MAT @ Medicine Anthropology Theory

## INTERVENTIONS

# Lost in translation?

On collaboration between anthropology and epidemiology

Denielle Elliott and Timothy K. Thomas

#### Abstract

This rather unorthodox essay is a dialogue between an anthropologist and an epidemiologist, both of whom were involved with a large-scale collaborative ethnographic project exploring medical field studies, or 'trial communities', in western Kenya. Reflecting on their involvement with this project, the authors consider the pragmatics of what 'collaboration' represents in different disciplines and how it is enacted. The dialogue, which included a follow-up interview after the research was completed, highlights the expectations and tensions in such collaborative projects and offers the epidemiologist an opportunity to highlight the ideas, methods, and possibilities that he perceived as being 'lost in translation' between sociocultural anthropology and experimental medicine. We raise critical issues regarding the disjuncture between epidemiological and anthropological practices in research design, methods, epistemology, and collaboration, with the hopes of provoking more discussions regarding best practices in collaborative research projects.

## Keywords

collaborative ethnography, epidemiology, anthropology of clinical trials, HIV/AIDS

Medicine Anthropology Theory 4, no. 2: 1–17; https://doi.org/10.17157/mat.4.2.497 © Denielle Elliott and Timothy K. Thomas, 2017. Published under a Creative Commons Attribution 4.0 International license.

#### Introduction

Today, interdisciplinary collaborative research is treated as a self-evident good (Callard and Fitzgerald 2015). The current research landscape encourages, if not demands, interdisciplinary collaborative research ventures, especially in public and global health. In Canada, the national health funding agency, the Canadian Institutes of Health Research, encourages collaborative research with industry and with Aboriginal communities, and the formation of interdisciplinary international study teams, as do many other large funding agencies and research organizations including the International Development Research Council, the National Institutes of Health, the Wellcome Trust, and the Gates Foundation. Yet, such collaborations can be epistemologically challenging, especially when they involve medical researchers and anthropologists, or those trained traditionally in a positivist or scientific paradigm and those trained in postpositivist or humanistic paradigms (Callard and Fitzgerald 2015; Mauthner and Doucet 2008). As Callard and Fitzgerald (2015, 15) have recently asked of the injunction to be collaborative: 'What is this space? What forms of practice and ethics does it call us towards? What holds it together?'

Within anthropology, there have been many different approaches to collaboration and a range of interpretations of what exactly collaboration means for ethnographic practice. It has played a critical role in how anthropologists conduct research since the discipline emerged. For instance, Luke Lassiter (2008) traces collaborative practices in anthropology to Lewis Henry Morgan's work with Seneca Native American Ely Parker in the 1840s, and others point to the work of Franz Boas and George Hunt on the Northwest Coast as collaborative. For anthropologists like Joanne Rappaport (2008, 1), collaborative anthropology is 'morally and ethically necessary' and contributes to an anthropological commitment of engagement and activism. Many social scientists turn to collaborative research as a means to 'level the playing field' with interlocutors who might not share the same privileges or power and as a means to develop local research capacity in communities that have historically not had a voice or role in academic research (for instance, see Elliott et al. 2015; Prentice et al. 2013). Anthropologists George Marcus and Douglas Holmes (2008, 82) argue that we understand collaborative research as part of a 'refunctioning of ethnography' that demands a 'deferral to subjects' modes of knowing', especially in collaborative research with 'epistemic communities' like the trial communities that we discuss here. They suggest that in epistemic communities we find scientists and health professionals with an ethnographic curiosity, who are willing to engage in critical debates about science, medicine, and technology (also see Rabinow and Stavrianakis 2013).

As Johannes Fabian (1990) reminds us, anthropologists' subjects' 'modes of knowing' have always shaped the discipline of anthropology. Ethnographic knowledge emerges from dialogues, debates, and disagreements among ethnographers and participants, not only from our field observations. Our conversations with our research participants are critical to ethnographic knowing and fieldwork is therefore inherently a coproductive process, but that doesn't always mean collaborative, or cooperative. Anthropologists may be intellectually sensitive and attuned to our interlocutors in a way other researchers are not, but practices of collaborative research require a different level of engagement in research design, methods, the sharing of conceptual frameworks, analysis, and writing.

Collaborations between medical anthropologists and epidemiologists have been a focus of discussion and debate for decades.<sup>1</sup> In 1957, Andrew Fleck Jr and Francis Ianni (1957, 38) optimistically stated, 'one of the most promising partnerships in scientific history is a growing liaison between social science and medicine'; yet almost sixty years later we (Tim and Denielle) felt that collaborative relationships between ethnography and epidemiology had not fulfilled that promise. For Michael Agar (1994), merging anthropology and epidemiology into 'epnography', as he lightheartedly terms it, offers a productive possibility to transform both fields: 'a conceptual shift' allowing epidemiology to consider social and environmental context. However, whether collaborative partnerships are mutually constructive for both the anthropologists and epidemiologists remains a subject of debate. Dominique Béhague and colleagues (2008) write that often public health and medical researchers turn to anthropology for a simplified, superficial 'tool box' that is free from theory (in essence, for qualitative methods). Indeed, Gilles Bibeau (1997, 247) has suggested that some anthropologists seem to survive working within public health by 'alienating' themselves from the theories and methods of their own discipline. Almost twenty years later, it is fair to say that many anthropologists have taken up Bibeau's (ibid.) call to adopt 'radical positions, to end sterile partnerships', producing many critical and important studies within and about experimental medicine and global health (for instance, see Nguyen 2010).

What do epidemiologists hope to gain from collaborations with anthropologists or other social scientists? Even today, some epidemiologists understand anthropology as a tool for getting at 'community knowledge' or 'local knowledge', while anthropologists who study epistemic communities (like medical research or AIDS interventions) may instead see ethnography as useful for the unexpected knowledge it produces about expertise, epistemology, and relations of power. As highlighted in the conversation that unfolds here, this epistemological difference can result in failed collaborative research if it is not addressed and resolved. As Holmes and Marcus (2008, 82) remind social researchers, interdisciplinary

See for instance, Fleck and Ianni 1957; Dunn and Janes 1986; Packard and Epstein 1991; Inhorn 1995; Trostle and Sommerfeld 1996; Bibeau 1997; Bourgois 2002; Janes and Corbett 2009; Béhague, Gonçalves, and Gomes Victora 2008; Pigg 2013.

collaborations need to start with 'conceptual work' – that is, defining or redefining what it is we do, explaining the questions we want to ask, and clarifying how we imagine such investigations unfolding. This includes, they write, revising 'preconceived research frames to their core' (Holmes and Marcus 2008, 83).

Building on these debates and critiques, we interrogate collaborative practices and conceptual interdisciplinarity, and raise questions regarding the ethics, politics, and practicalities of collaboratively studying experimental medicine and public health.<sup>2</sup> This essay emerges from a series of conversations between the authors: Denielle, who is an anthropologist, and Tim, who is an epidemiologist. Taking place over an eight-year period, these discussions were both formal – audiorecorded, semi-structured interviews – and informal. They form the basis of our inquiry into the deeper complexities of collaborative research and the epistemological tensions between sociocultural anthropology and epidemiology.

In essence, this essay captures an on-going debate about the expectations and tensions in such collaborative projects, and it offers us an opportunity to highlight the ideas, methods, and possibilities that we perceive as being 'lost in translation' between sociocultural anthropology and experimental medicine. We are especially interested in the disjuncture between epidemiological and social scientific practices in methods, epistemology, and collaboration. To this end, Tim speaks about his disillusionment with the overall experience of working with anthropologists, and Denielle responds with her own reflections on Tim's observations and the dilemmas they raise. Although these conversations are largely about anthropology and epidemiology, we hope they speak to the tensions that pervade interdisciplinary and collaborative research partnerships more generally.

## An ethnography of clinical trials in East Africa

We met in 2007 in Kenya when Tim was the director of HIV Research for a large Americanrun clinical research centre in Kenya and a coinvestigator on a collaborative ethnographic project exploring medical field studies, or 'trial communities', in western Kenya (led by a UK-based anthropologist). Denielle was hired to work on this project as a postdoctoral fellow,<sup>3</sup> and although Denielle left the project within the first year, Tim and Denielle have

<sup>3</sup> This essay is not meant in any way as a critique of the trial communities project but we both felt that there were important lessons to be learned from our experiences that were not being discussed.

<sup>&</sup>lt;sup>2</sup> In this respect, it continues a longstanding conversation about the relationship between social science and public health (for instance, see Bibeau 1997; Phillipson 2014; Mauthner and Doucet 2008; Dunn and Janes 1986; Packard and Epstein 1991; Inhorn 1995).

maintained a close friendship. This conversation was not spurred by a scholarly interest in theorizing collaborations between epidemiology and anthropology, but by both of us feeling rather misunderstood by the other. It became clear that we had different expectations of the collaboration and incongruous assumptions about the other's discipline. Like most good friends, we banter back and forth; poke fun at each other and what we do; offer sarcastic, sometimes biting commentary while we laugh; and continue to imagine collaborative, interdisciplinary projects – even if not with each other.

Though Denielle left the ethnographic project early, she continued to work in Kenya and on a similar project, a large, multisited, transnational clinical trial on pre-exposure prophylaxis (PrEP) antiretroviral therapy for couples among whom only one partner is HIV positive ('discordant couples') (see also, this issue, Ukpong and Peterson on collaborations within the context of PrEP). She continued to have conversations in the field with epidemiologists working on clinical trials and AIDS interventions, and felt that Tim's critiques of anthropology, social theory, and the 'trial communities' project helped clarify some of the frictions resulting from critically minded social scientists (and health researchers) working within experimental medicine and public health.

The context for the interest in this collaboration is important. In the early 2000s, when Tim started conversations about ethnographic collaboration, HIV was a highly stigmatizing infection in western Kenya. (It still is, but perhaps to a lesser extent.) Antiretroviral drugs were just becoming more available to more people at lower cost and HIV testing was being promoted widely, yet people would travel to other towns for testing and treatment for fear of being recognized. Research teams consisting of Kenyans from the same region who were conducting a study of the prevalence of HIV in a rural area were chased away with threats of violence; this occurred despite considerable efforts at community consultation, engagement, and employment.

In this volatile context, Tim and his organization proposed to conduct one of the first clinical trials in this region. The study was to evaluate the use of approved antiretroviral drugs to prevent the transmission of HIV from mothers to their children during late pregnancy and early breastfeeding. This entailed recruiting pregnant women who would agree to HIV testing, and then, among those who tested positive, agree to participate in a study that required a considerable commitment from them for over two years (see Thomas et al. 2011). There were many concerns about the community's acceptance of the study, despite it having been approved by a local scientific committee and the national institutional review board, and whether we would be able to recruit the five hundred women needed for the study. A community advisory board was established and focus group discussions were held with women representing the participating population. Almost all of the staff hired for

the study were from the region and spoke the local language. When the idea of collaborating with an anthropologist was proposed Tim thought this would help him, and perhaps the other local and non-Kenyan researchers, have a better understanding of the communities from which the participants came and thereby help in the design and conduct of future research studies or even guide modifications to the proposed pregnancy study.

The 'trial communities' ethnography project where we met was a very large, well-funded collaborative study of a medical research centre in western Kenya involving multiple partners from the United Kingdom, Kenya, and the United States. It featured a team of anthropology graduate students and research assistants, including Denielle as postdoctoral fellow, who were embedded within the medical research branch that Tim directed. The team observed the everyday practice of a wide range of activities, from management meetings to participant recruitment in rural field settings. The ethnographic research staff interviewed everyone in the project, from the drivers to the country director. This was essentially a collaborative ethnography of a collaborative medical research site, and, as such, entailed a rather complicated bureaucratic arrangement with many collaborators and coinvestigators who often had very different expectations regarding the research and their role within it.

At the centre of this conversation is a question about the pragmatics of what 'collaboration' represents in different disciplines and settings, and how it is enacted in funding proposals, data collection and analysis, and dissemination practices. In what follows we want to highlight two core issues that underlie our ongoing conversation. The first is the idea of collaborative research and what that entails, or, more specifically, what it does not entail. Disciplines such as anthropology and epidemiology have different expectations of collaborative partners. How we collaborate may be shaped by individual approaches to a particular conception of research and the different ways that scholarly workers see their work as being overtly political or apolitical. Second, as indicated in our title, is the issue of language and 'conceptual interdisciplinarity' (Béhague, Gonçavles, and Victoria 2008, 1706). Many concepts and keywords are disciplinary in nature, creating barriers in inter- or transdisciplinary dialogues. Over the years, Tim has frequently critiqued the use of academic jargon by anthropologists, which he finds often makes our writing unintelligible. We write this essay as a point of provocation, hoping it will force more discussions and debates about the ways in which anthropologists and epidemiologists successfully (or unsuccessfully) work together.

## 'Do anthropologists collaborate?'

Denielle approached Tim with the idea to cowrite a paper that spoke to anthropology and epidemiology collaborations after seeing a call for papers for a conference session in 2015

(organized by Eileen Moyer and Eva Vernooij for the European Association of Social Anthropology's Medical Anthropology conference) to which he replied, 'Do anthropologists collaborate?' Though Tim's experience with anthropologists was somewhat limited, this seemed like a good opportunity to try to come to some understanding of the intentions of and tensions between the two disciplines. His experience with putting the clinical trial together entailed multiple people discussing everything from ethics, design, recruitment, drug purchasing, participant reimbursement, data collection, analysis, publications, and more, all of which involved members of the study team, both local and in the United States. It was truly a collaboration of many individuals that continued for the duration of the study and still continues as more analyses are conducted and manuscripts written. In contrast, Tim's interaction with the anthropologists on the 'trial communities' study was quite limited. Tim advocated on behalf of the collaboration to other staff and for institutional approval, but felt the trial communities project lacked established and regular opportunities to discuss problems, insights, and next steps as the project progressed.<sup>4</sup>

In a follow-up interview in June 2015, we sat down with a list of questions that Denielle had drafted about collaborative ethnography in the context of the trial communities project, and Tim explained what had been his initial interest in the ethnographic research:

The purpose of the [trial communities] study as I saw it was to provide us [medical researchers] with a better insight into the dynamics between researchers and the researched. *I thought we might be able to explore more what participants in research studies really understood about research and what they were consenting to.* I hoped that perhaps we would get feedback that would allow for modifications in how we approached people about participants in the study and how we interacted with participants. I thought we could all benefit from some critical but constructive feedback. (emphasis added)

As the director of HIV research, Tim saw the ethnographic project as being a way to improve his study and the other studies for which he was responsible. In the original research protocol for the ethnography, Tim highlighted the objectives that clearly defined its usefulness to medical epidemiology: "The findings will *directly benefit ongoing and planned studies* by KEMRI and CDC and other research programmes in Kenya . . . in particular in the area of AIDS research and HIV vaccine development. Moreover, *their implications will be of use for medical interventions or trials in similar settings*" (emphasis added).

<sup>&</sup>lt;sup>4</sup> Some of the study staff allowed the anthropology team to observe their interactions with participants and others did not.

Tim imagined that the ethnographic project would strengthen the way he and his colleagues in medicine conducted their research. When Denielle asked Tim if he felt the project had accomplished these objectives and if it had changed the way he conducted research, he said it hadn't. Although there was feedback in 2010 from the principal investigator (a medical anthropologist), Tim had expected 'real-time' feedback so they could make changes during the trial, which started in 2003 and ended in 2009. He also expected that the published papers would not be limited to anthropology journals but had imagined publications that would inform experimental medicine and public health more generally. This didn't happen and Tim suggested these represented lost opportunities for real change in medical research practice.<sup>5</sup>

Tim felt that he was not treated as an equal partner in the collaboration, nor was he engaged in any authentic way in the various stages of the trial communities project. There is no reason that Tim, as a coinvestigator in a collaborative study, couldn't have participated in the writing of other papers or drafted the community report for the local partners. Part of the tension regarding the role and expectations of the coinvestigators was that Tim was both coinvestigator of the ethnography project and the director of HIV research at the centre, which made him a research subject to be interviewed by the ethnographic researchers. Coinvestigators often have full access to all data collected, but concerns that lower-level staff or participants might not trust the ethnographic team if their interview responses were shared with Tim meant that Tim was not given access to field notes, audio files, or transcripts. So, in fact, his 'collaborative' role in the ethnographic project was limited to setting up the study and guiding it through the institutional review boards. Once the study was started, he was, as he said, 'provided with occasional updates and [he] supported the various graduate and postgraduates' who joined the ethnographic team, a limited role that left him disappointed about the lack of collaboration.

Although the lone ethnographer is a familiar trope, it certainly was not the expectation, nor was it the experience that Tim had had with other scientific collaborations in which multiple coinvestigators worked as a team. When reflecting on the 'trial communities' project from beginning until end, Tim explained that although he was a coinvestigator on the application that was submitted to the institutional review board in Kenya, he had not been involved in the development of the project's funding proposal. The head of the 'trial communities' study had already secured the funding from a UK funder when Tim became involved in the project, which meant Tim had very little influence in defining the issues that he thought

<sup>&</sup>lt;sup>5</sup> Tim explained that the principal investigator did provide some sort of report, though well after Tim had left and Tim had not been asked for input.

needed to be investigated. Thus, although the project purported to be collaborative, it certainly did not follow the recommended practices for developing shared research agendas in collaborative research (for instance, as recommended by the National Aboriginal Health Organization, International Development Research Council, and the Canadian Institutes of Health Research). Although Tim's experience may have seemed like an aberration – a collaborative ethnography that does not follow collaborative research principles – it does speak to different historical practices in anthropology and epidemiology. Epidemiologists frequently work with a team of researchers, while anthropologists have historically worked on their own from beginning to end, making it a lonely experience for many.

Tim noted that he felt that he and the project's principal investigator also had different expectations about writing and authorship.<sup>6</sup> Tim explained: I guess collaboration can take many forms and there can be a greater or lesser degree of collaboration. Certainly when it came to publications I expected more input . . . maybe not as a coauthor, but to have an opportunity to review prior to publication. . . . I think most collaborators [and coinvestigators] in biomedical research are included as coauthors on papers if they have contributed to the concept, conduct, analysis, or writing up of study'. As a coinvestigator, Tim felt he should have been more meaningfully involved in the study, especially in analysing the data and in defining what the publications would focus on and where they would be published. While he recognized that the degree of collaboration might not warrant coauthorship and the differences in disciplinary norms regarding coauthorship, he made it clear that he didn't feel that an intellectual space had been created that fostered or even allowed a cooperative, coproduction of knowledge. To return to Holmes and Marcus, Tim felt that his 'mode of knowledge' did not inform the papers in a way that he expected.<sup>7</sup> Further, he stated that he didn't push to be listed as a coauthor because the use of academic jargon and the theoretical nature of the publications meant that he barely understood what

<sup>7</sup> The social sciences and medicine have different guidelines for what counts as coauthorship. Tim granted that he did not need to be coauthored, although his disciplinary guidelines (for instance, the International Committee of Medical Journals) would have counted his participation in the research to warrant coauthorship on all of the papers produced from the trial communities project (see <a href="http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html">http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html</a>). Compare these with the British Sociological Association's guidelines for coauthorship (<a href="http://www.britsoc.co.uk/publications/guidelines-reports/authorship-guidelines.aspx">http://www.britsoc.co.uk/publications/guidelines-reports/authorship-guidelines.aspx</a>).

<sup>&</sup>lt;sup>6</sup> In fact, at least two other team members from the study said the same thing to Denielle. There was a general lack of clarity regarding the roles of coinvestigators and research assistants in writing papers and authorship guidelines. As a postdoctoral fellow, Denielle experienced similar frustration when she asked for coauthorship guidelines.

was being argued.<sup>8</sup> This points to a serious misunderstanding in the overall conceptual framework of the trial communities project. If Tim felt he couldn't understand the papers, then it would be difficult to argue that the papers – and the research on which they were based – were somehow reflective of his mode of knowing.

His observations return us to the question of what collaboration means to different disciplines. Denielle thinks that part of this problem lies in the fact that we tend to ask different questions of the worlds we observe. Tim agrees, and explains further: 'I think in the context of the "trials study" the objectives of the anthropologists were more of academic interest to examine the research community and they didn't contribute to meeting the objectives of the studies being "observed". In other words, Tim suggests that the objectives of the anthropologists did not contribute to improving clinical trial research and community engagement in medical research. Given the stigma surrounding HIV and the rapidly changing field of HIV testing and treatment in Kenya at that time, it seemed imperative to have a better understanding of what the participating communities thought about the disease, research in general, and research on HIV, and how these insights could impact the work that Tim was doing. Perhaps some of the tension stems from the interpretation of the term 'trial communities'. In Tim's mind this meant the focus was the community/communities where the various HIV and other clinical trials were taking place; conversely, the anthropologists interpreted this to mean the whole environment of a trial and all the actors involved in it (including Tim as the principal investigator of the trial under study). Furthermore, the intent seemed purely to observe; there was no intent to necessarily 'improve' or change that community or clinical trial practices.

Marcus (2007, 7) pinpoints the 1986 publication of *Writing Culture* as the moment when there was a shift in how anthropologists do research, to a different type of collaboration in which two 'others' come together 'as epistemic partners' with a 'motivated interest in a "third" other, elsewhere – an object of curiosity, fear, anxiety, or speculation'. Or, in other words, collaborations are built on a field of intellectual, and perhaps political, mutuality (Gable 2014). In a sense, this is what Tim expected of his work with anthropologists. Tim and the

<sup>8</sup> Although Tim stated that he did not need to be listed as a coauthor, he did ask to see all papers prior for publication. He estimates that four edited books and approximately eight articles have been written that have directly or indirectly been informed by the collaborative ethnography, but he was only ever sent one of those papers for review and comment prior to publication. As recently as November 2016 Tim received an email from a graduate student on the project with an attached manuscript, saying, 'this is going to be published', but without any opportunity to contribute in a meaningful way. Denielle published two articles based on her work on this collaborative project and in both cases she gave Tim an opportunity to read, comment, and request changes to the drafts. principal investigator had identified a third other: concerns about community engagement and the relationship between researchers and researched. Yet, the anthropology team was more interested in the everyday work of the research site. The community focus was part of the larger study (taken up as two separate projects led by graduate students) but the theoretical interests led the principal investigator to focus on questions about value, evidence, and labour. This points to one of the frictions in the collaborative encounter between anthropology and epidemiology: The former is asking 'how is knowledge produced?' and the latter is asking 'what is the knowledge being produced and how can it be applied?' Given the different intellectual stakes, can anthropologists both advance the theoretical questions they want to ask and fulfil the needs and expectations of their epidemiologist collaborators?

## Irreconcilable interpretations?

Denielle realized in the process of cowriting this essay that a key difference, and perhaps the source of the misunderstanding between Tim and her, was related to the ways in which they differently understood the same story or same event. Tim's perspective on medicine, his practices in the field, and his particular ethics of medical research with marginalized groups (he now works with Indigenous communities as the director of the Alaska Native Tribal Health Consortium) has influenced how Denielle thinks about medical research and medical researchers in East Africa. Denielle respects his commitment to the work he has done in HIV trials and his approach to management and his staff, and she admires the way in which he often pushed back against institutional and disciplinary forces that he thought were unfair or inequitable. Tim told Denielle stories in Kenya about the CDC's institutional policies that unintentionally segregate American workers from Kenyan workers, which she was able to explore further. From Liberia, Tim shared stories and photographs of the intense militarization of Ebola treatment and care, which he saw as antithetical to what he had signed up to do. And in Alaska he voiced frustration over the inadequate engagement of Alaskan Natives in research in Alaskan Native communities. Tim offered what Denielle saw as social critiques of institutional and disciplinary structures, reflective of an anthropological sensibility.

Denielle has taken up and written about these issues, yet, often, when she has sent him drafts of articles for review prior to submission or presentation, he has disagreed with her retelling of his anecdotes. Denielle asked him: 'I see my papers as being fundamentally informed by the stories you tell me about your field practices. So when you disagree with my analyses, I'm always confused. Do you have thoughts on this?' Tim responded: 'I don't necessarily disagree, but sometimes your interpretation of an event comes from a different perspective, so some interaction or event that I might see at its most basic, face value – "this

is what happened" – level, you might interpret in the context of hierarchy or roles and relationship or colonial history, which hadn't necessarily occurred to me, or, might be reading more into it than maybe is really the case'. With this response, Tim was suggesting that perhaps simple human interactions get interpreted by the discipline of anthropology in ways that may or may not always apply. As a relatively wealthy, white, educated, professional male working in Kenya, he recognized that race, hierarchy, and privilege pervade so many interactions, yet he was asking: is there the possibility that there are moments when those issues do not apply and do not need to get interpreted by the anthropologist and buried in academic jargon?

But the other issue Tim highlights in this comment is that he thinks sometimes anthropologists' (or Denielle's, to be more specific) analyses make a mountain of a molehill. Although some epidemiologists have challenged traditional epidemiological methods and seriously consider socioeconomic factors and context in their analyses of health inequities (see, for example, Krieger 1999, 1994; Krieger and Smith 2004; Bartley, Smith, and Blane 1997), there are disciplinary differences between much of anthropology and most of epidemiology in how we understand the production of illness and disease. Ethnographers are fundamentally trained to think about the historical, political, economic, social, and cultural contexts of things, peoples, events, and spaces. HIV is never just a virus to an anthropologist. It is raced, sexed, gendered; it is shaped by capital accumulation, colonialism, migration, displacement, and violent encounters. Treatments, preventions, and possible cures are similarly shaped by these forces and histories, and so a clinical trial is never only medicine in the making, void of context. Tim asserts that it would be inappropriate to think that epidemiologists are naïve to forces that shape a disease and the response to it. That is what epidemiology is: the study of what causes disease, who it impacts, when, and how. However, Tim argues that the field of anthropology may perceive the field of epidemiology as having a somewhat superficial understanding of a disease, one that relies too heavily on tables and statistical analysis.

## Anthro-speak, epi-speak, and the problem of language

Sometimes anthropologists want to ask different questions from those of their collaborators. However, to be granted access to a state-run medical research field station and its clinical trials, anthropologists may be required to ask the same sort of questions as our colleagues in epidemiology, – to have a shared 'third other' in Marcus's terminology. As Denielle negotiated access to the PrEP trial, for example, the coinvestigators directed her to revise the sorts of questions she was asking. In light of the publications that have resulted from the trial communities project, it seems that the principal investigator may have wanted to ask different questions (about labour, value, and epistemic communities), but had to sacrifice these in order to gain access to the trial (see also Geissler 2013, 2011a, 2011b; Geissler and Molyneux 2013). Denielle's work has been guided by an attempt to answer theoretical questions being debated in social anthropology while also providing answers or helpful suggestions to epidemiologists on how to do better research. Yet, being able to produce publications that do both is challenging for anthropologists and epidemiologists. Tim was surprised by the sorts of publications that resulted from the project and often referred to those as 'esoteric and academic'. Although there was an understanding initially that some papers would be produced that involved more members of the HIV research team, those have not been written and are unlikely to be written at this point. Tim explains that, given the demands of the clinical trial and writing of manuscripts, it was certainly not possible to take a lead on writing any papers regarding the trial communities project, and it would have been hard to do so given how peripheral he was to that study.

The failure to produce papers that provide clear guidelines on how to improve clinical trials on the ground and contribute to theoretical debates in social anthropology is not reflective of effort; Denielle suggest that instead it is indicative of the incommensurability of epistemology, politics, and language, or at least the tensions among them. Perhaps more than any other issue, Tim has critiqued what he calls 'anthro-speak', by which he means the use of anthropology-specific jargon and theoretically dense discourse. He grew frustrated with the research proposal and subsequent papers that spoke of 'new social imaginaries'; 'What does that actually mean?!' he asked. When Denielle asked Tim what he would do differently, should he do the project again, he said he would insist on the use of accessible language in order to facilitate a more cooperative and cocreative process. Next time, he explained, he would 'make sure that publications use language that is understandable to the non-anthro audience if they are to have any impact'.

The question of language is transdisciplinary; medical epidemiologists also write for specialist audiences, often obscure to both the layperson and specialists from other fields. Anthropologists who commit to collaborative projects must be willing to ask questions that are less 'esoteric and academic' and medical doctors and epidemiologists also need to be open to considering questions that situate medicine in broader contexts of structural, institutional, and pedagogical practices. This is a larger issue of epistemology; it speaks to the different stakes we have in knowledge production and it acts as a reminder to all researchers to be cognizant of the ways in which our own writing and discourse may alienate possible collaborators, general audiences, students, and interlocutors.

# Conclusion

We went back and forth, more than either of us had anticipated, with this essay, trying to come to a place of agreement. We want to collaborate together and we see collaborations between anthropologists and epidemiologists as being potentially fruitful and necessary for addressing social and health inequities in the global setting. Tim ended our conversation with a funny text message that Denielle thought captured his overall sentiment about our exchange and his attitude toward anthropologists exploring epidemiology and public health. He suggested that Denielle 'hear from P.E.T.E. People for the Ethical Treatment of Epidemiologists. It's a growing movement. I'm a founding member'.

Although Tim jokes about P.E.T.E., his comment speaks to how ignored he felt, during the collaborative ethnographic research in Kenya. Both anthropologists and sociologists have written about the sense of betrayal expressed by their interlocutors, especially when they are critical of the structures they work within, such as medicine, clinical trials, and development projects.<sup>9</sup> We share our debates and conversations here in the hope that such honest, intellectual exchanges will contribute to stronger, more ethical, collaborative engagements in anthropology, in which collaborators will no longer feel peripheral to or betrayed by the research process. Our experiences remind us that in spite of decades of discussions and debates about collaboration, both disciplines fall short and have work to do. A contemporary, twenty-first-century anthropology must ensure that all collaborators have a chance to shape the research project at key junctures and are asked to coauthor the results, and that jargon gives way to a shared language. Within the discipline there seems growing consensus that collaborative research is 'morally and ethically necessary' (Rappaport 2008, 2), and yet as our experience highlights, the everyday practical reality suggests anthropologists still must reimagine and reform how we do collaborative anthropology.

## About the authors

Denielle Elliott is a sociocultural anthropologist at York University, Toronto, Canada. Her work focuses on the anthropology of medicine, science, and technologies in East Africa and Canada. She is currently working on a collaborative life-story book with Kenyan scientist Dr Davy Koech.

Timothy Thomas is a medical epidemiologist with broad clinical and research experience in Kenya and Alaska. He attended medical school in the United States and completed a

<sup>&</sup>lt;sup>9</sup> See Scheper-Hughes 1979; Brettell 1993; Bosk 2001; Mosse 2006.

residency in Family Practice. After several years working in hospitals in East Africa and Alaska he joined the CDC as an Epidemic Intelligence Service Officer. He returned to Kenya for seven years to work at the Kenya Medical Research Institute (KEMRI)/CDC field station in western Kenya. He is now in Alaska and engaged in research with the Alaska Native people.

#### References

- Agar, Michael. 1994. 'Recasting the "Ethno" in "Epidemiology". *Medical Anthropology* 16, no. 1–4: 391–403. <u>https://doi.org/10.1080/01459740.1994.9966123</u>.
- Bartley, Mel, George Davey Smith, and David Blane. 1997. 'Vital Comparisons: The Social Construction of Mortality Measurement'. Sociology of Health & Illness 19, no. 19B: 127–52. <u>https://doi.org/10.1111/1467-9566.00089</u>.
- Béhague, Dominique, Helen Gonçalves, and Cesar Gomes Victora. 2008. 'Anthropology and Epidemiology: Learning Epistemological Lessons through a Collaborative Venture'. *Ciencia & Saude Coletiva* 13, no. 6: 1701–10.
- Bibeau, Gilles. 1997. 'At Work in the Fields of Public Health: The Abuse of Rationality'. *Medical Anthropology Quarterly* 11, no. 2: 246–55.
- Bosk, Charles. 2001. 'Irony, Ethnography, and Informed Consent'. In *Bioethics in Social Context*, edited by C. Barry Hoffmaster, 199–220. Philadelphia: Temple University Press.
- Bourgois, Phillipe. 2002. 'Anthropology and Epidemiology on Drugs: The Challenges of Cross-methodological and Theoretical Dialogue'. *International Journal of Drug Policy* 13, no. 4: 259–69. <u>https://doi.org/10.1016/S0955-3959(02)00115-9</u>.
- Brettell, Caroline. 1993. When They Read What We Write: The Politics of Ethnography. New York: Praeger.
- Callard, Felicity, and Des Fitzgerald. 2015. Rethinking Interdisciplinarity across the Social Sciences and Neurosciences. London: Palgrave and Macmillan.
- Dunn, Frederick, and Craig Janes. 1986 'Introduction: Medical Anthropology and Epidemiology'. In *Anthropology and Epidemiology*, edited by Craig Janes, Ron Stall, and Sandra Gifford, 3–34. Norwell, MA: Kluwer Academic Publishers.
- Elliott, Denielle, Marian Krawcyzk, Corrina Gurney, Archie Myran, Rod Rockthunder, and Lyanna Storm. 2015. 'Reimagining Aboriginality, Addictions, and Collaborative Research in Inner City Vancouver, Canada'. *Creative Approaches to Research* 8, no. 1: 22–44.
- Fabian, Johannes. 1990. Power and Performance: Ethnographic Explorations through Proverbial Wisdom and Theater in Shaba, Zaire. Madison: University of Wisconsin Press.

- Fleck, Andrew, Jr., and Francis Ianni. 1957. 'Epidemiology and Anthropology: Some Suggested Affinities in Theory and Method'. Human Organization 16, no. 4: 38–40. <u>https://doi.org/10.17730/humo.16.4.b23p724j32447284</u>.
- Gable, Eric. 2014. 'The Anthropology of Guilt and Rapport: Moral Mutuality in Ethnographic Fieldwork'. HAU: Journal of Ethnographic Theory 4, no. 1: 237–58. <u>https://doi.org/10.14318/hau4.1.010</u>.
- Geissler, Paul Wenzel. 2011a. "'Transport to Where?'' Reflections on the Problem of Value and Time à propos an Awkward Practice in Medical Research'. Journal of Cultural Economy 4, no. 1: 45–64. <u>https://doi.org/10.1080/17530350.2011.535335</u>.
- Geissler, Paul Wenzel. 2011b. 'Parasite Lost: Remembering Modern Times with Kenyan Government Medical Scientists'. In Evidence, Ethos and Experiment: The Anthropology and History of Medical Research in Africa, edited by Paul Wenzel Geissler and Catherine Molyneux, 297–332. Oxford: Berghahn Books.
- Geissler, Paul Wenzel. 2013. 'Public Secrets in Public Health: Knowing Not to Know while Making Scientific Knowledge'. American Ethnologist 40, no. 1: 13–34. <u>https://doi.org/10.1111/amet.12002</u>.
- Geissler, Paul Wenzel, and Catherine Molyneux, eds. 2011. Evidence, Ethos and Experiment: The Anthropology and History of Medical Research in Africa. Oxford: Berghahn Books.
- Holmes, Douglas, and George Marcus. 2008. 'Collaboration Today and the Re-Imagination of the Classic Scene of Fieldwork Encounter'. Collaborative Anthropologies 1: 81– 101. <u>https://doi.org/10.1353/cla.0.0003</u>.
- Inhorn, Marcia. 1995. 'Medical Anthropology and Epidemiology: Divergences or Convergences?' *Social Science & Medicine* 40, no. 3: 285–290. <u>https://doi.org/10.1016/0277-9536(94)E0029-R</u>.
- Janes, Craig, and Kitty Corbett. 'Anthropology and Global Health'. *Annual Review of Anthropology* 38: 167–83. <u>https://doi.org/10.1146/annurev-anthro-091908-164314</u>.
- Krieger, Nancy. 1994. 'Epidemiology and the Web of Causation: Has Anyone Seen the Spider?' Social Science & Medicine 39, no. 7: 887–903.
- Krieger, Nancy. 1999. 'Embodying Inequality: A Review of Concepts, Measures, and Methods for Studying Health Consequences of Discrimination'. International Journal of Health Services 29, no. 2: 295–352. <u>https://doi.org/10.2190/M11W-VWXE-KQM9-G97Q</u>.
- Krieger, Nancy, and George Davey Smith. 2004. "Bodies Count", and Body Counts: Social Epidemiology and Embodying Inequality'. *Epidemiologic Reviews* 26, no. 1: 92–103. <u>https://doi.org/10.1093/epirev/mxh009</u>.
- Lassiter, Luke. 2008. 'When We Disagree: On Engaging the Force of Difference in Collaborative, Reciprocal, and Participatory Approaches'. Paper presented at the 107th Annual Meeting of the American Anthropological Association, San Francisco, California, 19–23 November.

- Marcus, George. 2007. 'Collaborative Imaginaries'. *Taiwan Journal of Anthropology* 5, no. 1: 1–17.
- Mauthner, Natasha, and Andrea Doucet. 2008. "Knowledge Once Divided Can Be Hard to Put Together Again": An Epistemological Critique of Collaborative and Team-Based Research Practices'. *Sociology* 42, no. 5: 971–85. <u>https://doi.org/10.1177%2F0038038508094574</u>.
- Mosse, David. 2006. 'Anti-social Anthropology? Objectivity, Objection, and the Ethnography of Public Policy and Professional Communities'. *Journal of the Royal Anthropological Institute* 12: 935–56.
- Nguyen, Vinh-Kim. 2010. The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS. Durham, NC: Duke University Press.
- Packard, Randall, and Paul Epstein. 1991. 'Epidemiologists, Social Scientists, and the Structure of Medical Research on AIDS in Africa'. *Social Science & Medicine* 33, no. 7: 771–94.
- Phillipson, Andrea. 2014. 'Translating Critical Public Health'. *Critical Public Health* 24, no. 3: 349–60. <u>https://doi.org/10.1080/09581596.2013.827326</u>.
- Pigg, Stacy Leigh. 2013. 'On Sitting and Doing: Ethnography as Action in Global Health'. Social Science & Medicine 99: 127–34. https://doi.org/10.1016/j.socscimed.2013.07.018.
- Rabinow, Paul, and Anthony Stavrianakis. 2013. Demands of the Day: On the Logic of Anthropological Inquiry. Chicago: University of Chicago Press.
- Rappaport, Joanne. 2008. 'Beyond Participant Observation: Collaborative Ethnography as Theoretical Innovation'. *Collaborative Anthropology* 1: 1–31. https://doi.org/10.1353/cla.0.0014.
- Scheper-Hughes, Nancy. 1979. Saints, Scholars, and Schizophrenics: Mental Illness in Rural Ireland. Berkeley: University of California Press.
- Thomas, Timothy, Rose Masaba, Craig Borkowf, et al. 2011. 'Triple-Antiretroviral Prophylaxis to Prevent Mother-To-Child HIV Transmission through Breastfeeding: The Kisumu Breastfeeding Study, Kenya: A Clinical Trial'. *PLoS Med* 8, no. 3: e1001015. <u>https://doi.org/10.1371/journal.pmed.1001015</u>.
- Trostle, James, and Johannes Sommerfeld. 1996. 'Medical Anthropology and Epidemiology'. *Annual Review of Anthropology* 25: 253–74. <u>https://doi.org/10.1146/annurev.anthro.25.1.253</u>.