Disparities in missingness contribute to algorithmic bias: An examination of availability and comprehensiveness of family health history data in the electronic medical record

ABSTRACT

Prior research has shown that individuals from minority racial and ethnic groups have decreased access to and utilization of genetic services, and that these disparities cannot be attributed only to cost. Individual-level factors (e.g., awareness, knowledge, attitudes) have been identified that may contribute to disparities in access to and use of genetic services, and the importance of health care system-level factors (e.g., insurance, access to specialists, language barriers) is increasingly being recognized. One study conducted with women diagnosed with breast cancer showed that, despite a strong desire for genetic testing, patients from minority groups had more unmet needs for discussion of testing with providers. Research is needed to determine how to increase access to and utilization of genetic services among racial and ethnic minority patients. To identify patients eligible for genetic services, a critical piece of information is a detailed family history which is one of the best predictors of cancer risks. While taking a family history is a key component of primary care, this information is often not adequately or routinely collected. Information about second-degree relatives and age at relatives’ disease diagnoses, required for risk stratification, is collected infrequently. The disparity in the availability of family history information in the EHR also contributes to bias in algorithms that aim to identify eligible patients. Our recent work suggests that Spanish-speaking and Hispanic patients are underrepresented in the pool identified by an EHR-based algorithm using structured data for identifying unaffected patients who qualify for cancer genetic services based on current guidelines from primary care clinics. We examine disparities in missingness by gender, race, ethnicity, and language.

Dr. Melody Goodman is available to meet with faculty, postdocs, and students over Zoom. Please reach out to razieh.nabi@emory.edu or benjamin.risk@emory.edu, if interested by Wednesday, October 26th.

Join Zoom Meeting: https://zoom.us/j/96843636744?pwd=NG145Wc5MIpkcmoxVF1HY21bGRnQT09

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