670. [Online 24 June 2005]

Israel BA, et al., 2005. **Community-Based Participatory Research: Lessons Learned from the NIEHS/EPA Centers for Children's Environmental Health and Disease Prevention Research.** *Environmental Health Perspectives* 113:1463–1471. doi:10.1289/ehp.7675. [Online 24 June 2005]

Community Outreach and Engagement

CBPR is a partnership approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process. The National Children's Study cannot follow a strict CBPR model because the Study will collect data to answer specific questions from multiple sites chosen to be representative of the US population. However, when feasible and appropriate, CBPR principles will be followed.

These principles include:

- Recognizing community as a unit of identify and building on strengths and resources within the community
- Facilitating a collaborative, equitable, empowering and power-sharing process that attends to social inequalities
- Fostering co-learning and capacity building among all partners
- Focusing on the local relevance of public health problems
- Disseminating results to all partners and involving them in the dissemination process
- Committing to involvement in a long-term process and sustainability

Methods

Recruitment

- Active recruitment, such as mailing study information directly to potential participants with follow-up by telephone and other means, is more successful than passive recruitment.
- Dedicated study staff is required – experience shows that health care personnel in clinical settings are often too busy to recruit participants into the studies or to collect outcome data.

Retention

- Maintaining frequent contacts with participants (every 1–2 months) and using a variety of means to contact them when they move is essential.
- Providing incentives or small gifts to encourage continuing participation may be necessary and appropriate. Cash is an appropriate but not the only incentive; continuing contact and educational information about participants' child or health care may also serve as an incentive for families with few resources.

Specimen Management

- Biological and environmental specimens should be carefully collected, processed, and banked in multiple aliquots. Specimen collection may need to vary from site to site to accommodate cultural concerns and logistical differences.

Ethical Issues

- Soliciting and answering questions is important to the informed consent process. Obtaining informed consent for low-literacy and immigrant populations may require additional steps; thus allowing adequate time for informed consent is necessary.
- Child assent is required by a certain age (generally 5–9 years) by IRBs, posing an additional set of challenges.
- Participants must be informed about and consent to future uses of banked biological samples. IRB reapproval for each new analysis has sometimes been required.

Communication

Reporting Results: Building Trust

Many of the NIEHS/EPA Children's Centers have made it a priority to share findings with participants and/or community advisory boards and steering committees before their publication in journals or in the media. This feedback has been an important step in building trust between researchers, participants, and communities.

Lessons Learned and Recommendations

Following is a summary of lessons learned from the CBPR and Methods papers:

1. Sufficient time, resources, and benefits are needed for all partners to ensure active and meaningful participation.
2. Considerable commitment and time are needed to establish and maintain trust.
3. Acknowledging and addressing power and equity issues is critical.
4. Commitment to translating research findings into interventions and policies is of utmost importance, and results need to be shared with the community in ways that are understandable and useful.
5. Hiring and training staff from the local community is essential.
6. Recognizing, respecting, and embracing different cultures of the partners and partner organizations is imperative for successful research efforts.
7. Building community infrastructure and trust is essential, especially in populations that are difficult to reach.
8. Research should be self-sufficient and rely minimally on clinical staff. Medical care facilities, particularly those treating low-income populations, are already overburdened.
9. Long-term, continuous employment of high-quality and flexible research staff is imperative for the success of the Study.
10. Study results must be communicated to participants and lay and scientific communities in a timely and sensitive manner. A communication plan needs to be developed with community partners.

Implications for the National Children's Study

The success of the NIEHS/EPA Children's Centers is clearly related to their emphasis on community-academic partnerships, and this has encouraged researchers to develop such partnerships and to expand their research in new ways. In addition, the multi-dimensional aspects of conducting longitudinal birth cohorts, as well as the challenges and opportunities experienced by the NIEHS/EPA Children's Centers discussed in these papers provide valuable information on what works well and what does not work. Drawing on this experience will be of vital importance for the National Children's Study as it moves forward.

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