

Stakeholder Perspectives on Public Health Genomics Applications for Sickle Cell Disease: A Methodology for a Human Heredity and Health in Africa (H3Africa) Qualitative Research Study

Marsha J. Treadwell, Julie Makani, Kwaku Ohene-Frempong, Solomon Ofori-Acquah, Sheryl McCurdy, Jantina de Vries, Daima Bukini, Jemima Dennis-Antwi, Karen Kengne Kamga, Columba Mbekenga, Edmond Tingang Wonkam, Godfrey Tangwa, Charmaine D. Royal, Ambroise Wonkam, and as members of the H3Africa Consortium

Published Online: 1 Jun 2017 <https://doi.org/10.1089/omi.2017.0047>

Abstract

Advances in omics technologies alone are not a guarantee that science will translate to robust responsible innovation that is firmly grounded in societal values. This study aimed to identify best practices for Ethical, Legal, and Social Implications (ELSI) research in Africa that allows for optimal integration of community perspectives into the design and implementation of genomics research. In a large sample of 346 stakeholders in Cameroon, Ghana, and Tanzania (59% women), we used a qualitative study design with a phenomenological approach and conducted 32 group and 74 individual interviews (25% rural). We imported interview recordings into NVivo software for analysis. We created a “concept map” to organize the coded information, with Perspectives on Genomics and Sickle Cell Disease (SCD) Public Health Interventions as the central themes. We found that (1) analyses of major subthemes across and within countries revealed differential knowledge and experiences of SCD, and perspectives on various aspects of research and genomics; (2) we were able to gather empirical data efficiently from urban and rural stakeholders, to study the issues related to sample sharing, consent processes, and return of clinical and genomic study results; (3) the concept of nondirectiveness in modern genetic medicine practice can be challenged by the views of stakeholders in the context of a high-burden disease such as SCD; and (4) linking community views to current and proposed public health interventions could be understood within the context of each specific country. Our work informs future qualitative social science and technology policy research designs on genomics applications in Africa.