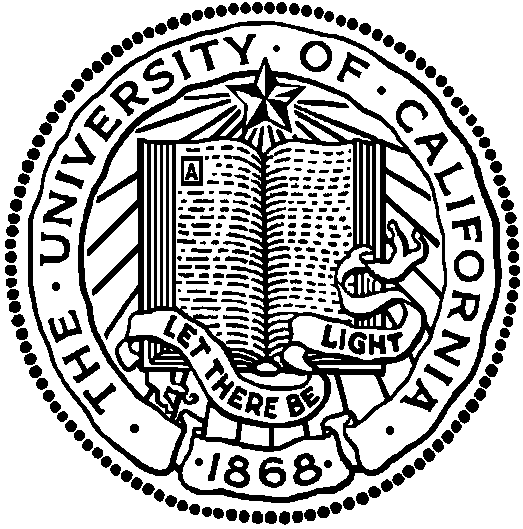
BERKELEY • DAVIS • IRVINE • LOS ANGELES • MERCED • RIVERSIDE • SAN DIEGO

SAN FRANCISCO • SANTA BARBARA • SANTA CRUZ



UNIVERSITY OF CALIFORNIA AT BERKELEY

**Part 1: INFORMATION SHEET - CONSENT TO PARTICIPATE IN RESEARCH**

***Title of Study: Assessing the feasibility of remote mortality estimation in the Democratic Republic of Congo***

*Tool 1a and 2a: Formative Research Tools*

**Key Information\***

* You are being invited to participate in a research study. Participation in research is completely voluntary.
* The purpose of the study is to determine the feasibility of remote public health surveillance methods to monitor mortality in Tanganyika Province, Democratic Republic of Congo.
* The study will take a total of 30 to 45 minutes and you will be asked to answer questions about your knowledge of mortality in Tanganyika province.
* There is no direct benefit to you for your participation in the study [or l*ist possible direct benefits*]. The results from the study may help inform the Health Department and other health service providers in Tanganyika Province.

**Introduction**

I am \_\_\_\_\_, working for IMPACT Initiatives, a sister organization to ACTED, an international non-profit organization working in this area. Together with the University of Kinshasha School of Public Health and University of California Berkeley, we are doing research on methods to improve reporting of deaths in the community to better inform the health department on the number and causes of death in this area. This information helps health actors plan and run health services for the population. We are approaching you today to try to better understand questions related to mortality and people’s social networks in Tanganyika Province. Would you have about 30 minutes to answer some questions about how on perceptions, awareness, and taboos in Tanganyika?

If yes, I would like to give you some information about our work and invite you to take part in this study. If there is any part that you don’t understand you can ask me to stop and I will take time to explain, or you can ask later.

**Purpose**

The reason we are doing this research is to test new methods of collecting this information in an accurate, timely and less expensive way so that the health department can better plan health services. This is why we are asking you, a key informant, about deaths that have occurred in your community which we can learn from and report to the health system.

**Procedures**

Today, we are purposely selecting people with knowledge about mortality in Tanganyika Province .

* *Do you know why we are asking you to take part in this study? Do you know what the study is about?*

If you agree to participate, we will conduct an interview with you that may last from 30 to 45 minutes.

**Benefits**

There is no additional incentive for you or your community for participating in this study, nor does this negatively impact you or your community’s access to humanitarian or other assistance. The information we collect will be provided to the local health department, and be used in our research to refine methods for measuring mortality in the community. Your participation in the research is entirely voluntary. If any of the interview questions make you uncomfortable or upset, you are free to decline to answer or change your mind and end the interview at any time.

* *Do you know that you do not have to take part in this research study, if you do not wish to? Do you have any questions?*

**Confidentiality**

The information you provide us today will be kept as confidential as possible. As with all research, there is a chance that confidentiality could be compromised; however, we are taking precautions to minimize this risk. All data collected will be securely stored and only the researchers will have access to the information. Any information that could be used to identify you will be kept private and not shared with anyone other than the study investigators.

If results of this study are published or presented, individual names and other personally identifiable information will not be used. When the research is complete, we will keep your information for up to 12 months after the study is over, after which personally identifiable information will be deleted/destroyed, and only anonymized data will be kept. The anonymized data could be shared with the local health departments, and other health agencies like the World Health Organization, for purposes of health service planning and response. The anonymized data could be used for future research studies or distributed to other investigators for future research studies without additional informed consent from the subject or the legally authorized representative.

Your personal information may be released if required by law. Authorized representatives from the following organizations may review your research data for purposes such as monitoring or managing the conduct of this study:

* University of California

**Risks/Discomforts**

Some of the research questions may make you uncomfortable or upset. You are free to decline to answer any questions you don't wish to, or to stop the interview at any time.

COVID-19 is a serious disease that has affected the world since March 2020, and can be spread through air and water droplets from an infected person. Our teams are screened daily with temperature checks, and take protection measures such as masks and hand sanitizer in order to prevent any spread to the community. The interview will also take place outdoors, and our team will maintain social a distance of at least 1.5 meters from you at all time. However, given the nature of the virus, there is an inherent risk of being infected with COVID-19 by proceeding with the interview. Should any of our staff become sick from COVID-19, we will inform you as soon as possible. If you are not comfortable

* *Are you aware of the risks of participating in this survey due to COVID-19? Do you understand the measures our teams are taking to mitigate that risk? Do you have any questions about them?*

# Part 2: CONSENT SHEET

**Consent Statement Participant**: I have read the information in Part 1: Information Sheet, or it has been read to me. I have had the opportunity to ask questions about it and all questions I have asked have been answered to my satisfaction. I voluntarily consent to participate in this research.

|  |  |
| --- | --- |
| **If the participant can write, write, sign and date below:** | **If the participant cannot write, print the participant's name, the name and signature of a witness, and take the participant's thumbprint below:** |
| **Printed name of participant \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**  **Signature of the participant \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**  **Date : ( JJ / MM / AAAA )** | **Printed name of participant \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**  **Date : ( JJ / MM / AAAA )**  **Participant's thumbprint** |
| **Participant Phone/Contact (if available):** | |

**Consent Statement Researcher/Person Taking Consent:** I have accurately read the information sheet to the prospective participant and have ensured, to the best of my ability, that the participant understands what is going to be done:

1. The purpose of the study
2. Why they were selected as a participant
3. Confidentiality and voluntary participation
4. Who to contact if they have further questions

I confirm that the participant has had the opportunity to ask questions about the study, and that I have answered all questions asked by the participant correctly and to the best of my ability. I confirm that the participant was not coerced into giving consent, and that consent was freely and voluntarily given. A copy of this ICF has been provided to the participant.

Printed name of researcher: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Signature of researcher: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date : ( DD / MM / YYYY )

Questions

If you have any questions or concerns about this study, you may ask them now or later, even after the interview has been completed. If you wish to ask questions later, you may contact any of the following:

|  |  |  |
| --- | --- | --- |
| **Person** | **Phone** | **Email** |
| Yoann Martin, Responsable Suivi et Evaluation/Mécanismes de réponse aux plaintes ACTED | +243811677031 | yoann.martin@acted.org |
| Ugo Semat, coordinateur national d'IMPACT Initiatives | +423 830 927 748 | ugo.semat@reach-initiative.org |
| Fiston-Muhigirwa Stanislas, agent de terrain de Kalamie | +243 822 526 385 / +243 975 435 675 | fiston-muhigirwa.stanislas@reach-initiative.org |
| Paulin Kasonga, Conseil d'examen institutionnel de l'Université de Kinshasha | +234 816 763 066 | kaskaspaul@yahoo.fr |
| Saeed Rahman, Spécialiste de l'évaluation de la nutrition et de la santé au siège | +1 (330) - 840 - 9661 (Whatsapp) | saeed.rahman@reach-initiative.org |
| Comité de l'UC Berkeley pour la protection des sujets humains | +1 (510) – 642 – 7461 | [subjects@berkeley.edu](mailto:subjects@berkeley.edu) |

If you have any questions or concerns about your rights and treatment as a research subject, you may contact the office of UC Berkeley's Committee for the Protection of Human Subjects, at 510-642-7461 or [subjects@berkeley.edu](mailto:subjects@berkeley.edu).

\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*