Missing Ethnicity and Language Information in Health Care Records of Patients from the Asian Diaspora

Visit Article

The electronic health record (EHR) should contain information to support culturally responsive care and research; however, the widely used default "Asian" demographic variable in most US social systems (including EHRs) lacks information to describe the diverse experience within the Asian diaspora (e.g., ethnicities, languages). This has a downstream effect on research, identifying disparities, and addressing health equity. We were particularly interested in EHRs of autistic patients from the Asian diaspora, since the presence of a developmental diagnosis might call for culturally responsive care around understanding causes, treatments, and services to support good outcomes. The aim of this study is to determine the degree to which information about Asian ethnicity, languages, and culture is documented and accessible in the EHR, and whether it is differentially available for patients with or without autism. Using electronic and manual medical chart review, all autistic and "Asian" children (group 1; n = 52) were compared to a randomly selected comparison sample of non-autistic and "Asian" children (group 2; n = 50). Across both groups, manual chart review identified more specific approximations of racial/ethnic backgrounds in 54.5% of patients, 56% for languages spoken, and that interpretation service use was underestimated by 13 percentage points. Our preliminary results highlight that culturally responsive information was inconsistent, missing, or located in progress notes rather than a central location where it could be accessed by providers. Recommendations about the inclusion of Asian ethnicity and language data are provided to potentially enhance cultural responsiveness and support better outcomes for families with an autistic child.

Journal:

Journal of Racial and Ethnic Health Disparities
Authors: Covello M, Pelella MR, Bennett A, Gerdes M, Guthrie W, Wallis KE, Wong ZM, Miller JS, Truong DM

Related Content

- Rates of Autism Increase, but Numbers Don’t Paint the Full Picture
  Blog Post
  Jan 18, 2023
- Disparities in Autism Screening and Well-Child Care Persisted During the Pandemic, but Novel Solutions to Promote Equity Exist
  Blog Post
  Jun 06, 2022