UNIVERSITY OF CALIFORNIA, IRVINE
Consent to Voluntary Participation as a Human Research Subject

Research Relations: An Ethnography of Qualitative Data Sharing in Nairobi

You are being asked to participate in a research study. Participation is completely voluntary. Please read the information below and ask questions about anything that you do not understand. A researcher listed below will be available to answer your questions.

RESEARCH TEAM
Lead Researcher
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STUDY LOCATION: Nairobi, Kenya

STUDY SPONSOR: Wenner-Gren Foundation

WHY IS THIS RESEARCH STUDY BEING DONE?
The purpose of this project is to advance understandings of what social scientists producing data about communities in Nairobi consider to be ethical. This project will especially investigate existing legal, social, and technical infrastructures that shaped qualitative data practices as well as those that are perceived to still be needed. A digital platform called the Platform for Collaborative and Experimental Ethnography (PECE) will be used to store and share project data with all participants.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?
This study will enroll approximately 100 participants for interviewing and focus group discussions.

WHAT PROCEDURES ARE INVOLVED WITH THIS STUDY AND HOW LONG WILL THEY TAKE?
Empirical material for this study will be collected through approximately 100 qualitative interviews (approximately one hour in length) with social scientists based in universities, private companies, governments or NGOs, where they have been part of the generating or using qualitative research for technology development. Most interviews will be conducted face-to-face, either at the interviewee's home organization, or at meetings or conferences that we will attend; some interviews will be done online, recorded with permission through Skye or Zoom. Prior to interviewing contact information (name, email, web URL, phone) will be recorded along with the informed consent form. When supporting consent is received, interviews collected for this project will be archived online, in a manner designed for public access and use by the scholarly community. Interview material will also be used in analyses published as working papers, journal articles and books. The research web platform built for this project will follow the lead of established projects in collaborative ethnography (e.g. The Asthma Files http://theasthmafiles.org/). The web platform is being updated to reflect best-practice research data management including privacy and security concerns as recommended by the Research Data Alliance's Practical Policies Working Group (available for review at https://rd-alliance.org/group/practical-policy-wg/outcomes/practical-policy).

WHAT ARE THE POSSIBLE DISCOMFORTS OR RISKS RELATED TO THE STUDY?
There are no known harms or discomforts associated with this study beyond those encountered in normal daily life. The possible risks and/or discomforts associated with the procedures described in this study include: social risks (e.g. stigma or harmed reputations) and a *potential for a breach of confidentiality*, but all risks are minimal and carefully monitored by the researchers.

ARE THERE BENEFITS TO TAKING PART IN THE STUDY?
Participant Benefits
You will have direct access to audio recordings, de-identified transcripts, and photos produced as a result of the focus group discussions that all participants have agreed to be released. These will be available to you through the research web platform and available for you to reuse for non-commercial purposes under a Creative Commons license (Attribution-NonCommerical-ShareAlike 4.0). This license lets you remix, tweak, and build upon the work non-commercially, as long as you credit the source and license any new creations under the identical terms.

Benefits to Others or Society
The project will result in a theoretically robust, empirically grounded conception of qualitative data practices and infrastructures. The project will advance understandings of Open Science and Open Data from non-Western contexts and will extend theorization of scientific ethics by addressing how scientific cultures, practices, and infrastructures shape the incentives, processes and outcomes of social science work. The project will also test and stabilize the process and cyberinfrastructure needed to support collaborative research in the social studies of science. Project results will have wide implications in efforts to improve collaboration between different scientific communities, spheres of capital investments, and scientists and other governing actors—to advance understanding of how research data is developed and used to govern complex societal problems.

WILL I BE PAID FOR TAKING PART IN THIS STUDY?
You will not be compensated for your participation in this research study.

WHAT HAPPENS IF I WANT TO STOP TAKING PART IN THIS STUDY?
You are free to withdraw from this study at any time. If you elect to withdraw or are withdrawn from this research study, the researchers will discuss with you what they intend to do with your study data. Researchers may choose to analyze the study data already collected or they may choose to exclude your data from the analysis of study data and destroy it, as per your request.

HOW WILL MY PERSONAL INFORMATION BE KEPT?
Subject Identifiable Data
All interviews will be voluntary. You will be given the option to be interviewed 1) without recording 2) with only-audio recording 3) with video recording. You will be given the opportunity 1) to be anonymous (except when video recorded) 2) to stop the interview at any point 3) to designate select portions "off the record." Following the interview, you may, at any time, ask for 1) select portions of recordings and transcripts to be redacted 2) recordings to be taken out of the project's publicly accessible online archive 3) for notes, recordings and transcripts of their interview to be destroyed. If you do not request destruction of interview records, these records will be preserved for public use over the long term. You can request destruction of these records (including notes and recordings) at any time.

Data Storage
Records of interviews will only be stored in Angela Okune's (locked) home office and in a web space with restricted access. All material will be treated as confidential to research team until it is determined how it should be treated to be in compliance with the consent form signed for a given interview. Materials designated "anonymous," or with other restrictions, will be stored only in Angela Okune's home office with identifying information redacted. This project utilizes cyberinfrastructure consisting of an open source (Drupal) content management system (CMS) customized for ethnographic researchers. The project web platform is an instance of the Platform for Experimental and Collaborative Ethnography

(PECE; world-pece.org), built and maintained at UC Irvine. PECE allows researchers to archive and annotate artifacts of many kinds (documents, photographs, audio and video recordings) and provides tools for collaborative analysis and presentation. PECE has been built with three layers of privacy and access control: open to the public; restricted to researchers; and fully inaccessible to both the search function and to any user other than the original uploader.

Data Retention
The research data is intended to be kept indefinitely, subject to the stipulations placed by you concerning accessibility as described above.

WHO WILL HAVE ACCESS TO MY STUDY DATA?
The research team, authorized UCI personnel, and regulatory entities such as the Office of Human Research Protections (OHRP), may have access to your study records to protect your safety and welfare.

Any information derived from this research project that personally identifies you will not be voluntarily released or disclosed by these entities without your separate consent, except as specifically required by law. Study records provided to authorized, non-UCI entities will not contain identifiable information about you; nor will any publications and/or presentations without your separate consent.

While the research team will make every effort to keep your personal information confidential, it is possible that an unauthorized person might see it. We cannot guarantee total privacy.

WHO CAN ANSWER MY QUESTIONS ABOUT THE STUDY?
If you have any comments, concerns, or questions regarding the conduct of this research, please contact the research team listed at the top of this form.

Please contact UCI's Office of Research by phone, (949) 824-6662, by e-mail at IRB@research.uci.edu or at 141 Innovation Drive, Suite 250, Irvine, CA 92697, if you are unable to reach the researchers listed at the top of the form and have general questions; have concerns or complaints about the research; have questions about your rights as a research subject; or have general comments or suggestions.

What is an IRB? An Institutional Review Board (IRB) is a committee made up of scientists and non-scientists. The IRB's role is to protect the rights and welfare of human subjects involved in research. The IRB also assures that the research complies with applicable regulations, laws, and institutional policies.

HOW DO I AGREE TO PARTICIPATE IN THIS STUDY?
You should not sign this consent form until all of your questions about this study have been answered by a member of the research team listed at the top of this form. You will be given a copy of this signed and dated consent form to keep. **Participation in this study is voluntary.**

I agree to be audiotaped: No _____ Yes _____

I agree to be videotaped: No _____ Yes _____

I agree to allow access to any existing, relevant data archives I have: No _____ Yes _____ N/A _____

I agree to have excerpts from the interview quoted in written reports and publications:
No _____ Yes _____

I agree to have quoted excerpts from the interview used in oral presentations: No _____ Yes _____

I agree to have all or parts of the audiotape/videotape posted on the project website:
No _____ Yes _____

I agree to have all or parts of the audiotape/videotape available on the project website to students, artists, journalists and others interested in the material for their own projects: No _____ Yes _____

I agree to have records of the interview (including notes and any recordings) preserved for public use permanently: No _____ Yes _____

I also recognize the following conditions:
• I can ask that the video and/or audiotape be turned off at any time during this interview, and the tape will be turned off.
• During the interview, I can designate any comments I make as "off the record" and these comments will be deleted from the audio and/or video recording.
• I can ask that my name not be attached to quotes or recordings by initialing here _____. I acknowledge that anonymity is not feasible if I am videotaped.
• I will be sent a copy of any publication in which I am quoted and will be sent links to any of my interview material on the project website.
• In the future, I can ask for all or parts of audio or video recordings to be: (1) removed from the project website, (2) taken out of the data set from which quoted material is drawn, (3) destroyed.
• I acknowledge that I will not be able to retract anything that is already in print or in press at the time I submit a retraction request.
• I can ask for additional conditions, and have listed these below:

Your signature below indicates you have read the information in this consent form and have had a chance to ask any questions you have about this study.
I agree to participate in the study.

_____   _____
Subject Signature   **Date**

_____
Printed Name of Subject

_____   _____
Researcher Signature   **Date**

_____
Printed Name of Researcher