

## **What Women Think About Participating in the National Children's Study: The Impact of Giving Samples From Their Children For Future Genetic Studies**

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**Introduction:** The National Children's Study (NCS) is the largest US study of children's health and development and will examine the role of genetics and environment in health outcomes. Women who are or will become pregnant will be recruited and their children followed for 21 years. However, little is known about women's attitudes towards the collection of biospecimens for future genetic testing.

**Objective:** We investigated women's willingness to participate and their attitudes, beliefs, and concerns related to the sections of the consent form that request genetic material. We investigated whether ethnicity and other factors were associated with willingness to participate.

**Design/Methods:** 50 women recruited from clinics at UNM participated in four focus groups. Women were asked to read the NCS consent form and then asked about their willingness to participate. They then participated in a focus group about the content of the consent form. Women completed a questionnaire that asked about their willingness to participate, the influence of specific study characteristics on their decisions, and items from the Genetic Attitudes Assessment Tool (GAAT).

**Results:** Women were 29.0±7.3 years (range:19-44), 51% had children and 26% were pregnant. 41% were Hispanic (H) white, 33% were non-H white and 26% other (including Native American-NA). One-third of the women initially indicated they would decline participation in the NCS; this did not change after the focus group. Most NA women indicated they would decline participation 71% (66%), H women would decline participation: 35% more than non-H women:7%. Several variables would influence NCS participation ( $p=0.0001$ ), with the 21-year length of the study having the most negative influence. Women who would not participate were more likely to perceive that the study would be unpleasant, stressful, and risky, and less likely to perceive that there were benefits to participation. The GAAT revealed that women differed in their opinions about genetic testing and was related to whether they would or wouldn't participate.

**Conclusions:** Native American and Hispanic women indicated they were less likely to agree to participate in the NCS and were more concerned about genetic testing. Given the importance of determining the genetic influence of health and disease, it is critical to understand why minority women and their families are unlikely to participate and address these concerns during consent.