

Paper Session B2: Reaching the Public: The Impact of Communication Methods on Pediatric Health Screening and Intervention

Use of Informatics and Social Networking Recruitment Strategies for Research on Children with Klinefelter Syndrome

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Purpose: Children with genetic conditions pose unique challenges in study design, recruitment, and logistics of participation. The purpose of this presentation is to describe traditional and novel strategies that were successful in recruitment of children with Klinefelter Syndrome (KS) for a research study and to share lessons learned.

Theoretical Framework: McGuire's Input-Output Persuasion Model guided this study. This communication model served as the conceptual basis for integrating traditional and novel approaches for maximum capture of attention, interest and motivation to participate in research.

Methods: We conducted a cross-sectional study of 42 KS boys between the ages of 8 and 18 years at an academic medical center in New York City. We began subject recruitment using traditional approaches (direct mail, community-based posters and clinical referrals). Our recruitment strategy expanded with the use of information technologies such as email, patient advocacy organization list serves, a recruitment website, teleconference and computer-based social networking. Enrollment was tracked by recruitment strategy. Descriptive statistics were used to analyze the recruitment response.

Results: Traditional recruitment approaches (direct mail [0%], clinical referral [7%], contacting advocacy groups [12%] and community brochure dissemination [0%] were least effective. The most effective strategies included direct recruitment from researcher interaction with support groups via live-presentation or teleconference (19%) and with web-based recruitment using a professional recruitment website, an individual website and the placement of advertisement on a social networking site. Initially the website response was 2-3 hits per day, but increased to an average of 64 hits per day following placement of the social networking ad. The website received a total of 519 hits with the social networking ad reporting 3,593,0000 exposures on their site. Overall the novel recruitment strategies facilitated recruitment of 81% of study subjects.

Conclusions and Implications: Traditional approaches to recruitment failed to achieve subject recruitment goals. Ascertainment of potential recruits requires innovative recruitment strategies. The integration of traditional and novel recruitment strategies resulted in attaining of the targeted sample size with continued interest in future research participation from new recruits after enrollment closed.