

## POSTER ABSTRACTS

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71

### **You Can't Ask That: Lessons Learned From a Race and Ethnicity Survey**

Lobb R, Pierre-Jacques M, Foley J, Wagner L, Adams A

**Background:** Insufficient information on race, ethnicity, and language is a key barrier to understanding and addressing disparities in health care. Health plans cite consumer concerns about sharing this information as the primary reason for avoiding routine data collection. However, little is known about patients' perceptions on sharing this information. We describe patients' reactions to a race and ethnicity survey conducted by a health plan in collaboration with a health care system and summarize procedural guidelines to assist health plans when collecting this data from members.

**Methods:** We mailed an English language questionnaire to 9,242 patients with diabetes to collect information on race, ethnicity, language, age of first diabetes diagnosis, and comments regarding the survey. We also distributed the survey in English and 7 non-English languages at 14 clinic sites. To evaluate the feasibility of distributing the survey at clinics, we interviewed the managers and interpreter coordinators from each clinic.

**Results:** We collected 4,292 surveys for a response rate of 44%. Fifteen percent of respondents included comments. Most respondents expressed a desire to understand why these data were needed to improve the quality of their care. An additional 29% of patients had questions regarding their diabetes diagnosis and 10% of patients commented about the quality of care they received from the clinic. Clinic managers felt that collection of race and ethnicity data at the time of a clinical encounter was feasible to administer.

**Conclusions:** We identified 5 procedural guidelines to assist health plans when collecting race and ethnicity data. (1) Develop a multi-level communication strategy that can reassure patients their information will not be misused, and educate patients about health disparities within the context of race, ethnicity, and other factors that influence health status. (2) Educate health care staff at all levels about health disparities and the laws governing collection of race and ethnicity information. (3) Engage health care staff at all levels to identify ways to maximize collection from hard-to-reach sub-groups. (4) Establish structures to support patients' questions in multiple languages. (5) Collaborate with health care systems to coordinate data collection with other initiatives occurring within the system.