

Title: Recruiting and Retaining African-American Children and Families in Clinical Research Studies

Authors: Monica J. Mitchell, Ph.D.,

Lori E. Crosby, Psy.D.,

Janelle Hines, B.A.

Julia H. Bloom, B.A.

I. Introduction:

Although African-Americans are disproportionately affected by a number of physical and mental health conditions, including diabetes, hypertension, stroke, sickle cell disease, and depression, they are under-represented in assessment and intervention research studies aimed at better understanding and treating these conditions (Warren-Findlow, 2003). Moreover, reducing and eliminating health disparities is contingent upon the successful recruitment and retention of African-Americans and other ethnically diverse participants into research studies and clinical trials (Wisdom, 2002). While there have been published commentaries on oversights and “lessons learned” with respect to recruiting African-American adult samples (Gorelick et al, 1998), the literature offers few replicable culturally-based strategies for recruiting representative samples of children, adolescents, and their families, as mandated by the National Institutes of Health, the Centers for Disease Control and other federal funding agencies.

II. Methods:

The goals of this presentation are: (1) to discuss the importance and implications of ensuring ethnic representation in recruitment and research efforts; (2) to review the historical, social, and cultural barriers to African-American participation in clinical research; and (3) to present strategies for overcoming recruitment and retention barriers, even in “hard to recruit” and “high-risk for dropout” samples. The presentation will also cover how to target recruitment strategies without stereotyping, how to obtain informed consent while building trust, and how to encourage participation without coercing.

This presentation will summarize strategies that have been successful in recruiting representative samples in three types of studies: phone survey, focus group, and clinical assessment studies. Critical aspects of planning and marketing the study, and recruiting and retaining subjects are summarized:

A. Phone Survey: Phone Survey to Assess and Improve African-American Adolescents’ Satisfaction with Clinic Services

Planning: Prior to implementing the study, a survey was conducted to determine where teens would most want to spend a \$20 gift certificate. The top three choices of (1) Movies, (2) Mall, and (3) Target served as the incentives in Flyers and Letters marketing the study. The plan also included developing a timeline that would facilitate obtaining consent from parents and adolescents, completing the phone survey, and mailing the gift certificate within a 48-hour window.

Marketing: The marketing plan having a “friendly face” in clinic to introduce the study and provide detailed informed consent information, the mailing of a teen-friendly and culturally-inclusive letter to potential participants, creating “word of mouth” about the study, and sending out fun reminder notes and personal thank you cards.

Recruitment: Recruitment strategies included getting primary and alternate phone numbers and addresses at the first point of contact, creating parent enthusiasm, make the survey fast and developmentally-sensitive, and noting that gift certificates would be mailed on the day of completion.

Retention: Completing the study within a tight time frame and finishing “incomplete” calls within 24 hours. All aspects of the recruitment and retention plan were IRB-approved.

B. Focus Group Study: Multi-Site Focus Group Study to Assess Treatment Issues Related to Sickle Cell Disease

Planning: Planning included taking a survey of good dates and times for the event, developing a 21-day timeline from “start to finish,” addressing barriers such as transportation and child care, and obtaining broad endorsement for the study from trusted medical care staff.

Marketing: Face-to-face, phone, and written communication was used to introduce the study.

Correspondence and other details of the study were written in a “we need you” manner that was respectful of participants’ backgrounds. The event also advertised a full lunch/dinner for participants and other family members and ensured that there was “something for everybody” to do.

Recruiting: The initial letter was sent out explaining all aspects of their participation, followed by a personal phone call, a confirmation card and directions, a reminder card, and a reminder phone call. The “red carpet” was rolled out at every opportunity, even before the actual event. Transportation vouchers were provided to

al parents and professional childcare was provided to children. Informed consent was obtained such that there were no “surprises” and a final “thank you” was mailed.

All aspects of the recruitment and retention plan were IRB-approved.

C. Assessment Study: Three-Phase Study on Growth and Nutrition

Planning: Planning included developing a timeline for getting participants through the three phases of the study within 45 days. The plan stressed convenience for families and coordination and communication among research staff. The first phase of the study involved a semi-structured family interview, which provided a basis for retention in the 2nd and 3rd phase.

Marketing: An acronym was used to promote the study (S.T.R.O.N.G. Program). Flyers were culturally sensitive and provided critical details of the study and its importance. Convenience was stressed as home visitation was used in Phase 1 and 2 of the study. Word of mouth and “refer a friend” was encouraged.

Recruitment: Subjects were recruited via face to face contact or physician/ participant referrals. Details of the study were provided in full-length letter and cookbook (1st, 2nd, 3rd, etc.) formats. Refer a family cards were provided to participants upon completion. Birthday and holiday cards were used to maintain rapport and to track moves.

Retention: All study materials were labeled with “who,” “what,” and “why” information, as well as a contact person and number for questions. Business cards and refrigerator magnets were also given to participants. Phone follow-up was provided at critical points of the study. Certificates of completion were promised and delivered upon completion of the study. Families were also invited to do an optional Phase IV upon completion of the first three phases.

All aspects of the recruitment and retention plan were IRB-approved.

This presentation will also include tips for successful culturally-based strategies mentioned in other published studies (Gilliss, C. et al., 2001; Ashing-Giwa, K. & Ganz, PA, 2000) as well as specific examples of “culturally-sensitive” and “developmentally sensitive” recruitment materials.

III. Results and/or Discussion:

The three studies that were discussed yielded recruitment and retention rates of 80 – 95% of eligible subjects, including high rates in “hard to reach” and “high-risk for dropout” populations. The presentation

provides “how to” strategies for recruitment planning, implementation, for ensuring effective marketing, and most importantly for ensuring that written and verbal communication is culturally-sensitive and culturally-targeted.

Important questions to consider in successful recruitment and retention include: (1) Why would participants say “yes” and why would they say “no?”; (2) How can knowing these facilitators and barriers to participation be used to refine planning and marketing strategies?; (3) Why would a participant continue in the study and why might they drop out? (4) How much follow-up is enough to engage participants and how much is too much?; (5) What factor should be considered in hiring and training a recruiter?; and (6) What are the pros and cons of working with a “third party” in recruiting subjects?

This presentation will provide answers to each of these questions and will encourage investigators and project managers to pose questions relevant to their own research topics and recruitment challenges.

Reference List

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Contact Information and Affiliations:

Monica J. Mitchell, Ph.D.

**Assistant Professor of Pediatrics
Cincinnati Children's Hospital Medical Center
3333 Burnet Ave. – MLC #3015
Phone: (513) 636-3375
Fax: (513) 636-7756**

Lori E. Crosby, Psy.D.

**Assistant Professor of Pediatrics
Cincinnati Children's Hospital Medical Center
3333 Burnet Ave. – MLC #3015
Phone: (513) 636-5380
Fax: (513) 636-7756**

Janelle Hines, B.A.

**Research Assistant
Cincinnati Children's Hospital Medical Center
3333 Burnet Ave. – MLC #3015
Phone: (513) 636-7817
Fax: (513) 636-7756**

Julia H. Bloom, B.A.

**Research Assistant
Assistant Professor of Pediatrics
Cincinnati Children's Hospital Medical Center
3333 Burnet Ave. – MLC #3015
Phone: (513) 636-3739
Fax: (513) 636-7756**