Stakeholders’ Perspectives on Community Engagement for Genomics Research in Africa – A Literature Review

Harriet Nankya¹

¹Makerere University, Uganda, Kawempe, Uganda

Published on: Jun 16, 2023
DOI: https://doi.org/10.21428/3d48c34a.f86cf63a
License: Creative Commons Attribution 4.0 International License (CC-BY 4.0)
Introduction: Community Engagement (CE) is recognized as a measure of addressing a number of ethical and social issues that pertain to genomics research. However, the knowledge base on how to effectively conduct CE in Africa is limited. This leads to conducting sub-optimal community engagement that can be potentially exploitative and disrespectful to communities. Objective: To explore the perspectives of key stakeholders (genomics researchers, communities, and research regulators) to inform effective CE for genomic research. Methods: Fifty-nine articles published from 2011 to 2022 were reviewed. Findings: CE is perceived to provide an avenue for continuous interaction between communities and genomics researchers. This supports the ethical conduct of genomics research by enabling the; Explanation of the genomics science to communities; Understanding of community norms to inform genomics study design and implementation; The informed consent process by allowing informed decision-making; The discussions on the return of genomics findings; Addressing any concerns that may pertain to sample and data storage and sharing; Minimization of stigmat; Anticipation, and mitigation of potential risks and misconceptions, among others. Engaging communities in genomics research was perceived to present the following challenges; Limited local and international guidelines on CE in genomics research; Limited technical ability of the Research ethics committees to review genomics research protocols; Difficulty explaining genomics to communities; Resistance by communities due to unfamiliar sampling procedures (large sampling, storage, sharing) and the involvement of healthy participants; Delay/never return of genomic findings indicating a lack of reciprocity for study participation; Difficulty involving communities in all stages of research (from study conception to design, implementation, dissemination, and post-study management) due to limited technical and logistic resources. Conclusion: Assessing key stakeholders’ perspectives highlights the strengths and weaknesses in fostering CE in Genomics research in the African context. Implications: These literature findings informed the designing of research tools to collect empirical data (using Uganda as a case study) that will inform further, the development of a framework for effective CE in genomics research in the African context.