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WEAVING A STRONG FABRIC OF TRUST FOR THE LEARNING HEALTH SYSTEM THROUGH COMMUNITY-ENGAGED RESEARCH WITH AN URBAN LATINO POPULATION

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A 2012 Institute of Medicine report highlighted the importance of the digital infrastructure for the learning health system and recommended that patients should participate in the development of a robust data utility, use new clinical communication tools for self-management and care activities, and be involved in building new knowledge through processes such as patient-reported outcomes. Shortliffe and others further emphasized the importance of building a strong fabric of trust in which individuals and society as a whole contribute personal data and clinical experiences to the development of a learning health system. However, it is often difficult to build such trust among racial and ethnic minorities as evidenced by low participation rates in research studies and biobanks as well as limited use of information technologies for health-related purposes. Consequently, those most at risk for health disparities may fail to benefit from the learning health system. Through the AHRQ-funded Washington Heights/Inwood Informatics Infrastructure for Comparative Effectiveness Research (WICER) and WICER 4 U projects, we have applied community-engaged research processes as a strategy for weaving a strong fabric of trust among urban Latinos. This presentation will include lessons related to participation in future research studies, biobank sample provision, clinical data linkage, and returning patient-reported outcomes and other data to research participants through infographics.