



SUZANNE BAKKEN, R.N., PH.D., FAAN, FACMI

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

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208 LIGHT HALL



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Upcoming Discovery Lecture:

JENNIFER DOUDNA, PH.D.

University of California, Berkeley

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VANDERBILT  UNIVERSITY
MEDICAL CENTER

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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.



**SUZANNE BAKKEN,
R.N., Ph.D., FAAN, FACMI**

SCHOOL OF NURSING AND
DEPARTMENT OF BIOMEDICAL INFORMATICS,
COLUMBIA UNIVERSITY, NEW YORK NEW YORK

Suzanne Bakken, R.N., Ph.D., FAAN, FACMI is the Alumni Professor of Nursing and Professor of Biomedical Informatics at Columbia University. Following doctoral study in nursing at the University of California, San Francisco, she completed a National Library of Medicine post-doctoral fellowship in Medical Informatics at Stanford University. She currently directs the Center for Evidence-based Practice in the Underserved and the Reducing Health Disparities Through Informatics (RHeaDI) pre- and post-doctoral training program. Dr. Bakken also served as Principal Investigator of the AHRQ-funded Washington Heights Inwood Informatics Infrastructure for Comparative Effectiveness

Research (WICER) and leads its follow-on study WICER 4 U, which focused on stakeholder engagement. She has also received funding from the National Institute of Nursing Research, National Cancer Institute, National Library of Medicine, and National Institute of Mental Health. Dr. Bakken has published more than 200 peer-reviewed papers. In 2010, she received the Pathfinder Award from the Friends of the National Institute of Nursing Research. She is President-Elect of the American College of Medical Informatics and an elected fellow of the New York Academy of Medicine, American Academy of Nursing, American College of Medical Informatics, and a member of the Institute of Medicine.
