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# Rethinking our Rigor Mortis: Creating space for more adaptive and inclusive truth-seeking in community-based global health research in Kenya

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#### **ABSTRACT**

As global health researchers, we have long embraced the conviction that the answers to complex problems of poverty and disease will reveal themselves if only we apply enough scientific rigor. Yet, at the community level, our group of American and Kenyan investigators has begun to question whether our veneration of rigor is itself contributing to the intractability of certain types of global health problems. Here, we illustrate examples from our experience among the remote island communities of Lake Victoria, Kenya, and join a chorus of emerging voices, to examine how our culture of control as global health scientists may marginalise truth-seekers and change-makers within communities we seek to serve. More broadly, we seek to acknowledge the limitations of control over truth that rigorous academic research affords. We suggest that by relinquishing this pervasive illusion of control, we can more fully appreciate complementary modes of answering important questions that rely upon the intrinsic resourcefulness and creativity of community-based enterprises taking place across sub-Saharan Africa. While such inquiries may never solve all problems facing the diverse populations of the continent, we advocate for a deeper appreciation of the inherent capacity of adaptive, locally contextualised investigations to identify meaningful and enduring solutions.

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#### Introduction

As global health researchers working in sub-Saharan Africa, we claim membership within a scientific community united by a common passion – translating methods and resources of academic science into meaningful health advancements that will improve lives within marginalised populations. Yet, many of us also acknowledge our inheritance in a historical scientific apparatus responsible for shocking complicity in support of racist policies (Gamble, 1993), colonial agendas (Geissler & Kelly, 2016; Horton, 2013), and persistent structural inequities (Farmer, 2003; Heimer, 2007). We click past these dark reminders each time we renew our online ethical research certificates (Braunschweiger & Goodman, 2007), reassuring ourselves that never again will we be complicit in injustice under the guise of research. Given the robust tools of contemporary health sciences, and the resources now at the disposal of our institutions, surely our

movement now advances with sound moral footing as we mobilise the armoury of cutting-edge research to subdue the chaos of critical health challenges faced by communities across sub-Saharan Africa.

Yet, for those of us who engage at the community-level with problems such as HIV/AIDS, it often appears that for every effective health intervention, numerous contingencies - the incidental political, economic, and logistical confounders that were well controlled within our studies - re-emerge time and again to thwart meaningful translation of innovative ideas into sustainable gains (Parker, 2000). Based on our own experience in Kenya, our group has begun to question whether this inertia persists not because our research designs generally lack sufficient clarity or statistical strength, but because of the subtle power dynamics that remain embedded in our cherished scientific methods and funding structures (Greenhalgh, Howick, & Maskrey, 2014), peer review processes (Smith, 2006), and authorship guidelines (Iyer, 2018; Sumathipala, Siribaddana, & Patel, 2004). Increasingly, members of our team have felt unduly handcuffed by global health's intensifying focus on certain scientific epistemologies that restrict 'truth-seeking' to rigorous predetermined paradigms, rather than modes of pragmatic problem solving that are inherently more inclusive and accessible at the community level (Nickles, 1988).

Here, we join a chorus of emerging voices (Adams, Burke, & Whitmarsh, 2014; Gautier, Sieleunou, & Kalolo, 2018; Geissler & Pool, 2006), and illustrate examples from our group's experience on Mfangano Island in Western Kenya, to examine our personal involvement in the cultures of control that are still very much alive within global health science, and that often marginalise truth-seekers and change-makers within the communities we seek to serve. Our group is comprised of American and Kenyan investigators, formalised through a research-training partnership we formed in 2018 called the Mfangano Community Health Field Station. As collaborators, we each view the enterprise of global health through our unique perspectives in the field, as a physician-anthropologist (Salmen), chair of public health department at a Kenyan University (Ndunyu), Director of a community-based health organisation in rural Kenya (Magerenge), and as the Executive Director of a global health institute at a large US university (Prasad). Across this range of viewpoints, we offer reflections upon our evolving practice of global health science and its capacity to identify and sustain pragmatic solutions in a rural community-based context.

Specifically, we seek to acknowledge the limitations regarding the control over truth that we now recognise within even our most rigorous study protocols. We suggest that by relinquishing the illusion of control, a perspective born out of the culture of our advanced scientific training, we can more fully appreciate complementary modes of answering important questions that rely upon the contextualised knowledge and resourcefulness of informal community-based investigations. Such inquiries may never solve all problems facing the diverse populations of sub-Saharan Africa. Nonetheless, we increasingly see ourselves as advocates for more inclusive community-based methodologies that hold inherent capacity to identify highly adaptable, and ultimately more sustainable, solutions to complex health problems facing specific communities.

#### Whose evidence counts?

During the regular activities that support our careers in global health research, from preparing grant applications, reviewing manuscripts, teaching and mentoring, designing protocols, analysing data, we have grown accustomed to standards and practices that reinforce our collective assumptions about the correct way to make truth. All of us implicitly recognise the ways in which we must employ certain language and utilise validated methodologies in order to survive and thrive in our respective fields. While we may facilitate internal debate about particular approaches, in the eyes of the public and the major funders who support our efforts, global health, like the majority of health sciences, now operates within an era of increasing fealty to 'evidence-based' principles, 'outcome-oriented' methods, and 'impact-driven' interventions.

It is precisely because these tenants are now so widely embraced and championed, that we have felt compelled to pay attention to those raising questions about the normative assumptions inherent in these evidence-based principles. Whose evidence is getting counted and prioritised by the administrators of global health funding (Adams, 2016; Sheikh, Bennett, El Jardali, & Gotsadze, 2017)? Which points of reference are we using to establish meaningful outcomes (Hunt & Godard, 2013)? And most challenging, what unintended impacts emerge from conducting global health research within marginalised communities (Crane, 2010; Fairhead, Leach, & Small, 2006)?

Certainly, questions of scientific hegemony and biomedical control have been raised and explored thoughtfully and in much more depth than provided here (Foucault, 2003), as well as the critical role of community-based participatory research (Minkler & Wallerstein, 2011). Yet, as the paradigms of 'evidence-based medicine' continue to gain momentum within global health, as well as in popular discourse regarding health research around the world (Aellah & Geissler, 2016), it is worth lifting up the hood and inspecting the normative structures that actually drive our 'best practices' and 'gold standards', as well as tracing their full impact where the rubber meets the dirt roads in communities where we work.

## More rigour equals more truth

According to Arturo Escobar's famous critique of 'International Development', the practice of development is problematic not only when aid agendas fail, but also when they succeed, because of the way that the development enterprise so strongly sets the terms of daily engagement and behaviour for poor people around the world (Escobar, 2011). Global health has sought to distinguish itself from the 'post-war incarnations of health development' by placing relatively greater emphasis on research itself (Adams et al., 2014). As researchers in global health, relying on lenses of scientific objectivity, we attempt to see past the normative pitfalls that ensnared our respective missionary, imperialist, and neo-liberal predecessors (Geissler, 2013; Walsh, Brugha, & Byrne, 2016). Rather than remaking the world in our own ideologies, we imagine that we are revealing objective phenomena in pursuit of better health outcomes. We remain steadfast in our conviction that the answers to the complex problems of poverty and disease will reveal themselves if only we can apply enough scientific rigour (Sandelowski, 1993). Yet, the question that has frequently troubled our group's position in the field is this: What if our veneration of rigor itself is further contributing to the intractability of certain global health problems?

As global health researchers, many of us feel enormous pressure to prove ourselves in the positivist terms set by the scientific gatekeepers of clinical biomedical research (Macfarlane, Jacobs, & Kaaya, 2008). As a result, within the academic halls where we type up protocols, teach, and hunt for grants, we unconsciously bear the leaden weight of this compulsion towards more rigour. We find ourselves apologising in our abstracts and conclusions when our community-based protocols fail to fit neatly into the gold standard of a randomised design. We assign our qualitative data to sit quietly in the background alongside 'anecdote'. Or, worst of all, we avoid asking the urgent questions raised by our community partners, opting instead to seek hypotheses and indicators that are more readily willing to cough up an answer under RCT inquisition.

Thus, the imagined admonitions of peer reviewers or potential funders frequently push us to exclude or minimise the common-sense conclusions that can be often drawn through the informal inquiries of contextually-experienced (i.e. local) investigators, unless they have 'the numbers' to back them up. We pre-emptively translate the narrative from the rich local context where disease and health, their sources and solutions, actually live (Schall, 1995), into the sterile idioms of biomedical research. When we decide to prioritise rigorous, reproducible results, our group has found that we are often forced to relegate a vast diversity of local resources, individual skillsets, and community perspectives to the sidelines of engagement as incidental confounders. Yet, in our experience, when we actually step back and acknowledge the contextualised relevance of these 'confounders', surprising conclusions and solutions have also emerged.

#### **Embracing confounders in Western Kenya**

Our group has been conducting research among HIV hyperendemic fishing villages along the shores of Lake Victoria in Western Kenya for the last 10 years. Here, we coordinate a community-based research department housed within a multipurpose resource centre operated by a local non-profit on remote Mfangano Island (www.organichealthresponse.org). All our studies are coordinated by trained local staff, working in collaboration with Kenyan and international investigators. Together, we have sought to understand and identify solutions to the social and ecological determinants of health impacting rural Lake Victoria populations (see Chang et al., 2018; DeLorme et al., 2018; Fiorella et al., 2017; Nagata et al., 2011, 2015; Salmen et al., 2015).

Mfangano is home to approximately 30,000 people who live in remote fishing villages, accessible from the mainland by a 1-hour boat ride. Families here rely on traditional farming, fishing, and boat building, a way of life that has persisted for dozens of generations. Mfangano is one of the last places on earth with first-language Suba speakers (Kenny, 1977). Sadly, due political marginalisation, ecological destruction, and the devastating impact of HIV/AIDS, UNESCO has designated the Suba language and culture as 'definitely endangered' (www.unesco.org/languages-atlas/index.php).

Like many investigators who dedicate longitudinal energy within a particular context, over the course of multiple community-based investigations, we have learned hard lessons about research processes that go beyond the formal conclusions we draw from the data logged into our spreadsheets. We highlight a few participant observations from our own fieldwork on Mfangano Island as a means of tracing our evolution in perspective and practice, mirroring what see as a broader transition-taking place among community-based researchers across sub-Saharan Africa. These reflections represent our attempts to critically understand our role as global health researchers, and acknowledge the humbling uncertainties that we frequently experience in the field.

### A 'sentient ecology'

Our fieldwork began as an ethnographic study among the Suba people of Lake Victoria to understand, ostensibly, how these remote fishing communities in Western Kenya came to represent one of the most HIV-prevalent populations in sub-Saharan Africa (Salmen, 2009). Over the past several decades, sentinel data has consistently demonstrated HIV prevalence of 25–30% among adults in the general population in this district, marking this as one of the most HIV-impacted communities in East Africa (NASCOP, 2008). As ethnographers among the Suba and Luo of Mfangano, we began to appreciate the unique ways in which these communities pay attention to the presence of HIV/AIDS. We learned that sentinel data relied upon by people on Mfangano are not merely epidemiological, but also relational, and ultimately ecological. While 'myths and misconceptions' abound, local attitudes about HIV among the Suba often reflect underlying biomedical trends and frequently incorporate a breadth of social and ecological observations that demographic statistics frequently neglect. This locally specific commentary on infectious disease maps onto what anthropologists in other contexts have described as 'sentient ecology' (Ingold, 2007) or the 'body ecologic'(Hsu, 2007).

Within these communities everyday conversations frequently centre around activities in and around the Lake itself. Initially, this discourse appeared for us as daily background noise; we remained intently focused on the biological and behavioural factors that we had already reasoned most likely modulated HIV risk. Yet, during those times when we put down our clipboards and recorders, and chatted informally with friends and neighbours on Mfangano, a rich conversation about the ecological determinants of HIV infection slowly came into resolution. Conversations about local trade practices such as *jaboya* (often translated as 'fish-for-sex') and terms with double meanings such as *tembea* (Swahili for 'drifting' in reference to an extractive type of unanchored fishing, but also referencing extramarital sex) began to draw myriad ecological connections between the fishery and sexual risk.



What may be considered common knowledge among residents on Mfangano, emerged for us as a surprising revelation - HIV epidemiology along these shores of Lake Victoria is closely linked to the introduction of foreign species of fish: Nile Perch (Salmen, 2009).

As we started paying attention to these conversations, we uncovered a diverse literature supporting this local sentient ecology. We learned that in the 1950s, against the warnings of numerous prominent ecologists, the British Colonial Administration began secretly stocking Lake Victoria with juvenile Nile Perch (Pringle, 2005). They sought to 'develop' Lake Victoria into a profitable export fishery, and they succeeded (Pringle, 2005). By 1980, the 'Nile perch boom' began (Bokea & Ikiara, 2000). While European financers began earning hundreds of millions of dollars a year (Abila, 2003), exporting millions of tons of perch to European markets (Balirwa, 2007), local communities began experiencing extreme protein-energy malnutrition (Geheb et al., 2008). During this period, Haplochromine Cichlids, celebrated by ecologists as 'the most spectacular freshwater species flock in the world' (Goldschmidt, 1998), experienced the most rapid mass vertebrate extinction in recorded history (Vitule, Freire, & Simberloff, 2009). At the same time, migrant fishermen began converging from across Africa like a gold rush. Many carried with them a newly emerging pathogen, human immunodeficiency virus, first recognised along these shores as 'slim disease' (Serwadda et al., 1985). The arrival of thousands of cash-solvent migrant fishermen, vulnerable women and customary trade practices such as 'fish-for-sex' (Camlin, Kwena, & Dworkin, 2013), rising food insecurity (Geheb & Binns, 1997), and ecological destruction culminated in a perfect storm of HIV/AIDS transmission, permanently disrupting the lake ecosystem and the lives of its people (Alison & Seeley, 2004; Salmen, 2009).

As informal conversations about Nile Perch, the fishing economy, sex, and HIV-risk opened up unexpected connections for the 'experts' on our team, we also began paying more attention to local discourse regarding the mysterious wasting illness known by the Dholuo word 'chira' (Hauge, 1974). Long before emergence of HIV/AIDS, Dholuo communities have described chira as an affliction suffered by individuals and their families as a consequence of having broken certain cultural traditions or relationship taboos (Dilger, 2008). While public health campaigns have sought to disavow the supernatural mechanisms and the stigma associated with *chira*, others have pointed out the ways in which chira discourse accurately describes the networked reality of health in Western Kenya where individual health is 'embedded in a context of family relations and gender relations' (Whyte & Kariuki, 1991).

For our group, the underlying social network phenomena articulated through chira and related concepts illuminated the dynamic pathways through which the biological, socio-economic, and psychological burdens of HIV/AIDS infection propagate risk and vulnerability across dense rural networks on Mfangano. We would later come to describe this phenomenon as 'HIV risk induction' (Salmen et al., 2015). In the process, our community partners helped us identify the HIV-affected social network itself, rather than the HIV-infected individual, as a more appropriate target here for subsequent interventions to improve long-term engagement with HIV/AIDS care. By giving space and attention to local discourse, what first appeared as irrelevant chatter or, worse, superstitious misconceptions in need of rectification, ultimately crystallized into a novel social network intervention.

Working with community leaders, we adapted a 'microclinic' model initially developed for chronic disease management (Ding et al., 2013), to develop the Kanyakla Program (Kanyakla translates as 'team' in local Dholuo). This intervention was designed to incorporate the types of social networks that already existed on Mfangano (i.e. small groups of extended families, neighbours, church-members, coworkers, etc) and thus catalyse community-wide engagement with HIV/AIDS care. We began by outlining a 10-session, 6-month social support curriculum for existing community groups that could be facilitated by trained community health workers at locations and times of each groups choosing, so as to accommodate an ever changing community calendar (Salmen et al., 2015).



#### The quasi-experimental design and participatory audit

As we attempted to solidify this intervention through a formal research study, we found ourselves conflicted about the right way to translate a highly contextualised social network approach into something generalisable and scalable. The real strength of the model relied upon harnessing informal community structures of support and dialogue, and the resilience of specific pre-existing social networks. These organic social processes were embedded into the life and activities of this Mfangano community, and did not easily lend themselves to any controlled randomisation framework. However, in our desire to generate reproducible results, we felt compelled to create prescriptive protocols, and exclude potential local partners, co-occurring governmental programmes, and other resources specific to this population that may not be present in other communities. We feared that by incorporating these types of confounders into our intervention and protocols, we would add such complexity, and subsequent bias, that our academic peers would never accept results about this approach as valid.

In the end, we settled on a somewhat awkward compromise – a quasi-experimental design. Looking at the geography of Mfangano Island, we were able to define the four administrative units or 'Locations' of Mfangano as relatively comparable populations with very similar demographics, language, and health infrastructure. We then designed a cohort study, recruiting all patients enrolled in antiretroviral care at the primary Ministry of Health Clinic. We then compared outcomes between participants residing in the villages of Mfangano East Location where the Kanyakla programme was first launched, and 'control' participants residing in Mfangano North and West locations, prior to subsequent expansion of the programme. While lacking the rigour of a randomised design, this quasi-experimental format enabled us to compare preliminary impact of the intervention between participants residing in pilot communities and all other patients on Mfangano. Most importantly, the intervention remained highly flexible in the hands of local programme staff, adaptive to the specific actors, networks, and informal resources of individual participating communities, incorporating rolling feedback throughout implementation.

Ultimately, we felt it was not the inherent efficacy of a prescribed intervention, but the inclusivity of this engagement process, that contributed most to the significant improvements in retention in HIV care demonstrated among participants over 22-months of follow-up, and allowing us to make a preliminary case for the utility of this programme to improve HIV status disclosure, stigma reduction, and retention in care (Hickey et al., 2015; Salmen et al., 2015).

These experiences with the Kanyakla programme and subsequent interventions on Mfangano, have bent the arc of our research agenda in Kenya towards increasing informality and adaptability. In the process, we've learned to pay closer attention to the local contingencies that define daily life. Recognising the contextualised knowledge of our study participants as core research assets, we have redesigned our data collection methods accordingly. For instance, in our ongoing study of barriers affecting access to emergency maternal and newborn health on Mfangano, we have opted out of structured survey instruments all together, relying instead on participatory case audits that allow local enumerators to work with patients, local clinical staff, and appropriate family members to populate data fields together as a team regarding the circumstances surrounding obstetric, pregnancy-related, and neonatal emergencies on Mfangano. By trading precision of predetermined data points, we gain a more contextualised view of the full continuum of circumstances surrounding maternal emergencies, translating into both quantitative and qualitative information that is more inclusive and, perhaps, more readily actionable (MOMENTUM Study).

Yet, as we hone in on locally specific barriers, opportunities and skills, we have had to grapple time and again with the requisite trade-off in the generalizability of our data. Whereas we were motivated at the onset to generate universal research conclusions, we now must admit that lessons from our context may not always apply elsewhere. At times, this has raised questions amongst our group about whether we should even consider our investigations as 'rigorous research', or more accurately, as highly contextualised programme evaluations?

We feel that what is at stake is more than simply aligning a study strategy with established methodologies, in our case, community-based participatory research or implementation science. Nor is it about merely choosing from the respective toolkits of quantitative versus qualitative frameworks. Our concerns here hinge upon the many compromises that arise while navigating institutional expectations, funding priorities, and professional obligations, as we seek to translate the vast resources of global health science into lasting, meaningful change for those who choose to participate in our studies within communities where basic needs remain largely unmet. Alongside trying to select the right mode of inquiry to answer a question, or the best way to present an argument, we are now also paying increasing attention to how the unfolding of our research enterprise itself influences community interactions and expectations going forward. These questions have forced us to reckon with how our community partners and we define research in the first place, and who is really 'in control' of the outcomes, and disruptions, that these research activities inevitably generate.

#### Our collective illusion of control

As global health researchers, we suggest that not only have we been trained to lean towards rigour, but also to embrace a collective illusion of control. By and large, and despite the ardent pleas of qualitative investigators across many disciplines, the global health community maintains a remarkable level of self-assurance in the positivist approach to global health sciences, namely the ability of formal research to deliver impacts through interventions that have been prospectively designed to measure predetermined, discrete outcomes. It goes almost without saying that more we can tightly define and control this process, the more conclusive, and ultimately, persuasive, our data will be. Yet, since the 1970s, psychologists have been aware of a remarkable phenomenon, described as the 'illusion of control' (Langer & Roth, 1975). Studies demonstrated that individuals engaging with trials of pure chance (coin tosses, card draws, etc), report an increasing sense of control over a purely random outcome the more 'skill cues' that are present. These cues are associated with exercise of expertise, such as agency in making decisions, competition, and intellectual familiarity with the subject matter. As highly trained investigators, we have dedicated years of our lives to picking up exactly these types of skill cues in our respective fields, and we have the degrees to prove it!

Thus, while we adjust for 'chance' in our statistical models, we rarely notice the ways that our advanced training, our skill cues, unconsciously influence our perception of control over the randomness of life in the first place. Moreover, as assessors of data, we may be more willing to accept the validity of a random outcome when it is desirable, or fits with previous assumptions, and only demand higher standards of evidence for unpalatable outcomes (Ditto & Lopez, 1992). We are also primed to accept that a statistically significant result from a carefully designed study maps onto the reality we intended to measure, despite emerging arguments that the vast majority of 'significant' results, across all fields of academic research, may be more random and less meaningful than we are prepared to admit (Amerhien, Greenland, & McShane, 2019; Ioannidis, 2016). This is a hard pill to swallow - what is the path forward in global health research if we question the basic capacity of formal prospective investigations to ascertain truth?

By recognising that over-confidence in control over randomness is an acquired trait inherent in scientific training, we suggest that we can move past a major stumbling block in how we engage with community-based research. Instead of assuming that rigorous research is strictly a process of intentional, accurate measurement, let us acknowledge that most research, out in the world, is also an act of disruption. Our colleagues in quantum physics have long embraced the implications of 'uncertainty' and 'disturbance' (Busch, Lahti, & Werner, 2013). This doesn't mean we are wrong to initiate a formal study or measure defined impacts. Across Lake Victoria, like many similar populations around the world, interventions are desperately needed to disrupt the cycles of disease and poverty. Yet, alongside the intended outcomes of our research interventions, we must also, acknowledge the inevitable unintended disruptions that the formal research enterprise generates. In order to pay attention to the disturbances that continue long after we've collected all our data and retired our protocols, and own the uncertainty that is also part of this work, we need to recognise the subtle signals that arise only at the edges of our study domains.

# **Authoring disruption**

In Kenya, it has taken us a decade to start seeing some of these unintended disruptions. In the island communities of Mfangano, many households have now participated in formal research, including our studies as well as those of numerous other international institutions. Residents are increasingly familiar with names of the academic centres they see on their consent paperwork and the logos blazed on staff t-shirts. As our own studies have drawn attention to health problems that our group has identified as important, efforts to address longstanding needs identified by the community, such as safe drinking water, latrine construction, and community health worker training, risk stagnation as community energy realigns with the latest internationally sponsored research intervention.

While local Ministry of Health facilities struggle to maintain staffing, our local study managers regularly receive applications from many highly overqualified individuals for even temporary, entry-level positions. At the same time, participant expectations of compensation for study participation have increased dramatically. Similarly, as we've actively incorporated local community health workers onto our research teams, providing stipends for their professional contributions, we've heard concerns from our Ministry of Health partners that this research compensation may in fact make it more difficult for the under-resourced Ministry to request their volunteer services for critical activities in the future, a complex dynamic that must be addressed in the myraid settings where CHWs play important roles in underserved systems (Palazuelos, Farmer, & Mukherjee, 2018).

In our community-advisory group (CAG) meetings, there are now frequent requests for international Universities to address community problems far beyond the scope of our specific studies. This shouldn't be surprising, given the fact that we've spent 10 years trying to convince our CAG participants, in much the same way same students are indoctrinated in academic institutions around the world, that the most responsible way to *really* understand and address problems is through formal, expensive, *rigorous* research. In the process of 'training' our CAG members, we may be undermining local confidence to simply go out and seek answers to problems that appear complicated. Community members have also rightly assessed that nearby Kenyan Universities often lack 'global health' funding and resources compared to their International counterparts. Local universities may be near physically, yet far away in terms of being in a position to readily partner with local communities to address these issues. These signals taken together highlight the fraught nature of our disruptions – undermining local resilience, or the capacity of local institutions is, in fact, the exact opposite of our intended goal as a research enterprise.

Not all of our unintended impacts have been negative however. Our efforts, like those of researchers across sub-Saharan Africa, are bringing attention to neglected issues, energising a new generation of talented investigators, employing local staff who provide for their families and send their children to school, activating cross-cultural partnerships, and putting cutting-edge tools directly into the hands of people who have a vested, long-term interest in solving their own problems. These types of positive disruptions to the status quo, catalysed by the activities of our research, rarely appear as primary or secondary endpoints in any of our manuscripts. Yet, we realise, these may be the most lasting real-world benefits of many of our studies.

Thus if we insist on 'being intentional' with our research, we have also learned to be explicit about incorporating outcomes such as capacity built and personnel trained, trans-cultural partnerships established, local investigators empowered, and other such measures into our chosen methods. We are more comfortable acknowledging that in many instances, we have less control over certain

clinical or behavioural outcomes, and still hold onto the capacity to design research in ways that answer important questions and serve a lasting and meaningful purpose. By embracing flexibility and inclusivity in the research enterprise, we have improved our ability to adapt methods in realtime so as to continually validate and operationalise the knowledge and practices of our community partners.

# Building more inclusive vehicles for community-based research

Academic research, with its emphasis on prescriptive protocols and predetermined hypotheses, relies heavily on strict adherence to the implementation strategy. In this lens, notions of informality appear anathema to the practice of good science. In terms of public health implementation, these notions are further viewed as barriers or challenges that must be controlled through guidelines, regulations, and good governance. Yet, all of us who work in challenging contexts like Lake Victoria, are familiar with the demands of the field that require fluidity, inventiveness, and adaptation. In many ways, these traits are the defining characteristics of diverse communities across sub-Saharan Africa. In urban planning for example, an active conversation has recently emerged about how one can harness informality as a resource rather than hindrance to development in Africa, recognising the inherent resilience in informal transportation systems, money-saving cooperatives, 'Jua Kali' industries, etc (Kamete, 2013; Potts, 2008).

The *matatu*, or ubiquitous 'mini-bus' as it is known in Kenya, comes to mind as a loose analogy. Casual, scrappy, and often criticised as reckless, even dangerous, matatus nonetheless represents a highly adaptive, reliable, and economical transportation network, upon which riders invariably 'make room' for yet another. This informal network doesn't need to be wholly replaced with a more structured system, rather with basic improvements in vehicle safety it could be strengthened while preserving its flexibility and affordability.

In Kenya, we have learned a great deal from our local research staff whose lived experiences are embedded in cultures of adaptation and resourcefulness. We have felt increasingly emboldened to take our study designs out of their sterile packages, loosen them up to allow for local contingency, and reprioritize each investigation not as a search for the definite answer to a generalisable health question, but as a tool to build a more inclusive vehicle for 'truth-seeking' within in the specific communities we seek to serve.

A shining recent example that has inspired us can be found in the ongoing PREMAND study out of Ghana (Kaselitz et al., 2018). Here researchers collected verbal and social autopsies regarding deaths of mothers and babies in four rural districts, and then presented this data to community-leaders and elders in large community meetings. Community groups were then provided with small grants to generate solutions based on this data and their own previous experiences, working with researchers to evaluate their impacts in various ways (Moyer et al., 2016). Creative studies like PRE-MAND equip local truth-seekers with confidence and capacity to address not only their current problems, but also to build networks and social infrastructures to address the inevitable, unexpected challenges of the future.

#### Conclusion

In global health, we frequently encounter calls for new movements. Rather than calling for a total overhaul, we seek to contribute a humble suggestion to the admixture of our endeavours – perhaps more scientific rigour is not the only way to advance global health research. The arguments presented here may not apply whatsoever to the important studies being conducted by many dedicated investigators. Yet, alongside the gold standard, multi-site, cluster randomised trails we celebrate, let us also pay respect to the inventive, nuanced, and locally-specific inquiries that grow out of deep, community-based engagement. In reference to the 'slow food' movement, and its celebration of local diversity, Adams et al champion this type of inquiry as 'slow research' (Adams et al., 2014). Similarly, we

suggest that making research somewhat less formal or somewhat smaller in scope in no way minimises its potential value. Alongside our all-consuming focus on measuring outcomes and impacts, we assert that we can create space for the delicate studies that seek to understand the dynamic forces of human potential, resilience, and capacity.

When we allow ourselves to slow down, see beyond the next funding cycle, and release our anxiety about designing an airtight protocol or delivering the most generalisable data, we begin to hear the voices of local inquirers advocating for a chance to answer their own relevant questions. The modes of investigation and solutions they uncover don't have to apply across vast populations to remain valid and important. We have found that it is not enough for us to adhere to overarching ethical principles; like the vast majority of investigators in our field, we are already deeply concerned with notions of justice, equity and empowerment. Yet, we've realised that we need to continually help each other translate our rhetoric into practice. For our group, taking a moment to set down our constant need for control, and putting ourselves, and our methods, in the shoes of our knowledgeable community partners in Kenya, is one way we've learned to start walking that difficult walk.

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#### References

Abila, R. O. (2003). Fish trade and food security: Are they reconcilable in Lake Victoria. Kenya Marine and Fisheries,

Adams, V. (Ed.). (2016). Metrics: What counts in global health. Durham, NC: Duke University Press.

Adams, V., Burke, N. J., & Whitmarsh, I. (2014). Slow research: Thoughts for a movement in global health. Medical Anthropology, 33(3), 179-197.

Aellah, G., & Geissler, P. W. (2016). Seeking exposure: Conversions of scientific knowledge in an African city. The Journal of Modern African Studies, 54(3), 389-417.

Allison, E. H., & Seeley, J. A. (2004). HIV and AIDS among fisherfolk: A threat to 'responsible fisheries'? Fish and Fisheries, 5(3), 215–234.

Amerhien, V., Greenland, S., & McShane, B. (2019, March). Scientists rise up against statistical significance. Nature, 567, 305-307.

Balirwa, J. S. (2007). Ecological, environmental and socioeconomic aspects of the Lake Victoria's introduced Nile Perch fishery in relation to the native fisheries and the species culture potential: Lessons to learn. African Journal of Ecology, 45(2), 120-129.

Bokea, C., & Ikiara, M. (2000). The Macroeconomy of the export fishing industry in Lake Victoria (Kenya).

Braunschweiger, P., & Goodman, K. W. (2007). The CITI program: An international online resource for education in human subjects protection and the responsible conduct of research. Academic Medicine, 82(9), 861-864.

Busch, P., Lahti, P., & Werner, R. F. (2013). Proof of Heisenberg's error-disturbance relation. Physical Review Letters, 111(16), 160405.



- Camlin, C. S., Kwena, Z. A., & Dworkin, S. L. (2013). Jaboya vs. Jakambi: Status, negotiation, and HIV risks among female migrants in the "sex for fish" economy in Nyanza Province, Kenya. AIDS Education and Prevention, 25 (3), 216-231.
- Chang, A., Fiorella, K. J., Hickey, M. D., Salmen, C. R., Bukusi, E. A., Cohen, C. R., & Auerswald, C. L. (2018). Marginalization and community perception of HIV care, Treatment, and support on Mfangano Island, Kenya. Progress in Community Health Partnerships: Research, Education, and Action, 12(2), 121-133.
- Crane, J. T. (2010). Unequal 'partners'. AIDS, academia, and the rise of global health. BEHEMOTH-A Journal on Civilisation, 3(3), 78-97.
- DeLorme, A. L., Gavenus, E. R., Salmen, C. R., Benard, G. O., Mattah, B., Bukusi, E., & Fiorella, K. J. (2018). Nourishing networks: A social-ecological analysis of a network intervention for improving household nutrition in Western Kenya. Social Science & Medicine, 197, 95-103.
- Dilger, H. (2008). "We are all going to die": Kinship, belonging, and the morality of HIV/AIDS-related illnesses and deaths in rural Tanzania. Anthropological Quarterly, 81, 207-232.
- Ding, E. L., Prescott, M. R., Watson, K. T., Bui, N., Makarechi, L., & Zoughbie, D. E. (2013). Microclinic social network lifestyle intervention for weight loss and obesity management: A 10-month randomized controlled trial.
- Ditto, P. H., & Lopez, D. F. (1992). Motivated skepticism: Use of differential decision criteria for preferred and nonpreferred conclusions. Journal of Personality and Social Psychology, 63(4), 568-584.
- Escobar, A. (2011). Encountering development: The making and unmaking of the third world. Princeton, NJ: Princeton University Press.
- Fairhead, J., Leach, M., & Small, M. (2006). Where techno-science meets poverty: Medical research and the economy of blood in The Gambia, West Africa. Social Science & Medicine, 63(4), 1109-1120.
- Farmer, P. (2003). Pathologies of power: Health, human rights, and the new war on the poor. North American Dialogue, 6(1), 1–4.
- Fiorella, K. J., Camlin, C. S., Salmen, C. R., Omondi, R., Hickey, M. D., Omollo, D. O., & Brashares, J. S. (2015). Transactional fish-for-sex relationships amid declining fish access in Kenya. World Development, 74, 323-332.
- Fiorella, K. J., Milner, E. M., Salmen, C. R., Hickey, M. D., Omollo, D. O., Odhiambo, A., & Brashares, J. S. (2017). Human health alters the sustainability of fishing practices in East Africa. Proceedings of the National Academy of Sciences, 114(16), 4171-4176.
- Foucault, M. (2003). The birth of the clinic [1963]. (A. M. Sheridan, Trans.). New York and London: Routledge.
- Gamble, V. N. (1993). A legacy of distrust: African Americans and medical research. American Journal of Preventive Medicine.
- Gautier, L., Sieleunou, I., & Kalolo, A. (2018). Deconstructing the notion of "global health research partnerships" across Northern and African contexts. BMC Medical Ethics, 19(1), 49.
- Geheb, K., & Binns, T. (1997). 'Fishing farmers' or 'farming fishermen'? The quest for household income and nutritional security on the Kenyan shores of Lake Victoria. African Affairs, 96(382), 73-93.
- Geheb, K., Kalloch, S., Medard, M., Nyapendi, A. T., Lwenya, C., & Kyangwa, M. (2008). Nile Perch and the hungry of Lake Victoria: Gender, status and food in an East African fishery. Food Policy, 33(1), 85-98.
- Geissler, P. W. (2013). Public secrets in public health: Knowing not to know while making scientific knowledge. American Ethnologist, 40(1), 13-34.
- Geissler, P. W., & Kelly, A. H. (2016). Field station as stage: Re-enacting scientific work and life in Amani, Tanzania. Social Studies of Science, 46(6), 912–937.
- Geissler, P. W., & Pool, R. (2006). Popular concerns about medical research projects in sub-Saharan Africa-a critical voice in debates about medical research ethics. Tropical Medicine & International Health, 11(7), 975-982.
- Goldschmidt, T. (1998). Darwin's dreampond: Drama in Lake Victoria. Cambridge, MA: MIT Press.
- Greenhalgh, T., Howick, J., & Maskrey, N. (2014). Evidence based medicine: A movement in crisis? BMJ, 348, g3725– g3725.
- Hauge, H. E. (1974). Luo religion and folklore. Universitetsforlaget.
- Heimer, C. A. (2007). Old inequalities, new disease: HIV/AIDS in sub-Saharan Africa. Annual Review of Sociology, 33,
- Hickey, M. D., Salmen, C. R., Omollo, D., Mattah, B., Fiorella, K. J., Geng, E. H., ... Cohen, C. R. (2015). Implementation and Operational Research: Pulling the Network Together: Quasiexperimental Trial of a Patient-Defined Support Network Intervention for Promoting Engagement in HIV Care and Medication Adherence on Mfangano Island, Kenya. Journal of Acquired Immune Deficiency Syndromes (1999), 69(4), e127-e134.
- Horton, R. (2013). Offline: Is global health neocolonialist? The Lancet, 382(9906), 1690.
- Hsu, E. (2007). Chapter 4—The biological in the cultural: the five agents and the body ecologic in Chinese medicine. In D. J. Parkin & S. J. Ulijaszek (Eds.), Holistic anthropology: Emergence and convergence (Vol. 16, pp. 91-126). New York: Berghahn Books.
- Hunt, M. R., & Godard, B. (2013). Beyond procedural ethics: Foregrounding questions of justice in global health research ethics training for students. Global Public Health, 8(6), 713-724.
- Ingold, T. (2007). Chapter 8—Movement, knowledge, and description. In D. J. Parkin & S. J. Ulijaszek (Eds.), Holistic anthropology: Emergence and convergence (Vol. 16, pp. 194-211). New York: Berghahn Books.



Ioannidis, J. P. (2016). The mass production of redundant, misleading, and conflicted systematic reviews and metaanalyses. The Milbank Quarterly, 94(3), 485-514.

Iyer, A. R. (2018). Authorship trends in The Lancet global health. The Lancet Global Health, 6(2), e142.

Kamete, A. Y. (2013). On handling urban informality in Southern Africa. Geografiska Annaler: Series B, Human *Geography*, 95(1), 17–31.

Kaselitz, E., Aborigo, R., James, K., Agorinya, I., Williams, J., & Moyer, C. A. (2018). Using community-driven solutions to improve maternal and neonatal outcomes in rural northern Ghana: The PREMAND project. The Lancet Global Health, 6, S13.

Kenny, M. G. (1977). The relation of oral history to social structure in South Nyanza, Kenya. Africa, 47(3), 276-288. Langer, E. J., & Roth, J. (1975). Heads I win, tails it's chance: The illusion of control as a function of the sequence of outcomes in a purely chance task. Journal of Personality and Social Psychology, 32(6), 951-955.

Macfarlane, S. B., Jacobs, M., & Kaaya, E. E. (2008). In the name of global health: Trends in academic institutions. Journal of Public Health Policy, 29(4), 383-401.

Minkler, M., & Wallerstein, N. (Eds.). (2011). Community-based participatory research for health: From process to outcomes. San Francisco, CA: John Wiley & Sons.

Moyer, C. A., Aborigo, R. A., Kaselitz, E. B., Gupta, M. L., Oduro, A., & Williams, J. (2016). PREventing maternal and neonatal deaths (PREMAND): A study protocol for examining social and cultural factors contributing to infant and maternal deaths and near-misses in rural northern Ghana. Reproductive Health, 13(1), 20.

Nagata, J. M., Fiorella, K. J., Salmen, C. R., Hickey, M. D., Mattah, B., Magerenge, R., & Cohen, C. R. (2015). Around the table: Food insecurity, socioeconomic status, and instrumental social support among women living in a rural Kenyan island community. Ecology of Food and Nutrition, 54(4), 358-369.

Nagata, J. M., Jew, A. R., Kimeu, J. M., Salmen, C. R., Bukusi, E. A., & Cohen, C. R. (2011). Medical pluralism on Mfangano Island: Use of medicinal plants among persons living with HIV/AIDS in Suba district, Kenya. Journal of Ethnopharmacology, 135(2), 501-509.

NASCOP. (2008). National AIDS and STI control programme. Ministry of Public Health and Sanitation, Kenya.

Nickles, T. (1988). Questioning and problems in philosophy of science: Problem-solving versus directly truth-seeking epistemologies. In M. Meyer (Ed.), Questions and questioning (pp. 43-67). Berlin: Walter de Gruyter & Co.

Palazuelos, D., Farmer, P. E., & Mukherjee, J. (2018). Community health and equity of outcomes: The partners in health experience. The Lancet Global Health, 6(5), e491-e493.

Parker, R. (2000). Administering the epidemic: HIV/AIDS policy, models of development, and international health. In B. Whitford, & P. Mandelson (Eds.), Global health policy, local realities: The fallacy of a level-playing field (pp. 39– 55.) Boulder, CO: Lynne Rienner Publishers.

Potts, D. (2008). The urban informal sector in sub-Saharan Africa: From bad to good (and back again? Development Southern Africa, 25(2), 151-167.

Pringle, R. M. (2005). The Nile Perch in Lake Victoria: Local responses and adaptations. Africa, 75(4), 510-538.

Pringle, R. M. (2005). The origins of the Nile perch in Lake Victoria. BioScience, 55(9), 780-787.

Salmen, C. (2009). Towards an anthropology of organic health: The relational fields of HIV/AIDS among the Suba of Lake Victoria: Institute of social and cultural anthropology.

Salmen, C. R., Hickey, M. D., Fiorella, K. J., Omollo, D., Ouma, G., Zoughbie, D., & Geng, E. (2015). "Wan Kanyakla" (We are together): Community transformations in Kenya following a social network intervention for HIV care. Social Science & Medicine, 147, 332-340.

Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. ANS. Advances in Nursing Science, 16(2), 1-8.

Schall, E. (1995). Learning to love the swamp: Reshaping education for public service. Journal of Policy Analysis and Management, 14(2), 202-220.

Serwadda, D., Sewankambo, N. K., Carswell, J. W., Bayley, A. C., Tedder, R. S., Weiss, R. A., & Clayden, S. A. (1985). Slim disease: A new disease in Uganda and its association with HTLV-III infection. The Lancet, 326(8460), 849-852.

Sheikh, K., Bennett, S. C., El Jardali, F., & Gotsadze, G. (2017). Privilege and inclusivity in shaping global health agendas. Health Policy and Planning, 32(3), 303-304.

Smith, R. (2006). Peer review: A flawed process at the heart of science and journals. Journal of the Royal Society of Medicine, 99(4), 178-182.

Sumathipala, A., Siribaddana, S., & Patel, V. (2004). Under-representation of developing countries in the research literature: Ethical issues arising from a survey of five leading medical journals. BMC Medical Ethics, 5(1), 5.

The MOMENTUM Study (Monitoring Maternal Emergency Navigation and Triage on Mfangano). www.clinicaltrials.

Vitule, J. R. S., Freire, C. A., & Simberloff, D. (2009). Introduction of non-native freshwater fish can certainly be bad. Fish and Fisheries, 10(1), 98-108.

Walsh, A., Brugha, R., & Byrne, E. (2016). "The way the country has been carved up by researchers": Ethics and power in north-south public health research. International Journal for Equity in Health, 15(1), 204.

Whyte, S. R., & Kariuki, P. W. (1991). Malnutrition and gender relations in Western Kenya. Health Transition Review, 1(2), 171-187.