



HHS Public Access

Author manuscript

J Empir Res Hum Res Ethics. Author manuscript; available in PMC 2024 March 22.

Published in final edited form as:

J Empir Res Hum Res Ethics. 2024 February ; 19(1-2): 48–57. doi:10.1177/15562646231224374.

Trust in Medical Research: A comparative study among Patients at a Regional Referral Hospital and Community Members in Lira District, Northern Uganda

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Abstract

Events such as the Tuskegee syphilis study shaped how the public perceives and trusts medical research globally. However, few studies have examined trust in medical research in developing countries. We tested the hypothesis that levels of trust may be lower among community members compared to hospitalized persons in Uganda. We enrolled 296 participants in rural northern Uganda, and 148(50%) were from the community, 192(65%) were female. Mean level of trust for medical research was higher among hospitalized persons compared to community members ($p=0.0001$). Previous research participation ($p=0.03$), and willingness to participate in future research ($p=0.001$) were positively associated with trust. Medical personnel should engage more with the communities in which they practice fostering trust in medical research.

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Authors' contributions

JP and FB conceived the research idea

GNK and SL contributed to the refinement of the research idea

JP collected, cleaned and analyzed the data

FB Provided leadership and oversight during the project

JP drafted the manuscript

All authors read, revised and approved the manuscript for publication

Ethical considerations

Mbarara University of Science and Technology Research Ethics Committee reviewed and approved the proposal (study no: MUST-2021-124) The study was registered at the Uganda National Council of science and Technology. (Registration number: HS1685ES)

Ethics approval and consent to participate

Faculty Research Committee (FRC), Mbarara University of Science and Technology Research Ethics Committee (MUST REC) reviewed and approved the proposal (#MUST-2021-124). The Uganda National Council of Science and Technology (UNCST) also reviewed and approved the study (# HS1685ES).

Informed consent was obtained from all participants of the study according to Good Clinical Practice. In consideration of the (SARS-COV-2) pandemic, WHO measures and SOPs as outlined by the Uganda Ministry of Health, were observed to protect both participants and researchers from the virus.

Keywords

Trust; Medical Research; Research Ethics; CBPR; Research Ethics; RCR

Introduction

Globally, certain historical events have shaped how the public perceives medical research and may have significantly influenced the trust communities have in medical research (Harnett & Neuman, 2015) to the present day. These events include unethical acts such as those performed by the Nazi doctors, many of whom were responsible for the conduct of “torturing and killing by experiment” (Spitz, 2005). Another major event was the U.S. physicians’ conduct of a natural history study of syphilis among black men, in which the men were denied treatment for their infection in the Tuskegee Study of Untreated Syphilis (Alsan & Wanamaker, 2018).

The concept of trust is broad, and the Cambridge dictionary defines it as “to believe that someone is good and honest and will not harm you, or that something is safe and reliable” (Dictionary, 2008). From a behavioral sciences perspective, Mishra and Morrissey define trust as “one party’s willingness to be vulnerable to another party based on the belief that the latter party is competent, open, concerned, and reliable” (Mishra & Morrissey, 1990). In the medical research context, Smirnov et al. indicate that respondents expressed trust or mistrust in four domains namely: general trustworthiness, perception of deception, perception of exploitation and perception of discriminatory treatment (M. Smirnov et al., 2018). Therefore, in research, the trust for medical researchers may be viewed in terms of perceived vulnerability that the participants have towards the researcher and the moral responsibility of the researcher to “do no harm” (Department of Health, Welfare, National Commission for the Protection of Human Subjects of, & Behavioral, 2014).

Medical research involves interaction with individuals within communities. These interactions require that the general public trust the medical researcher and the research enterprise (Shamoo & Resnik, 2009). Moreover, without trust potential study participants or entire communities might be unwilling to participate in medical research studies. This would make it difficult to collect representative data, ultimately affecting the generalizability of research findings and breaches the principle of “justice” when certain sections the population are left out of research (Tilburt et al., 2007).

Trust in medical research may be affected by race and historical events such as segregation. For instance, some research conducted in the US shows that among African Americans, there are low levels of trust in medical research (Rivers, August, Sehovic, Lee Green, & Quinn, 2013). A study in South Africa found that participation in medical research was influenced by segregation and a historical mistrust between races (Pillay & Wassenaar, 2018). Trust may also be influenced by the relationship between the researcher and the research participant. In a study to understand willingness to participate in clinical trials, a participant who had had a good relationship with the researcher through building rapport and exchange of information had better prospects for future research participation due to the trust built in the process (Chu, Kim, Jeong, & Park, 2015). Previous unfavorable research

experiences in a country can also lower public levels of trust for medical research especially considering several scandals in medical research where the life of participants in research studies has been endangered (Elliott, 2017).

Unethical research practices may have far reaching consequences even decades after their occurrence. The Tuskegee Syphilis study in the US is reported to have led to mistrust of medical researchers and low research participation in subsequent studies among African American communities (Shavers, Lynch, & Burmeister, 2002). This mistrust appears to be particularly prominent in the context of research involving new approaches, e.g., genomic study techniques (Wright, Koornhof, Adeyemo, & Tiffin, 2013) or the testing of new products such as HIV vaccines (Thabethe et al., 2018).

Uganda has over the past few years experienced a growth in the volume of medical research and developed a relatively well-defined framework for review and approval of research involving human subjects. Very little of this research examines trust, yet reports from a recent vaccine clinical trial in Uganda suggest mistrust in medical research exists (Musisi, 2020). The question of trust in medical research shot to prominence during the course of the SARS-CoV-2 pandemic. A proposed COVID-19 vaccine trial in Uganda met with stiff resistance with respondents questioning why Uganda was selected as a study site (TrialSite, 2020).

Data show that hospitalization is strongly associated with trust for physicians (Kim, Bae, Kang, Kim, & Lee, 2018). Studies with hospitalized persons indicate that their experiences during hospitalization may improve their trust and cause them to gain confidence in the health care systems (Chegini & Islam, 2021) and presumptively research. Some studies suggest that the influence on trust in hospitalized conditions may be due to patient interactions with health workers and getting more comfortable to in the process of receiving healthcare (Chegini & Islam, 2021). However, most of these data are from resource rich settings. There is very limited research on trust in medical research in resource limited settings such as Uganda. Second, there is also a need for empirical research to gauge the levels of trust in research among the general public compared to hospitalized persons. Such data will provide a foundation to examine whether hospitalization influences trust but will also inform researchers on how to engage with the public and likely improve participation and uptake of research products. Therefore, the purpose of this study was to measure and compare the level of trust for medical research among community members and hospitalized persons and to identify other factors associated with trust in medical research.

Methods

Study design

We conducted a cross-sectional study between September and November 2021 using quantitative methods to compare trust between hospitalized persons and community members, and to identify factors that were significant for trust in medical research.

Study setting

The study was conducted in two locations in Lira district and city in Northern Uganda: (a) Lira Regional Referral Hospital (LRRH) in Lira City, and (ii) the community in peri-urban Lira district. Lira is a district of northern Uganda, with a population of over 400,000 people and is located 339 km from Kampala, Uganda's capital (Ongom, 2020). The city has four divisions namely: Railway, Central, Ojwina and Adyel. Lira district is predominantly rural, with fast-growing urban population of Lira City, typical of the present-day Uganda demographics. The region experienced insurgency from the Lord's Resistance Army (LRA) war but has been largely peaceful and developing over the past 15 years.

Lira Regional Referral Hospital (LRRH) is a 400-bed government owned hospital and the largest in Lango sub-region. It is located approximately 1 km from the heart of Lira City. LRRH serves a population of over three million people in its catchment area (Health, 2018). LRRH offers a wide variety of healthcare services including specialized clinics. LRRH is also a teaching hospital for many health institutions of higher learning including Lira University and is also a site for many ongoing medical research projects.

Study population

Participants consisted of persons admitted to the adult wards and were receiving medical care in Lira Regional referral hospital at the time of the study. The community members were adults residing in the peri-urban areas of Lira City.

Eligibility criteria

We enrolled adults 18 years or older. In the hospital we recruited hospitalized adults but excluded hospitalized patients who were admitted in critical emergency state, patients whose condition was not stable, severely ill patients, and those not in stable condition to respond to the survey questionnaire. In the community, we included those who resided in Lira City for at least the past 3 months prior to study enrollment. We excluded persons from outside Lira who were visitors in the selected households. Only individuals who provided written informed consent were recruited to participate in this study.

Sample size estimation

Sample size was estimated using Stata version 16 software. We hypothesized that hospitalized persons would have higher levels of trust, compared to the community residents, and mean difference in levels of trust would be 2.0, and standard deviation of 6.2 as measured on the trust scale (Hall et al., 2006). We aimed to have an equal number of participants in the two groups. Using a level of significance of 0.05, and at least 80% power to detect the mean difference, 152 individuals were needed per group. Therefore, the calculated total sample size was 304.

Sampling techniques

a. Hospital sample: We used a systematic sampling technique to sample all patients admitted to inpatient departments of LRRH during the study period for study participation.

All adult patient wards were considered for recruitment of study participants, and from the admission register for each ward, we sampled every third patient.

b. Community sampling—We conducted a three-level multistage household-based sampling procedure to select the community participants. The three stages of sampling were at division, parish, and village levels. Two largest divisions, namely Adyel and Ojwina, which represent over 70% of inhabitants of Lira City were purposively selected. Uganda Bureau of Statistics (UBOS) projections indicated that Lira City had a population of 114,089 people in 2020 and that the average number of persons per household was 4.6 (Statistics, 2020). This UBOS data further indicated the population of the divisions of Lira comprised 36,813 in Adyel, 44,693 in Ojwina, 26,034 in Central and 6,547 in Railway division. From each of the 2 selected divisions, 2 parishes were randomly selected. Two villages were randomly selected from each of the parishes. Overall, 8 villages from 2 divisions were selected. In the selected villages, households were sampled using a systematic sampling technique. In each village, the complete list of all households was obtained from the local village chairperson and the ‘nth’ interval (the total number of households in the village/sample size of households needed in that village). Starting from the presumed center of the village by the help of the village chairperson, the team tossed a coin to determine the direction in which to start with the selection of households. The total number of households selected was proportionate to village size. Only one adult per household meeting the inclusion criteria was enrolled in this study. Where a household sampled had no occupants present at the time of the visit, it was revisited one more time, and if on the second time no one was present, the next household was considered as a replacement. The lists of parishes, villages and households were obtained from the division headquarters, parishes, and local village chairpersons, respectively and constituted the sampling frames at the different stages of sampling. The flow diagram of the 3 stages of sampling is shown in figure 1.

Data collection methods and procedures

In the hospital, trained research assistants selected participants in the in-patient wards. Prospective participants were provided with information on the study, and written informed consent obtained before the research assistants administered structured questionnaires. Participation in this study was voluntary, with no payment to participants. Responses to the study questions were recorded in a data collection form and checked for completion. On average, the study procedures took 15 to 20 minutes to complete.

In the community, the research assistants approached and selected households and requested permission to explain the study information. Only one eligible member per household was asked to volunteer to participate in the study.

Variable measurements

The dependent variable was Level of trust of medical researchers. We used a 12-item scale to measure trust with domains of researcher fidelity (5 items), honesty (2 items), safety (2 items) and global trust (3 items). The scale has internal consistency of Cronbach’s alpha 0.87 (Hall et al., 2006). The items are scored 1 to 5, from strongly disagree to strongly agree, with negative items reverse-coded so that higher score indicates more trust.

Independent variables—We used the socioecological model to determine the independent variables to be considered. The independent variables included: age, sex, tribe, religion, marital status, number of children, and district of residence, previous study participation, education level, estimated monthly income, employment and source of income. Other independent variables included willingness to participate in research, health status and knowledge that research is regulated.

Quality control

The survey tool was pilot tested among a small sample of 20 persons. We used these data to identify difficult questions, refine the tool and to identify any other challenges with the data collection process. We recruited three research assistants and trained them for 2 days on the study protocol, Standard Operating Procedures (SOPs), systematic sampling procedures, data collection techniques and use of data collection tools. All the RAs had prior training in Good Clinical Practice (GCP). The research assistants were required to have good knowledge of English language, and be able to speak Langi, the commonly used local language in the community. The questions were translated to Langi during training and the RAs engaged in role play of different anticipated scenarios to ensure familiarization with the questionnaire.

Data analysis

Data were analyzed with STATA software version 16. Socio-demographics have been presented using descriptive statistics; proportions, mean and standard deviation. Categorical variables of gender, tribe religion, and district of residence, disease status, and marital status are presented using frequencies, proportions and percentages. In the analysis, the primary outcome is level of medical research trust which was scored on a linear scale. The mean level of trust was converted to a 100- percentage point scale with 0 being lowest and 100 highest. The difference in mean levels of trust in medical research between community and hospital sample was tested using an independent samples t-test.

Correlation analysis was conducted for all explanatory variables. Dummy variables were not included in this analysis. For all variables that were plausible and identified from literature to influence level of trust, we conducted a bivariate linear regression. Multiple linear regression was used to model for factors that are significant at bivariate level. Variables were considered to be statistically significant if the associated p-value was less than 0.05 and results reported for the 95% confidence intervals. The level of trust scores were tested for normality. The data were skewed to the left and therefore, the data were log transformed to meet the assumptions of linear regression.

Ethical considerations

Mbarara University of Science and Technology Research Ethics Committee reviewed and approved the proposal (study no: MUST-2021-124) The study was registered at the Uganda National Council of Science and Technology. (Registration number: HS1685ES).

Informed consent was obtained from all participants of the study according to good clinical practice. Twelve persons from community and 4 from the hospital did not consent to

this study and were therefore not included. In consideration of the ongoing SARS-COV-2 pandemic during the data collection, WHO measures and SOPs as outlined by the Uganda Ministry of Health were observed to protect both participants and data collection team from acquiring/transmitting the virus.

Results

Demographics

We enrolled 296 participants 148 (50%) of whom were from the community. 192 (65%) were female. The average age was 29.5 years (standard deviation 9.2). The majority of the participants were of the Langi tribe (n=243 or 82%), the native inhabitants of Lira.

Demographic characteristics are summarized in Table 1.

Level of trust

Scores for level of trust, measured to percentage scale indicated a lower mean level of trust of medical research at 60.3 (SD 9.6) among the community group compared to 68.68 (SD 4.1) among the hospitalized group, and the difference was statistically significant ($p=0.0001$).

Pearson correlation analysis

There was a strong correlation between participant group by location (community, hospital) and level of trust with a coefficient of 0.4596 ($p=0.0001$). Age ($p=0.0092$), employment status ($p=0.05$), willingness to participate in research ($p=0.0001$), and knowledge that research is regulated ($p=0.05$) were also significantly correlated with level of trust.

Bivariate regression analysis

In the bivariate analysis, factors that were significant include: participant location (Coeff= 0.143381, CI= 0.1115831, 0.1751788, $p=0.0001$), age (Coeff= 0.0024747, CI= 0.0006171, 0.0043324, $p=0.009$), willingness to participate in research (Coeff= 0.1544758, CI= 0.0937669, 0.2151847, $p=0.0001$). Employment (Coeff= -0.0356115 , CI= -0.0712112 , -0.0000117 , $p= 0.05$) was negatively associated with level of trust. Results of the bivariate regression analysis are presented in Table 2.

Multiple linear regression model

We selected variables based on their plausibility to explain trust as presented in the literature. All variables that were significant at bivariate regression analysis (p value < 0.05) were included in the multiple linear regression model. The final model included logarithm transformation of trust level as the outcome and the independent variables as participants group by location, participant age, previous participation in medical research, willingness to participate in future research, employment status, and health status. Participant group by location, i.e., hospital or community alone explained 20.86% of the variation. Overall, the final model explained 26.7% variation in level of trust.

Variables significant in final model included group of participants by location being hospital (Coeff= 0.12, CI= 0.0867393, 0.1559811, p= 0.0001), previous participation in medical research study (Coeff=0.04, CI= 0.0038377, 0.0767686, p=0.03), willingness to participate in medical research (Coeff= 0.095, CI= 0.0387596, 0.1507104, p= 0.001) and health status (Coeff= 0.067, CI= 0.0003017, 0.1332552, p=0.05).

Discussion

This study measured and compared the level of trust in medical research among two groups, the community members, and hospitalized persons, to test the hypothesis that persons who had interacted with medical personnel more recently would indicate greater levels of trust in medical research compared with those who had not had such recent interactions. This study further determined the factors for trust in medical research and explored perceptions of trust in medical research. Our findings suggest that hospitalized persons had more trust for medical research than their community counterparts. Our study also suggests that previous research participation, willingness to participate in research and health status were associated with trust for medical research.

Our finding that hospitalized persons had more trust for medical research than community members may be due to building rapport and intentional relationships that hospitalized patients are exposed to when compared to community members as explained in a study on willingness to participate in clinical trials (Chu et al., 2015). These findings also resonate with previous work that found that the personalization that occurs when an individual relationship is formed between patients and medical personnel may give an immediate boost to the level of trust that one has in the general profession or industry (Hall, 2006). Our results support findings from a “RECRUIT” trial in which trust-based intervention increased minority recruitment to intervention trials and physician-investigators participation was critical to recruitment success (Tilley et al., 2021). One can argue that meaningful interaction in whichever form fosters trust that the persons in the community have in the medical personnel, which may in turn transferable to medical research.

Secondly, results from this study indicate that previous research participation predicted high level of trust in medical research. This finding supports a study by Diaz et al., where individuals who had participated in a clinical research before tended to express high levels of trust for medical researchers and therefore highly likely to participate in another trial (Diaz, Mainous, McCall, & Geesey, 2008). A study by Smirnoff et al. on trust and mistrust in medical research also indicated that participants who felt a greater general sense of trust in researchers were less likely to see them as deceptive, exploitative, or treating patients differently according to race or ethnicity (Margaret Smirnoff et al., 2018). This may be explained by having experiences of prior participation, demystifying research and the associated uncertainties. Our other finding that willingness to participate in research was associated with trust for medical research also resonates with previous studies (Haas et al., 2016).

Our study found no differences in level of trust by gender. While it is widely known that women are more likely to seek health care compared to men in general (Möller-Leimkühler,

2002), this does not seem to impact on trust in medical research. Other factors investigated in this study such as tribe, age and employment status did not seem to affect trust levels. It therefore appears to be that individuals' level of trust in research is not dependent on demographic factors.

Our study has important strengths. First, it is among the few studies that have examined trust for medical research in a resource-limited setting. Second, we derived our data from both hospitalized patients and community members, which allows us to examine differences in level of trust across the two contexts. Our findings are limited by the lack of data relating to community members' contacts with health workers and their history of hospitalization. Since this variable was not included in the final model, it may present residual confounding in our final model estimates. Hospitalized persons may inherently carry higher trust by virtue of their illness and health seeking behaviors. And lastly, our number of recruited participants fell slightly short of the calculated sample size, but the difference is small and unlikely influenced the direction of the results.

Conclusions

Participants who were hospitalized had higher levels of trust compared to those in the community, and this may be due to close interaction with health workers. Our findings add to the body of knowledge on trust in medical research, emphasizing the importance of medical personnel and medical researchers intently designing programs that support more interaction with members of the community to foster trust in medical research.

Best Practices

Activities that enhance interaction with health workers such as medical education and community engagement should be harnessed in the research implementation process in order to enhance trust in medical research. There are well-studied techniques for proper community engagement that can help guide medical workers' interaction with communities.

Research Agenda

Future research should focus on comparison of levels of trust among communities known to have been heavily involved in medical research over the past decades and areas where medical research is still relatively low; effectiveness of community awareness methods in fostering trust and understanding extensively the implications of trust on research participation specific to SARS-CoV-2 pandemic experience.

Educational implications

Trust in medical research has potential impact on participation in research, trust in the findings and application of these results to influence policy and practice. Our study suggests that educating health workers on ways to engage the community within which they live, and practice will promote their participation in such activities which will foster trust in the medical research enterprise.

Acknowledgements

We are grateful to Mbarara University Research Ethics Education Program (MUREEP), supported by the Fogarty International Center of the National Institutes of Health (NIH) under Award Number R25TW010507, who supported this work. We also appreciate the community in Lira district and patients at Lira Regional Referral Hospital for participating in this study. We are grateful for the contributions of the research assistants Medrine Akullu, Solomon Odongo, Brenda Apudu and Catherine Arec. The content of this publication is solely the responsibility of the authors and does not necessarily represent the opinions of the funding agency.

Source(s) of support:

Mbarara University Research Ethics Education Program (MUREEP), supported by the Fogarty International Center of the National Institutes of Health (NIH) under Award Number R25TW010507. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

Biographies

JP is a fellow of Research Ethics under MUREEP. With a background in nursing, JP has been working in the medical research enterprise for more than 5 years. He is currently a Program Lead and coordinates several research projects at the Rheumatic Heart Disease Research Collaborative (RRCU) at Uganda Heart Institute. JP works closely with communities where research is conducted and is very interested in the relationship and trust between the researchers and research participants. JP conceived the research idea collected, cleaned and analyzed the data, drafted the manuscript

SL is a Professor in the Department of Bioethics and serves as the Vice Dean for Faculty Development and Diversity in the School of Medicine of Case Western Reserve University, Cleveland, Ohio. She has secondary appointments in the Departments of Epidemiology and Biostatistics, Psychiatry, and Global Health and at MSASS, the Mandel School of Applied Social Sciences. SL holds graduate degrees in law (J.D.), epidemiology (Ph.D.), medical anthropology (Ph.D.), social work (M.S.S.A.), and secondary education (M.A.). She is also ordained as an interfaith minister. SL primary research focus is on HIV risk and prevention and family violence in marginalized communities. SL is also interested in ethical issues in the conduct of research with vulnerable persons. She has authored over 70 peer-reviewed articles and 58 book chapters and has authored and/or edited 27 books. SL is a faculty of MUREEP, the program and provided support in the conception, implementation and execution of this study. SL contributed to the refinement of the research idea, read, revised, and approved the manuscript for publication.

GNK is an associate professor biochemistry at Mbarara University of science and technology and is the immediate past dean of the faculty of medicine. GNK's is interested in research ethics and is currently the program director of the MUREEP program designed to support research ethics education and training in Southwestern Uganda. GNK contributed to the refinement of the research idea, read, revised, and approved the manuscript for publication

FB is a Senior Lecturer and researcher at Mbarara University of science and Technology. FB teaches Biostatistics and Epidemiology is faculty at the MUREEP program. FB serves as the chair of the Research Ethics Committee at Mbarara university and is interested in community-based research and ethical issues around engaging the community in research.

FB contributed to the refinement of the research idea, provided leadership and oversight during the project, read, revised, and approved the manuscript for publication

List of Abbreviations

ANREC	Annual National Research Ethics Conference
CBPR	Community Based Participatory Research
FGD	Focus Group Discussions
LRRH	Lira Regional Referral Hospital
MUST	Mbarara University of Science and Technology
MUST REC	Mbarara University of Science and Technology Research Ethics Committee
SARS-COV-2	Severe Acute Respiratory Syndrome Coronavirus 2
SOP	Standard Operating Procedure
UNCST	Uganda National Council for Science and Technology
WHO	World Health Organization

References

- Alsan M, & Wanamaker M (2018). TUSKEGEE AND THE HEALTH OF BLACK MEN. *Q J Econ*, 133(1), 407–455. doi:10.1093/qje/qjx029 [PubMed: 30505005]
- Chegini Z, & Islam SMS (2021). Shared-decision-making Behavior in Hospitalized Patients: Investigating the Impact of Patient’s Trust in Physicians, Emotional Support, Informational Support, and Tendency to Excuse Using a Structural Equation Modeling Approach. *Journal of Patient Experience*, 8, 23743735211049661. doi:10.1177/23743735211049661 [PubMed: 34671702]
- Chu SH, Kim EJ, Jeong SH, & Park GL (2015). Factors associated with willingness to participate in clinical trials: a nationwide survey study. *BMC Public Health*, 15(1), 10. [PubMed: 25595373]
- Department of Health, E., Welfare, National Commission for the Protection of Human Subjects of, B., & Behavioral. R. (2014). The Belmont Report. Ethical principles and guidelines for the protection of human subjects of research. *J Am Coll Dent*, 81(3), 4–13. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/25951677>
- Diaz VA, Mainous A, McCall AA, & Geesey ME (2008). Factors affecting research participation in African American college students. *FAMILY MEDICINE-KANSAS CITY-*, 40(1), 46.
- Dictionary, C. (2008). Cambridge advanced learner’s dictionary. PONS-Worterbucher, Klett Ernst Verlag GmbH.
- Elliott C (2017). The anatomy of research scandals. *Hastings Center Report*, 47(3), inside back coverside back cover.
- Haas K, Costley D, Falkmer M, Richdale A, Sofronoff K, & Falkmer T (2016). Factors influencing the research participation of adults with autism spectrum disorders. *Journal of autism and developmental disorders*, 46, 1793–1805. [PubMed: 26810436]
- Hall MA (2006). Researching medical trust in the United States. *Journal of health organization and management*.
- Hall MA, Camacho F, Lawlor JS, DePuy V, Sugarman J, & Weinfurt K (2006). Measuring trust in medical researchers. *Medical care*, 1048–1053. [PubMed: 17063137]

- Harnett JD, & Neuman R (2015). Research ethics for clinical researchers. *Methods Mol Biol*, 1281, 19–30. doi:10.1007/978-1-4939-2428-8_2 [PubMed: 25694302]
- Health, M. o. (2018). Lira Regional Referral Hospital. Retrieved from <https://www.health.go.ug/?s=lira+regional+referral+hospital>
- Kim AM, Bae J, Kang S, Kim Y-Y, & Lee J-S (2018). Patient factors that affect trust in physicians: a cross-sectional study. *BMC family practice*, 19(1), 1–8. [PubMed: 29291706]
- Mishra J, & Morrissey MA (1990). Trust in employee/employer relationships: A survey of West Michigan managers. *Public personnel management*, 19(4), 443–486.
- Möller-Leimkühler AM (2002). Barriers to help-seeking by men: a review of sociocultural and clinical literature with particular reference to depression. *Journal of affective disorders*, 71(1–3), 1–9. [PubMed: 12167495]
- Musisi F (2020, Monday, May 11th). UVRI wins Hepatitis B drug trial case. *Daily Monitor*. Retrieved from <https://www.monitor.co.ug/News/National/UVRI-Hepatitis-B-drug-trial-case-Ssekana-Ebola-Hepatitis/688334-5549336-6qw4h0z/index.html>
- Ongom P (2020). Lira District Local Government. Retrieved from <https://liradistrict.com/>
- Pillay D, & Wassenaar DR (2018). Racial differences in willingness to participate in HIV prevention clinical trials among university students in KwaZulu-Natal, South Africa. *South African Journal of Psychology*, 48(1), 112–128. doi:10.1177/0081246317708094
- Rivers D, August EM, Schovic I, Lee Green B, & Quinn GP (2013). A systematic review of the factors influencing African Americans' participation in cancer clinical trials. *Contemp Clin Trials*, 35(2), 13–32. doi:10.1016/j.cct.2013.03.007 [PubMed: 23557729]
- Shamoo AE, & Resnik DB (2009). *Responsible conduct of research*: Oxford University Press.
- Shavers VL, Lynch CF, & Burmeister LF (2002). Racial differences in factors that influence the willingness to participate in medical research studies. *Ann Epidemiol*, 12(4), 248–256. doi:10.1016/s1047-2797(01)00265-4 [PubMed: 11988413]
- Smirnoff M, Wilets I, Ragin DF, Adams R, Holohan J, Rhodes R, ... Richardson LD (2018). A paradigm for understanding trust and mistrust in medical research: The Community VOICES study. *AJOB Empir Bioeth*, 9(1), 39–47. doi:10.1080/23294515.2018.1432718 [PubMed: 29368998]
- Spitz V (2005). *Doctors from hell: The horrific account of Nazi experiments on humans*: Sentient Publications.
- Statistics, U. B. O. (2020). 2020 Statistical Abstract. Retrieved from https://www.ubos.org/wp-content/uploads/publications/11_2020STATISTICAL__ABSTRACT_2020.pdf
- Thabethe S, Slack C, Lindegger G, Wilkinson A, Wassenaar D, Kerr P, ... Newman PA (2018). “Why Don’t You Go Into Suburbs? Why Are You Targeting Us?”: Trust and Mistrust in HIV Vaccine Trials in South Africa. *J Empir Res Hum Res Ethics*, 13(5), 525–536. doi:10.1177/1556264618804740 [PubMed: 30417754]
- Thiessen C, Ssekubugu R, Wagman J, Kiddugavu M, Wawer MJ, Emanuel E, ... Grady C (2007). Personal and community benefits and harms of research: views from Rakai, Uganda. *Aids*, 21(18), 2493–2501. [PubMed: 18025886]
- Tilburt J, Ford JG, Howerton MW, Gary TL, Lai GY, Bolen S, ... Sugarman J (2007). Applying justice in clinical trials for diverse populations. *Clin Trials*, 4(3), 264–269. doi:10.1177/1740774507079440 [PubMed: 17715253]
- Tilley BC, Mainous III AG, Amorrortu RP, McKee MD, Smith DW, Li R, ... Ford ME (2021). Using increased trust in medical researchers to increase minority recruitment: the RECRUIT cluster randomized clinical trial. *Contemporary Clinical Trials*, 109, 106519. [PubMed: 34333138]
- TrialSite (Producer). (2020, 19th February 2021). Imperial College of London Vaccine to be Tested in Uganda by December 2020. Retrieved from <https://trialsitenews.com/imperial-college-of-london-vaccine-to-be-tested-in-uganda-by-december-2020/>
- Wright GE, Koornhof PG, Adeyemo AA, & Tiffin N (2013). Ethical and legal implications of whole genome and whole exome sequencing in African populations. *BMC Med Ethics*, 14, 21. doi:10.1186/1472-6939-14-21 [PubMed: 23714101]

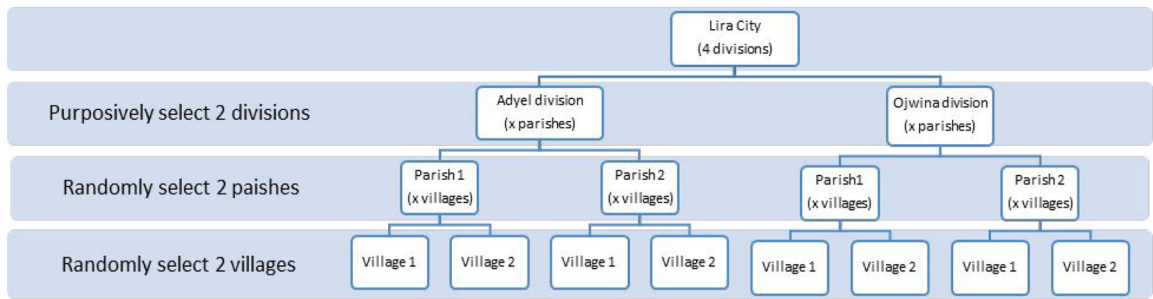


Figure 1:
Flow diagram showing the multi-stage sampling

Table 1:

Demographic Characteristics of Participants

Variable	Community n= 148 (50%)	Hospital n= 148 (50%)	p-value
Age (Mean, SD)	28.0 (6.8)	30.9 (11.5)	0.0085
Gender			0.088
Male	45 (30.4)	59 (39.9)	
Female	103 (69.6)	89 (60.1)	
Tribe			0.49
Langi	118 (79.7)	125 (84.46)	
Acholi	18 (12.2)	12 (8.1)	
Others	12 (8.1)	11 (7.4)	
Religion			0.0001
Catholic	72 (48.7)	25 (16.9)	
Protestant	37 (25)	84 (56.8)	
Muslim	13 (8.8)	10 (6.8)	
Others	26 (17.6)	29 (19.6)	
Education level			0.0001
None	14 (9.5)	5 (3.4)	
Primary	53 (35.8)	74 (50)	
Secondary	47 (31.8)	63 (42.6)	
College/ University	34 (23)	6 (4)	
Primary source of income			0.0001
Formal employment	36 (24.3)	33 (22.3)	
Relative/ spouse	60 (40.5)	106 (71.6)	
Others	52 (35.1)	9 (6.1)	
Employed			0.01
No	66 (44.6)	88 (59.5)	
Yes	82 (55.4)	60 (40.5)	
Monthly income (Uganda shillings)			0.77
<200,000	93 (62.8)	98 (66.2)	
200,000–500,000	34 (23)	29 (19.6)	
>500,000	21 (14.2)	21 (14.2)	
Marital status			0.004
Single	47 (31.8)	23 (15.5)	
Married	94 (63.5)	115 (77.7)	
Separated/ Widowed	7 (4.7)	10 (6.7)	
Number of children (Mean/ SD)	1.6 (3.5)	2.7 (7.8)	0.0001
General health status			0.0001
Poor	10 (6.8)	10 (6.8)	

Variable	Community n= 148 (50%)	Hospital n= 148 (50%)	p-value
Fair	50 (33.8)	26 (17.6)	
Good	59 (40)	105 (70.9)	
Very good/ Excellent	29 (19.6)	7 (4.7)	
Previously participated in research			0.69
No	108 (49.3)	111 (50.7)	
Yes	40 (52.0)	37 (48)	

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Table 2:

Bivariate analysis of dependent variables and the outcome variable as level of trust

Variable		Co-efficient	Confidence intervals	p-values
Hospital versus community	Hospital	0.143381	0.1115831, 0.1751788	0.0001
Age (years)		0.0024747	0.0006171, 0.0043324	0.009
Gender	Female	-0.0176066	-0.0550519, 0.0198387	0.36
Education	None	1		
	Primary	0.0250495	-0.0502895, 0.1003884	0.5
	Secondary	0.0419785	-0.0341143, 0.1180713	0.3
	College/University	-0.0213768	-0.1067145, 0.0639609	0.6
Religion	Catholic	1		
	Protestant	0.0418051	-0.0000159, 0.0836261	0.05
	Muslim	0.0422791	-0.0288891, 0.1134473	0.24
	Other	0.0279802	-0.0238162, 0.0797766	0.29
Participated in research before	No	1		
	Yes	0.0337126	-0.0069099, 0.0743351	0.1
Willing to participate in research	No	1		
	Yes	0.1544758	0.0937669, 0.2151847	0.0001
Harmed in research before	No	1		
	Yes	-0.1119122	-0.2290242, 0.0051997	0.061
Benefited from research before	No	1		
	Yes	0.0256053	-0.0177826, 0.0689931	0.24
Employed	No	1		
	Yes	-0.0356115	-0.0712112, -0.0000117	0.05
Monthly income	<200,000	1		
	200,000–500,000	-0.0100398	-0.0548044, 0.0347248	0.66
	>500,000	0.0177723	-0.0347377, 0.0702823	0.5
Health status	Poor	1		
	Fair	0.0479482	-0.0273435, 0.1232398	0.21
	Good	0.0632564	-0.0077022, 0.134215	0.08
	Very good/excellent	-0.0526694	-0.1362221, 0.0308834	0.22
Know anyone who participated in research	No	1		
	Yes	0.010592	-0.0268066, 0.0479906	0.58
Know anyone who was harmed in research	No	1		
	Yes	-0.074928	-0.1588233, 0.0089672	0.08
Knows that medical research is regulated	No	1		
	Yes	-0.0364888	-0.0309877, 0.0478504	0.046
Know any laws governing medical research	No	1		
	Yes	0.0028258	-0.0406602, 0.0463119	0.9

Table 3:

Coefficients and p-values of variables in the final regression analysis model with level of trust as the dependent variable

Variable	Category	Coefficient	Confidence intervals	p-value
Hospital versus community	Community	Ref		
	Hospital	0.12	0.0867393, 0.1559811	0.0001
Age		0.00119	-0.0004786, 0.0028553	0.16
Participated in research before	No	Ref		
	Yes	0.04	0.0038377, 0.0767686	0.03
Willing to participate in research	No	Ref		
	Yes	0.095	0.0387596, 0.1507104	0.001
Employed	No	Ref		
	Yes	-0.023	-0.0588553, 0.012807	0.2
Health status	Poor	Ref		
	Fair	0.067	0.0003017, 0.1332552	0.05
	Good	0.05		0.12
	Very good/ excellent	0.003		0.94
<i>Ref: Referent category</i>				

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