

# THE EXPERIMENT MUST CONTINUE

## Medical Research and Ethics in East Africa, 1940–2014

Melissa Graboyes

### STUDY GUIDE



---

#### CHAPTER 1

1. What is medical research? How is it defined? What is the goal of medical research? (page 8)
2. How is medical research different than medical treatment? (8)
3. Identify the book's four main arguments. (9-10)
4. What does it mean that East Africans were "active participants" in medical research? Give some examples of what this looked like. (13-14)
5. Why has the author considered the East African region rather than a single country? (15)

#### ACTIVITY IDEAS

Visit the website of three different media sources (such as the *New York Times*, *USA Today*, *National Geographic*) and search for "medical research Africa." What do you find? Are there particular words or phrases that are used regularly? What types of stories are being reported, and from what places? What kinds of patterns do you see?

---

#### CHAPTER 2 PERCEPTIONS

6. This chapter begins with hard-to-believe stories that the author argues can be linked to biomedical practices in the region historically. Do you agree with her? What kinds of evidence does she use to make this argument?
7. What was Mama Nzito's story? Do you believe it? Why or why not? (21)

8. Who is Bwana Matende? Do you think he was a real person? What does he have to do with medical research? (23)
9. Why do East Africans believe researchers can both heal and harm? (29)
10. How is an East African *mganga* different than a biomedical doctor you might visit? How are they the same? (30-31)
11. What is *damu*? How might an East African define the term beyond just “blood”? (31)
12. What is *dawa*? How might an East African define the term beyond just “medicine”? (42)
13. Why might it be a problem that there is no easy or clear way to say “experimental medicine” in Swahili? (43-45)

#### ACTIVITY IDEAS

Examine photos A and B included in this study guide. What can you figure out from these images? Then re-read pages 32-34 that discusses how stories often circulated of blood theft using tubes, and of generic sets of experts. Do these stories seem more reasonable after viewing the images?

Examine photo C included in this study guide. This image shows a Tanganyikan woman wearing a portable respirator as part of a medical research project on energy expenditures. What can you figure out from this image? Does the woman look comfortable? Would you participate in this project? What do you think is being studied?

---

### **CHAPTER 3 RESEARCHERS ARRIVE**

14. What were some of the differences in how biomedical researchers and East Africans understood lymphatic filariasis in the 1950s? (Consider how the disease was defined, how it was spread, was it treatable, whether it was thought to be a problem and if symptoms were considered normal?) (64)
15. When trying to control or eliminate a vector-borne disease like malaria or lymphatic filariasis, what is an “entomological approach and what is a “medical approach”? (65)
16. What kinds of interactions helped shape how researchers were received when they arrived in a new place to conduct research? (68)
17. What are three reasons why residents of Pate Island did not support Goiny’s attempt to eliminate lymphatic filariasis? (70)
18. What was the role of the African assistants who participated in the project on Pate Island? As Africans not from that island, do you think their work was harder or easier than that of Goiny? (75)

#### ACTIVITY IDEAS

Have you ever participated in a medical research trial? What motivated you to participate? If you have NOT participate, what would persuade you to participate?

Read the primary source document D included in this study guide. This is a letter that Goiny wrote after a failed week of work on Pate Island.

What do you notice about the mood and tone of the document?

Do you agree with Goiny calling his work “government-sponsored” but also “non-political”? Are these statements in conflict with each other?

How would you react if a team of medical researchers/foreigners/experts/strangers came to your house in the middle of the night to request a blood sample? What information would you want to know before deciding to participate? What might make you feel pressured to participate (a police officer standing behind the researchers)? What might make you feel reassured (the mayor/your teacher/your pastor coming to introduce the researchers)?

---

#### **SECTION 4 CONSENT OR COERCION?**

19. If you were a medical researcher and wanted to collect blood a single drop of blood/spinal fluid/a brain sample, how do you think you should recruit someone to participate? What information would be relevant to share?
20. What is “therapeutic misconception” and why is it a threat to informed consent? (104-5)
21. Is therapeutic misconception a problem only in Africa? (105)
22. How would you define the term “volunteer”? (100)
23. What groups of people do you think should be labeled as “vulnerable” for medical research and why? (101-2)
24. What does “group consent” refer to, and what do modern East Africans think of the concept? (111-12)

#### ACTIVITY IDEAS

Read the primary source document E, which is a letter from the Kenyan man, Julius Mwangi. After reading the whole document, what is the thing that stands out most to you? What do you think was Mwangi’s goal in writing this letter? What else would you like to know about this case? What other sources could be used to piece together the story?

---

#### **SECTION 5 BALANCING RISKS AND BENEFITS**

25. Why did the Rakai circumcision trial stop early? What did the experiment find? (124)
26. How might the “risk” of blood taking be assessed differently by an East African and a biomedical researcher? (129)
27. What was the question being debated with the “drug question”? What is your opinion about what should be given to participants? Do you agree with Trant or Laurie, or do you have a different opinion? (134)
28. How did Hope Trant characterize her responsibilities as a medical researcher? What did she feel was the goal of medical research? (136)
29. When an individual participates in a medical research project, how might they benefit? (Consider direct, indirect and future benefit) (130-31)
30. What was the risk that Avery Jones was worried about in the Makueni experiment? Why did he want the experiment to be modified or ended? (142)

31. Why are some people unwilling to give cash as compensation for participants of medical research? What is your opinion? (150-51)

#### ACTIVITY IDEAS

Watch a video [1] and look at some of the images [2] of mouth pipetting. What do you think of rumors of blood sucking after seeing these images? (132)

If you were a medical researcher, what would be fair/appropriate to offer participants as compensation? In your opinion, what should the compensation be for? Should it be to compensate for time lost, inconvenience, discomfort of participation? Should it correspond to the risk? Should it be enough to entice someone? Would your answers to these questions depend on what you were asking participants to do or give?

[1] <http://goo.gl/PwTthA>  
[2] <http://goo.gl/MsbEUT>

---

## **CHAPTER 6 EXITS AND LONGER TERM OBLIGATIONS**

32. When a research trial is successful and a new treatment/drug/intervention is deemed valid, do you believe there is an obligation for the new intervention to be offered to those who were experimented upon? (184)

33. What is acquired immunity and how does it protect against malaria? (170)

34. What is the difference between “controlling” a disease, “eliminating” it and “eradicating” it? (172)

35. What did local community members want from researchers? Do you think these were reasonable requests? (179)

36. Consider the Swahili words (and their English translations) that were used to describe the Pare Taveta scheme. Is it important to know whether local communities understood Pare Taveta as an experiment or as a public health intervention? Why might this change researchers’ long-term obligations? (180)

#### ACTIVITY IDEAS

Should researchers be required to participate in the medical research projects they organize? Avery Jones was following in a long line of earlier researchers who practiced self-experimentation, sometimes with dangerous or deadly outcomes. Do you think there should be a rule about self-experimentation, and would that prevent or deter unethical research?

In 2015, the final sets of data from the RTS,S malaria vaccine trial became available. Based on these findings, the WHO decided that beginning in 2016 there will be “3-5 large pilot implementation projects” and depending on the safety and efficacy, these pilot programs “could pave the way for wider deployment of the vaccine in 3 to 5 years.” [3] Other groups, such as Doctors Without Borders, have decided that they will not purchase or administer the vaccine. They stated that the RTS,S vaccine “ultimately does not meet the criteria needed to provide adequate protection for those who need it most” and called for further research to develop a vaccine that is “safe, effective, affordable, and easy-to-use in the highest-burden areas.” [4]

The vaccine is now in limbo about next steps. What do you think of these two different approaches—more research on humans versus waiting for something better and directing scarce resources (funds and professional staffing) elsewhere? Is there anything participant communities deserve having participated in vaccine trials (and borne those risks) for multiple years? Should participant communities have a role in deciding whether the vaccine is made available in their areas?

[3] <http://goo.gl/tb3rAc>  
<http://goo.gl/PkXu6F>

[4] <http://goo.gl/LxaQKd>

---

**CHAPTER 7**  
**CONCLUSIONS**

37. Why was the Nandi malaria control experiment ethically suspect? Why did Avery Jones oppose the project? (189)
38. What is retrospective moral judgment? Why is it hard to make ethical judgments about things that happened in the past? (190)
39. Why does the author call Thomas Fletcher's work "unethical"? Do you agree with her assessment? (191-93)
40. Is it acceptable for medical researchers from one country to go to another country to conduct medical research? If the answer is yes, under what conditions: because a trial will be cheaper in another place? Because the disease only exists in some countries? Because wealthier/healthier people won't volunteer? Because an experiment is potentially dangerous? (194)
41. With the AZT trial in Uganda in 1997, what was the "standard of care" debate about? Generally, what is the difference between a local standard of care and a global standard of care; and specific to Uganda, what was the difference for the global and local standards for treating pregnant women who were HIV positive? (197)
42. In the Trovan drug trial that occurred in Nigeria in 1996, why did parents of participants sue the drug company Pfizer? (198)
43. Why does the author argue that global medical research must continue? (200)

**ACTIVITY IDEAS**

Read the *New York Times* articles on the widespread Hepatitis C epidemic in Egypt [5] and the decision by Turing Pharmaceuticals to significantly increase the price of some of their drugs. [6]

Do you think pharmaceutical companies have any obligation to offer drugs at "reasonable" prices or to make them available in poor countries, or to consumers who would be unlikely to access them otherwise? Does it matter whether the drug was tested in that place in the past?

[5] <http://goo.gl/dZ3gY9>

[6] <http://goo.gl/3QFrkL>

## ADDITIONAL TEACHING MATERIALS

---

### ESSAY PROMPT

Discuss at least one example of medical research presented in the Graboyes reading. Working with the criteria laid out in the Nuremberg Code and the Declaration of Helsinki, how would you assess the research project? In your essay, provide:

detailed description of what the project was about, what it intended to study, with whom, where, when, etc,

detailed ethical analysis. Do you find the project to be ethical or unethical, and in what ways? (Here, you must be very specific in referencing which passages and criteria of the different codes you are judging it on.) If you believe the project should have been modified in some way, what would you change, and how?

how the research project *could* be linked with improvements in “health” or “development” and whether or not you believe these improvements actually happened.

When analyzing the Nuremberg Code and the Declaration of Helsinki, be sure to identify the most salient aspects of each code.

Are there things that are unclear? If so, does that create difficulties when assessing the medical research project?

Do you think these codes are appropriate for governing research in the “developing” world in general, or East Africa specifically?

## ADDITIONAL TEACHING MATERIALS

**FIGURE A**

“The search for and the capture of anopheline mosquitoes in their natural habitat is an important task of the entomologist attached to the malaria control services.”

Source: WHO Regional Office for Africa. *Public Health Work in Africa: Ten Years of Progress*. 1958.



## ADDITIONAL TEACHING MATERIALS

**FIGURE B**

Entomologist Tony Kiszewski in Ethiopia, 2007.

Source: Courtesy of James McCann.



## ADDITIONAL TEACHING MATERIALS

**FIGURE C**

"The estimations of energy expenditure of African women...have been continued at intervals throughout the year... Observations were made on 15 domestic science students at Bwiru Girls' School, four cooks from the school, and one laboratory assistant..." The activities the women performed while "wearing the portable respirometer on her back and with the mouthpiece in position" included sitting, walking around the school grounds, walking with a head load, pounding ground nuts, digging. It appears that "figures obtained for European women would be applicable to Africans." They had hoped to do the activities with multiple people on multiple occasions, but "it was only possible to do one determination of pounding nuts with each of the four as they become very uncooperative."

Source: East African Institute for Medical Research Report, 1958-59



## ADDITIONAL TEACHING MATERIALS

---

**FIGURE D**  
**PRIMARY SOURCE**  
**H.H. GOINY**

February 9, 1956. From H.H. Goiny (Entomological Field Officer) to Senior Parasitologist. CC District Commissioner, Lamu. "Patte Island"

**Displacement to Siyu and Faza.** On Friday, the 3rd February 1956, the announcement of police action against uncooperative boat owners in Lamu (referred to in my Jan report) resulted in motor launch transport to Siyu and Faza being offered to the DIBD at a cost of Shs 120/00. The operation involved a) calling at Siyu creek landing stage and landing camp and work equipment including two 44 gallon drums of water (no fresh water being available on the island) as well as ten members of the Health Office staff required for the moving of the equipment to Siyu villages 1.5 mile further inland and the pitching of the tents b) depositing Michael Okata and Faros Enos, and their belongings and two drums of water at Faza; c) calling again at Siyu creek on the return journey to collect the Health Officer and staff; and d) returning the said staff to Lamu. It was schedule to occupy about 15 hours. The price named therefore appeared reasonable. The Patte Island parties left Lamu on Sat, the 4th of February, at 8 am.

However, it soon appeared that the time table could not be adhered to. The skipper apparently had miscalculated the speed of his launch (the 'Lamy Boat') was capable of. Arriving at the large of Siyu creek two hours behind schedule, the launch was unable to reach destination and was left stranded in the creek some two hundred yards below the landing stage. The enormous difficulties experienced as a consequence in landing the heavy equipment and transporting it by land to Siyu village, especially the vital water drums, swallowed up the whole afternoon, half the night and most of the following morning, when the launch had already returned to Siyu creek after completing its delayed trip to Faza. The 'Lamy Boat' therefore could not be expected to reach Lamu before 8 or 9 pm on Tuesday, after an absence of nearer 36 than the 15 hours initially agreed upon.

The owner of the launch therefore warned me that he would have to present an additional bill for the extra time. I should appreciate a ruling on how to deal with this demand, also in case of similar contingencies which may conceivably arise in the future.

**Developments at Siyu village.** After establishing my tent camp close to the ruined fortifications opposite Siyu village I devoted the remainder of Sunday the 5th February to renewing contact with certain seemingly friendly elements in the locality. I took pains to keep these contacts on a predominantly personal level, having reached the conclusion that the best policy at this stage would be one of 'letting sleeping dogs lie'—that is, of avoiding to summon pompous and ponderous 'barazas' and thereby stir up latent hostilities in the village. Of the existence of such I was, indeed, made aware soon enough. For instance, the offers of accommodation for my assistant Henry Gigiri made during my previous visit to Siyu were now politely and evasively, but nevertheless conclusively, withdrawn, and Henry was forced to go under canvas from the start. Moreover, a group of Arabs presented themselves at the camp and desired to know by whose authority I had established myself in the shadow of the ruined fort, the ground surrounding it being some-

**FIGURE D**  
**PRIMARY SOURCE**  
**H.H. GOINY**

body's private property—like all the rest of the land adjoining Siyu village in any direction I might choose to name. By exercising much tact, however, and by a grand display of my little-known personal charm (which can be effective enough in a dire emergency such as I was facing then) I succeeded in staving off the worst. Permission was half grudgingly, half graciously granted me by the professed owner of the plot to occupy the site for the period of my present stay—say one or two weeks.

It was only on the following day (Monday 6th February) that I was stripped of the last rags of any illusions I may have harboured with regard to the real attitude of the Siyu villagers towards the scheme of investigations which I was about to bring into operation. Very early on that morning a delegation from the village, including one of my personal acquaintances, appeared at my tent. Some of the local householders have congregated, so it was explained to me, to discuss my plans with me, in particular the time of day at which I wished to visit their houses. This with regard to the fact that the majority of them would perforce be absent in the fields during many hours each day. It was precisely such a gathering and such collective explanations I had apprehended; but I persuaded myself to see in the request, plausibly worded as it was, a rather hopeful sign. I hurriedly forsook my breakfast and followed the delegates to the village.

To my speechless amazement I found a milling crowd, many hundred strong, waiting for me across the concrete bridge leading to the village, on the other side of the creek. They packed the verandah of the communal store which usually serve as a meeting place and a sort of club for the male population of Siyu, and every inch of available ground amongst the surrounding shacks, huts and hovels. The serried ranks of sullen, sulking countenances opened at my and Henry Gigiri's approach to allow my passage to the verandah where I was received by the headman and a number of the more prominent notables of the village.

Even before the debate was initiated I was left with no doubt whatsoever that what I found myself in the presence of was a deliberately planned and punctiliously organized defiance meeting. The aged headman, acting as a spokesman, wished it to be made known to me that all the householders of Siyu had assembled to impart to me their views on my proposed activities. These views, it transpired, were that any activities aimed at any form of domestic control whatsoever, and for whatever reason, was considered undesirable from every point of view and would be opposed by every man, child and woman in the village. I asked to be given a chance to consult the various householders individually and at their own premises so as to ascertain their willingness or otherwise to let me proceed with my work. It was retorted that this course would be wholly superfluous, seeing that all—the emphasis was laid on the 'all'—the population of Siyu was present here, and this with the precise object to manifest their unanimous objection of the measures I intended to introduce. In the end I proposed that such amongst the householders as were not opposed to granting us access to their homes make themselves known by raising an arm. Not one arm went up. The result of this 'count' was greeted by laughter and jeers from several groups, and I left the meeting and immediately returned to camp.

There I was joined later in the day by some of the villagers who had previously befriended me, or pretended to befriend me. By them I was given to understand that I had been wise—in fact, wiser than I realized—in desisting from entering any of the houses that morning. The population in a number of meetings held previously in the local mosks [sic] had endorsed a resolution to obstruct any such attempt by all and any means, not excluding the extremist, such as offering violence to the person of the European in charge himself.

**FIGURE D**  
**PRIMARY SOURCE**  
**H.H. GOINY**

On Tuesday morning I decided upon a stratagem to break the deadlock. I approached the Headman and asked him whether he would be good enough to lend me bucket and a rope (implying that I had neglected to bring this equipment to Siyu myself) so as to enable me to investigate wells and other mosquito breeding places outside the house. The headman, although doubtful for a moment, allowed himself to be surprised into assenting. Thus it was equipped with the headman's own gear that we began checking wells and waste water puddles in the village. However this move was equally brought to a premature standstill. Wherever we went, groups of inquisitive adolescents formed followed us. Their behavior became progressively more hooligan-like and provocative. Some remarked that the wells were neither the headman's nor the 'serikali's' [government's] property, and would we therefore please decamp. Even grown ups began to join the youngsters and called to me insolently that wells in Siyu were private property in the same way as the houses on whose ground they stood, and should therefore be let alone exactly like the houses. When at one stage I absented myself to look round for new wells, one of the adolescents actually tried to push the Health Office labourer who was helping Henry Gigiri down a well. Thereupon both fled back to camp, where I found them an hour later after a vain search for them of the village during which I had been persistently misinformed and misdirected by all of whom I asked the whereabouts of my assistants.

No further work has since been attempted in Siyu.

**Developments in Faza.** Equally on Tues the 7th February Michael Ikate arrived in the afternoon from Faza by dhow upon previous instructions to report on his reception there. Events in Faza had shaped very much in the same way as in Siyu. The promised accommodation had been withheld from Michael Ikata and Faros Enos, who had been forced to seek the hospitality of one of the dispensary dressers stationed at Faza. No permission was given them to enter houses. They were repeatedly warned that if they attempted to do so they must be prepared to take the consequences. The Mudir himself has advised them to be as discreet and cautious as possible. According to the Mudir, the question of the adoption or rejection of the house inspection program was going to be decided communally by a mass baraza to be held shortly. Meanwhile, they also had found themselves prevented from doing out-of-doors work by similar tactics of intimidation as those employed in Siyu.

Next morning (Wednesday 8th) I walked myself to Faza, where I intended to discuss the situation with the Mudir. I also expected to meet the District Surgeon of Lamu, Dr Shah, there on his monthly inspection tour. When I arrived in Faza at 9.30 am after a two hours march, I learned that at that precise moment mass demonstrations against our activities were in progress in the locality. For a later hour that morning the population had been convoked to assemble at the mosk. Prayers and sacrificial slaughterings were to be offered up for the deliverance of the island from the wiles and schemes of those inspeakable [sic] entomologists, harbingers of Allah alone knows what pernicious forms of government interference in our domestic affairs in the disguise of benefactors! Not only that we would have to bury contraband ware underground, we might actually have to keep clean and orderly our interiors! (Fact. Arguments of this nature have been advanced to me personally when inquiring into the reasons of the general opposition.) The District surgeon and the Mudir had both been invited to participate in these politico-religious ceremonies. I understand that, while Dr Shah has not followed the invitation, the Mudir, owing to his admittedly rather delicate position in the community, has not found it possible to absent himself.

**FIGURE D**  
**PRIMARY SOURCE**  
**H.H. GOINY**

**Conclusions.** My renewed visit to Faza, following upon that of Patte village and my stay at Siyu, has brought fresh confirmation of my previously gained impression of the existence of a concerted movement to defy and defeat the planned anti-filariasis investigations on the island. Additional intelligence gleaned yesterday in Faza points to the fact that the ceremonial gatherings there had already been preceded by similar meetings and resolutions in the mosks [sic], first of Patte village and then of Siyu, and that an obvious and patently successful attempt has been made to arouse widespread and in fact general popular feeling against a government-sponsored venture of a non-political and strictly medico-scientific nature by irresponsible appeals to Mahometan [sic] canonical law.

I have laid my facts, intelligence and impressions before you in so much detail in order to facilitate your judgment of the advisability or inadvisability of pressing forward the scheme of filariasis investigations on Patte Island. While I refrain from uttering my personal views on this matter, I cannot conclude without calling attention to the striking similarity between the local methods for discrediting and undermining government influence and those applied through the Kikuyu insurrection: here as there a covertly operating ring of wirepullers appears to depend for their hold upon the masses upon organized gatherings, ceremonials, sacrifices and invocations of a religious or pseudo-religious character. The coincidence may or may not be fortuitous, it is nevertheless unmistakable.

In deciding the future of the proposed investigations it will not be inopportune to give a certain amount of consideration to the not unduly remote possibility of touching off on the underdeveloped and underpoliced Protectorate Coast a seditious movement comparable to the Mau Mau rebellion in scope, if not extent.

While awaiting your further instructions, I will benefit from the interval of enforced inactivity to have my organic complaint examined by the Provincial Surgeon in Mombasa. Kindly therefore contact me regarding the next move at the Division's usual address in Mombasa.

## ADDITIONAL TEACHING MATERIALS

---

**FIGURE E**  
**PRIMARY SOURCE**  
**JULIUS MWANGI**

August 14, 1961. From Julius Mwangi to Director of Medical Services, Kenya.  
"King George Hospital"

I am writing to ask you kindly to consider my case which I have stated below:

On 6th March 1961, I was admitted to King George Hospital for ordinary treatment, but on 14th March 1961 I was transferred to the infections disease hospital. While there I was told by Sister Miller that I was to undergo six months treatment so as to be fully cured, and that meanwhile I should not bother about my job for I would not lose it and over that I was to be getting my usual pay while in the Hospital. But she did not specify whether it was trial treatment or ordinary. However, these statements were contradicted by a letter I received from my then employers, which promised me full pay for three months only and then for the other three months half monthly pay.

On learning this I tried to get help from sister Miller but she was very unfriendly and even she threatened to dismiss me from Hospital before I was cured.

On 16th June 1961, the Doctor with the Sister called me into his office and asked me whether I would like to continue with the trial treatment but I was unable to tell them anything, for as I have mentioned above it had not been explained to me clearly which treatment I was to be having. At this I was upset, and I tried to explain to them how it would be difficult for my family staying in Nairobi to be able to live on half pay as promised by my employers.

After a time this trial Medicine was stopped but things were never the same again, for the general treatment I was then receiving changed much. They treated me most unkindly.

On 19th June 1961, they stopped this trial medicine, and on my cards and other relative documents on my case, the Doctor commented that I was uncooperative; after twelve days of ordinary treatment, I was discharged as a cured case, without culture sensitivity results chit. As a result of this early discharge I strongly believe I might be a danger to my family and public, for such cases before have proved so.

When I returned to my job I was sacked immediately for apparently someone at the Hospital had undermined me by sending bad information. Now, this is worrying me greatly for the doctor had told me I should be eating good food, but how can I get this when out of employment?

Secondly, I would like to know whether a patient is to be forced to accept a trial treatment or to be requested to so?

Thirdly I would like to know the authority which the Hospital staff have over ones employment.

**FIGURE E**  
**PRIMARY SOURCE**  
**JULIUS MWANGI**

Fourthly, I would like to know the persons who is responsible for paying me compensation for my lost job.

Fifth, I would like to know what arrangements have been made to provide for my family in case I lose my life as a result of this half treatment.

There are many things that are worrying me over this issue, but I do not want to tire you unduly, but before I finish this letter, I request you kindly to weigh the facts as they are, and in case of you wanting details, I am ready to submit them on request.