Content Summaries of Selected Best Papers for the 2022 IMIA Yearbook, Special Section on Inclusive Digital Health

Braun L, Wentz A, Baker R, Richardson E, Tsai J

Racialized algorithms for kidney function: Erasing social experience

Soc Sci Med 2021 Jan;268:113548

This paper uses chronic kidney disease (CKD) to highlight how algorithmic bias can institutionalize racial injustice in health care delivery and biomedical research. Because African Americans disproportionately make up the population affected by CKD in the United States, and outcomes in this population are worse than other populations, a racial correction to kidney measurement functions was introduced in 1999 and subsequently "tacitly accepted" by the medical community. Adoption of racial bias in CKD measurement correction factors drove further research on CKD for the past two decades, illustrating the concept of "coded inequity" into algorithms and other decision-support tools designed to guide clinicians on the diagnosis and treatment of CKD. The article further explores how systemic racism in the U.S. influences medical education and algorithms around the world. Moreover, the authors highlight that although racialization is most associated with the United States, it is truly an international phenomenon and therefore racial bias from algorithms is not simply a problem in America. The

article is an important foundational paper for anyone interested in the concepts of algorithmic bias, social determinants, and social justice in medicine.

Pho AT, Bakken S, Lunn MR, Lubensky ME, Flentje A, Dastur Z, Obedin-Maliver J

Online health information seeking, health literacy, and human papillomavirus vaccination among transgender and gender-diverse people

J Am Med Inform Assoc 2022 Jan 12;29(2):285-95

This paper summarizes research that examined the online health information seeking behaviors of transgender and gender diverse (TGD) individuals compared with cisgender individuals, or those whose sense of gender and identity corresponds to their birth sex. Moreover, the study examined whether general health literacy and eHealth literacy moderated information seeking behaviors. Using standardized survey instruments and items, the researchers sampled individuals from the Population Research in Identity and Disparities for Equality (PRIDE) Study (pridestudy.org), a longitudinal, U.S.-based, national health study of sexual and gender minority people. The research focused on information seeking behaviors related to receipt of the HPV vaccine, a vaccine that prevents transmission of the human papillomavirus during sexual contact reducing incidence of cervical, anal, oropharyngeal, vaginal, vulvar, and penile cancers for which the TGD community is at higher risk. Both groups reported very high general health literacy and eHealth literacy, which resulted in a null effect on information seeking behaviors. The study highlights the importance, however, of examining health literacy and eHealth literacy as well as its moderating effect on activities such as online information seeking behaviors with respect to vaccines and other forms of preventative health. Marginalized populations especially may be vulnerable to misinformation.

Vigil-Hayes M, Collier AF, Hagemann S, Castillo G, Mikkelson K, Dingman J, Muñoz A, Luther J, McLaughlin A

Integrating cultural relevance into a behavioral mHealth intervention for native american youth

Proc ACM Hum Comput Interact 2021 Apr;5(CSCW1):165

In this proceedings paper, the authors describe how they engaged with Native American youth to co-design a behavioral mHealth intervention involving the youth, a community advisory board, and a clinical psychologist. The researchers sought to explicitly incorporate Native culture and values into the mHealth intervention to make it meaningful and culturally-relevant to users. The application sought to cultivate mindfulness among Native youth to improve their resilience and ability to cope with stress, important behavioral determinants of health. By co-designing the application with members of the community, the researchers sought to not only make the content meaningful but also address lack of Internet access issues that face Native communities. The paper is an important example of the challenging but critical work involved in designing an mHealth application for use by a minority population in a manner that is culturally relevant. These same techniques would be important for designing global mHealth applications.