PARTICIPANT EXPERIENCE IN THE U.S. NATIONAL CHILDREN'S STUDY, SALT LAKE COUNTY VANGUARD CENTER

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Background and Aims: Participant retention is important to the success of the population-based U.S. National Children’s Study (NCS). In order to determine motivators and barriers to participation, participants are asked to complete a self-administered questionnaire about experience in the study. We report on responses from English- and Spanish-speaking participants in Salt Lake County Vanguard Center.

Methods: Study data collection visits to participants' homes occurred during the 1st and 3rd trimesters of pregnancy, and included biological and environmental sample collection, anthropometrics and questionnaires. We summarized results of self-administered Participant Evaluation Questionnaires on which women were asked to rate the importance of factors in their decision to take part in the study and to describe their study experience on a scale from mostly negative to mostly positive.

Results: In-home study visits with multiple modes of data collection typically were 2 to 3 hours duration in the Vanguard phase of the NCS. Among early participants who had completed two study visits, factors rated highest as contributors to a decision to take part in the study included “feeling as if I can help children now and in the future,” identified as very important by 62 of 69 (93%), and “helping doctors and researchers learn more about children and their health,” rated as very important by 64 of 69 (96%). 55 of 69 (83%) participants rated their experience with the National Children’s Study as mostly positive. When asked which study activities participants liked the most, 23 participants mentioned an ultrasound.

Conclusions: Despite the significant time commitment, study participants who complete a first study visit are very likely to be retained in the study through the second and subsequent visits. A high proportion of participants reported motivating factors that align well with the goals of the study, i.e. helping children and learning about their health.