

“Utafiti Mbaya”

**A Research Ethics Video Series developed by
Kilimanjaro Christian Medical University College (KCMUC)
and Duke Global Health Institute (DGHI)
Spring 2015**

Facilitator’s Guide for Scenarios 1 through 5

Acknowledgments

CAST

Scenario 1: “Bloodsuckers”

Duke PI	Rose Mwangi
Researcher:	Zephania Msunza
CAB Member	Nevil Sombe
CAB Member	Eunice Haikamesia Barnabas
CAB Member	Erick Alexander Mboya
CAB Member	Angelina P. Kasimba
Village Elder	Beatrice Temba
Mama Manka	Faraja David Ngida
Baba Kikuu	Alex Morice

Scenario 2: “What about our results?”

Duke PI	Rose Mwangi
Researcher:	Zephania Msunza
CAB Member	Erick Alexander Mboya
Village Elder	Beatrice Temba
Participant	Faraja David Ngida
Participant	Angelina P. Kasimba
Participant	Rukia Ibrahim
Past CAB Member	Eunice Haikamesia Barnabas
Past Researcher	Alex Morice
Past Researcher	Nevil Sombe
Past Researcher	Jenae Logan

Scenario 3: “Health or Wealth?”

Duke PI	Rose Mwangi
Researcher:	Zephania Msunza
CAB Member	Eunice Haikamesia Barnabas
CAB Member	Erick Alexander Mboya
CAB Member	Alex Morice
Village Elder	Beatrice Temba
Villager	Faraja David Ngida
Villager	Angelina P. Kasimba

Scenario 4: “Where are they?”

Duke PI	Rose Mwangi
Researcher:	Zephania Msunza
CAB Member	Erick Alexander Mboya
CAB Member	Faraja David Ngida
Participant	Angelina P. Kasimba
Participant	Rukia Ibrahim
Past CAB Member	Eunice Haikamesia Barnabas
Past CAB Member	Alex Morice
Past Researcher	Nevil Sombe

Scenario 5: “Late versus busy”

Duke PI	Rose Mwangi
Researcher:	Zephania Msunza
CAB Member	Nevil Sombe
CAB Member	Eunice Haikamesia Barnabas
Participant	Faraja David Ngida
Participant	Angelina P. Kasimba
Participant	Alex Morice
Researcher	Erick Alexander Mboya
Researcher	Rukia Ibrahim

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Introduction

Kilimanjaro Christian Medical Centre and Duke University have a history of collaboration in numerous research projects. The partnership has been productive but has not been immune to challenges. A series of interviews and focus group discussions with individuals involved in collaborative research at KCMC highlighted a number of issues that have arisen in the past. This video series, consisting of 5 short scenarios (each approximately 5 minutes) seeks to identify where these issues come from and to generate discussion about how they can be overcome to promote more responsible and effective research moving forward. Viewers of the scenarios will discuss the implications of the topics covered, for KCMC faculty and students as well as for future Duke investigators working at KCMC and elsewhere in East Africa.

This Facilitator's Guide provides a description of each scenario, identifies themes to guide discussion, and provides a number of possible discussion questions. Each scenario may be shown alone or in combination with the others. Discussion content may overlap, and we encourage facilitators to identify any links or discussion themes overlooked within this guide.

Overview

In the United States, training in responsible conduct of research (RCR) is required in many grant applications. As low- and middle-income countries develop their own research protocols and portfolios, RCR and research ethics training are an important part of the process.

Areas that fall under RCR include:

1. Conflicts of interest
2. Policies regarding human and live animal subject in research
3. Mentor/mentee relationships
4. Collaborative research
5. Peer review
6. Data acquisition and ownership
7. Research misconduct
8. Responsible authorship
9. Social impact of research (a relatively new area of RCR education)

The scripts for these video scenarios were developed based on culturally relevant issues in research, identified during focus group discussions and interviews conducted by Rose Mwangi and Beatrice Temba of KCMC. The issues raised indicate that some RCR areas, including research with human subjects, collaborative research, and social impact of research, are particularly relevant at KCMC as it continues to work with Duke and with other institutions. These areas are the primary foci of this facilitation manual, though participants may highlight other relevant areas. Additional scenarios may be developed to address the other areas and supplement this pilot project.

Among the specific issues identified at KCMC are that projects have not adequately involved or informed the communities they work in, or adequately informed their Community Advisory Board (CAB) members. Participants have expected payment or the return of test results, but have not received them. The distinction between CAB member and research participants has not been clear to all parties involved. Finally, differing concepts of time and other cultural factors have led to miscommunications that have hampered research projects. These challenges have led some individuals in Moshi and the villages around it to mistrust researchers and have created uncertainty about the purpose and possible benefits of collaborative work.

Directions to the Facilitator of Discussion:

Please read these instructions before viewing the scenarios. This guide highlights a number of RCR areas that have been identified as important in the work going on at KCMC, but please feel free to focus on those most important to the individuals who will participate in your viewing and discussion session.

- 1. Before the viewing and discussion:** Review each scenario and its discussion guide to identify possible RCR areas (discussed in the Overview section) on which you will focus. Familiarize yourself with the list of questions suggested for each, and tailor them to your own speaking style if necessary.
- 2. Before showing the first scenario:** Set rules for your participants to encourage attentiveness and respectfulness. Suggested rules include:
 - Respect the ideas of all other participants, regardless of whether you agree with them. There are no right or wrong answers.
 - Express disagreement, but do so respectfully.
 - Listen to ideas others raise. Consider how your own relate to theirs.
 - Do not feel pressured to speak if you are not comfortable.
 - Ask for clarification if any question is not clear.
 - Feel free to bring up other RCR areas not mentioned, but that you feel are important to the discussion.
- 3. Sequence of showings and discussion:**
 - Before showing each scenario, you may choose to give a brief description of what participants will see. Don't give too much information; allow participants to draw their own conclusions and generate unique contributions to discussion.
 - Play the scenario, and then initiate discussion with your choice of the questions provided in the guide, or with one of your own.
 - Use probing questions to encourage participants to elaborate on interesting ideas, or on topics that seemed to spark the most interest.
 - Encourage participants to share their own experiences with research, or stories they have heard that relate to the video they have just seen.
 - Highlight RCR principles as they come up, asking the participants what they know of the principles and how the individuals in the video scenarios could have upheld them.
 - Repeat this process for all scenarios. Link points of discussion to any related points that came up in discussions of subsequent scenarios.
- 4. Final tips:** This video project will continue to evolve. Please take the opportunity to ask participants for feedback on their experience at the end of the session. Ask them to comment on the usefulness of the exercise and the relevance of the scenarios to their work, or to others' work, at KCMC. Please circulate their comments to the developers of this guide for future adaptations.

Discussion Content:

Scenario 1: Bloodsuckers

Synopsis

This is an introductory scenario highlighting why it is important to be aware of the ethical challenges in conducting research in the KCMC/Duke setting. It illustrates that researchers must be careful of the social value of their research. It begins with a land dispute between two villagers, which leads them to the office of the village chairperson. She will handle their case, but must first meet with a group of researchers and advisory board members who wish to carry out a project in the village. She is reluctant to approve the project, particularly because participation involves a blood sample.

Discussion Themes

- Social value of research.
 - Community engagement and accountability are critical to success
 - Community involvement in setting research agendas gives researchers a chance to explain the need for a study and its possible outcomes
- Collaborative research
 - Communication with CAB about the purpose of research
 - Collaboration with community members beyond the CAB (e.g. village chairperson)
- Respect for human subjects
 - Involve community in recruitment procedures and in selection of incentives
 - Informed consent
 - Disclose information in linguistically and culturally appropriate formats

Discussion Questions

1. What happened in this scenario?
2. Have you experienced any similar issues, whether involving you or your family?
Probe: Have you heard any stories? How was this issue addressed, if it was?
3. What motivates the Duke PI to carry out her work? Is it clear from her explanation?
4. How might the motivation of the other KCMC researchers differ? How might the motivations of CAB members differ? Of participants?
5. Why do the CAB members say people aren't participating?
Probe: In your experiences, whether here or growing up, what are other reasons people might not participate?
6. Do you think that the decision to consult the village chairperson was a good one? Why?
Probes: What are the advantages or disadvantages of involving the village chairperson? Who else might they be able to approach for assistance?
7. Why do you think the village chairperson is hesitating to allow the researchers to proceed?
Probe: What do you think of her reasoning?
8. What are the reasons the researcher and advisory members give to convince the mwanakiti? What do you think of their answers?
Probes: Are there others you think they could have given?
9. Do you think the chairperson's responses were influenced by the presence of the villagers having an argument? If so, how?
10. What could the researchers do differently to have more success in convincing the village chairperson?

Scenario 2: What about our results?

Synopsis

This scenario digs deeper into the social value of research, looking at a blood draw from the point of view of the community members. It illustrates that they may not just be superstitious; they have a great interest in learning their results, whether out of curiosity or out of the desire to learn their health statuses or prevent/treat conditions that ail them.

Discussion Themes

- Social value of research.
 - Maximize social value of research by disseminating results to participants and policy makers after research is completed
 - Perceived potential benefits of research to a community are important, and may be different from what the researchers consider to be benefits.
- Respect for human subjects
 - Ensure that participants know their rights
 - Give participants information arising from the study
 - Feedback findings in a timely manner, if appropriate

Discussion Questions

1. What happened in this scenario?
2. Have you experienced any similar issues, whether involving you or your family?
Probe: Have you heard any stories? How was this issue addressed, if it was?
3. In your opinion, were the participants appropriately informed of what their participant meant? What they would receive?
Probes: What is required for informed consent?
4. Do you think the village members should have asked about getting the results before or after they gave?
Probes: Should they have had to ask for their results? Was the researcher's response adequate?
5. What could be reasons the researchers have not delivered results? (Examples: too many samples for labs to process quickly, delays in reagent shipments, power outages, need for confirmation, neglect)
Probes: What do you think of these reasons? Could they be explained to the participants? When, and by whom?
6. Are there any situations in which results should not be returned to participants as part of a research project?
7. How could the researchers have avoided these problems? Put another way, how could situations like this—where people are angry and feel lied to—be avoided?
8. (*If ending the scenario before the visit to mwanakiti*) What will the participants do? What should they do? How could this have been avoided?

Scenario 3: Health or Wealth?

Synopsis

Scenario 3 addresses the relationship between CAB members and research participants, which may be unclear to some in the community and lead to resentment about differences in compensation. CAB members often receive modest compensation for their efforts to sensitize the community. Participants may receive a more modest compensation, or no compensation.

Discussion Themes

- Collaborative research
 - Identify local partners
 - Negotiate/clarify roles and responsibilities prior to study and re-evaluate throughout study
 - Be respectful of community values and promote fair benefits
 - Collaborative networks “must agree on certain principles regarding their relationships with their participants.”
<http://www.ndph.ox.ac.uk/research/ethox-centre/research-projects/global-health-ethics/the-ethics-of-collaborative-global-health-research>
- Respect for human subjects
 - Avoid coercive incentives
 - Promote justice through providing equitable sharing of benefits and risks

Discussion Questions

1. What happened in this scenario?
2. Have you experienced any similar issues, whether involving you or your family?
Probe: Have you heard any stories? How was this issue addressed, if it was?
3. The CAB member suggested that some participants wish to be paid for their participation. Do you think they should be? If yes, why?
Probe: In some cases but not in others? Please elaborate.
4. Do you think that this is a good way to approach the villagers and request that they participate?
5. What are other ways they might approach participants?
Probes: In other settings? Public or private settings? Could it vary with the setting of a project? How much should participants be paid?
6. Why do you think the villagers are so concerned about the money? (Examples: Poverty, experience of being paid in past research or hearing of those who have been paid)
7. How do you think the CAB members could respond to situations like this, or to people who ask them why they get money but participants don't?
Probes: Do you think there are other possible benefits to participation than receiving money? Do you think the villagers would be convinced by those reasons?

Scenario 4: Where are they?

Synopsis

This scenario again addresses the role of CAB members in research projects, but it looks at the relationship between researchers and CAB members. Without proper information about the purpose of studies and projected timelines for their completion, CAB members struggle to fulfill their roles as liaisons and may encounter hostility.

Discussion Themes

- Collaboration
 - Identify local partners
 - Negotiate/clarify roles and responsibilities prior to study and re-evaluate throughout study
 - Must build and then maintain relationships with collaborators
 - Must determine how and when a collaboration will end
- Respect for Participants
 - Ensure that participants know their rights
 - Give participants information arising from the study
 - Feedback findings

Discussion Questions

1. What happened in this scenario?
2. Have you heard of any similar stories? What happened?
3. Let's discuss the relationship between the researchers and the CAB members.
 - What are the roles of each?
 - When should roles be discussed and established?
 - What information should CAB members receive, and how often?
 - Who is ultimately responsible for the outcome of the research and the experiences of its participants?
4. What steps should be taken to bring a project to completion in a manner that respects all persons involved?

Probe: How might a research team avoid the issues we saw in this scenario?

Scenario 5: Late versus busy

Synopsis

This scenario does not so much address a particular research principle, but rather cultural considerations that may factor into all research projects conducted in the KCMC/Duke setting. Partners in collaborative projects may have different concepts of time. While seemingly minor, this can be a significant barrier to carrying out projects in a respectful manner.

Discussion Themes

- Social value of research
 - Community engagement and accountability are critical to carry out research
 - Be respectful of community values
- Respect for human subjects
 - Ensure that participants know their rights
 - Informed consent
 - Disclose information in linguistically and culturally appropriate formats

Discussion Questions

1. What happened in this scenario?
 - What happened from the point of view of the researchers?
 - What happened from the point of view of the participants?
 - Do these views agree with one another?
2. Have you experienced anything similar to this situation, or has your family?
Probe: Have you heard any stories? Can you describe the experience?
3. Can you think of other misunderstandings that might occur between researchers and participants coming from different backgrounds?
4. What consequences could cultural misunderstandings have for the success of a research project?
5. How could these researchers and participants have better addressed the situation, when the participants arrived late?
6. What could the current Duke and KCMC research team do to prevent something like this from happening again?

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