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Everyday life in a site of transnational medical research in Western Kenya:

an ethnographic study

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Declaration of own work

I, Gemma Jane Aellah, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Gemma Jane Aellah

Abstract

This thesis is about life in Luoland, Western Kenya, which, like other places in Africa, has experienced the profound impact of large-scale biomedical research programmes, intertwined with much larger transnational HIV/AIDS interventions. My aim was to explore the lived experience of being within intensive sites of medical research and intervention: what this looks and feels like to residents, and how transnational medical research is understood in relation to their broader, multi-sided lives.

It is grounded in two periods of intertwining ethnographic fieldwork that I conducted between 2008-12 with people living around two places associated with a major transnational biomedical research station, headquartered on the outskirts of Kisumu City: a HIV research clinic in the city-centre; and the station's oldest fieldsite, a long-standing Health and Demographic Surveillance System site in a rural location. Ethnography was based in the city in 2008-09 (22 months) and in the rural location in 2010-2012 (17 months). I used multiple qualitative tools – including observation, embodied and experiential learning, in-depth interviews, focus group discussions, and visual methods - to follow how the stories of people living their lives in these spaces unfolded over time.

Empirical findings add to regional ethnography of JoLuo. They also add to the literature on anthropology of transnational biomedical research by underscoring a recognition that the 'research communities' that converge around research activity are not first and foremost defined by research. Instead, the stories of individuals and communities presented in this thesis reveal how research is folded into, understood through, and supported by existing relationships, biographies, and histories. They also show that lines between 'researcher' and 'researched' can be blurry. Further, theoretical findings add to literature on precarity, especially in contexts of extreme health and economic vulnerabilities, by showing that transnational medical research can be both a contributor to precarity, and a resource creatively used by its participants to navigate through it. My work also demonstrated that precarity can be experienced as having elements of predictability.

Acknowledgements

Table of Contents

List of figures

Glossary[1]

JoLuo	Luo people. *Jo* means 'people' in Dholuo language. Joluo are the fourth largest ethnic community in Kenya, representing a population of approximately 5 million, 66 thousand people (KNBS, 2019). They are a Nilotic language speaking group, believed to have originated from Sudan, and now settled around the Lake Victoria/*NamLolwe* (Lake of the Giant called Lolwe) basin in Western Kenya and Tanzania. Other Luo groups are found in Uganda, Congo, Ethiopia, and Sudan.
Dholuo	Luo language, often referred to by speakers as 'mother-tongue.
NCRO	A Kenyan **N**ational **C**linical **R**esearch **O**rganisation (pseudonym).
CHA	An American **C**entral **H**ealth **A**gency (pseudonym).
NCRO/CHA	Anacronym representing the entity that emerged through a 'collaborative agreement' between NCRO and CHA (pseudonym).
LSHTM	London School of Hygiene and Tropical Medicine.
HDSS	A Health and Demographic Surveillance System.
IEIP	An International Emerging Infections Programme
Akinda	A rural location in Luoland, Western Kenya (pseudonym). The name is used interchangeably to designate people from a place; a group of sub-clans; a collection of administrative locations; a grouping of homes, compounds, and their lands; NCRO/CHA's oldest rural research fieldsite, an HDSS site, and an IEIP site. All these designations overlay each other, but do not match exactly. Everyone in them knows where they are.
*Jo*Akinda	People of Akinda (Dholuo).

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[1] Not alphabetical. In order of Need to Know.

Global South	A socio-economic, political division of Earth. Tends to group countries in Africa, Latin America, parts of Asia (global south) against countries in Europe, North America, and other parts of Asia (global north). Also used to refer respectively to poor or richer communities found both within and between countries. Not everyone in the Global South/North agrees where they are. (For alternative ideas see The Chimurenga Chronic, 2015).
Nyamrerwa	Dholuo category of person, with expanded meanings in Akinda: encompasses 'Immediate helper in trouble'/Woman skilled in maternal and child-wellbeing, including advice, herbal remedies, dealing with misfortune, men and witches, as well as nutrition, hygiene, biomedicine, navigating health, education and administrative services/Traditional Birth Attendant (TBA) or home mid-wife or person who knows how to help pregnant women/Volunteer Community Health Worker/ Village reporter for NCRO/CHA. Above all: person who is always learning, who knows their village well, can talk to people well, keep secrets well, and navigate relationships between *Jo*Akinda and organisations seeking to do interventions in Akinda.
RCS	Research Communities Study. The short-form title of the approved research protocol between NCRO and LSHTM, CHA and another Global North research institution, under which my doctoral thesis falls. Acronymised by NCRO/CHA staff and research participants to the RCS Study.
EBS	The **E**xclusive **B**reastfeeding **S**tudy (pseudonym). A study in Kisumu City to trial the prevention of mother-to-child HIV transmission through a combination of: giving pregnant women first diagnosed with HIV at a pre-natal clinic visit 'highly active antiretroviral therapy' from late pregnancy until 6 months post-partum; giving a single dose of Nevirapine, an antiretroviral medication, to their infants within 72 hours of birth; and promoting exclusive breastfeeding.

Maps

Luoland as landmarks, names, and roads
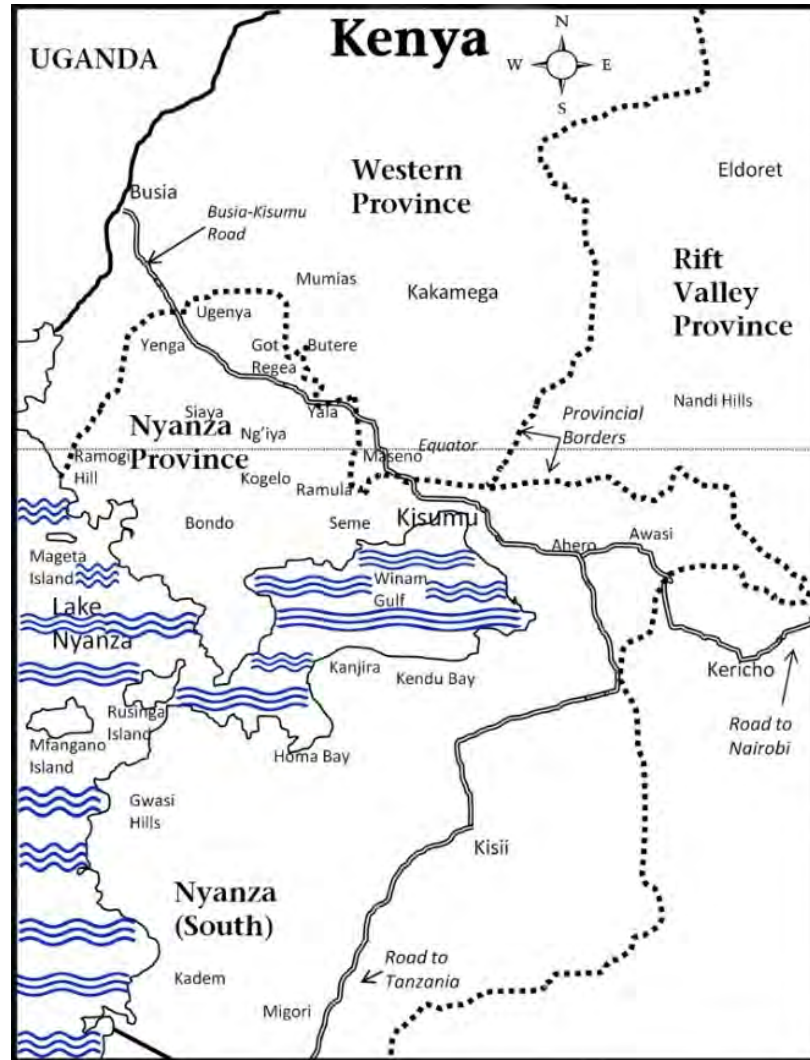
Figure 1: One version of Nyanza/Luoland. This map includes Ramogi Hill, a sacred place where Luo warrior Ramogi Ajwang first settled when he led the first JoLuo into Kenya through Uganda from Southern Sudan in the 15th Century (Ogot, 1967). This map was drawn in 2010 for the historical memoir 'Staring at the Nyanza Sun' by Dr Amos Otieno Odenyo, a JaLuo who was born in Gem and joined the 1961 'Kennedy Airlift' to America, together with his American-born son Odera Odenyo (Odenyo and Odenyo, 2010). Reproduced with kind permission of the makers © Odera Odenyo, 2010, www.nyanzasun.com.

Luoland as a cluster of premature mortalities
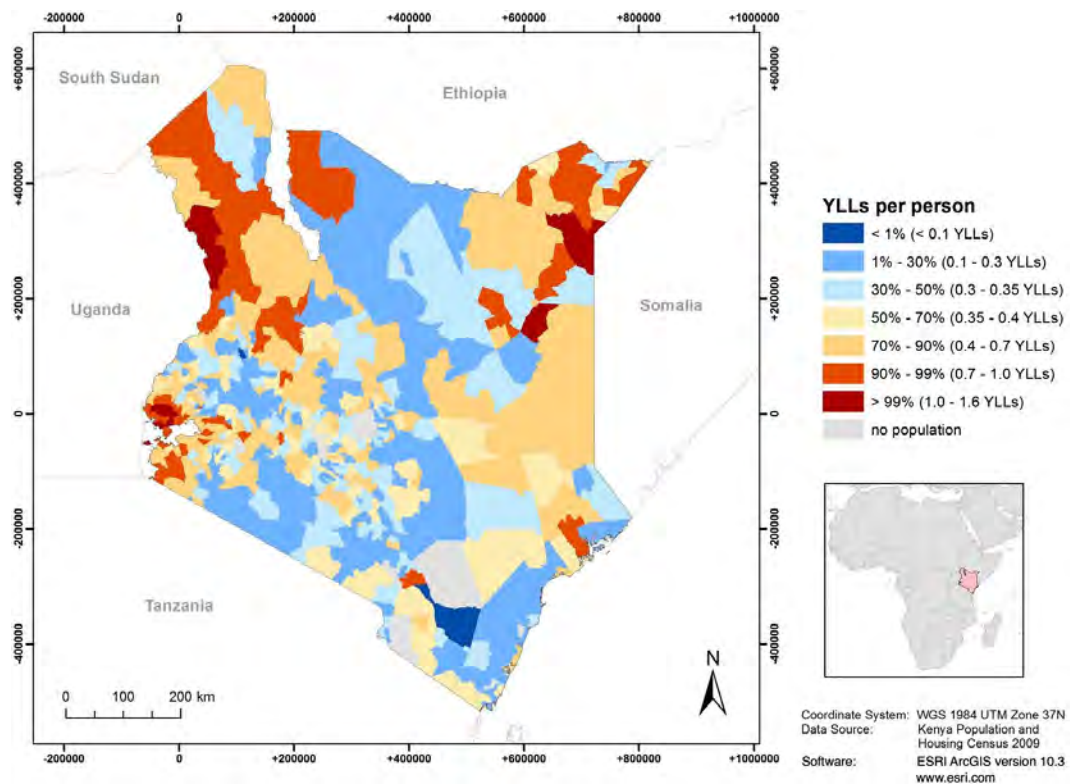
Figure 2: Representation of spatial patterns of Years of Life Lost (YLL) due to premature mortality in Kenya in 2009. The map depicts Luoland (near and around Lake Victoria) as several spatial clusters of high YLL rates. Areas with higher shares of people with Luo ethnicity was the strongest association with high YLL levels in Kenyan divisions. The leading causes of YLL are HIV/AIDS, lower respiratory infections, diarrheal diseases, tuberculosis, and malaria. Source: (Frings et al., 2018. Creative Commons Attribution 4.0 International License).

Akinda as seen by a Health and Demographic Surveillance System
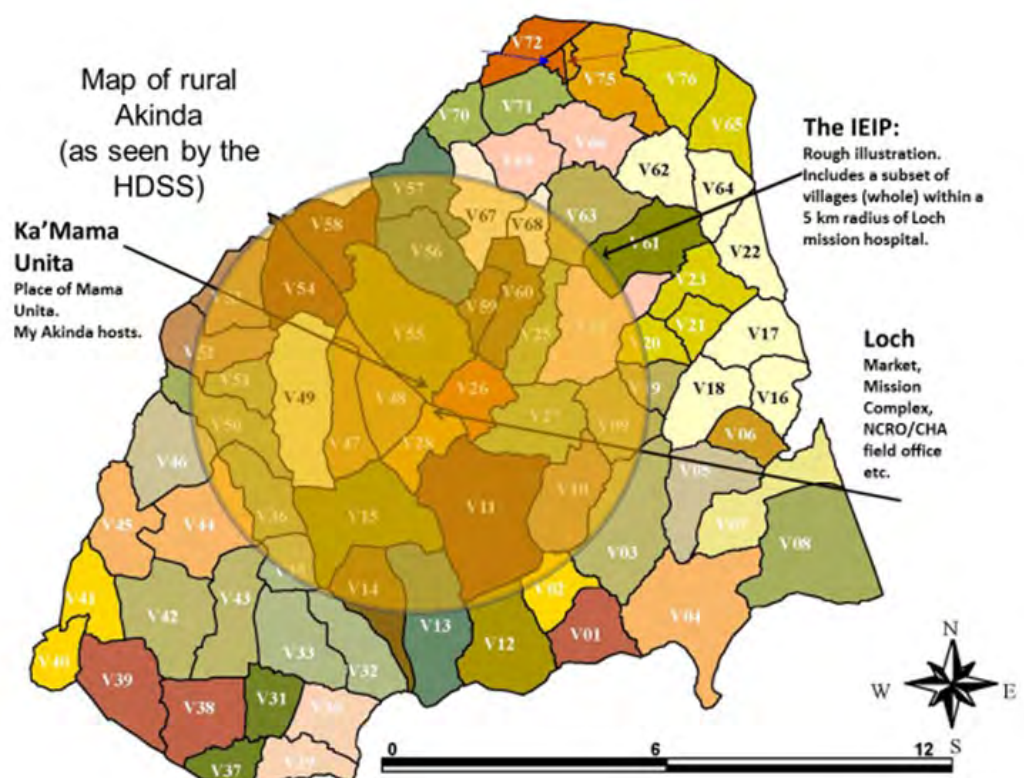
Figure 3: Map of rural Akinda in Luoland when seen as one site in a bigger Health and Demographic Surveillance System. Numbered villages also have HDSS names. They do not quite map onto either their locally known names or administrative locations because they have been modified over time to organise them for more efficient data collection. This map is for illustration purposes only. Source: Gemma Aellah (my modification of an illustrative paper map obtained from NCRO/CHA staff during fieldwork).

NCRO/CHA Headquarters on the outskirts of Kisumu City as seen by a child

Figure 4: Child's drawing of the NCRO/CHA headquarters submitted to a drawing competition run by NCRO/CHA at a nearby primary school, 2010. Photographed with permission.

Prelude

Night-driving, Night-running and Human-Landing Catching

Figure 5: Left: Drawing by Johnson Alouch Ondiek, artist, clinician, and a former study co-ordinator for the NCRCO/CHA transnational biomedical research collaboration (pencils on paper, 2011, jaoarts@yahoo.com). Right: Photo of a human-landing catcher at work in his home ©Aellah 2011.

23rd June 2011, 9pm

As the other residents of my compound in a village in rural 'Akinda'[2] in Western Kenya were preparing for bed, two highly skilled and experienced senior entomologists came to collect me in their large white Land-Rover, branded with a 'NCRO/CHA'[3] Research station logo. One was from Cameroon, the other born in Akinda but now living in the nearest city, Kisumu. That evening, they had driven 45 minutes from the city; stopping first at the NCRO/CHA headquarters on the city outskirts to collect their technical supplies, and then to drop their overnight things in the small lakeside hotel they and their driver would sleep in later that night. Together we were going to check on a sample of 150 so-called 'human landing catchers.' These were men dotted around Akinda, sitting up all night trying to suck mosquitoes off their legs through plastic tubes for an overseas funded research study. This was about a year after I first came to live in Akinda.

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[2] A pseudonym.
[3] NCRO/CHA is the pseudonymised anacronym I use to represent a collaboration between a Kenyan **N**ational **C**linical **R**esearch **O**rganisation (NCRO) and an America **C**entral **H**ealth **A**gency (CHA).

Mama Unita, my host and a *nyamrerwa* since the 1970s (a local Dholuo term encompassing 'immediate helper in trouble'/skill in matters of family well-being and childbirth/volunteer community health worker/village reporter for NCRO/CHA) was anxious about letting me roam at night. She insisted the men, whom she knew well, drive inside the compound right up to the door.

In our large car with its big headlights, we bumped quickly through the dark murram main roads of Akinda, turning off onto smaller tracks and moving deeper into the villages. The driver partially relied on a specialist satellite navigation tool to know where to go, made possible because all the homes we were to visit were enrolled and numbered within a Health and Demographic Surveillance system (HDSS). But, eventually, going on foot was the only option. So, we left behind the car and driver, who pulled his cap over his eyes and made himself invisible by slinking down low in his seat. Carefully, we picked our way in the pitch-black to the first compound on the list, where a team of human landing catchers had lit a huge bonfire. The fire provided warmth during Akinda's cold months at the tail end of the long rains. It also warned off potential *Juogi* or 'night-runners', ordinary people who turn into relatively harmless but scary tricksters at night. As well as more dangerous people: witches masquerading as night-runners, thieves, and the police, who had recently shot a schoolboy returning from a late-night funeral disco.

The wife of the home greeted us. She was cooking hot chocolate on the fire, then pouring it into a thermos provided by the research team to keep the catchers warm and attentive throughout the night. One catcher was sitting on a rickety chair outside the tiny mud thatched hut, woolly hat pulled down low and his eyes glued to his bare legs, plastic tube at the ready for the sight of a mosquito. Inside the hut, the two catchers not yet on shift sat drinking tea and chatting. The hut consisted of a single room separated into living and sleeping areas by a torn curtain and lit by a paraffin lamp, also provided by the research team.

The owner of the *simba* (term for a son's hut constructed in his father's compound) was on the inside shift, wearing a sports top and shorts. His bare legs were laid out before him. His name was George. He was a 27-year-old married subsistence farmer with two small children, one of whom was awake and helping her mother look after the catchers. The entomologists caught up with news from their catchers. They reported that things were going well, although the previous night three of them had been stopped and harassed by the police on their way to George's compound. When asked what they were

doing wandering around the village late at night, they had to produce their equipment as evidence of no wrongdoing.

George

The catchers were amused to hear me speaking what they joked was *Eng-Luo* (English flavoured Dholuo language). Using excellent English, George told me about how he had completed secondary school. Then both his parents had died from AIDS and there was no one to find money for fees to take him any further. This was his first paid work since leaving school. He would be paid 800 Kenyan shillings per night shift; four nights a week for six weeks, totalling 19,200 shillings (about £150). In rural Akinda, where there was little access to cash, this represented a large sum. It was nearly enough to pay two lots of yearly secondary school fees, to buy two cows, or to pay for half of the HIV Voluntary Testing and Counselling certificate course in Kisumu City that many young people sought to do.

George showed me the equipment he used to catch the mosquitoes. I was surprised at the simplicity of the arrangement of plastic tubes, plastic cups, elastic bands and pen and paper. "Ah, but we are *Jo*Analogue (Analogue people) here!", George joked, referring to Kenya's ongoing troubled migration from analogue to digital TV. He took a very technical, thorough approach to his 'analogue' work, demonstrating the exact way he would feel the mosquito land on his legs, let it settle for a while and then quickly suck it up the tube. He described how yesterday they got a 'good catch', but tonight – perhaps because of the cold and rain – numbers were down. "It's something I'm observing", he said, "there are less mosquitoes when it is raining. The catch changes with the weather patterns."

George recollected earlier generations of human landing catchers who he had witnessed working around Akinda when he was still in school in the 1990s. Some of them, he told me, were now 'big men', study co-ordinators and lab technicians with concreted compounds, higher education, cars, and exposure to other lifestyles and international conferences. "At that time they were unique people doing unique things," George said. "If we can be with them now, on the periphery but moving closer to them, it's a sign that our lives are also changing." Later, I found that George had been given an additional quality-control role on a casual but paid basis in the project's temporary field-office due to his diligence. He hoped this might turn into something else. The Principal Investigator was doubtful, though the chance was there.

Peter and his colleagues

Moving on to the next compound in a village on the other side of Akinda, we found three catchers instead of the expected four. The Team Leader was Tim, married with one child. Tim had grown up in the village but went to Nairobi to look for work straight after school, where he ended up working as a mechanic. He had been back in the village for eight months because his older brother had a stroke and could no longer look after their farm or feed his family. There was also 'Steve Bico', named after the late South African anti-apartheid activist who died in police custody. Bico was in his thirties and a carpenter. He wore a football shirt branded with a World Aids Day red ribbon and the slogan 'Play it Safe', a material trace of a recent HIV awareness roadshow that had passed through Akinda, run by a Kenyan social enterprise ball manufacturer, and financially supported by the charitable foundation of a mobile network operator.

There was also James, educated to primary level and in his fifties. James served as a village elder, an unpaid but formal administrative position which involved assisting the sublocation Chief. James had two wives, many children, and even more grandchildren. He passed his greetings to my host Mama Unita and told me he was planning to run for local ward councillor in the 2013 national elections. I thought of him a year so later when the government changed the rules and insisted all new councillors needed a post-secondary education qualification.

The wife of the human landing catcher who owned the hut was present, but her husband, Peter, was trapped in a nearby hospital. He had been admitted due to his diabetes, a disease often complicated by HIV medications. Peter had apparently recovered but was unable to leave because of an outstanding hospital fees balance. The other catchers had been covering his work for the last two nights and had planned to discuss with him later about how they were going to divide his money. In a highly formalised manner, Tim, the team leader, explained that he wanted to discuss a matter on behalf of his team and addressed the Principal Investigator as if we were at a formal meeting, rather than inside the hut late at night.

The catchers referred to themselves as 'colleagues' ("my esteemed colleague etc...") and debated the fairness of one of their members receiving money for work not done. The Principal Investigator explained to them that they could not continue to do what they had been doing. If Peter was unable to be present, they had to just leave out that section of the shift. The money could not be redistributed. He suggested that they consider the work they had

already done on Peter's behalf as a contribution to clearing his hospital bill. The discussion that followed with the Principal Investigator was fairly heated. The Principal Investigator seemed to think of the catchers as friends who of course would want to help each other out. But the colleagues clearly saw it as an issue to do with the value of labour. They wanted the study to pay them for the extra work done and clear their colleague's hospital balance as an additional bonus. Eventually the team of catchers agreed to nominate one team member to go to the hospital with Peter's payment to clear the bill and allow him to return to work.

Talking to the entomologists back in the car, I discovered that although George, Tim and the others experienced human landing catching as work and the cash they received in exchange as their wages, being research this money could not be referred to as 'payment' nor the human landing catchers as 'workers'. In research parlance, they were known as 'volunteers' and 'participants' in a research study exploring the relationship between biting behaviour of mosquitoes and the time of evening/night. For, as well as using their bodies as tools for the collection of mosquitoes, the human landing catchers' blood was also subject to research scrutiny and participation.

For a long time, the use of Human Landing Catchers had been the gold standard for assessing mosquito biting behaviour. But getting such kind of studies past ethical review boards was becoming increasingly difficult because of the dominance of the treated bed net as a malaria prevention measure. In fact, Akinda had been a site for a phenomenally successful large intervention study run by NCRO/CHA that proved the efficacy of treated bed nets in the late 1990s. Some of the homes we would visit this night still had old calendars distributed by bed-net study teams tacked to the walls. The vast majority of Akinda residents now slept under treated nets.

Asking these male villagers to act as human landing catchers, therefore, artificially placed them outside the protective effect of their treated bed-nets during key biting times. With his study the Cameroonian Principal Investigator, among other aims, wanted to put a definitive end to globalised ethical debates on the use of human landing catchers by proving that it could be made so that they were not at any higher risk of contracting malaria than their matched control counterparts. Their counterparts were simply asked to continue with their normal routines, and report for malaria testing every two weeks.

The human landing catchers were given the premi anti-malaria drug Malarone throughout the study and their blood was regularly tested for levels

of parasites. Malarone is usually prescribed for short-term travellers to Africa. Interestingly, Malarone itself was first trialled in Akinda in the early 1990s by a US military research organisation motivated by its potential use for their army. That early 1990s trial was remembered by residents alternatingly as the 'Chapati Study', because of the luxury feast food given to research participants every day, or the *nonro* (research) 'where some people died'. The total cost of the Malarone now being used in the NCRO/CHA human landing catcher study two decades later was 36,000 dollars, a fact the Principal Investigator was a little embarrassed to tell me. Much of the funding for the study, including the purchase of the expensive Malarone, came from the Bill and Melinda Gates Foundation.

Worker/participant/patient

These human landing catchers and their families had volunteered their information for routine health and demographic surveillance (HDSS) for decades. In fact, the data they were busy collecting on mosquito behaviour over the six weeks would be analysed in the context of wider patterns of human-behaviour obtained via the HDSS (net-use, sleeping arrangements etc). Tomorrow they might even get a routine visit from a HDSS fieldworker on a bicycle, armed with a handheld computer and lots of questions for whoever they found in the compound.

On this night it seemed to me that these human landing catchers represented the long-standing entanglement of Akinda residents as research workers, research participants and patients most clearly. They acted as labourers undertaking tedious work, sucking mosquitoes from their legs. They were also donating their bodies – in the form of their blood – to science for a bigger, global cause. And they were also sick – recipients of a biomedical intervention to clear the parasites from their bodies before work-proper could start, and, perhaps, recipients of future innovative biomedical intervention prompted by the success or failure of such studies. In fact, the study findings eventually showed that the human-land catchers had nearly 100% less incidences of malaria than those in the control group over those six weeks, which was one of peaks in the intense perennial malaria transmission that Akinda experiences. The study gave their bodies temporary rest from parasitic infection. During this peak I, a British Citizen present in Kenya on a research visa, happened to catch malaria myself. I had stayed in Kenya much too long to find a source and prescription for Malarone. Its UK product license stated it could only be prescribed for up to 28 days of travel.

Exposure and 'just trying'

I also found the striking image of a human landing catcher up late at night, on alert, patiently scouring his legs for mosquitoes and quietly hoping, like George, to one day move from the periphery to the centre of research things, a good metaphor for the state of mind of many Akinda residents when it came to the potential opportunities transnational medical research offers. George literally and figuratively sought to move forward through his exposure, with its double-edged meaning of risk and opportunity. This was, I would learn, part of a much broader contemplative attitude towards the future, and life generally, often described as *'tema atema'* ('just trying').

Relatedness

The figure of the human landing-catcher also threw into sharp relief how the apparatus of global health research was held together by intimate, local and complex relationships. Over the next few weeks, I learnt more about how the human landing catchers were chosen. The study team took the advice of the village *nyamrerwa,* like Mama Unita, as to which men (within the sampling criteria of the study) would be reliable participants/workers. The *nyamrerwa* recommended their men based on a careful measurement. They weighed up giving chances to those they felt needed it (or to whom they owed favours), against making sure that the men chosen best represented the *nyamrerwa's* essential skills of 'knowing' their villages well and managing relationships to allow both research and their own NCRO/CHA casual employment to continue peacefully. I heard, for example, one *nyamrerwa* counsel one of her chosen men who was upset because he was randomised to the much less lucrative control group to "*chaura chaya ukawe, ka ukao to udhi moro, nyamrerwa next time un udhi bedo head-line front-line koro chaurachaya ukwe chuny nyamrerwa*" ("just take the study, because if you take it then next time if something comes up, you will sit at the headline, be frontline. So just take it to cool the heart of your *nyamrerwa*"). I also realised that Mama Unita's son, who had recently lost his job as a caterer, was annoyed that she had not nominated him for one of the chances.

Multiple lives and multiple scales

After a year of living in Akinda, when accompanying the NCRO/CHA entomologists on their night-drive the Akinda villages presented themselves strangely to me. We moved between villages rapidly, covering an area that would usually take a whole day or so on foot or bicycle. Compounds and homes emerged out of the darkness, and we were suddenly plunged into

intimate, everyday spaces – children in their sleeping clothes, wives pouring coffee for the men into their project-provided thermoses. As well as into the middle of everyday predicaments, like those facing Peter who, it seemed, was going to have to spend all his volunteering compensation on managing a different illness. Then just as quickly we were gone, moving onto the next one, and the next one. Finally, the entomologists departed to their cheap lakeside hotel after dropping me off at my home where my host, Mama Unita, had been anxiously waiting up for me. I shared the various greetings I had collected for her from around Akinda. Then we bolted the door, tucked in our bed nets, and went to sleep.

In 2020, nine years later, I happened upon the traces of these human landing catchers again – in a citation of the entomologists' findings in an international journal article on the Pub-Med online Database. The paper explored the best ways of identifying biting behaviour in Indonesia using human landing catchers versus a host decoy trap. Despite the 'compelling' evidence from the Akinda study, it argued that ethical issues around human land-catchers remain unsolved because of potential risk of exposure to non-malarial arboviral disease transmission. I wondered what the Indonesian human landing catchers might have thought about other kinds of 'exposure' – both risk and opportunity — that they, perhaps, experienced during the work/participation that produced this finding.

So, through an online database, I therefore know a little bit about some of the afterlives of the data generated by the Akinda human landing catchers. And I learnt that all the efforts of the Akinda study's Cameroonian Principal Investigator (now living with his Kenyan wife in Uganda, working for a different transnational research organisation) did not, after all, manage to achieve the likely impossible aim of permanently securing the human landing catcher approach as a globalised research 'gold standard'. Another ethical risk had superseded.

But I do not know what happened to Peter, the Akinda human landing catcher stranded that night in hospital because of his fees balance while his colleagues debated different but also somehow connected ethical questions: questions concerned with the multiple values and meanings transnational medical research and intervention can have to those who encounter it. These are questions that strike to the heart of what is value/valued/valuable? And when, and by whom? Questions underscored by a fundamental recognition that Akinda residents seem to hold especially tight: that value, like exposure with its flexible meanings of opportunity and risk, is always contingent.

Precarity and predictability

I do know one of the Akinda human landing catchers died of a long-standing chronic disease a few weeks after the study ended. This 'Serious Adverse Event' or SAE in research parlance, was noted by researchers, but was not classed as having any indirect or direct causal relationship with the Malarone used in the study. Nor was it a **U**-SAE. The death was not **U**nexpected, neither for the person-as-participant, nor for the person-as-*Jo*Akinda, where death of any kind is never unexpected. Whether this death was 'related' to the study depends on how relationships are being defined, and by whom.

Could this SAE have stood for Peter with his diabetes? Did I witness a small but serious event that was part of the end of someone's life? Did Peter rush back to his human landing catcher 'work' whilst still sick with uncontrolled diabetes or HIV? Was he helped or hindered by his colleagues clearing his hospital bill with his 'payment'? Was this cash planned for something that would one day come to matter seriously to one of his dependants? Perhaps someone's school fees were not paid, a different chance lost. And so on, and so forth. Or perhaps, Peter is 'just okay' at home, and what I witnessed was a small example among many of life's ongoing, multiple challenges being worked out between people in Akinda. The ethnographic sensibility I have slowly gained through long-term fieldwork and engagement with this place tells me both futures are equally plausible.

So, perhaps this death was Peter's. Or perhaps not. I met him in the dark on a night of night-drivers and night-runners. I did not jot down the HDSS number of his home, handwritten above his doorframe, and I do not think I could find my way by foot in the light of day to his compound to ask. But I am sure that Mama Unita, using her *nyamrerwa* skills, could find a way to know. As Akinda residents might have said about this night using a popular idiom that rang out through the region a couple of years later:

Okbichaloni...

Meaning: 'things aren't always what they seem to be. But you can, at least, know *that* for sure.

Chapter 1: Introduction

Figure 6: Painting by Johnson Alouch Ondiek, artist and a study co-ordinator for the NCRCO/CHA transnational medical research collaboration (paint on cloth, 2013, jaoarts@yahoo.com).

'Doing a Research about Research!' And/or 'Studying how the people of this place live'

'Timo nonro kuom nonro!'/ 'Somo kaka JoGweng odak'

These two sentences were often used by those living around me in Western Kenya to explain my research to others. They capture the essence of my long-term ethnographic project about biomedical 'researched communities' in Luoland, Nyanza province, a region with extremely high prevalence of both HIV infection and transnational medical research activity. My focus is on the 'researched communities' that live around the HIV branch of a major transnational medical research field station headquartered in Kisumu City (NCRO/CHA), and in its oldest rural 'fieldsite' (Akinda), active since the 1980s and now one of several Health and Demographic Surveillance Sites in the region.

With this thesis, I set out to understand how transnational medical research and intervention activities are intertwined with the lives of people who live, work and plan for their futures in areas where intense biomedical research activity takes place. My contribution to anthropological literature on transnational biomedical medical research conducted in the Global South is, therefore, in the realm of the concrete everyday lives, spaces, and relationships that animate research. My doctoral research is situated within a broader collaborative ethnographic project[4], and guided by the following research questions:

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[4] 'Studying 'Research Communities': an ethnographic exploration of medical field research on HIV/AIDS in Western Kenya' (Principal Investigator: Wenzel Geissler). The study was originally funded by a Wellcome Trust Grant (P.I: Wenzel Geissler). An extension that allowed for my doctoral research was funded by a Leverhulme Trust Research Leadership

Research questions:

1. How is transnational biomedical research and intervention understood and folded into the lives of those living within its midst?
2. What value and meaning does transnational biomedical research and intervention have to those who encounter it? What (other) things matter to people as they navigate their lives?
3. Where does transnational biomedical research sit in relation to other interventions and responses to ill health, both historical and current, in this region?
4. What ethical challenges emerge in the everyday practices of transnational biomedical research, and how can we best talk about them?

In this ethnographic context, biomedical research is part of how life is managed that goes over and beyond scientific knowledge and scientific questions to the realm of everyday life, survival, and aspirational futures. For, as demonstrated in the two sentences that entitle this introduction (which came to be used interchangeable by myself and others to introduce my anthropological project during ethnographic fieldwork), in Kisumu City and Akinda doing a 'research about research' means learning about how people live. And, conversely, learning about how people live means, inevitably, learning something about the practices of global health research and interventions as conducted in a region where the effects of global, political, economic and health inequalities are particularly evident.

During 2008-2012, when I conducted my ethnographic fieldwork for this thesis, HIV prevalence in this region was amongst the highest in the

continent. In both Kisumu city and its surrounding rural areas, medical research and intervention related to HIV was the biggest provider of formal employment, material resources, and cash-flow in areas otherwise characterised by informal or subsistence farming economies, economies whose fragility was particularly felt during this period (Prince, 2013b, Schmidt, 2017a)

During 2008-2012, a rise in life expectancy and some economic recovery was in evidence since the 1990s peak of the AIDS crisis and the reduction of growth in key industries like fish/cotton processing and breweries that occurred around the same time. A major new airport was under construction and, in 2008, hopes were held that the election of Obama, who has Luo heritage, as U.S President might herald a new era of tourism and resource allocation (Madiega et al., 2008).

Yet my fieldwork period was also characterised by social uncertainty driven by the 2007 post-election violence. This was a time that could be characterised economically as post-neoliberal and depressed for most people. Inflation was at a record high. In 2010/2011 it reached a new peak as evidenced by the doubling price of sugar. A perceived 'famine' in Nyanza in 2010 was nicknamed *'Asumbi Nyal'*, or the 'Bachelor Can,' meaning only a bachelor could manage to live in town where 'life is all money'. The famine the following year was nicknamed 'Ocampo' after the International Criminal Court Chief Prosecutor Moreno Ocampo, who had called six of Kenyan's prominent political figures to stand trial for their part in organising the post-election violence. Connections were made between the political and social challenges facing the country, and the challenges of everyday survival.

Rather than centering research organisations in my ethnography, as some anthropological studies have done, my thesis takes as its starting point the idea that the 'research communities' that converge around research activity are not first and foremost defined by research. Instead, the stories of individuals and communities presented here reveal how research is folded

32

into, understood through, and supported by existing relationships, lives, and histories.

The papers contained in this thesis are an exploration of lives into which medical research has become interstitched. The papers reveal the multiple meanings of medical research as much as they explore lives lived at a particular historical juncture where, it could be argued, uncertainty was a prevailing theme, and life often involved inventive navigations through precarious socio-economic conditions (Cooper and Pratten, 2015, Haram and Bawa Yamba, 2009). Post-colonial transnational medical research activity which exists in a state of perpetual temporariness was both a contributor to this uncertainty, and a productive resource creatively utilised by residents in their navigations through it. Therefore, my research speaks to several bodies of literature concerned with ethnography of JoLuo, the anthropology of transnational medical research, the ontological experience of precarity, and how to write about post-colonial African lives.

I have used the term 'everyday' in the title of my thesis to try and capture an emphasis on lived experience over time. But I would like to be somewhat careful with this term. Blom Hansen has argued that 'the realm of the everyday' has often simply been used as a substitute word for culture or community, or as the realm of the human efforts of 'small people' (Blom Hansen, 2009). The poor, he argues, are more likely to be seen to live in the everyday than others – it is the (only) place where they get to resist systems. This is not what I am trying to say with this term. I share with Blom Hansen the idea that the everyday contains history in emblematic forms and that ideas of the state and state power (and the power of other institutions) have everyday forms (Blom Hansen, 2001).

I am concerned with 'everydayness' as a way of contrasting myself with some of the anthropology of commercial clinical trial work that I will describe in detail later. In Rajan's work on clinical trials in India, for example, medial research participants only emerge in his writing in the moment capital

attaches itself to them (Rajan Sunder, 2008, 2017). I want to look at people as they act, and imagine, over time. Everydayness does not mean ordinariness – extraordinary things happen in everyday time – but it means paying attention to concerns, jokes, routines, arguments, as they occur day to day. To me, this also means paying attention to how histories and memories are told in the everyday.

Locations

Hots spots of disease and intervention

Luoland is a region with long, layered histories of colonial and post-colonial population-level interventions relating to religion, labour, development, and health, all often intermingled (Cohen and Odhiambo, 1992, Cooper, 2011b, Geissler and Prince, 2010, Ochwada, 2007, Ogot, 1963, Parkin, 1978, Shipton, 2007). Kisumu City and Akinda are historic and current 'hot spots' for multiple infectious and parasitic diseases, notably sleeping sickness, schistosomiasis, intestinal worms, tuberculosis, typhoid, and malaria (Stresman et al., 2019, Wiegand et al., 2017, Zhou et al., 2016). This is especially true of Akinda which continues to experience intense malaria transmission year-round, despite extensive intervention and research.

Kisumu City, the regional capital with a population *circa* 567,963 (KNBS, 2019), hosts at least three major transnational medical research organisations and multiple overseas-funded HIV programmes, in addition to the collaboration between a National Clinical Research Organisation (NCRO) and an America Central Health Agency (CHA) which formally hosted my project. NCRO/CHA is one of the biggest private employers in the region. It employs approximately 1000-1200 people from its large field-station headquarters on the outskirts of the city and touches on the lives of at least several hundred thousand more. It has a satellite HIV research clinic within

the city centre, other satellite research centres in the surrounding areas, and maintains several Health and Demographic Surveillance (HDSS) sites, mainly in rural areas.

Akinda, one of NCRO/CHA's oldest rural field-sites, is a group of small 'villages' (population *circa* 65,000) about an hour's drive from Kisumu City where transnational medical research and intervention has been a significant feature of the social, physical, and economic landscapes for at least forty years. In addition to the HDSS in operation across 77 villages, there is an even more intensely researched group of 33 villages that are also part of an International Emerging Infectious Disease Programme (IEIP). IEIP residents are visited every two weeks and receive free treatment for infectious diseases at the local mission hospital. A plethora of other studies and interventions hang off these two platforms, addressing multiple diseases, and operating through various collaborative configurations involving NCRO, CHA and other national and transnational research organisations, including universities, parastatal, and non-governmental organisations.

In these villages medical research is very much a normalised feature of everyday life, especially visible in the movements it entails– of people, vehicles, samples. During the week large white cars shuttle back and forth carrying staff and samples between the research station headquarters in Kisumu city and its field offices in Akinda. Teams of local fieldworkers armed with palmtop computers move from household to household on heavy black Chinese bicycles, monitored by supervisors on motorbikes. Their work is supported by female *nyamrerwa* or 'village-reporters' selected for their intimate knowledge of the individuals in their marital villages. These reporters regularly walk around the earthen *panda* (mouse) paths of their villages monitoring births and deaths, offering home pregnancy-tests, and encouraging villagers to attend meetings and programme activities. Some of these village-reporters have been involved with research for decades and many have long histories of voluntary community service pre-dating research

involvement, as home birth attendants, family planning distributors and HIV care home visitors.

In Akinda the division between researcher and researched is blurry. Fieldworkers and village-reporters are also residents and, as such, are also enrolled in the HDSS and IEIP. Many residents have biographies of research participation that include enrolment as participants in multiple studies, interspaced with short-term casual employment on research projects as temporary human landing catchers (catching mosquitoes off their bare legs), or TB ambassadors. Their children go to Kisumu City to take certificate courses in HIV testing and counselling in the hope of future research employment. Their grandchildren might be enrolled in studies testing new childhood vaccines, and their cows and goats in zoonotic studies.

Yet, for all its pervasiveness and a powerful presence in this region for generations, transnational medical research exists in a temporal state of enduring short-termism, or perpetual temporariness. It periodically expands, contracts, and shifts. In Akinda it has continued for over forty years but is always potentially leaving at the end of the next project, as evidenced in the biographies of its village reporters employed on a 'causal' basis for a lifetime. Research is always only observing and never (officially) interfering with the landscape and infrastructure.

A significant proportion of research funding is connected to HIV. Luoland has some of highest HIV prevalence in the world and, like others living in parts of Africa with high HIV prevalence, Kisumu City and rural Akinda residents have experienced the profound impact of large-scale transnational biomedical research programmes, intertwined with much larger HIV/AIDS interventions (See also Beckmann et al., 2014, Brown, 2015, Brown and Prince, 2016, Crane, 2013b, Geissler, 2013a, Geissler, 2015, Nguyen, 2015, Prince and Otieno, 2014).

In 2012, HIV prevalence was 15.1% in the province overall (NASCOP, 2014). The most recent available data (2018) indicates it is now at 17.5% (KENPHIA, 2020). Breaking this figure apart based on available data: in rural Akinda a cross-sectional study of a random sample of 1822 residents revealed HIV prevalence of an astounding 40% among men aged between 25-34 in 2004 (Amornkul et al., 2009). This figure is likely to have been similar during the main period of my ethnographic fieldwork that this thesis draws on (2010-11), as other rates of HIV prevalence in Nyanza have remained roughly the same since 2003 (NASCOP, 2014).

Figure 7: Mobile HIV voluntary counselling and testing tent in the middle of the city. Painting by Johnson A Ondiek, 2010.

The research presented in this thesis refers to a specific transitional moment in Kenya's HIV epidemic and addresses a time (2008-2012) that encompassed the beginning of a rapid and largely successful scaling up of free antiretroviral treatment for HIV. This was a time when HIV started to become a manageable chronic condition rather than a certain death sentence. It was a time when, compared to other slightly earlier regional ethnographic studies (e.g Brown, 2010, Geissler and Prince, 2010, Prince, 2007) I found some people could talk somewhat directly about their HIV status. Rather than relying only on oblique references to this 'death of today', 'the disease going around' or *chira* (suffering brought on by forgetting about traditional

'rules' and rituals), I witnessed people name themselves with the acronym PLWHA (person living with HIV/AIDS) or refer to *Chalna*, a literal, and tellingly idiomatic translation of 'My Status', *chal* being otherwise used in casual enquires about the status/situation of things in the (Luo) world/earth (e.g. *piny chal nade?/*What is the status of things there?)[5]. Yet others could not talk freely about HIV, and the spectre of death, as well as actual death from AIDS complications, maintained a strong presence.

In terms of biomedical research this time-period saw several landmark, highly globally influential HIV studies conducted in Kisumu City and Akinda; including a prevention of mother to child HIV transmission study, male circumcision for HIV prevention studies, a mass home-based HIV testing intervention, and discordant couple study that contributed to the eventual scientific declaration that a person living with HIV with a controlled viral load cannot transmit HIV, known as Undetectable = Untransmittable (U=U) (Eisinger et al., 2019).

How unique are these spaces?

Although Akinda and Kisumu City are somewhat exceptional spaces due to the degree of intensity of transnational medical research practiced there, they are not unique. Living within an HDSS site represents one possible version of life in late modern East Africa for a significant number of people. As such, they are exemplary places to understand life in late modernist Africa, illuminating issues such as the dimensions and experiences of precariousness.

There are currently 37 African HDSS sites registered with the INDEPTH Network, an international organisation which coordinates the world's health and demographic surveillance systems (www.indepth-network.org).

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[5] See also Parkin (2015 p. 9-10) for a consideration of the relationship between changing cultural concepts of HIV/AIDS and advances in treatment and prevention as reflected in the use of changing keywords/key terms among Dholuo speakers over time.

Collectively the African sites contain 2, 904,425 people. All have been running for more than 10 years. 15 have been in operation for more than 20 years and 7, like Akinda, have histories stretching back more than 30 years. This represents nearly 3 million people and, in some cases, multiple generations growing up with transnational medical research as a backdrop to their lives. This is a growing practice, for example, as of 2016, there is now an urban HDSS in Kisumu City which encompasses 77,000 people in an estate bordering the one in which I lived (Cunningham et al., 2019).

There are also many other places on what Geissler has called the 'archipelago' of global science across Africa (Geissler, 2013a). Places like Kisumu City where the majority of people may not live within an HDSS, but where medical research is an everyday, ordinary experience. This includes countries like The Gambia as described by Fairhead and Kelly, where the UK Medical Research Council established research laboratories in 1949 and is now the county's third largest employer (Fairhead et al., 2005, Kelly, 2015). Or cities like Lusaka, in Zambia, where residents see research participation as part of a wider landscape of piecework and casual employment opportunities. (Bruun, 2014, Bruun, 2016). Furthermore, across Sub-Saharan Africa many other villages are involved in not dissimilar programmatic interventions run by international non-governmental organisations (Geissler, 2015, Nguyen, 2009, Rottenburg, 2009, Swidler and Watkins, 2009, Watkins and Swidler, 2013).

Orientation

My aim is to provide an account of everyday life in a site of intense transnational research activity that seeks to expand and deepen understanding of the narratives of the people who live within such places. As such, the thesis sits within a long anthropological tradition, sometimes marginalised, that emphasises storytelling (Hurston, 1938, Hurston and Walker, 2018, Jackson, 1998, 2002, Maggio, 2014, McGranahan, 2015). I use several different techniques to try to convey the zeitgeist of this time,

interspersing stories of people – and their deaths – in between published papers, illustrated with paintings. I also include a more unconventional paper written in the form of a song to try to underscore the rhythm of everyday life where precarity mixed with precarity and apathy and despair alternated with creativity and vitality.

In this spirit, I also borrow several complex cultural 'elastic idioms' (Nyairo and Ogude, 2005) in circulation in this region during my fieldwork as ways to think through the multiple-edged meanings of different aspects of my findings. Drawing on actual metaphors in use in these places also enabled me to circumvent thinking in imposed dichotomies, such as between tradition and modernity, or local and global, i.e., avoiding conceptualising transnational medical research as purely global, versus the everyday life of medical researchers and participants as purely local (See Burawoy et al., 2000, Piot, 1999, Weiss, 2009).

Among other idioms, I use the flexible metaphor of *'exposure'* for considering the value and risk inherent in an economy driven by HIV science (Chapter 6). I also use the expression *okbichaloni* ('things aren't what they seem to be. But you can know that for sure') to analyse the felt-experience of precarity as something knowable and predictable in this context (Chapter 9).

I would like to now offer the story of one of these complex cultural elastic idioms, that of '*analogue*' and '*digital*.' Throughout the writing-up process, I drew upon these idioms to provide me with an overarching conceptual frame for thinking about the *zeitgeist* of life during this post-colonial period, including the place of transnational medical research within it.

Living in a time of analogue and digital

Figure 8: Small shop painted with the slogan of the pay-tv Chinese company StarTimes, Kisumu City 2012. Source: Gemma Aellah

Over the last ten years or so, one country after another has switched off their analogue TV signals. At roughly the same time as I began ethnographic fieldwork, Kenya began its own official, slow, and patchy six-year journey towards digital broadcasting.

Analogue TV transmits programming through a single continuous signal varying in amplitude depending on the amount of data sent, with each TV station assigned its own frequency. The signal can deteriorate over long distances and can suffer interference from other sources leading to fading, snow, and ghosts. The limited number of channels ensures maximum audiences and the prioritising of national TV stations. Digital broadcasting in comparison converts data into little bits, recombining into a whole so that the viewer receives a complete, perfect picture at the other end. The picture is high quality, with no fuzziness or snow. Multiple digital channels can be broadcast in the space of one analogue channel, greatly increasing the output of programming. A switch to digital programming allows in many different competitors to the market, but also a fragmentation of viewership. In Kenya, this has led to an offering that now includes over 70 TV stations, mixing free channels with pay-for-view services, national, regional, international and

specialist providers. Kenyan TV can now be watched on the internet, and even from outside the country.

Kenya's so-called 'great migration' from analogue to digital television – a pun on Kenya's most famous tourist attraction, the Great Wildebeest Migration across the river Mara, officially began in December 2009 when then-President Mwai Kibaki launched the digital signal. The initiative – branded as 'Digital Kenya' – quickly became a powerful metaphor for visions of political, ideological, and economic change and futures. The migration was regarded as a flagship project of Vision 2030, Kenya's national development plan. Current President Uhuru Kenyatta's Jubilee party utilized it in their election campaign slogans, dubbing themselves 'digital boys', versus the 'analogue old boys vanguard'. And 'analogue' and 'digital' firmly found their place in sheng, a popular slang patois that constantly mixes and reinvents Kenya's multiple languages.

President Uhuru Kenyatta – like the then US President Obama – was on one level supposed to be the ultimate cosmopolitan or cosmo-politician - in his dress, his speech, his mobility, and seemingly national and global rather than tribal connections. But, of course, he was also the son of Jomo Kenyatta, Kenya's first president and – not coincidentally – the richest president in Africa through his family's wealth. His personal wealth is undisclosed but estimated to be in the region of 500 million dollars. This includes massive tracts of land, the Kenyan Commercial Bank and Brooks Dairies which produce most of the supermarket milk consumed in Kenya. Uhuru Kenyatta was also, at the time of his election, under indictment at the International Criminal Court for his perceived role in the post-election violence that rocked Kenya in 2007 and exposed tribal fault-lines.

The tropes of 'digital' and 'analogue' became, in Kenyan popular discourse, playful and imaginative linguistic short-cuts referring to perceived modern versus traditional ways of acting, thinking and being. They were ways of talking about youth versus age, the future versus the past, speed versus

slowness, globalisation versus nationalism and tribalism, and connectivity versus connectedness. In rural Akinda people made subtle, layered jokes about becoming (or not) '*JoDigital*' or 'digital people'. But, reflecting the experience of the migration itself, which was marred by delays, strong resistance to the transition by national TV stations and corruption scandals, such terms were not seen as unambiguously good or bad.

Analogue and digital metaphors were deployed ironically, cynically, and with self-deprecating humour to comment on the absurdity of life. A good example was a televised presidential debate in 2013 which was supposed to showcase how 'digital', as in modern and cosmopolitan, Kenyan political life had become. But, in fact, it was perceived in Kenya as just a digital new 'gloss' applied to familiar, or analogue, political relations. Watching at home in the UK, I saw how my friends in Kenya used their social media platforms to criticize the event as a political mimicry of American politics, where pseudo cosmo-politicians talked about giving a one-off donation of that global icon of progress - sanitary towels - to girls across the nation when pressed about how they were going to tackle systemic radical underfunding and unequal access to education and health.

In Akinda, I heard the terms when I was doing piloting stories about medical research ethics that I had collected during my fieldwork to be used in a training resource for global health researchers. I had asked the local NCROC/CHA community advisory board members to comment on some paintings I had commissioned that depicted scenes of ethical dilemmas. One painting showed an older Ministry of Health worker on secondment to a transnational medical research project. He was giving soap to an elderly widow as both an expression of kinship and paternalism and a violation of informed consent to medical research participation. As the community advisory board members put it, to much general amusement, 'the world is now digital, that researcher is being analogue!' With the implications being that of course analogue ways of being were not going away, and that digital ways were not necessarily better.

In Kenya, during this transition from analogue to digital, both ways of programming were in operation at the same time. The country was moving towards a digital future, but analogue programming persisted in the continued existence of analogue TV sets and, sometimes, as defiant acts of resistance to this new future, such as when several major national TV stations went off air in protest at the digital takeover. The same was true of the metaphorical digital versus analogue ways of acting, thinking and being. Themes of digital versus analogue pervade the papers presented in this thesis. 'Digital life' may represent the future, but it co-exists with analogue ways of being in the present. In some cases, a renewed commitment to analogue life is an act of resistance to this kind of future.

In Akinda, the seemingly digital activity of the health and demographic surveillance system constantly transmits little pieces of data collected from the villages overseas to be recombined into a complete abstracted picture of the village in global health journals and international conferences. But this is only possible because of the analogue work of resident fieldworkers. The collected digital data is based on years of friendships, kin relations and deep knowledge of the rooted ways Akinda residents relate to each other, as well as the hard physical labour of walking or cycling around the villages daily.

Furthermore, Chapter 5 describes the biography and lifework of one fieldworker who would very much describe himself, proudly, as an 'analogue' person, despite his exposure to 'digital life' through employment with a transnational medical research organisation. In this paper I describe the ways he strives to reclaim what could be described as analogue ways of living by celebrating ruralism and resisting the light-footedness of the 'digital' nature of transnational medical research. In Chapter 7 I look at the flipside of this: the consequences faced by young men striving for a 'digital' life, who move too fast and who struggle to find a workable place for themselves in this transition period between old and new, or analogue and digital, ways of being.

Thesis Structure

This is presented as a Research Paper Style thesis consisting of four published papers, extracts from a book and an unpublished contextual chapter. Each of the introductions to the individual papers is prefaced with the story of a death. Death was ever-present during my research but these five touched me especially. Each of them shaped the way I thought about the associated paper. They shaped what I wanted to write about and are part of the reason why I chose to include papers on these topics over others. The stories did not make it into the final papers, but I present them alongside by way of introduction. And, also, of remembering.

Each of the introductions are also accompanied by an illustration by Kenyan medical researcher and artist, Johnson Ondiek. These illustrations depict scenes related to my fieldwork. The paintings are based on descriptions I gave to Johnson, but they also encapsulate his viewpoint. The process of creating them is described in detail in Chapter 3.

Chapter 2: Background literature

This introduction is followed by a discussion of several bodies of background literature against which I situate my research. I start with a review of ethnography of JoLuo, outlining some key texts to better situate my own ethnography, conducted during a historical juncture of in-betweens and afters (post-election violence, expansion of transnational medical research, rapid scale-up of HIV care) against an older background of ethnographies that reveal continuities co-existing with changes.

Transnational biomedical research is a key feature of the social, economic, and physical landscape of contemporary Luoland. To contextualise the current form that post-colonial transnational biomedical research takes, I then present a historical overview of medical research and its relationship with colonialism. Following this, I explore wider literature on the

anthropology of transnational biomedical research to understand how other anthropologists have conceptualised the phenomena and to look for points of comparison and contrast with my ethnographic case.

Finally, I consider literature that explores precarity as a lived experience, or a 'structure of feeling', which commentators argue has become a dominant trope across sub-Saharan Africa. I focus on studies that have asked about how precarity links with people's experience of lived time, timelines, and lifetimes.

Chapter 3: Methods

This chapter contains a detailed description of my methodological approach. I describe my research practices in Kisumu City and rural Akinda, demonstrating how I have taken a methodological approach that involves learning through embodied experience, as well as through in-depth interviews, focus group discussions and observations. This chapter also includes discussion of my approach to presentation and writing.

Chapter 4: Akinda and its histories: Stories of magicians, missionaries, and scientists

This is a detailed contextual chapter in which I explore the different historical strands and stories of arrival that has led to how Akinda is today. It weaves together stories of magicians, missionaries, and research scientists. By locating this chapter within Akinda, rather than from Kisumu City, or telling a history of the field station, I aim to show clearly and concretely that history in this place does not begin (or end) with post-colonial global health intervention. The chapter provides a descriptive analysis of multiple layered histories of intervention, including how these are experienced simultaneously in the present in the biographies of residents and physical traces in local health dispensaries.

Chapter 5: "Living honourably and independently": Dreaming of a good village life in an African rural Health and Demographic Surveillance site.

Chapter 5 contains a paper that focuses on transnational medical research practices and experiences in rural Akinda. It was written for Etnofoor and published in a thematic issue on 'the village'. It builds on Chapter 4 by focusing on the story of one of the Luo fieldworkers who has been brought into Akinda on the tails of transnational research activity. Its' ethnographic object is a singular individual – JaKenya. The paper takes his biography, dreams, and creations to think through the construction of new Luo subjectivities that centre on rural life. At the same time as carrying out his research duties, JaKenya slowly builds a home and creates a forest in the village that he hopes will transform the landscape and last for generations after his death. The paper, therefore, uses his dreams and concrete actions to implicitly critique the light-footed, temporary form that transnational medical research takes in the village. This paper aims to bring into the fore the complexity and multiplicity of 'local' lives. It looks at what matters to JaKenya as he makes his life, and the place of medical research in this.

This paper is co-authored by JaKenya, using one of his given names not in common use, in order to blur his identity a little. When I decided I wanted to write a paper so explicitly about one person, I approached him to gain permission, share ideas and work out the best way to author it. This did not feel like it should be a single authored paper. JaKenya decided how he should be named, both within the paper and in the by-line. Although the writing voice is clearly mine, both the story and much of the critical reflection is JaKenya's. His voice also comes through in the images we selected to accompany the text, images which show his creativity in dress, house-building and forest-growing.

Chapter 6: Seeking Exposure: Conversions of scientific knowledge in an African city.

Chapter 6 is a paper that was co-authored with the Principal Investigator of the Research Community Study, Wenzel Geissler, and takes as its ethnographic lens a metaphor often used by our interviewees: 'exposure.' It focuses on transnational research in the city, rather than the village. Using the metaphor of 'exposure' (i.e., the exposure of analogue film to light), we trace the everyday relationships between science and sociality in Kisumu city. We look at the value of 'exposure' to transnational medical research to research staff and research participants trying to make lives in an economically fragile situation. We consider sites of intensive transnational medical research like Kisumu City as one configuration of life in late modern sub-Saharan Africa.

The paper is also a treatise on the nature of scientific knowledge and its circulation through communities where it takes on new meanings related to development and survival. The paper's contribution is, therefore, to African studies, as well as to Science and Technology studies. It was published in the Journal of Modern Africa Studies.

This paper was sent for comments to several NCRO/CHA researchers. It was also sent to one of the study participants, Min Favour, whose story is described in the latter part of the paper.

Chapter 7: "The earth does not get full": Understanding men, mood, and avoidable deaths from AIDS in Western Kenya.

Chapter 7 is a paper that steps further back from medical research to foreground what is, perhaps, an issue of more pressing concern to both Kisumu City and Akinda residents, young men living with HIV who struggle to adhere to their life-saving HIV medication.

It draws on data gathered across both the city and the village. One of the main drivers for the continued and expanding place of transnational medical research in the region is Kisumu City and rural Akinda's HIV epidemic. Despite considerable intervention, certain groups like young HIV+ men are 'blind spots' for targeted policy. The focus of this paper is on these men. It links their current perspectives on adherence to their memories of the height of the HIV crisis and their dreams of what counts as a good life today. It is written with policy makers in mind and calls for a need to take concepts like 'mood' seriously in policy decisions. It was published in Culture, Health and Sexuality.

This paper was reviewed by several Kenyan male HIV researchers in Kisumu City, and several male researchers based in rural Akinda. I also sent it for comments to Oki, a male HIV activist, himself living with HIV. As well as representing people living with HIV/AIDS for the NCRO/CHA community advisory board, Oki runs several voluntary HIV programmes in Kisumu, including a post-test club for men. I found his insights invaluable. I also sent this paper for feedback to the *Star-kuzz*, a male friendship group to which Atomic, the man whose death opens the paper, belonged.

Chapter 8: Talking about ethics in transnational medical research

Chapter 9 concentrates on a specific, practical application of my ethnographic fieldwork, one concerned with relational ethics under conditions of inequality. Relational ethics, in contrast to regulatory ethics, are understood to refer to ethical ideas that emerge in the moment in relations with others. This chapter consists of extracts from a book of ethical case studies written for global health researchers working across conditions of inequality in Africa. This book was co-authored with Wenzel Geissler and Tracey Chantler. It also included contributions from other members of our research group: Anthropologies of African Biosciences: Birgitte Brunn, Lusia Enria, Ann H. Kelly, Shelley Lees, Philister A. Madiega and Ferdinand Okwaro. NCRO/CHA researcher and artist Johnson Ondiek provided

illustrations. The book draws on the concept of 'relational' ethics and 40 case studies to show how ethics in transnational medical research encounters such as those taking place in Kisumu City and rural Akinda are experienced in the moment and are enmeshed in social relations.

Here, I present the introduction to the book, and three ethics case studies which draw on stories collected during my fieldwork. This chapter, therefore, focuses on the question of what kinds of ethical challenges emerge in the everyday practice of transnational medical research, and how we can best create spaces to talk about them. It represents an attempt to repackage ethnographic data to provoke discussion among global health workers, and between people in different hierarchical positions.

Chapter 9: Okbichaloni (things aren't always what they seem to be. Know that for sure): Hustling, HIV and hope in Luoland, Western Kenya.

The final paper of the thesis brings together the underlying themes of the thesis through the presentation of a piece of writing featured in a special issue of the Irish Journal of Anthropology on Creative Ethnography: Epistemologies, Pedagogies, Possibilities. The piece is a broader reflection on the 'rhythm' of life during the entire time-period of my fieldwork, trying to convey its intangible zeitgeist, as captured in the essence of a Luo phrase '*okbichaloni*' which emerged during this time. Meaning 'things aren't what they seem to be, but you can know that for sure' the phrase picks up on a prevailing patterning of life that is consistent across all the papers in this collection. This is the predictability of the precarity that characterised life (and by extension medical research practice).

The piece was sent for comments to several NCRO/CHA researchers, as well as a non-Kenyan researcher who was principal investigator on several Akinda studies. I also sent this to some of the friends and friends/research participants I have lived in proximity to in Kisumu to check if I had captured at least something of the 'feel' of the time.

This chapter is followed by my conclusions and, finally, a post-script which offers an insight into how the lives of those in my ethnography are continuing.

Research questions and corresponding chapters

This table indicates how my thesis chapters address my research questions.

Questions	Chapters
1. How is transnational medical research understood and folded into the broader lives of those living within its midst?	Cuts across all chapters. Especially: Chapter 4 Chapter 5 Chapter 6 Chapter 9
2. What value and meaning does transnational medical research have to those who encounter it? What (other) things matter to people as they navigate their lives in this place?	Cuts across all chapters.
3. Where does transnational medical research sit in relation to other interventions and responses to ill health, both historical and current, in this region?	Chapter 4 Chapter 7
4. What ethical challenges emerge in the everyday practice of transnational biomedical research, and how can we best talk about them?	Chapter 8

Chapter 2: Background Literature

Figure 9: Junior, who lived in my house in Kisumu City for a while, rearranging books from my 'community library' (2010). Source: Gemma Aellah, with permission of Junior's mother.

This chapter outlines several bodies of background literature against which the conceptual underpinnings of this thesis are situated. It begins with a review of ethnography of JoLuo; ethnography which has always been concerned with tensions between traditions and radical social transformations. I outline some key texts to better situate my own ethnography, conducted during a historical juncture of in-betweens and afters (e.g., post-election violence, expansion of transnational medical research, rapid scale-up of HIV care) against an older background of ethnographies that reveal continuities co-existing with changes.

Like me, some of these ethnographers chose to organise their narrations of the life-worlds of those they studied through analyses of Luo idioms at given points in time. I detail several analyses of idioms concerning money and the state of the world, finding this a useful way to provide background context for the 2008-2012 period of my research.

My thesis offers a narrative ethnography of JoLuo living at a point in time where transnational medical research and intervention was ubiquitous: one of the defining features contributing to the *zeitgeist* of this time and place. However, few ethnographers of JoLuo have included it in their analysis. To contextualise the current form that post-colonial transnational biomedical research takes, I therefore present a historical overview of medical research and its relationship with colonialism.

I then turn to anthropological studies of transnational medical research taking place across the global south. The specific experience in Luoland reflects a broader, global increase in biomedical research conducted in the global south since the 2000s. I draw on this wider literature to understand how other anthropologists have conceptualised the phenomena and to look for points of comparison and contrast with my ethnographic case.

Some of this body of work outlines the logics of globalised techno-scientific regimes that, despite often producing radical life-transforming health innovation, also participate in, or perpetuate, exploitative economic modes sustained by precarity. As my focus is on the multi-sided lives of people engaging with these regimes in Western Kenya, I continue these debates by considering them alongside anthropological literature on the concept of precarity beyond the specific arena of transnational medical research and intervention. I consider literature that explores precarity as a lived experience, or a 'structure of feeling', which commentators argue has become a dominant trope across sub-Saharan Africa. I focus on studies that have asked about how precarity links with people's experience of lived time, timelines, and lifetimes.

The literature concludes that across many places in post-colonial, post-millennium Africa, vulnerable people – especially younger generations - are living in a time of prolonged limbo, or waithood, which has led to a new realm of improvisation (e.g Honwana, 2012b). But I find it more useful for my ethnographic case to think about precarity in terms of people making concrete and adjustable judgements about when they think they might be likely to die, and the effect this has on their future-planning. Therefore, I draw on Morris's concept of *rush* as opposed to panic in the context of the pre-ART HIV crisis in South Africa to help think this through (2008). This approach allows me to question whether precarious contexts are necessarily experienced as un-knowable/unpredictable by those living with them. I also find in Morris's work useful ideas about analysing collective assumptions around life expectancy, death and what makes a good life.

The discussion takes me to broader philosophical literature on the best ways of understanding, describing, and representing post-colonial African lives in this context. I take from this literature an overarching philosophical approach to conceptualising individual and collective subjectivities, and continuity and change, which I feel resonates well with my concrete ethnography in Luoland: that of thinking of lives as lived in *multiplicities* and in *multi-durées* (Mbembe, 2001, Tembo and Gerber, 2020).

Ethnography of JoLuo

History and anthropology of, and by, JoLuo has always been concerned with tensions between traditions and radical transformations, a line of enquiry which my work continues. Two significant early figures in ethnography of JoLuo, at least from the Global North perspective, are C.W. Hobley (1867-1947), and Evans-Pritchard (1902-173). Evans-Pritchard and C.W. Hobley were interested in Luo political structures. Their work shows how existing forms of Luo authority were overlaid with colonial plans. However, their

research was limited. Evans-Pritchard's visit to an area encompassing Akinda in the 1930s was less than six weeks (Campbell, 2006). It only involved interviewing Luo mission converts, in English, and produced two short surveys (Evans-Pritchard, 1950, 2012 (1950)).

Parkin's ethnography of JoLuo living in an estate in Nairobi offers a more in-depth account of the blurring of 'tradition' with modernity (Parkin, 1978). He reveals how through the circulation of multiple wives between urban houses and rural homes, JoLuo bolstered their distinct cultural identity or 'tribalism', despite mass relocation to urban areas. His work shows the importance of thinking about urban and rural JoLuo as part of one society, straddling and circulating ideas and resources between the different spaces.

However, he also argued that JoLuo were affected by a condition of 'stifled cultural debate'. But arguably there is a strong tradition of historicity among JoLuo, who have produced elaborate genealogies and origins narratives, as well as multiple public and local debates about cultural practices and traditions (Atieno Odhiambo, 2001, Ogot, 2001, Prince, 2007). Seminal work produced in collaboration between an American and Luo historian focuses on the ways that JoLuo themselves have been constantly involved in intellectual debates about what constitutes their culture, and what constitutes their history (Cohen and Odhiambo, 1989, 1992).

In fact, much of the more recent ethnographic work focuses on how JoLuo are finding ways to be together in the face of multiple challenges and assaults on their identity. Shipton's ethnography of JoLuo in Southern Nyanza shows how credit and debt in this context are as much cultural as they are economic and political (Shipton, 1992, 1995, 2007, 2009, 2014, Shipton, 2010). He shows how large external aid programmes, sponsored by the World Bank are transmuted and manipulated by JoLuo to serve their own purposes and perpetuate ways of belonging to each other through generations.

But, building on Shipton's work, Schmidt draws on the use of idioms relating to money to show how JoLuo's economic situation is changing (Schmidt, 2017a, b, 2020). In the 1980s, Shipton observed the use of a specific idiom *pesa makech* (bitter money) to denote money gained in an amoral way. *Pesa makech* was acquired by selling objects constitutive of sociality: other human beings, ancestral land, and political influence. Such acts blocked pathways to social growth, and therefore relationships between people. Houses built with *pesa makech* might collapse, cows might die, and its use as bride wealth might result in barrenness. In this way, JoLuo ensured that global economic forces did not erode their own cultural ideas about value and exchange (Shipton, 2010).

Yet, several decades later Schmidt found this term no longer in use. His interlocutors commented simply that 'money is money: the money's origin does not matter as long as it enables you to survive' (Schmidt, 2017a p. 279). Instead, he found a broader term in use - *pesa marach* (wicked money). This is money which seduces its owner to spend it on unnecessary things like alcohol and gambling, and so cause their ruin. The cause of the disorder prompted by the acquisition of what was formerly bitter money, he argues, was seen as internal (to Luo society) and therefore potentially controllable. But the causes of wicked money are perceived as external and radically uncontrollable, linked to the wider Kenyan economy and to the actions of 'others', such as those Kenyan tribes with more political power or global forces. JoLuo, according to Schmidt, now experience the state of their world as irreversibly tainted by economic failure, economic marginalisation, and political impasse. Alongside such fatalism runs as a lament that relationships have become more individualistic and 'communal life is not there these days' (ibid, p. 281).

Yet, other ethnographers have highlighted the ways that JoLuo are still trying to find a sense of 'communal life.' Cooper's ethnography in a peri-urban part of Kisumu City explores the ways residents try to care for AIDS crisis orphans whilst managing the help/pressures produced by international child

sponsorship programmes and the manufactured concepts of 'chance', and subsequent mistrust, they bring, all whilst still 'being together' (Cooper, 2011a, 2015, 2017).

Cooper draws on the idioms-in-use of 'sitting' and 'standing' to analyse how families determine solutions to the problem of how to manage the growth in AIDS orphans and to maintain *riwruok* (togetherness) (Cooper, 2012). She describes how 'traditional' practices of sitting together and 'standing for' other kin members are purposively deployed to ensure the tenacity of families is clearly demonstrated and, consequently make it persuasive and reinforcing during a time of uncertainty.

Geissler and Prince's ethnography is also concerned with how to produce growth and move forward at a historical moment described by their interlocuters when '*piny tho'* – the land is dying (Geissler and Prince, 2010). Their ethnography of a Luo village at the turn of the twenty-first century refers to an earlier moment in the AIDS crisis before the introduction of antiretroviral therapy, when AIDS was known as the 'death of today.' In their descriptions of the zeitgeist of this time, they argue that 'the most salient trait of this community is its profound doubt in itself' (ibid p.2). They show that a pervasive sense of loss is experienced by JoLuo, many of whom have not in fact personally experienced a more hopeful time before the economic decline and austerity of the 1980s, authoritarian political rule, corruption, and the HIV/AIDS epidemic.

Collectively, therefore, other ethnographers of JoLuo have described a community defined by struggle, by 'wicked money', death, and a sense of being at the end of the world, with unclear ways forward. Yet, much of this ethnography also shows people desiring to be together and engaging in debates about how to do this. This theme of *trying* is something I will come back throughout the thesis.

Although other ethnographers of JoLuo have addressed large scale interventions such as development programmes, child sponsorship and HIV intervention, less attention has been paid to transnational medical research, which provides much of the flows of material resources in the areas where I conducted fieldwork. An exception is Geissler's article, based on his own experiences as a natural scientist working in a Luo village. He explores moments of friction between medical researchers and researched, through analysis of blood stealing accusations levelled at medical researchers working on a de-worming study (Geissler, 2005). Geissler points out that in Luoland medical research activity was the first frame through which residents experienced Western biomedicine and is likely still the most prominent aspect of biomedicine encountered. However, the shape and vision of the biomedical research endeavour has changed, the history of which I will now outline.

Colonial and post-colonial biomedical research

Medical research and intervention by overseas governments has a long history in Kenya and, as in many parts of Africa, is intertwined with its colonial history (Comaroff, 1993, Olumwullah, 2002, Packard, 1993). The first researchers arrived in the first decades of the twentieth century, during a period of intense colonialism. In its earliest colonial forms transnational biomedical research took the form of expeditions and control campaigns, see for example Dawson's description of the Yaws eradication campaign in the 1920s (Dawson, 1987) or sleeping sickness control programmes (Hoppe, 1997, Tilley, 2004, Wijers, 1969). In fact, medical officers were among the few representatives of the Empire that people living around Lake Victoria encountered (Beck, 1973). Some of these campaigns were experienced as violent encounters, especially sleeping sickness campaigns which were

performed in a military style and involved relocations from Tsetse-infected areas, and confinement of those infected.

In 1940 the British Research Fund was created as part of the Colonial Development and Welfare Act representing a huge increase in research activities in the British colonies and the instiutionalisation of research. Clarke argues that this fund, and subsequent policies, symbolised:

> 'a belief amongst officials in London of the need to rationalize the development process, a faith in the efficacy of scientific solutions to colonial problems' (Clarke, 2007 p. 456).

Research committees and around forty research institutions were created across British East Africa (Beck, 1973). The Kenyan Division of Vector Borne Disease (DVBD) (originally the Yellow Fever programme) was created just before this in 1938 and was the first medical research institution in Kenya, preceding NCRO (Geissler, 2011a). Geissler has explored the history and memories of DVBD staff. He focuses on men who worked with DVBD during the late 1930s to early 1980s, encompassing the period before Kenya's formal independence in 1963 (what Cooper has described as a time of the 'imperialism of knowledge' (Cooper, 2002)), and the period of postcolonial scientific national government.

Interestingly, the biographies and narratives of these men did not often emphasize decolonisation. Rather they conceptualised the period from the end of the Second World War until the economic crisis of the 1980s as an era of 'developmental modernity' (Geissler, 2011a). Visions during this time were of participation in science and research directly concerned with early nation building and national development. In the 1940s and 1950s, for example, DVBD concentrated on research and eradication of river blindness within Kenya. Interviews with elderly DVBD men reveal stories of professional pride, of what it meant to 'be with the government' and 'go to

the field.' They connected scientific progress with *dongruok* (growth), applying this equally to science and society (Geissler, 2011a). Involvement of whole communities through working with chiefs and employment of casual workers connected 'the people' to the government as 'citizens of public health' through research and disease control. Underlying these stories told to Geissler in 2004 are memories of a better, hopeful past.

After the break-up of the East African Community in 1977, NCRO, a parastatal organisation, was created in 1978 and since 1979 all biomedical research, except sleeping sickness, has been under its responsibility. In 1979 NCRO began its collaboration with CHA, but the visions of the NCRO scientists at the time were to maintain their self-sufficiency. Hutchinson collected narratives about the plans of the first NCRO scientists employed in the late 1970s and 1980s (Hutchinson, 2017). Her interviews reveal that this was a time where Kenyan scientists envisioned making malaria science which was relevant to the context of Kenya and infused with an ethos of African socialism. Here, we can see that in the early post-colonial period, medical research shifted from an activity driven by an imperial logic to a national and civic commitment.

Yet, this vision could not be maintained, and now Hutchison argues that the purpose of the research NCRO conducts has become increasingly 'dislocated from local concerns' (Hutchinson, 2017), and more concerned with the needs of its collaborators, the most prominent of which is CHA.

CHA, which formed a collaboration with NCRO in 1979, is descended from a World War Two agency to fight malaria in the southern United States. It created 'disease detectives' and the Epidemic Intelligence Service, whose symbol was a shoe with a hole representing their commitment to 'on the ground' fieldwork or 'shoe leather' epidemiology and surveillance. Described as 'sentinel for health for the nation and the world' (Etheridge, 1992 xv), during the Cold War it focused on epidemiology as 'the first line of defense against enemy germs' (Etheridge, 1992 xv). National security, therefore, has

played an important role since in driving its interest in global health. Initially focused within its own borders, at a national immunisation conference in 1965 a new approach to enhancing the nation's health was broached: 'to take the attack on infectious diseases overseas' (Etheridge, 1992 p. 145).

As a result, CHA became heavily involved in the eradication of smallpox worldwide campaigns. Its' interest in international health was also related to a boom in jet travel. Etheridge's history of the organisation in the late 1960s through to 70s is peppered with stories of individual Epidemic Intelligence Officers on heroic missions to help during epidemics and bring back samples.

King (2002, 2004), in an exploration of documents produced by American scientists, public health officials and national security experts, has argued that the idea of CHA as the 'sentinel' of global health was replaced from the 1990s onwards with an 'emerging diseases worldview' (as in literally a view of the world from the perspective of the USA). Central to this worldview, he argues, is the importance of mapping of space and an emphasis on information and commodity exchange. He contrasts this worldview with that of colonial medicine which was concerned with conversion through medical modernisation and the diffusion of knowledge from 'centre' to 'periphery.' The 'emerging diseases worldview' of CHA is now:

> 'rather more concerned with efficiently managing the global
> circulation of medical products: the integration of locations
> into a global marketplace: not just a global clinical, but a
> global HMO' (King, 2002 p 779).

A 1992 report by the National Academy of Science's Institute of Medicine: Emerging Infections: Microbial Threats to Health in the United States sums this up well:

'in the context of infectious diseases, there is nowhere in the
world from which we are remote and no one from whom we
are disconnected' (Lederberg et al., 1992).

It is under this context that CHA initiated a specific plan for protecting the
American nation's health in 'an era of globalisation.' They recommended
replacing ad-hoc outbreak investigations with technologically sophisticated
surveillance networks around the world and International Emerging
Infections Programmes, one of which is based in Akinda and centered
around the mission hospital at Loch.

Contemporary neoliberal postcolonial medical research in Kenya therefore
takes a different form from its predecessors though it carries within it its
colonial and post-independence legacies. Geissler describes the distribution
of transnational medical research across sub-Saharan Africa as taking the
form of an 'archipelago' (Geissler, 2013a). Rather than such activity being
dissipated through national health ministries and universities, it operates
through a series of intense, highly resourced enclaves or 'islands' where
global health research knowledge is extracted and constructed. Such islands,
of which Kisumu City and Akinda are one, have come about through two
inversely related changes: on the one hand the increasing standards,
technologies, and possibilities of global science, and on the other, the post-
colonial economic and political crises since the 1970s that have made it
difficult for such standards to be achieved in local and national universities
and ministries of health without outside overseas partners.

Here, a colonial utopian vision of a medical micro-colony is replaced with the
'ideal of a utopian biomedical macro-colony, in which global surveillance
networks allow risks to be identified and managed quickly and efficiently'
(King, 2002 p.775). As such, places like Akinda become informational nodes
– albeit unequal nodes - seamlessly integrated into an unending global
network. Although, this rather masks the way in which current transnational
medical research is played out on the ground as a series of hard-won, short-

term projects; a domain of practice perceived as existing in a state of precarious, if perpetual, temporariness by residents.

Anthropology of transnational medical research

As described in the Introduction, Kisumu City and Akinda are unique but not exceptional places in terms of the intensity of medical research conducted. In tandem with a global increase in biomedical research conducted in the global south, a significant body of anthropological work on transnational medical research has developed since the 2000s, (Sariola, 2020). I will now look at how other anthropologists have conceptualised the phenomena.

It is possible to roughly divide this work into three related areas: firstly, those primarily concerned with practical, 'applied' or embedded studies within clinical trials. Secondly, there are those concerned with anthropology of clinical trials. Often these involve analysing the global political economy of clinical trials and new forms of global assemblage, networks, actors, and objects involved in knowledge production. Thirdly, a smaller number of studies have focused specifically on Health and Demographic Surveillance as a domain of practice. All, it could be argued, are concerned with problematising the field of bioethics.

Bioethics and the emergence of clinical trials as an object of ethnographic enquiry

Bioethics - the systematic application of principles of right and wrong to medical activity – emerged as an organising domain of practice in the late 1960s/1970s (Chadwick and Wilson, 2018, Muller, 1994). It developed as a specific area of study in the United States in large part in relation to the revelations about Tuskegee Syphilis Study, a United States Public Health

Services Study which had tracked the effect of untreated syphilis in African American men for forty years, withholding penicillin for decades after it had been established as an effective treatment (Mays, 2012).

The origins of the discipline of bioethics was found in a hybrid of philosophy, theology, and medical law (Jonsen, 2003). It aimed to provide what Simpson describes as a 'meta-commentary on biomedical practice that soon came to acquire all the paraphernalia of an academic discipline (Simpson, 2003 p. 12). Because of its Western philosophical background, the discipline took a distinctive kind of highly individualised person as its ethical subject. It focused on the primacy of the individual, and was concerned with emphasising individual rights, especially autonomy and privacy, and with codifying the protection of these in governing procedures (Fox, 1990). Underlying such an approach was/is an illusion of objectivity and of the universal applicability of certain ethical principles.

Although questions about the constructed, contextual, and multiple nature of morality have always been at the heart of anthropology, anthropologists were somewhat slow to engage directly with this new field (Muller, 1994). Historians of anthropology postulate this was because the developments in Western biomedicine that triggered the emergence of a distinctive discipline of bioethics were not the 'traditional' subjects of study for anthropologists (Lieban, 1990).

However, during the 1990s this was to change. There was both an increase in anthropological studies of science and technology, and a number of significant publications that directly linked anthropological insights to bioethics discussions (Marshall, 1992, Weisz, 1990). Ethnographies of people's encounters with the new medical technologies that the field of bioethics was concerned with, such as amniocentesis and life-support technologies, placed them in specific social and cultural perspective (Rapp, 1993, Slomka, 1992). In doing so, they also raised questions that challenged the fundamental idea of the universality of the concept of personhood on

which universalising bioethics principles were based (Kaufert and O'Neil, 1990).

At the same time, the 1990s also saw a significant growth in clinical trials related to HIV carried out in Africa, which brought new dimensions to global bioethics debates. A major controversy concerned what became known as the 'standard of care' controversy (Angell, 1997, Lie et al., 2004, Lurie and Wolfe, 1997, Wendland, 2008). African research participants in trials of a cheap drug to prevent mother to child transmission of HIV received placebos, rather than the standard treatment readily available in North America. This caused fraught debates about what standard of care should be owed to research participants in clinical trials in developing countries. The controversy animated awareness that what was 'right' could not so easily be defined, and highlighted that 'simplistic notions' of ethics would not help move discussions forward (Benatar and Singer, 2000).

Through such debates clinical trial participants emerged as a problem requiring social analysis. Given anthropology's interest in holistic context, as well as the perception that communities within the global south were the 'traditional' domain of anthropology, clinical trial participants became a potential object of ethnographic enquiry. This led to the beginning of what would become a significant body of work on the ethnography of clinical trials as carried out in the global south, including thick descriptions of the realities of processes like informed consent and community engagement. Such in-depth studies served to reveal how thin the bioethical accounts of these contexts had previously been.

At the same time, a significant shift from most clinical trials being run by academic institutions to a proliferation of trials run by commercial Contract Research Organisations dovetailed with anthropological interests in the unevenness of globalisation, the neo liberalisation of health and the intersections of health, economics and politics (biopower and biopolitics), leading to theorisation of clinical trial participation as a form of embodied

labour (Cooper and Waldby, 2014, Rajan Sunder, 2006, Waldby and Cooper, 2010). Such critical studies further extended questions of bioethics from the moments surrounding the clinical trial encounter into the realm of global economic inequalities and social justice.

Studies of the emergent properties of research

There have been multiple nuanced, in-depth qualitative studies that have revealed how research routines play out in practice, and which demonstrate the complexities of what had been lost in the universalising approach of more conventional approaches to bioethics. Ethnographies of clinical trials in practice have challenged conceptualisations of informed consent as taking place in a straightforward single encounter, and of the purity of the bioethical concept of 'autonomy', which presupposes an individualised person able to make a 'pure' individual decision about participation (Enria et al., 2016, Gikonyo et al., 2008, Kamuya et al., 2017, Marsh et al., 2008b, Molyneux et al., 2005, Molyneux et al., 2013). Such studies tend to focus on the emergent properties of research and ask how it could better (and more ethically) achieve its goals.

Related to this, there is a growing body of ethnographic literature focusing on the cadre of local fieldworkers or frontline workers as a specific, crucial, and often overlooked category of active, moral players within global health research (Kingori, 2013, Kingori and Gerrets, 2016). Ethnographic work on transnational medical research fieldworkers in Africa has focused on the ways these local fieldworkers grapple with differences in universalised bioethics conceptualised in formal globalised protocols and those experienced in practice (Chantler et al., 2013b, Kamuya et al., 2013a, Kamuya et al., 2014, Kamuya et al., 2017, Kamuya et al., 2015, Kamuya et al., 2013b, Kingori, 2013, 2015, Kingori and Gerrets, 2016, 2019, Madiega et al., 2013, Molyneux et al., 2013).

These studies have encouraged a focus on 'the who' of bioethics in transnational medical research and shown that it is integral to 'the what'.

Kingori's work, for example, shows how ethics enacted in the everyday practice of fieldworkers during their research work is shaped by the sense of obligation and expectation provoked when witnessing the suffering of others. Institutional interpretations of bioethics became peripheral 'on the ground' (Kingori, 2013). Moved by witnessing suffering among their participants, fieldworkers sometimes chose to help with money or gifts of food, despite these actions threatening the potential autonomy of participants' decision-making.

But these actions were not entirely driven by a sense of moral obligations. Kingori notes that they were also motivated by a concern that not providing help could jeopardise their future attempts to collect data. Such small, secret ethical acts by fieldworkers allowed the research institution not to have to consider the idiosyncrasies of every-day life, or to take account of what has been described elsewhere as the kin-like relations between researchers and researched which help sustain research (Geissler et al., 2008). Kingori's work highlights the gaps between regulatory ethics and what could be described as relational ethics, the complex and spontaneous pursuit of morally right actions during interactions with, and relationships between, others (Chantler et al., 2013b, Given, 2008, Meloni et al., 2015).

Political economy of clinical trials and embodied labour

There has also been a strong body of anthropological work that focuses on the global political economy of clinical trials, taking the global assemblages of institutions, networks, and actors as the object of ethnographic inquiry.

Crane's seminal work on HIV/AIDS in East Africa is an exploration of how inequalities in the global political economy of clinical trial practice play out on multiple levels (Crane, 2010, 2013a, Crane, 2011). The title of her monograph 'Scramble for Africa' refers to the fact that in the 2000s the vast populations of treatment-naïve patients with AIDS in Africa became a major draw for both university researchers and students in the Global North seeking to gain experience in global health and forge careers. Universities in

the Global North searched the African continent for resource-poor hospitals in which to base their research and interventions. In this scramble, inequalities between North and South were revealed and reinforced. While Global North partners sought to cement their high-profile research reputations, African collaborators lost out on authorship recognition with the knock-on effect of stagnating independent African national capacity for future research. Their access to the opportunities and benefits research projects could bring was lesser than their Global South collaborators. In fact, global health institutions relied upon the very inequalities that they hoped to fight to establish their authority and presence as the global experts and as researchers.

Petryna's 'When Experiments Travel: Clinical Trials and the Global Search for Human Subjects' explores a parallel 'scramble' on behalf of contract research organisations (CROs) (Petryna, 2009). She describes the shift over the last twenty years from most clinical trials being run by academic institutions to an increase in those run by competitive, commercial transnational corporations subcontracted by pharmaceutical industries to find more and more new clinical trial sites in order to produce the evidence needed for drug approval.

Petryna's work shows how vulnerable populations in resource-poor settings are increasingly recruited by CROs to become new experimental groups, in a search for 'clean' bodies which have not already been treated. As populations available to be researched in the United States reach 'treatment saturation', CROs competitively search for new bodies, willing countries, and host institutions in other places. Resource-poor populations are especially attractive because their existing low standards of healthcare make achieving the 'ethical' requirement to offer locally comparable treatment to placebo groups much cheaper. Administrators in underfunded public health-care systems – as well as desperate patients – seek to host or participate in clinical trials as means of bolstering (in the short term) infrastructure and obtaining experimental drugs that would otherwise be out of reach.

Yet, as Petryna shows, once adequate data for FDA approval is obtained and a clinical trial ends, post-trial participants remain, now dependent on medications financially out of their reach. Moreover, in the process the offshored clinical trial itself has become a powerful marketing campaign for expensive treatment regimens over older but perhaps more cost-effective drugs, to this newly created overseas market. Patients are forced into a form of 'market mediated biological citizenship (Petryna, 2009 p. 189), where the only recourse for patient groups is to lobby drug-purchasing states for treatment access. Human rights are transferred away from the public domain to the private citizen. Here, the lines between what counts as experiment and what counts as healthcare become blurred. Petryna's work describes a new cartography of pharmaceutical power and capital, and unravels the bioethical conundrums this involves, many of which are hidden from immediate view despite oversight by regulatory and ethics boards.

Sunder Rajan is another anthropologist whose work has heavily influenced theoretical thinking about the relationships between bioscience, the market, and politics (2006, 2008, 2009, 2010, 2017). He introduces the concept of 'pharmocracy' to understand the global hegemony of the multinational pharmaceutical industry (Rajan Sunder, 2017). He describes the ways that health becomes appropriated by capital and transformed from an embodied state of well-being into an abstract category made subject to capital's interests (Rajan Sunder, 2010 p. 57). In India he shows how national regulatory frameworks come to pit the interests of global capitalism against the public health interests of citizens. These kinds of political machinations have been critiqued as a new form of colonialism by Indian doctors (Nundy and Gulhati, 2005).

I find Rajan's work particularly interesting for its recognition that the global economy of clinical trials creates new forms of (oppressive) labour and new labouring classes; what he calls the 'labour of experimental subjectivity' (Rajan Sunder, 2017 p. 73). His ethnography of the changing situation in a depressed mill district in Bombay, and genomic research and drug

development marketplaces in the US and India offers one of the clearest examples of this process at work (2006, 2008, 2009).

Rajan describes the creation of a new 'experimental subject formation' in Patel, a mill district in Bombay, where textile mills have been shutting down and unemployed millworkers are the subjects most recruited into clinical trials, which is now one of the major industries of the area. Their healthiness, or rather their 'surplus health', is exploited not to provide the basis for a (conventional) workforce but rather for pharmaceutical capital. Rajan locates the experiential subjectivity of these research participants as 'consequential' to the creation of a bio-capital that reflects larger changes in the structure of capitalism and provides their 'conditions of possibility' (2008 p. 1978).

The changes in capitalism he refers to relate to the growth of speculative capitalism: the global service industry and real estate. Rajan describes how as mills are torn down for real estate (including the massive clinical trial hospital), structural violence is committed by global capital when the social fabric of mill-worker life is destroyed. Old workers commit suicide and the young join gangs. He shows how the original mill owners, the real estate speculators and the owners of the clinical trial industry can be virtually identical, as one family, for example, owns all three, with 'no disruption in class consciousness' (2008 p. 169). However, the working lives of this new class of experimental subjects are infinitely more precarious than before. Their labour is individualised and – by ethical requirement – anonymous. The trade unions that offered some measure of protection for these former mill workers are absent from the world of clinical trial work.

Other anthropologists have also highlighted the fact that embodied labour is central to the clinical trials that fuel biomedical innovation. Cooper and Waldby, influenced by Rajan, have argued that 'clinical labour', such as surrogacy or clinical trial participation, is emblematic of labour within current neoliberal economies (Cooper, 2008, Cooper and Waldby, 2014).

During experimentation for drug testing on humans, research participants undergo what Cooper calls a form of 'transformative exposure.' In exchange for benefits (monetary and otherwise), they are expected to experience, in an embodied and often unpredictable way, the metabolic effects of pharmaceuticals. They are also expected to perform the tasks involved in adhering to the routines of the experiment. Their labour is somewhere between active and passive. But, ultimately, it is the experience of self-transformation commodified (Cooper, 2008 p. 76). In this value exchange, what the funder/investor receives is information. Or in the case of stem cell donation, a surplus of biological potentiality that can then be transformed into surplus value. The neoliberal philosophies of deregulation, privatisation, and global competition – and the resulting accentuation of global North-South inequalities - are also applied to life itself.

Importantly, a concern with clinical research participation as embodied labour has not been restricted to the analysis of commercial research. Anthropologists studying publicly funded research have also explored this concept noting that, especially in ostentatiously non-commercial contexts, research participation is rarely considered or acknowledged as labour. A special issue on 'The Value of Transnational Medical Research' (Kelly and Geissler, 2011) offers a collection of papers that widen understandings of 'value' by considering the complex 'material politics' (Law and Mol, 2008) of clinical trials in different contexts (Cooper, 2011c, Geissler, 2011c, Kelly, 2011, Oluwatoyin Folayan and Allman, 2011, Samsky, 2011, Will, 2011). Collectively, they ask how 'research value is multiply configured in therapeutic, social, and economic landscapes' (Kelly and Geissler, 2011 p. 3). An aspect this collection lays bare is how the benefits of participation are conceptualised from the perspective of research participants (See also Abadie, 2010, Alenichev, 2020, Biruk, 2017, Lairumbi et al., 2012, Zvonareva et al., 2015). In many cases, cash transfers such as 'transport reimbursement' are perceived by research participants as forms of payment (Geissler, 2011c).

Figure 10: Figure 2: 'The participants had different ideas of what to do with their bus fare money'. Painting by Johnson Ondiek, paint on cloth, 2011.

Bruun's ethnography of trial participants in Lusaka, Zambia, also conceptualises participants' perspectives on the value of medical research (Bruun, 2014, Bruun, 2016). She followed people's trajectories through research projects and other interventions, exploring what they mean within a wider landscape of multiple projects. She shows how people in Lusaka see a wide variety of possibilities within engagement with projects, as well as sensing their exploitative power.

Bruun situates her findings in relation to Rajan's critical exposition of the way in which transnational research is shaped by global inequalities and operates as extractive and exploitative. She recognises that exploitation is a central tenet of global medical research as practiced in Lusaka, framing it as a form of 'body mining.' But, from the perspective of research participants ' exploitation and possibility are intertwined' (Bruun, 2016 p. 55). Importantly these extremes are not experienced by participants as paradoxical. Rather, people seeking to engage with medical research tended to 'background' their concerns about exploitation and 'foreground' possibilities such as care,

treatment, potential employment, new connections, and networks. She shows how the same person could move between scenarios of exploitation and possibility in their engagement with transnational medical research. By focusing on how potential research participants think about their engagement, Bruun's ethnography adds nuance to critical theories of experimental subjectivity. She recognises that research participants are not the equivalent of 'lumenproletariat' workers. Although placed in exploited positions by global inequalities, they are also pragmatic and think critically about their situations.

Moral worlds, identities, and rumours

One of the ways in which research participants have been conceptualised as thinking critically is through the production of rumours about biomedical research. Within global health, rumour is often held up in contrast to truth and to logic: a fault in transmission or reception of knowledge, and something that can and should be countered with clearer information. Anthropological analysis of rumour in medical research, on the other hand, is heavily influenced by anthropologists looking at blood stealing stories in twentieth century Africa, who demonstrated that rumours are neither true nor false (White, 1995, White, 2000). Rather, rumours are analysed as ways of talking about moral concerns and critiquing uneasy, unequal relationships. (Fairhead et al., 2006b, Geissler and Pool, 2006a, Geissler, 2005, Kaler, 2009, Kingori et al., 2010, O'Neill et al., 2016, Stadler and Saethre, 2010, Tappan, 2014, Tengbeh et al., 2018, White)

Geissler and Pool argue that rumours are also closely linked to the 'mystery of money' and the acquisition of capital (Geissler and Pool, 2006b). Transnational medical research conducted in the Global South in collaboration with sponsors in the Global North offers a highly visual expression of wealth, with its many material resources; expensive vehicles, new technologies, as well as expatriate researchers living in gated compounds, and the growth of newly middle-class local researchers

expressing their wealth through new lifestyles and commodity acquisition. It is often hard to see directly how research activities generate this wealth, or why.

Transnational medical research has also been configured in moral worlds in other ways. Anthropologists working with Ebola trials in Sierra Leone analysed participants' motivations for volunteering (Tengbeh et al., 2018). They were interested to explore why people might themselves forward to take an experimental vaccine during a time of uncertainty, despite significant ambivalence towards external intervention, and in a region with limited experience of medical research. They found a language of 'altruism' and 'heroism' was often used by participants, as well as interest in access to better healthcare and perceived possibilities of future employment opportunities through networks. The authors argue that although concerned about negative rumours:

> 'at the same time, participants' self-reported motivations for joining reveal their efforts to create alternative, socially shared narratives based on hope, optimism and a sense of commitment to one's community' (Tengbeh et al., 2018 p. 40).

Enria and Lees take this further to suggest that the encounter with the time-bound biomedical intervention of this Ebola vaccine trial provided 'opportunities to articulate multiple, at times contradictory, ideas about the boundaries of political community' and so reveals the 'complexities of belonging' (Enria and Lees, 2018 p.36). Trial participation here is seen as an enactment of 'biological citizenship'; a broader theoretical concept used to describe how groups and populations can come together, create subjectivities and mobilize around biological or therapeutic categories such as specific diseases, medical technologies or, indeed, trial participation (Nguyen et al., 2007, Petryna, 2004, Rose and Novas, 2005).

In the case of the Ebola vaccine, trial participants used their participation to simultaneously reference abstract notions of patriotism while making demands on the state based on more exclusive notions of ethnicity and locality. They used the clinical trial to tell stories about themselves and their political subjectivities in a moment of extreme crisis, while also using it instrumentally in 'broader, often messy, discussions and contestations about their relation to the state, what it means to be a citizen, and who should benefit from interventions' (Enria and Lees, 2018 p.39, See also Lees and Enria, 2020).

Social relationships, communities, and publics

A further major contribution of anthropology towards understanding of clinical trials has been to conceptualise the new social relationships, communities, and publics it creates. An edited collection entitled 'Studying trial communities: anthropological and historical inquiries into ethos, politics and economy of medical research in Africa' deployed the term 'trial community' to refer to the network of actors (including non-human) engaged in medical research. (Geissler, 2011b) The authors encourage the discerning of new collectives and solidarities formed through the network of those brought together in new relations through research. This could include researchers, funders, field staff, community advisory boards, national ethics committees, research participants, their families, institutions and even those providing tertiary services such as transport for research participants. Their aim was to move away from binaries and taken for granted divisions, such between scientific institutions and the 'local community', or between researcher and researched.

A later article argues for a conceptual shift from 'trial community' to 'experimental publics' in order to capture the multiple and emergent qualities of these collectives (Montgomery and Pool, 2017). Using a case study of an HIV prevention trial in Zambia, the authors argue that such publics are more usually dynamic and transient, they do not pre-exist research activities but

are enacted in concert with them. They argue that experimental publics are situated at the intersection of various forms of inclusion and exclusion, both locally and globally.

A reference to what kinds of experimental 'publics' can be created brings up a further important point. Rajan's study of the political economy of clinical trials in India described earlier, outlines the conditions for structural violence of the global pharmaceutical industry mediated through the Indian government against its citizens. However, this is not the full story. Intertwined with this story is the story of the creation of an alternative experimental public —made up of activist social health movements, researchers, doctors, and sections of the mass media – which mobilised around these clinical trials to lobby the Indian government to contest the economic policies that allowed the rapid increase of underregulated, unethical clinical trials. Sariola et al trace how the subaltern voices of 'civil society' invoked ideas of global social justice and collective power, and managed to change the regulation of clinical trials in India in 2013 (Sariola et al., 2019). Their actions led to decline in clinical trials taking place in the country from 2013. This study of civil society and its ability to mobilize and resist 'pharmacracy' shows the importance of attending to the multiplicity of actors and voices (or perhaps, publics) engaging with the clinical trials industry.

Challenges to key ideas within Global Health: centres, peripheries, and collaboration

A further contribution made by ethnographic studies of research relationships that attend to alternative voices and publics, has been to complicate taken-for-granted concepts or keywords deployed in global health rhetoric like 'collaboration' or 'partnership' (Brown, 2015).

Okwaro and Geissler explore how the 'promissory term' of collaboration is understood from the perspective of African scientists (Moyi Okwaro and Geissler, 2015). Collaboration – used in tandem with partnership – is a

relatively new term, replacing colonial ideas of medical expedition, and post-colonial ideas of transfers of funding and expertise from centres to peripheries. Geissler and Okwaro argue that the core moral values envisioned in the use of the term imply freedom, autonomy, independence, and equality. Yet, ethnographic fieldwork in an HIV laboratory of an East African state university shows that this rhetorical emphasis might instead hinder critical engagement with conflicts of interest and injustice. To achieve 'collaboration' within a context of persistent inequalities African scientists quietly adopt strategies to sustain their institutions, such as establishing a qualified but flexible and non-permanent workforce. Northern counterparts rarely openly discuss inequalities. This is part of broader 'unknowing' strategies deployed in global health research (Geissler, 2013b).

In their ethnography 'Research as Development' Sariola and Simpson also complicate the concept of 'collaboration' by considering it as an 'emic' (insider) concept, looking at it as both a practice and a value (Sariola and Simpson, 2019). Taking up the call to look at the spaces between macro-ethics and micro-realities, they explore the 'entanglement of biomedical research, bioethics and development' (ibid p. 19).

Sariola and Simpson's focus is on the ways that researchers set up international collaborations and the aspirations and potentialities played out through these relationships. They show that interests in collaboration move beyond scientific interest in a research question to foreground social and economic benefits, such as increases in human capacity and infrastructural development. By focusing on how local researchers navigate international collaboration in the specific context of Sri Lanka, it becomes apparent that, in contrast to the 'Scramble for Africa' described by Crane, Sri Lankan researchers are proactive and creative participants. They are thus able to show how 'researchers operate pragmatically and strategically to accomplish collaboration on their terms and in ways that work in their own setting' (Sariola and Simpson, 2019). This feels different to the quiet getting-by described by Okwaro and Geissler.

Sariola and Simpson bypass the traditional dichotomies used in development literature that conceptualise a diffusion of knowledge from North to South, developed to developing, centres to peripheries, or hubs to spokes. In these dichotomous narratives:

> 'Progress is generally seen in terms of the degree to which the techno-rational systems of the West are imitated at the periphery – and here we would include the growing imbrication of biomedical sciences and bioethics' (Sariola and Simpson, 2019)

In contrast, they deploy the metaphor of a rhizome to think about the multiple connections and possibilities created through international collaboration. This is a philosophical construct to think about interconnections and multiplicities. In biological terms a rhizome is a continuously growing horizontal underground stem which puts out lateral shoots and adventitious roots at intervals. Collaboration in this sense occurs in ways which are irregular, continuous, and surprising, rather than following a programmatic script. For example, they describe how in a Joint Pain Trial, the initiating Sri Lankan clinicians carefully courted specific collaborators as part of their longer-term vision for developing expertise in clinical trials in genetic disorders which would directly help their patients. In this way, the trial afforded not only infrastructural development but what Sariola and Simpson call 'second-order development.'

Anthropology of Health and Demographic Surveillance

Compared to the anthropology of clinical trials, there has been rather less attention paid to Health and Demographic Surveillance Sites (HDSS). HDSS differs as a domain of practice from clinical trials in several fundamental respects, although the two often occur in the same places. Firstly, HDSS involves everyone in a selected community. Secondly, HDSS tends to occur over a much longer timeframe, usually with no fixed endpoint. This can give a quality of permanence to research activities.

Several studies have explored the nuances of consent and processes of setting up new HDSS sites, as well as offering ethnographic insight on certain HDSS practices such as verbal autopsies (Allotey et al., 2014, Allotey et al., 2015, Kamuya et al., 2017, Kamuya et al., 2015, Marsh et al., 2008a, Reynolds, 2014).

Biruk's ethnographic account of an HIV demographic surveillance programme in Malawi takes a more theoretical perspective on HDSS as an activity (Biruk, 2012, Biruk, 2018). She demonstrates how the numeric evidence of global health surveillance is socially contingent, both in terms of the production of categories and identities, and in terms of the construction of standardised values. Biruk asks us to move away from binary ideas of clean /dirty or true/false demographic data. Data, she argues, is always 'cooked' during production, and is inevitably entangled with the lives of those who produce it. Here, she takes up Lévi-Strauss's binary of 'raw' and 'cooked', where the former represents nature and the latter human production (Lévi-Strauss, 1969). She shows the many processes involved in the cooking of data, right from initial survey design to dissemination to policy makers and aims to 'show what kinds of worlds come about through numbers, raw, cooked, or otherwise' (Biruk, 2018 p. 201).

Most interestingly, she looks at how images of 'the field' inform practices. For example, in the survey design phase this image carries a colonial hangover vision of a messy, exotic space that needs simplified design to tame it. Survey researchers often prefer visual ways of communicating scales, using beans to express probabilities for instance. Yet in the reality of the field participants find these devices infantilising. Equally, the young Malawians hired as local fieldworkers because of their in-between status as 'culturally closer' to villagers, make efforts to distance themselves from the village and align themselves with higher status urban researchers and American researchers. In the process they join in with the construction of a backwards image of rural Malawi and reinforce urban/rural class hierarchies in Malawi.

The studies described above place the HDSS at the centre of their perspective. An ethnography, that starts, somewhat, from the other way around – more from the context in which HDSS practices take place is an ethnographic PhD study by Ourvier (2013a, b, 2014, publications in French). She conducted ethnographic fieldwork inside a rural Niakhar HDSS site (sometimes called the Niakhar Observatory) in Senegal, which has been in operation since the 1960s.

Created in 1962 by researchers from the French Institute for Development (formerly ORSTOM) to build a national demographic surveillance system, the Franco-African ruled 'research area' of Niakhar soon came to host multiple medical research studies, including vaccine trials, therapeutic interventions, and epidemiological studies. Ourvier's ethnography shows that the people living in this area have experienced a multi-generational long-term interaction with research that is connected to a wider global and transnational history. They, therefore, situate any current research practices within a 'local micro-culture of research', which includes the appropriation of international and institutional scientific rules. Through appropriations such as the long-practised use of research vehicles for local emergencies, or clinical research's abilities to build health care facilities the experimental logics of globally funded research can be diverted by both HDSS residents and local researchers into local developmental, caring ones. In this way the 'power to heal' possessed by researchers is transformed into a 'duty to treat'.

This work shows how medical research practice is folded into local systems of power and patronage and enacted through the repeated blurring of the lines between research and development by so-called 'local intermediaries' who, in the author's narrative, are generally more powerful than they might otherwise be seen.

Precarity

Much of anthropology of clinical trials work discussed above outlines the logics of techno-scientific regimes that, despite often producing radical life-transforming health improvements, at the same time participate in, and perpetuate, exploitative economic modes sustained by precarity. However, anthropological interest in precarity as both economic mode and pervasive ontological experience extends beyond the realm of transnational medical research.

Precarity as a concept has been described as a new 'emergent keyword' in anthropology (Zucker, 2018). Sometimes used interchangeably with 'uncertainty', some scholars argue it is the new central problem in contemporary anthropological thought and practice (Samimian-Darash and Rabinow, 2015). It has been deployed to capture a perception that the dominant trope, or 'inevitable fore' in the subjective experience of contemporary societies, especially in Africa, has increasingly become one of uncertainty (Johnson-Hanks, 2005c p. 366). Precarity as used here refers to the experience of 'life without the promise of stability' (Tsing, 2017 p. 2).

Anthropologists interested in the concept of precarity have focused on two, related, aspects. The first concerns the actual material conditions which may have given rise to increasingly precarious economic and living conditions globally. The second is a focus on precarity as an ontological condition, or a 'structure of feeling' (Johnson-Hanks, 2005b). Much of the body of anthropological work on this is concerned with the relationship between the experience of precarity and orientations towards the future. In other words, how does both a felt and pervasive experience of uncertainty structure the way people dream of, hope for, and imagine their futures?

Material precarity

Studies of actual material conditions engendering precarity focus on new and ongoing forms of economic, political, and planetary vulnerability and instability produced by neoliberal rationality and policy. Therefore, attending to precarity has been described as a way of studying 'actually existing neoliberalism' (Brenner and Theodore, 2002). Such studies are concerned with the lives of the 'precariat', an emerging class employed within new configurations of labour in the global economy that have significantly increased worker insecurity, marginalisation, and lack of power (Kalleberg, 2011, Munck, 2013, Standing, 2011). The proliferation of global supply chains, deregulated labour markets, and transnational corporations de-anchored from nation states has produced employment relations that are more flexible, temporary, and individualised (Prentice and L. Trueba, 2018). At the same time, social protection and trade union collectivising power has diminished.

Some scholars have argued that precarity is new, presenting a distinct phase of capitalist development specifically associated with neoliberalism and a global shift to flexible labour regimes (Standing, 2011). However, it has been argued precarity has always been a feature of capitalist societies in some way, especially in the global south. Therefore, the experience of the global shift in labour regimes is likely to be less meaningful in Africa. For example, Hart shows that informal work has been a feature of the urban economy in Ghana since its beginning (Hart, 1973, See also King, 1995). In Luoland, where my study takes place, informal entrepreneurial activities as supplements to farming or formal employment also have a long history (Shipton, 2007). It is, therefore, important to recognise that what might be novel is not precariousness itself but, rather, the way the (current) present is 'framed' as characterised by intensified uncertainty and unpredictability (Kleist and Jansen, 2016). Much of the ethnography of JoLuo discussed earlier also supports this characterisation of the present as an era of doubt.

However, it is fair to say that the expansion of the global clinical trials industry and the increased availability of research participation as a potential form of precarious labour does represent something new, or at least is occurring on a much larger scale than previously. Anthropology of labour studies of the precariat, such as analyses of Bolivian miners and Trinidadian garment workers (Prentice and L. Trueba, 2018), share striking similarities with anthropological analyses of the embodied labour of 'experimental subjects' in these global clinical trials. It is possible, as many of the more 'grand narrative' studies of clinical trial labour do, to read clinical trial 'work' as another version of precarious labour within a global neoliberal economy. Such work has been conceived as a form of post-Fordist service work: high risk, low paid labour, without labour protection (Cooper and Waldby, 2014, Parry, 2015). In this conceptualisation research participants represent a specific type of precariat, one whose labour is embodied.

Measuring or quantifying the scope of the actual contribution medical research activity makes to material conditions of precarity in Western Kenya at this historical moment is beyond the scope of my study. What the papers in this thesis can contribute, however, is a reflection on the felt experiences of living amid the double-edged swords of the promise and precarity of transnational medical research, as well as biographical case studies capturing the ambivalence and multiplicities of these experiences. To situate this further I now turn to anthropological studies of the ontological experiences of precarity or what has been described as precarity/uncertainty as a 'structure of feeling', referring to:

> '...the lived experience of a pervasive sense of vulnerability, anxiety, hope, and possibility mediated through the material assemblages that underpin, saturate, and sustain everyday life' (Cooper and Pratten, 2015 p. 6)

Precarity as a structure of feeling

Theorists concerned with the concept of precarity are quick to recognise that life itself is always, and has always been, inherently precarious (Butler, 2006). In Butler's words, the persistence of life is 'not guaranteed.' And, as Reynolds-Whyte describes, an inability to predict the future is an existential component of humanity, regardless of economic context (Whyte, 1997a).

Indeed, during my fieldwork period actual life expectancy throughout the region was back to pre-AIDS crisis levels. Free HIV care and treatment was being scaled up. The NCRO/CHA field-station was the largest it had ever been. In rural Akinda, the Emerging Infectious Disease programme was offering some degree of protection through the provision of free medical care in exchange for participation. And, although still suffering from the aftermath of post-election violence and inflation, signs were pointing to some recovery and the promise of a new political constitution. This was, concretely, not the most precarious moment to be alive in recent history.

Yet, this optimistic demographic fact was not always reflected in people's perceptions of their own lives. Therefore, what is of interest here is how history (and the present and future) is perceived affectively (Johnson-Hanks, 2005b). Central to this is analyses of how precarity reconfigures relations between subjects and understanding of the self (Brenner and Theodore, 2002), especially in relation to 'future-thinking' (Di Nunzio, 2012, Pettit, 2019). Attending to future-thinking means thinking about temporalities (the experience of time), the experience, for example, of anticipation, dread, or cyclical return (Zucker, 2018). Some examples of the effect of this will be discussed below.

There are a significant number of anthropological studies that have focused on the impact of precarity on temporalities and future thinking across

various contexts[6]. However, below, I will focus on one aspect of future-thinking which has emerged from this large and growing body of work: suspension/waiting. During the time of my fieldwork, 'youth', understood as encompassing people aged 18-35 years, were depicted as a source of concern in the media and popular discourse (Al Jazeera, 2013, Danner, 2016). They were accused of 'not being serious' (Cooper, 2018). Several national schemes were initiated to provide opportunity for youth who were seen as existing in a dangerously liminal state: the USAID sponsored 'Yes Youth Can' project (which by 2014 listed among its achievements 'One million Youth Empowered! (USAID, 2014)) and the 'Kazi Va Vijana' (Work for Youth) national government scheme (Hope, 2012).

Many anthropologists have presented evidence that young people's trajectories, especially in Africa, are being blocked by lack of material resources and opportunities, with resultant consequences of 'getting stuck' (Fokwang, 2008, Hansen, 2005).

Suspension

A number of ethnographers have suggested that the contemporary lived experience of such precarity is one of suspension (Han, 2012, Pettit, 2019), or chronic 'waithood' (Honwana, 2012a, Stasik et al., 2020). Other related conceptualisations are of 'stuckness' (Hage, 2005) referring to loss of hope or sense of mobility, 'time-pass' (Jeffery, 2010), or 'social limbo' (Cole and Lukose, 2011). In Johnson-Hanks's ethnography of women in Cameroon, for example, women forfeit planning their reproductive futures, and submit to 'letting the future decide' (Johnson-Hanks, 2005a, c)

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[6] (Ådahl, 2007, Agbiboa, 2016, Agbiboa, 2019, Allison, 2014, Amit and Dyck, 2011, Archambault, 2013, Bear, 2016, Berlant, 2011, Chalfin, 2019, Cooper and Pratten, 2015, Di Nunzio, 2012, 2017, Di Nunzio, 2019, Ettlinger, 2007, Han, 2012, Haram and Bawa Yamba, 2009, Jenkins et al., 2005a, Jenkins et al., 2005b, Johnson-Hanks, 2005a, b, Lamont, 2010, Mains, 2011, McCormack and Salmenniemi, 2015, Molé, 2010, Ocobock, 2017, Pettit, 2019, Stewart, 2007, Werber, 2002, Whyte, 1997b, 2002).

In her ethnography of a barrio, La Pincoya, in Santiago, Chile, Han (2012) focuses on women's projects of care. She describes how households are faced with intense economic uncertainty, never-ending cycles of debt repayment, and poor access to medical provision. But she also shows how women find ways to regain their agency through representations of time as possibility, and through thinking of their lives as a process of waiting. Thinking of the immediate present as a period of waiting (for a better future) allows them to preserve and manage increasingly extractive debt relations and medical and financial crises.

This has some resonance with Archambault's work on young people in Inhambane, Mozambique, where she demonstrates how material uncertainties are shaped by payday rhythms (Archambault, 2013). Although she shows how people use such temporal rhythms to feel alive, rather than just survive, their actions are very much orientated towards the near or immediate future.

Pettit's ethnography traces how rural migrants to Cairo working in call centres 'emotionally endure' precarity (Pettit, 2019). He describes how the overriding experience of their precarious employment is of frustration and boredom, bolstered by a sense that their work was deskilling, demeaning, and placing them in an 'impasse.' Pettit draws on Berlant's depiction of a 'cruel optimism' (Berlant, 2011) that has prevailed since the 1980s with the dominance of neoliberalism and the collapse of post-war social-democratic promise in Europe and the United States. Berlant argues that people have remained attached to unachievable and obsessive fantasies of a good life, which produces endless cycles of defeat. In Pettit's example, Indian call centre workers repeatedly coped with their sense of suspension by engaging in distracting forms of consumption, such as Hollywood movies, self-help ideologies and religious Islamic narratives. Engagement in short-term acts of 'cruel hope' deflect away structural explanations for precarity.

Honwana's work with young people in Mozambique, Senegal, South Africa, and Tunisia, between 2008 and 2012 has conceptualised suspension as life lived in 'waithood' (Honwana, 2012a, Honwana and Boeck, 2005). By this she means the creation of a prolonged period of suspension between childhood and adulthood, where young people are 'waiting for adulthood'. Their access to social adulthood is denied because they are unable to obtain its social markers, such as independence, establishing families and providing for them. Here she draws on the concept of waithood as used by Singerman, in the context of delayed family formation and increasing youth employment in the middle-East (Singerman, 2008).

However, Honwana moves beyond Singerman's usage of waithood, which invokes a sense of passivity. Rather she shows that in the period of waithood or permanent youth, young people also take action. She describes the creation of a new realm of improvisation. Improvisation, or 'making it up as you go along' is also sensed in other work on precarity, especially in the work of Di Nunzio in Addis Ababa and Turner with Burundian refugees in Nairobi (Di Nunzio, 2012, Di Nunzio, 2019, Turner, 2020).

My ethnographic case has some resonance with this literature but also represents a departure. In my ethnographic context, precarity is not really understood as a series of crises, or the abandonment of any sense of control. Rather as chapter 10 shows, precarity has elements of knowability and predictability. This includes both the vulnerabilities of everyday life, and the status of fragile organisations, such as those practicing transnational medical research.

The concept of improvisation does have some resonance but, here, people's orientation looks beyond the immediacy of the moment. In some cases, precarity affects, truncates and speeds-up futures-thinking, but the futures being thought about still are big and long, extending before the lives of individuals. Some responses to precarity, such as JaKenya's described in

Chapter 5 are to put down (literal) roots and create something that will last after his death.

Expectations of life expectancy play an important role here. In this, my ethnographic case agrees with Morris' analysis of youth in the time pre-antiretroviral therapy (ART) in South Africa at the turn of the millennium (Morris, 2008). Morris reported a collective, inflationary assumption of imminent catastrophe; namely, that everyone will die. She asked about the effect of this inflation on 'the capacity of those who believe such statistics to orient themselves toward a future horizon' (Morris, 2008 p. 201), noting that economic deprivation and employment concerns were equally, if not more, pressing, and that this assumption of catastrophe was expressed not as panic, but as rush – with risk 'now utterly internalised as the nature of life in the new South Africa' (Morris 2008 p. 229).

In a post-ART Kenya I found some youth still in rush, a hang-over of the AIDS crisis that persists into the present. As described in Chapter 87 a sense of rush and truncated life expectancies meant youth were not prepared to wait out their 'waithood'. Elements of the cruel hope described by Berlant and Pettit emerge here when such youth neglected their own health in favour of big hustler dreams. Yet, these dreams were not just distracting obsessions, but rather attempts to make good lives for themselves and their dependents.

My approach

My approach to studying life within the researched communities of Akinda and Kisumu City is to concentrate on the everyday, lived experience of being within an intensive site of medical research: what this looks and feels like to residents, how this current moment relates to other responses to ill-health, and what value is taken from the presence of transnational medical research in this region during a time of felt-precarity. In this I offer an ethnography of JoLuo that takes account of the presence of transnational medical research as a dominant feature of life in the 2008-2012 period.

In this ethnographic context, the long history of medical research and its current pervasiveness means it does not make sense to think about emergent, temporary 'experimental publics' as suggested by some anthropologists of clinical trials discussed above (Montgomery and Pool, 2017). Rather, following a period of decline in the 1980s/1990s with a reduction of growth in key industries like fish/cotton processing and breweries, Kisumu City and Akinda have come to have an 'HIV driven economy', of which research activities are an integral ongoing part (Prince, 2012). Research practice is so pervasive that, for example, NCRO/CHA's community advisory board took very seriously a suggestion to rebrand themselves as an independent body vetting all proposed research conducted by the multiple organisations interested in researching in the region. They went as far as developing a constitution and considered how to raise funds for the fee to register themselves with local government as a 'community-based organisation'.

With this in mind, there is potential in drawing a limited analogy with company towns (or in the case of Akinda, more of a company village) and ethnographies of mines or factories (Ferguson, 1992, Ong, 1987) to highlight the increasingly important economic and commercialised rhythm to these spaces. Rajan Sunder's work on the transformation of a former Patel mill district into, essentially, a company town for pharmaceutical trials also has resonance (Rajan Sunder, 2008).

There are elements of the way transnational medical research figures in everyday life that make such an analogy compelling. In Akinda, NCRO/CHA provides a version of 'company healthcare' for its workers through medical insurance, and to its participants to lesser extent through the provision of healthcare in exchange for what could be described as embodied labour.

However, any analogy with company towns falls ultimately short because of the way that medical research and intervention in Akinda has long been constituted through, and scaffolded onto, existing personal relationships and other earlier responses to ill-health, as will be shown in Chapter 4. Also,

people do not/cannot migrate from other places to Akinda to seek work within the nexus of research activity because most of that work requires and relies on a person being JoAkinda, or at least being able to claim relatedness. And any divides between researched and researcher are constrained by the fact that living within with HDSS automatically makes you a research participant. Finally, in contrast to the 'lumpenproletariat' described as lost in hospital beds in Rajan Sunder's account of a biomedical research 'company town', my research participants were actively involved in imbuing their research experiences, which were at any rate only part of their lives, with multiple meanings.

It could be possible to conceptualize the Kisumu, and especially the Akinda, 'research community' through the lens of biological citizenship as used in the work of Enria and Lees (2018) by thinking of them as people brought together through identification with a demographic surveillance system. But of course, Akinda existed before the HDSS and will continue after. In the words of one elderly resident, NCRO/CHA, despite its 40-year heritage, is 'just a thing of yesterday.' In fact, as I will show in Chapter 4 the arrangement of the current HDSS is shaped by an earlier, locally driven census where women elected by their communities numbered the 100 homes around their own. And, in Akinda, there is a pervasive recognition that HDSS and Akinda are not interchangeable entities. One day research will leave and, in the words of one resident 'only we will remain, the people of Akinda'.

Studies that draw on ideas of biological citizenship, as well as anthropological studies of global health research that focus solely on the emergent properties of research and ask how it could better achieve its goals tend to conceptualise the village as providing the backdrop to global health research practice. Consequently, the richness, idiosyncrasies and creativeness of local lives are sometimes underplayed. Therefore, biological citizenship is not a concept I draw on explicitly here. I am interested in the ways that health and health research is involved in 'the formation of identity and subjectivity' (Whyte, 2009) but I share Reynolds-Whyte's concern that:

'By defining research problems based on identifications like diabetic, Down syndrome, HIV+ [or research participant], we essentialise, fragment, and decontextualise what is really only part of life. And it is, after all, a life and not an identity that people are usually seeking' (Reynolds-Whyte 2009 p. 13).

To explore 'life' experienced as unfragmented and contextualised, my approach departs from anthropological studies that tend to frame their research from the perspectives of research organisations rather than from the perspectives of those living their everyday lives within the spaces of transnational medical research. I offer a complimentary counterpoint to the more theoretical 'grand narrative' anthropological studies of clinical trials discussed above (Cooper, 2008, Petryna, 2005, 2007, Rajan Sunder, 2005, 2006, 2008, 2009, 2017). Such studies explore networks, or 'global assemblages' (Ong and Collier, 2005) at macro levels of scale, unravelling the global construction, and transformation, of scientific knowledge production. These studies have considerable analytical power and have brought important insights into the functioning of the global economy of medical research, and the inequalities enacted through it. I take seriously the ideas generated by this body of work relating to the concept of trial participation as a form of 'embodied labour'.

But I am interested in to exploring 'subjectivity' in a different way to these macro-anthropological studies. In Rajan's work, for example, the formation of the 'experimental subject' is explored (2008, 2009, 2010, 2017). But the experiential subjectivity of research participants is located as 'consequential' to the creation of a bio-capital that reflects larger changes in the structure of capitalism and provides their 'conditions of possibility' (2008 p. 1978). The anonymous research clinic and individualized informed consent come to replace a class consciousness mediated through factory unions and social housing. In this account, and in contrast to the elaboration of the owners of capital and the clinical trial industries, the experimental subjects themselves

are, in Rajan's words, an 'evocative metaphor in the shadows' (2008 p. 179). This is partly because the only access he was able to get to them was in a tour through the clinical trial hospitals where he describes them as sitting, doing nothing, looking lost in hospital beds. But this is also, he argues, because structurally they do not have a voice.

Rajan states explicitly that he is interested 'to start with not in the ethnographically realist experimental subject, but in its epistemology – how is it constructed as a subject of global biomedicine?' (2009). The sweep and explanatory power of this work is compelling, but it also rests on the disappearance of the experimental subject him/herself. Through Rajan's analysis we can only see subjects as lost, either in their hospital beds or as forced out of the structure by committing suicide or turning into lumpen proletariat smashing up things in gangs.

I agree with Rajan when he argues that those who have suggested he talk to the experimental subjects to 'get their story' are assuming that 'ethnographic realism is the only way to access some kind of 'pure subjectivity'' (Rajan Sunder, 2009). But my research presses me to recognise these kinds of 'grand' accounts as too smooth. I am interested in self and experience, rather than explicitly 'subject' and 'subjectification', a perspective which can transform individual lives into abstracted subject positions (Biehl et al., 2007). Taking an ethnographically grounded approach, therefore, I look at the 'concrete constellations in which people forge and foreclose their lives around what is most at stake' (Biehl et al., 2007 p. 7).

This means describing individual and family biographies and trajectories, attending to meaning, practice, affect and struggle in lives which are multiple and have multiple concerns. Medical research is only one part of life, so attending only the political economy of experimental subjectivity can totalise the expansive experiences of its participants. Therefore, following ethnographers like Reynolds-Whyte, Brunn and Das, who have looked at how health and illness are experienced in the texture of everyday life, I try to

follow people as they move through their lives and navigate their life-situations, foregrounding their ambitions and concerns (Bruun, 2016, Das, 2015, Whyte, 1997b, Whyte, 2002). As Reynolds-Whyte argues:

> 'Subjectivities in postcolonial Africa are shaped by global cultural flows as well as national political economics …but…as ethnographers, an important part of our job must be to inquire about what people as subjects are trying to do - what they are hoping for, how they deal with their life conditions, and how things unfold for them over time' (Reynolds-Whyte 2002 p 172).

Multiplicities and multiple durées

I consider subjectivity to represent both a concern with personal lives and individuals (Biehl et al., 2007) and the historically contingent possibilities and workings of power that create certain kinds of persons or constrain individual subjectivities at particular historical junctures (Foucault, 1990 (1973), Foucault and Rabinow, 1997).

Subjectivity is sometimes offered as a poststructuralist term for 'identity' and is presumed to be coherent and stable. Yet, as Akoth, a Luo scholar, argues, manifestations in post-colonial times attest that subjectivity is internally fragmented, multiple, and often produced and positioned in everyday life (Akoth, 2014). There are spaces for creativity and invention. This is also captured in Biehl et al's reflection that 'subjects are themselves unfinished and unfinishable' (Biehl et al., 2007 p. 15).

Subjectivity is also often thought of as pertaining to the individual. However, I am mindful of the recognition that thinking about the formation of the self as separate from relations with others is perhaps not the right way to conceptualise subjectivity in this (or perhaps in any) context. Therefore, I am

approaching it in a similar vein to Kenyan philosopher Ogude's reflections on *ubuntu* as a useful way of understanding the animating principle of life in East African cultural contexts. Ubuntu refers to a sense of self/personhood that is only fostered or fully realised in relation to other people: 'I am because You are' (Chuwa, 2014, Mbiti, 1969, Nyairo and Ogude, 2005, Ogude, 2018a, b, 2019). There is no equivalent of this Bantu term in Dholuo. Though one of my research participants suggests that the tendency of Luo men to greet each other even if unknown as *Omera* (Son of my mother) comes close to capturing the spirit of ubuntu that underscores this version of subjectivity.

I, therefore, find it helpful to think of 'subjectivity' as a gloss for lived experiences, or modes of being in the world, which takes account of ideas of multiplicities (Mbembe, 2001, Tembo and Gerber, 2020). I understand this philosophical approach as encouraging the recognition that the condition of life generally (and expressed in *a* life in particular) contains many different aspects of the same reality and contains many relationships. Furthermore, life is lived with reference to multiple historical reference-points at once. Importantly, this is not experienced as chaos, nor as without order, although it is 'rich in unexpected turns, meanders and changes of course, without this implying their necessary abolition…' (Mbembe, 2001p. 8).

Mbembe has characterised the processes of transition and change in postcolonial Africa in his book 'On the Postcolony'. Change, he argues, does not move 'in a closed orbit' but rather points in several directions at once, and simultaneously occurs at different speeds, on different time scales (Mbembe, 2001). This chimes with the history of medical research in Kenya outlined earlier. His writing on 'entanglement' in the post-colony forces recognition of post-colonial experience across Africa where:

> 'As an age the post colony encloses multiple durées made up
> of discontinuities, reversals, inertia and swings that overlay
> one another, interpenetrate one another and envelope one
> another, an entanglement' (Mbembe, 2001 p.14).

95

This, he argues, encapsulates the distinctive lifeworld or *zeitgeist* of the contemporary post-colonial age.

In my thesis, I will, therefore, try to describe this zeitgeist as experienced in Kisumu City and rural Akina, by attending to *simultaneous multiplicities* and *multiple durées* when theorising and representing the actualities of post-colonial African lives. After outlining my methodological approach in the following chapter, I will return to these ideas in Chapter 4 by outlining several different, intertwining histories of Akinda and showing how they continue to be lived through in biographies, memories and even buildings.

Chapter 3: Methods

Figure 11: Depiction of me running a focus group discussion about NCRO/CHA's research activities (paint on cloth, 2014, jaoarts@yahoo.com).

Introduction

Overview

The materials presented in this thesis are grounded in two periods of intertwining ethnographic fieldwork between 2008-2012 in two interrelated places — Kisumu City and rural Akinda. Research consisted of formal in-depth interviews and focus-group discussions, mixed with more informal conversations, observations, and embodied learning. A final, third stage of fieldwork involved piloting one of the outcomes of the research: a training book for global health researchers designed to provoke reflection on everyday ethical conundrums encountered when conducting biomedical research across inequalities.

My project was embedded in a larger project entitled 'Studying 'Research Communities': an ethnographic exploration of medical field research on HIV/AIDS in Western Kenya' (Principal Investigator: Wenzel Geissler). My entry-point to these places was through a research permit issued by the Kenyan parastatal partner of the collaboration that formed the NCRO/CHA transnational medical research station, via a research protocol also approved by two overseas partners involved in HIV research activities. The staff connected to the HIV branch of the field-station were, therefore, my first institutional collaborators. Their main physical offices were in a satellite HIV research clinic housed within the provincial hospital compound in Kisumu City where they were running two clinic-based studies. But the historical and current spaces of their activity encompassed both Kisumu City and rural Akinda. Their first major project had been an HIV incidence cohort study in Akinda in the early 2000s, and a major HIV youth intervention programme in Akinda was nearing completion. During my ethnographic research these staff also set up a study-specific HIV research clinic within the compound of an Akinda health dispensary.

However, my own ethnographic 'field' or spatial horizon came to be much broader than this starting point might suggest. In Akinda it moved beyond a narrow focus on HIV research to include the plethora of other research and intervention activities in operation there, including a long-running HDSS. In both places it expanded beyond the confines of the research clinic. It came to encompass the multiple spaces of Kisumu City, including its housing estates, health and research facilities, transport modes and circuits, shopping centres, nightclubs; the small villages, markets, health dispensaries, churches, compounds, and homes of rural Akinda; as well as the roads and relationships connecting Akinda to Kisumu City and beyond. My research participants, therefore, consisted of a diversity of people living within Kisumu City and rural Akinda. Many were medical research workers and/or medical research participants and/or receivers of intervention, but there were also many others whose lives came into the orbit of biomedical research in more nebulous ways.

The first block of ethnographic fieldwork covered a period of 22 months (March 2008 – December 2009). I was part of a small team of three ethnographers and was mainly based in Kisumu City. Our fieldwork spiralled out from the NCRO/CHA satellite HIV research clinic with a special focus on those staff and female research participants who were involved in an Exclusive Breastfeeding Study (EBS), which aimed to prevent mother-to-child transmission of HIV. I rented a small house in an estate that had become popular with mid-level Kenyan research workers. Through this I tried to learn, in an embodied way, what it might be like to experience the city as part of a category of people known locally as the 'working class' (those working for a regular salary). Many of my neighbours worked for the various organisations undertaking HIV research in the city, or for non-governmental organisations running intervention programmes. Several EBS research participants also lived nearby.

The second piece of fieldwork took place mainly in rural Akinda over a period of 17 months between July 2010 and December 2011. I stepped back from working collaboratively with the RCS team, who remained working in Kisumu City. I located myself inside the home of a multi-generational Akinda family headed by a widowed NCRO/CHA *nyamrerwa*, learning how research activities figured in everyday life from this positioning.

The Research Protocol and Research Questions

I joined the RCS team when the study had been up and running for a year. Study objectives had been discussed with NCRO/CHA staff. In-depth biographical interviews were underway with HIV research staff working in two studies running in Kisumu City and one in Akinda. Observations had started but only around the Kisumu City HIV Research Clinic.

The overall aim of the RCS project was to 'improve the understanding of social relations within a community of long-term collaborative medical research', with a primary objective of ethnographically describing the

'researched communities' initiated by the NCRO/CHA fieldstation in both Kisumu City and rural Akinda.

Under the umbrella aim of the RCS study, I created 4 research questions to guide my doctoral project. I quickly realised that my personal interest was less in the social process and routines of medical research or specifically on research-related concerns. I found myself more interested in the everyday experiences, struggles and biographies of people who were living in an economically and politically marginalised region at a particular historical juncture marked by both the dominance of transnational medical research and intervention as an economic mainstay, and the collective experience of the greatest rapid dip and then recovery in life expectancies in Kenya's history created by the 1990s AIDS crisis, and the national scale-up of universal free access to HIV treatment which was rolling out as I arrived. This felt like a time of 'posts': post-election violence, post-structural adjustment, post-AIDS, post-digital revolution. It also seemed, as epitomised in the story of Kenya's migration from analogue to digital TV, a time of incomplete transitions and liminalities. My research questions, therefore, focused on interpreting and understanding transnational research as one aspect of this broader experience. In developing this focus, I was especially influenced by an early friendship with Zeiki, whose death opens Chapter 7. Zeiki was a hustler and a volunteer who helped with some NCRO/CHA HIV community engagement activities. He enthusiastically engaged with NCRO/CHA, hoping for 'exposure' to people and new opportunities that would transform the life trajectories of himself and his small daughter. Zeiki showed me his version of the city. He showed me how he moved within one day between the expensive rented offices of a brand-new NGO in the city's most affluent suburb who he was helping 'connect with the community', to his one room mud-walled hut in the city's most impoverished slum, and a piece of wasteland where he coached an enthusiastic kids' football team who were dreaming of international sponsorship. Zeiki helped NCRO/CHA researchers recruit participants for an HIV incidence cohort study, and he died from AIDS related complications eight months after we met.

With Zeiki's biography in mind, I decided to focus on 4 research questions:

1.   How is transnational medical research and intervention understood and folded into the broader lives of those living within its midst?

2.   What value and meaning does transnational medical research and intervention have to those who encounter it? What (other) things matter to people as they navigate their lives in these places?

3.   Where does transnational medical research sit in relation to other interventions and responses to ill health, both historical and current, in this region?

4.   What ethical challenges emerge in the everyday practice of transnational medical research, and how can we best talk about them?

The first and second questions are closely related. However, I decided to separate them out to allow for the possibility that transnational medical research is not always foregrounded in people's everyday experiences or concerns.

My approach

As will be discussed below, there were important differences in my positioning and research practices in Kisumu City and Akinda. However, there were key commonalities in my approach to ethnographic practice across both places. Firstly, I took an approach similar to what Pigg has called 'patient ethnographic sitting' (Pigg, 2013), following what emerged from various viewing points, as well as making concrete research activity plans. Secondly, I learned through embodied experiences as well as through listening to in-depth-interviews and making more distanced observations. Thirdly, I paid close attention to people's stories, and finally I tried to expand their narratives by staying in touch with some of my research participants over longer periods of time. This allowed me to follow the twists and turns of

their biographies over nearly a decade, and better contextualise and reflect on the significance of what I learnt during the intense periods of ethnography.

Sitting

Although I did deliberately follow certain NCRO/CHA research and intervention activities, I also tried to pick up the tendrils of what to follow based on what became visible to me from spaces that I daily spent time in, as well as what was happening in the lives of people who I developed enduring relationships with. In this, I subscribed to an approach similar to what Pigg has called the practice of 'patient ethnographic "sitting" as a means to understanding' (Pigg, 2013 p.128). She argues that ethnography of global health shows that the definitions of what matters and why are produced in specific social locations, what Whtye-Reynolds has termed 'situated concerns' (Reynolds Whyte and Etyang Siu, 2014, Whyte, 2002, 2009). Describing ethnography as a 'mode of attentiveness and openness to being taken off course', Pigg maintains that the 'capacity to be surprised' is what drives ethnography forward (Pigg, 2013 p. 130).

During fieldwork in both places, I spent much time both literally sitting in various locations (inside others' homes sharing tea, on verandas, outside soda shops, on pieces of cloth laid on the ground) and metaphorically "sitting": watching and waiting to see how things unfolded. In between planned research activities, I accepted as many invitations as I could to 'come and see something interesting', ending up on one occasion attending a night-time fund-raising event on a tiny fishing island in Lake Victoria organised by its fishermen to send the young man who ran their only pharmacy to medical school.

My approach, therefore, differs in some ways from those ethnographers of transnational medical research who have focused solely on accompanying researchers carrying out their work, or specifically on research clinics, the work-lives of researchers, or research experiences of research participants

(e.g Biruk, 2018, Chantler et al., 2013a, Kingori, 2013, Saethre and Stadler, 2017). Although I came with research questions framed around the place of transnational medical research in everyday life and took care to follow some biomedical research practices, the central viewing points through which I observed daily life was rather where I lived and the immediate houses and homes around me.

Experiencing

Throughout ethnographic fieldwork I tried, as far as was practical, to participate in things happening around me. I could not participate in conducting medical research. I attended research meetings and clinics in Kisumu City and accompanied *nyamrerwa* on their home visits in Akinda, as a non-participant observer rather than learning through apprenticeship as some other anthropologists have done (Downey et al., 2014). Although in Akinda I participated by default in the HDSS by dint of living in an HIDSS enrolled home.

However, I tried not to delineate between a 'field' where my ethnographic fieldwork took place and my everyday life (as sometimes is nessecitated for urban ethnographers working in insecure areas e.g Thieme, 2017). In Kisumu City, I attended an office daily, so on first appearances at least, it felt like there was some separation between my home and social life and work life. This turned out to be an early perceptual mistake on my behalf. I soon realised that much of the notes in the fieldwork diary I kept were about things that happened in the general flow of life, and in this I experienced a more embodied form of learning. In my life in Kisumu City, much of this learning centred around the challenges of life in my estate – namely, the daily travails of taking public transport into the city centre, obtaining a regular supply of water and electricity and, above all, security.

Over time, one of things I learnt to experience somehow physically was the mood of the city, especially when it came to times of trouble. A few weeks after moving to Kisumu City, a 'war' broke out between matatu (public

minibus) crews and motorbike drivers, after a matatu ploughed into a taxi stand outside the district hospital. The disturbance rushed past our office, in a whirl of motorbikes and runners as Gertrude, my Kenyan colleague, and I tried to cross the road. The compound security guard calmly opened the gate for us, and then casually walked into the middle of things to retrieve my hat, something I found surprising at the time. The fighting spilled into the morgue compound, separated from us with a wire-mesh gate. Gertrude and I watched, tightly holding hands, shocked and speechless as a man was beaten, then carried away. Yet, a couple of years later, I found myself, equally as calm as the security guard had been, waiting out another episode of 'trouble in *tao*' (town) by having a pedicure in a town centre salon, as I ignored the multiple security warning texts forwarded from expatriates working with NCRO/CHA which bombarded my phone. When my painted toes were dry, I walked out on the streets and picked up one of my regular motorbike taxis, requesting he take me the back way home to avoid protests in the town centre. At this point, I realised that I had started to experience insecurity in the city as more of a kind of low-level background rhythm, punctuating everyday life.

But it was only when violence affected me directly that I started to better understand the implications for those living around me. The estate where I lived was surrounded by more insecure areas. Every month or so, I would walk past scorched earth on the unmade roads, a sign that a thief had been burnt in the night by community vigilantes. These vigilantes seemed distant from me, and I struggled to understand their actions until my neighbours participated in a lynching.

I had continued to rent a house in the city while living in Akinda. One night, when everyone who usually stayed there was away, thieves broke into my house. My neighbours shouted to scare them away and then, fearing they would come back with reinforcements, bravely went into my house to take out any valuable things. A few hours later, a young man came back. But this time, the neighbourhood was waiting for him. My immediate neighbours screamed and hit their pots and pans, bringing others outside. The boy told

them he was a matatu tout, on his way to an early workday, claiming he worked for a crew whose chairman lived nearby. But he was holding my *lesso* (piece of cloth), which they recognised. My neighbours insisted he take them to the chairman to prove his identity. When he ran, he was chased and caught by some of Maasai security guards who worked in the neighbourhood. I called one of the NCRO/CHA researchers, James, who lived nearby at 2am to seek advice on how to stop my neighbours lynching the young man. James called the Chief of Police directly on a personal number to try to get someone to come out to take him into custody. This was not successful. Another participant in my ethnography, Atomic (whose death is described in Chapter 7) even walked in the night to a local police station to ask for help in person. He was told by the police there that they would give him some kerosene (to burn the thief), and they would come for the body in the morning. The thief died on my veranda and the police did indeed come for the body in the morning. My friend Ratwar also (the focus of Chapter 5) came in the morning to mop up the blood and fix the lock on my front door. Another friend who worked for the local radio made sure that I was not named in the news report.

Talking to my neighbours about what had happened afterwards, I learned how the everyday precarities of life in the city, and lack of faith in the police, had created a situation where my neighbours felt they had no other safe option than late-night vigilante justice for the theft of broken electronic speakers by a desperate teenager. My neighbour Gladys, who had a teenage son of her own, was especially sad, but told me that they all knew that the police would have let him go, and then the whole gang would have come back for revenge. In this way, I learnt how living with a low-level background radiation of insecurity could sometimes spill out into dramatic nights like this.

But it is important to stress that the felt experience of my participation in life in both Akinda and Kisumu City was limited by what Niehaus has called the 'absence of shared vulnerability' (Niehaus, 2014). I was not a JaLuo. I would

not remain here. I could, and would, eventually, go to a home somewhere else.

In rural Akinda, my experience of embodied learning was less in terms of being alert to the rhythms of a busy city, but more to tuning into the daily routines of living as a fictive daughter of my host, Mama Unita. Through this positioning, which started as a joke on her side ('I went to England, gave birth there and here is my daughter returned!'), I found myself involved in a myriad of complicated family relationships between a mother-in-law and her daughters-in-law. During this time, I also got married, became pregnant and gave birth to twins that died shortly after birth. These events changed my relationships with some of those around me. In weeks after losing my children I felt, for a moment, a small sense of 'shared vulnerability' as people came to bring food and empathise with their own stories of loss.

Storying

Josigana agannue? Ganuwa jasigana! Chon gilala….

'People who like stories, can I tell you a long story? Tell us story-teller! Long long ago…'

Throughout ethnographic fieldwork, I was interested in people's stories, especially their biographies and recollection of significant events in their lives. I was interested in not just the details but in the ways of telling, referred to by people as 'storying.' I collected stories in several different ways. Most of the in-depth interviews I conducted started with biographical stories, often recounted over several interviews. I also asked several of the older members to 'tell me the story of Akinda, of *chon gilala'* (long ago). But I also found people telling stories in other, more natural, occasions. For example, in an HIV self-help I attended in rural Akinda, each participant introduced themselves to me by telling me their story of HIV diagnosis and coming terms with illness, following a similar oratory pattern. This form of testifying was an important part of living with HIV and creating a sense of belonging

106

within the group, as well as preparing to make claims on resources available to people living with HIV (Nguyen, 2004).

Following

One of my aims became to expand the stories that I collected beyond the moments of telling. In this, I was helped by the length of time I was able to do ethnography and, therefore, the length of time I have been able to 'follow' the ups and downs of the lives of many of my research participants. The opportunity turned my ethnographic approach from an intense ethnography of two related places into an ethnography of people moving through them over time. Over time I witnessed several deaths and many challenges. But I also witnessed many successes and transformations, the most remarkable of which is encapsulated in the story of Ratwar creating a whole forest in the time it took me to complete a PhD thesis, as described in Chapter 5.

Research in Kisumu City

Teamwork and team positionalities

In the first phase of research in Kisumu City, I worked within a small team of ethnographers consisting of myself, my Kenyan colleague Gertrude, and our LSHTM Principal Investigator (P.I) who joined us from August 2008 - June 2009. Our team, therefore, encompassed multiple positionalities and experiences. By positionalities I am referring to the way that:

> 'ethnographic knowledge is shaped by the shifting,
> contextual, and relational contours of the researcher's social
> identity and her social situatedness or positionality (in terms
> of gender, race, class, sexuality, and other axes of social
> difference), with respect to her subjects' (Nagar and Geiger,
> 2007 p. 267).

Gemx[7]

When I started, I was unmarried, aged 27 with no children. I am female, white, and a British citizen. I was brought up to be familiar with the routines and rituals of Roman Catholicism, and as part of a large extended family.

I had a broad-based social science background; originally studying social and political sciences, with a later Masters' degree in Social Anthropology. I had experience as an NHS social science researcher on trials of interventions for people living with schizophrenia in the UK. Through this, I also carried with me to Kenya PhD level training in a socio-linguistic approach to the study of talk-as-interaction/sociality, known as Conversation Analysis (Sidnell, 2016). I had also worked as Education Officer for the Royal Anthropological Institute, and spent time working with a group of anthropologists with interests in flexible meanings and othering practices within conventional ideas of literacy, linguistics, and literature (e.g Hendry and Watson, 2001, Street, 1993).

During the Akinda phase of research some of my positionality changed: I got married to a neighbour from Kisumu City, who was Luo. I was pregnant during the latter stages of research in Akinda. I delivered twin boys in Kisumu City prematurely who died at birth. During the piloting for materials prepared for the workbook (Chapter 9), I returned with a new baby. These changing states affected how people related to me, and the kind of things they shared with me. For example, whilst I was pregnant, I received intimate advice from the *nyamrerwa* about how to deal with difficult husbands. And when I got married I became the subject of a half-joking rumour among

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[7] Over the course of my fieldwork and long-engagement with my research participants I've held several names to those around me, following Luo naming practices of referring to people in multiple ways according to situations, customs, and relatedness: mixing nicknames with real names, naming after places of birth, marriage, first-born children, qualities – often done creatively and jokingly. Gemx is what one of the mothers in the NCRO/CHA prevention of mother-to-child HIV transmission study who became a long-term friend calls me. For a long time she thought it was perhaps my given name, based on the way I ended text-messages to her with 'Gem x' [Kiss].

NCRO/CHA staff in Kisumu City that I had married because my husband's family suffered from an unusual disease (epilepsy) and my marriage would give me a great opportunity to study it. I found this interesting, not least because it demonstrated how ingrained the idea of global north researchers thinking of Kenyans solely as data sources was.

My Colleagues

The team's Principal Investigator was German, older, male, and married with children. He had doctorates in both tropical medical parasitology and social anthropology and had carried out fieldwork for both in a (non NCRO/CHA) rural location within Luoland, Nyanza province not too far away from Kisumu City between 1992 and 2002. Gertrude was female, Kenyan, Luo and had children. She was about a decade older than me, and a bit younger than our P.I. She had grown up in both rural Nyanza and urban areas and now lived in Kisumu City. She was a former early years' education teacher and had worked with our P.I (and others) on his doctoral projects. She was an experienced ethnographer and during the study she completed a Masters' degree in Public Health by distance learning.

Over the years the RCS project operated we also had five (up to three at any one time) dedicated transcriber-translators.

My house

Each of us lived in different parts of the city. Gertrude rented a *landhie* (row-house) in a central, low-income but not quite slum area. She later moved to a better-quality rental house in a quieter neighbourhood. When our P.I visited he rented a room in a catholic mission institution in a leafy affluent area, popular with ex-patriates, international workers, upper-class Kenyans, and Kenyan Asians. Many of the houses in this area had large gardens, 'servants' quarters' and were looked after by security guards, with various intensities of security. When he joined us for a longer period of fieldwork, he and his family rented a house like this. Most NGOs had their headquarters in this

area. The international school and international/Asian clubs were located here. And it was the only area approved by CHA for CHA staff who were American citizens to live (as well as international staff employed on direct contracts with CHA).

In contrast, I rented a small house in a compound with four other houses, in an estate that was popular with mid-level science and NGO workers. An American VSO worker had lived in the house before me, and later had shared with a Canadian anthropology PhD student, Alizi. Initially I lived there alone for a few months while Alizi was away. We then shared for a few more months before she returned to her university. Alizi was doing ethnographic research in a peri-urban part of Kisumu. I learnt a lot from her, both from her friendship and her ethnographic insights into life in Kisumu City.

My house was located on the other side of city from both Gertrude and our PI. To get into town, you had to pass through an open, insecure area where lorries often parked up. The estate had no running water and was bordered on all sides by much more insecure areas which residents passed through daily. Yet, it was also an aspirational area. Many of the small houses and apartments had inside toilets and tiled bathrooms constructed in the hope of future piped water. There were several blocks of flats. My house had no tiles, and a concrete floor. But it did have an inside (non-flushing) toilet. The compound had its own well, so most of the time I did not have to buy water from the estate's water-vendors who sold water by the jerry-can from carts. The roads into the estate were tarmacked, though the roads through were not, and often flooded. There were no ancestral homes here. Many mid-level staff from NCRO/CHA rented houses in this estate, and my neighbours mostly included Kenyans with regular (ish) incomes, known as the 'working classes', such as those working with NGOs, in government healthcare, teaching, hospitality, supermarkets and universities, as well as more successful market-traders and entrepreneurs ('hustlers').

Rents for a two-bedroom apartment were between 6,000 and 15,000 Kenyan shillings a month (£60-£150), although some cheaper housing was interspersed throughout the estate. My rent was around 6,000 KES (£60) a month. This was compared to around 3,000 KES (£30) or less in some estates, and 50,000 KES (£5000), or much more, in the leafy suburb where expatriate CHA staff were stationed. See (Elliott, 2014, Geissler, 2013c) for further discussions of the geographies of Kisumu City with particular reference to global health and intervention activities and staff.

Through living in this house, I learnt a lot about certain frustrations of daily living in Kisumu City. I learnt about power cuts and lack of water. And about what it meant to be 'working class' – which in this instance and at that time, meant having tiled floors but buying water from a cart, shopping in the market on Saturdays because it was cheaper than the supermarket but having a smartphone. I learnt about how to arrive at work smartly dressed after a dusty hectic bus ride, and I learnt about fluctuating rent prices, security issues and vigilante groups.

Although I rented a house independently, rather than being hosted by a family as I was to do later in Akinda, I built up close relationships with my compound neighbours. My landlord's son lived in the compound. He worked as an HIV counsellor for a Kenyan NGO. My landlord's niece, Rose, also lived there. She sold vegetables and chips from a wooden stand outside the compound and knew everyone. I paid her to come once a week to help with laundry and cleaning and to look after the house when I was away in the UK or in Akinda. But she also looked after me in greater ways than this. I sought her advice about small things to do with daily living, and shared stories about our days, sitting by her stand. Our compound was right by a matatu (minibus) stop and there were always groups of young men gathered outside. Rose introduced me and made sure that they knew I was part of her compound and, so, I became part of this corner. I never felt personally insecure in this place, despite the relative vulnerability of its location.

My neighbours included a pair of brothers, one of which had previously worked for NCRO/CHA but was now pursuing a career with Safaricom, the major provider of mobile communications. Another neighbour, Maz, was working as a research assistant and translator for an American PhD student conducting research on male circumcision with a different transnational medical research organisation in the city. Maz lived with her young daughter, and occasionally her cousin who worked as an HIV counsellor.

Figure 12: The Adetta Crew. Source: Gemma Aellah.

I was lucky to find myself living in this compound. I became good friends with my neighbours and, through them, met others living nearby. We were similar ages and working at similar levels. We soon developed into a solid group of friends living around the area. Through them I gained insights into life in the city for a group of people, then in their late twenties, attached in various ways to transnational medical research and intervention, but outside the specific NCRO/CHA HIV research clinic where I was conducting observations. We often ate together, and every weekend we went out to the clubs in the city, sometimes hiring a whole *matatu* (minibus) from a tout who parked it overnight outside my house.

Because this was long-term research that I took a particularly long time to do, I have been able to follow their ebbs and flows over time. We were together as some of us got married, had children, lost relatives, and moved cities, and even countries. Some of us who were very junior staff members in 2008 are now senior managers of international projects. Others are struggling. The song presented in Chapter 9 is particularly about and for

them, not least because of our experiences of listening to music and going out dancing in the city.

Our office

Our team worked out of a disused laboratory in the compound of the Ministry of Health's Nyanza Division of Vector Borne Disease (DVBD), part of the bigger compound of the Kisumu District Hospital. It was a peaceful place, except on Fridays when mourners came to collect the bodies of their loved ones from the morgue next door, and on the few occasions when trouble occurred along the main roads of the city centre and would sweep past our office.

Figure 13: Our office. Here we are throwing a party for our hosts, the entomologists working with the Division of Vector Borne Disease. Source: Gemma Aellah.

DVBD was more than just office space. It was also a central location for my learning about life and science in this place. This office, the DVBD staff in the other laboratories around it, the morgue, the District Hospital next to it (especially the HIV patient support and treatment centre), the motorbike/bicycle transport 'stage' in front of it, and the sports-ground

opposite would become one of the central 'viewing points' through which I ethnographically experienced the city.

Being hosted by a group of government workers rather inside the NCRO/CHA clinic had a profound effect on my understanding. The contrast between the two places was marked. The DVBD offices suffered from a distinct lack of funds for both maintenance and fieldwork activities. Its style was different from that of the NCRO/CHA office, something which helped me see more clearly the value of the 'exposure' experienced by NCRO/CHA researchers described in Chapter 6.

Research activities

Interviews

Collectively we formally interviewed over 100 staff involved in NCRO/CHA HIV research projects. Interviews often stretched over several sessions of up to two hours each, and evolved, following only a very rough guide, from biographical information, current living circumstances and future plans, through to detailed reflections on work practices and perceptions of research, collaboration and its wider social and political context. We also conducted extensive, repeated, interviews with 89 women living with HIV participating in the Exclusive Breastfeeding Study. The trial involved over 500 women recruited from antenatal care centres upon HIV diagnosis and followed for two years after delivery. We began interviewing these participants towards the close of the study, when some were still attending the clinic, and others had already 'exited'. We followed several of these participants after the end of their participation, visiting them at their (often shifting) homes, and joining them during their visits to public HIV treatment centres (See Madiega et al., 2013 for a co-authored publication arising from this work). Participants were offered the choice for where to be interviewed, in our offices or in our or their homes. Interviews in their homes took us into different parts of the city, allowing us more insight into their daily lives.

Focus group discussions

We also carried out focus-group discussions with different groups including *piki piki* (motorbike) riders, youth group members, women's group members. Members of the NCRO/CHA Community Advisory Board helped us identify these naturally occurring groups.

Other activities

We also drew on other ways of learning including: reviewing and clipping all national and local newspapers for any references to science, research or HIV; document analysis of NCRO/CHA meeting minutes and study documents; asking a short-term research assistant to create a photo diary of 'working class' lifestyles in the city; going with others on tours of their city spaces; and asking one of the NCRO/CHA clinical officers who was also an artist to draw/paint 'scenes' of research and intervention in the city. We also created a map of where city based NCRO/CHA HIV Research staff lived, which informed a paper on the shifting geographies of science.

Observations

NCRO/CHA observations involved attending regular weekly team meetings in the HIV research clinic for the two HIV studies we observed, as well the Community Advisory Board meetings. We also attended clinical and laboratory procedures, dissemination meetings, training, and conference travel, as well as informal visits, funerals and social activities with research staff and research participants.
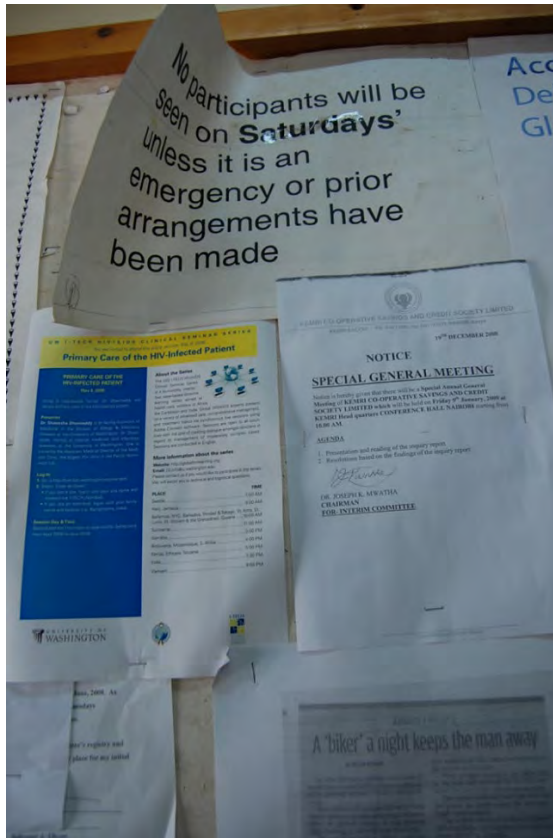
Figure 14: Clinic noticeboard in the Kisumu HIV Research Clinic. Source: Gemma Aellah

Teamwork

Although working in a team, we carried out in-depth interviews individually, often discussing who we felt the participant might be most comfortable with, or most productively interviewed by. We ran some of the focus group discussions together, and others alone. I read all the transcribed/translated interviews and focus group discussions that I was not present in. Some observations we did together, especially of one-off NCRO/CHA events, funerals, parties, and situations where there was a lot for one person to observe. But most of the time we did our ethnographic fieldwork separately and kept our own separate, personal field-diaries.

However, Gertrude and I (and our PI when he was with us) came together daily for long, reflective discussions about our experiences and what we had learned that day from interviews, observations, conversations, and general

life experiences. Often our transcribers, all Kenyan young women living in different parts of the city, joined in discussions reflecting on the meaning of the material they had been transcribing.

This experience of regularly talking with other ethnographers of different positionalities, backgrounds, relationships with the city, and who were living in different spaces in the city was fundamental for me in learning about and reflecting on life – and changing life - in this place.

Research in rural Akinda

The second main piece of immersive ethnographic fieldwork that this thesis draws on took place over a period of 17 months between July 2010 and December 2011. Although my research assistant, Lily, continued with some follow-up research and interviews alone until March 2012, after I had to return to the UK unexpectedly due to illness. The other RCS ethnographers remained in Kisumu City, working on aspects of the protocol related to their own interests. Though we sometimes came together to share how our independent projects were going, discuss emerging themes and seek advice from each other.

My Akinda hosts

In 2008 I had become friends with Ratwar, an Akinda NCRO/CHA fieldworker who co-authors the first paper in the thesis. We met on a trip to interview one of the Akinda area chiefs, when he was allocated to be my guide. Ratwar was the one who suggested I stay with Mama Unita, a widowed village reporter/*nyamrerwa* in her 60s, when I moved to Akinda.

Mama Unita's home was located close to market and the small field-office NCRO/CHA maintained in Akinda. She had worked for NCRO/CHA as a village reporter since the late 1980s but had worked 'in the community' since the late 1970s when she became a *nyamrerwa* with a church based rural

development programme. She was highly respected in the area and, according to Ratwar, 'knew how to talk to people.'

In 2009 Ratwar took me to her home. We found the family grieving over the recent death of one of Mama Unita's sons, who had lived with his wife and three children in Mama Unita's compound. Mama Unita's son Joe had not yet had the funds to make his own home properly, so his family of five lived within a simple two room, crumbling mud *simba* (bachelor hut). He had died after a long, painful, and expensive battle with throat cancer, leaving behind a young widow, Min Thea, with three children and little means of future support. Ratwar took me straight to say 'sorry' to Min Thea, the new widow. She was quiet, thin, and shocked.

A month or so after this funeral I returned and spent a few days staying with Mama Unita in her house, getting to know each other, seeing if it she comfortable with me staying with her, and thinking about the best way to do ethnography in Akinda. She had lots of advice and she had already decided and arranged a room where I should sleep. We agreed that I would call her to let her know when I had returned from the UK in 6 months or so and wanted to come and stay.

However, when I returned, I found that Mama Unita was living mostly away from her Akinda home caring for another desperately ill adult son, Jim, in a hospice in a nearby town. Jim was suffering from TB and other opportunistic infections. He had a young son, but was estranged from his son's mother, both of whom lived in Nairobi, so his mother was the one caring for him. This was not a good time to start fieldwork within her home. Mama Unita stayed by her son's side in the hospice for several months and I remained in Kisumu City. She called me when he died, both to let me know about the funeral preparations and to invite me to stay. At Jim's funeral, her family told me they were happy I would be staying with her as they were worried that she would be lonely having lost two sons within a year. Her 7-year-old granddaughter, Queenie, had been sleeping and eating in her house to keep

her company but Queenie's mother, Min Thea, Joe's widow, had also only been bereaved for a year, and wanted Queenie to sleep close to her again.

My move to live in rural Akinda full-time in October 2010, therefore, occurred on the tails of two funerals. I lent our study Land Rover to Mama Unita to carry Joe's body from the city morgue to their home for the funeral. I travelled on the coach hired to take the many mourners home. In this way I found myself cast straight into the heart of family dynamics, which continued throughout my fieldwork.

Figure 15: Standing with Mama Unita and family at the burial of her son. Source: Jasmey Aellah

At this funeral I learnt just how much of a consummate professional Mama Unita was, and why Ratwar had insisted I lived with her. With over thirty years' experience of acting as a liaison between her neighbours and overseas medical researchers, Mama Unita knew exactly the right way to introduce me. During the funeral she called me to stand by her side. She told the crowd of several hundred people that I was a new *Nyar* Akinda (daughter of Akinda) and that I wanted to learn the way *Jo*Akinda did their things. She joked that when she was younger, she had travelled to the UK and I was her

long-lost daughter born from that trip (when I got married she extended this performance by making the point of following cultural rules governing relationships between mothers-in-law and sons-in-law). I had the chance to introduce myself and say a few words of commiseration in Dholuo.

The area chief then stood up. As part of his speech, he gave a stern talk to the audience about how to treat me, pointing out that one day their children might get the chance to go to the UK, so they should treat me as they wished their children to be treated. This introduction through a funeral meant that when I returned to live with Mama Unita a week later most people already knew who I was. It offered me an easy transition into this place. I was known.

During my research, I lived within Mama Unita's home within a relationship which could be classified as more of an 'honorary daughter' than an economic transaction (compared to my rental agreements for accommodation in Kisumu City). I did not pay Mama Unita rent and found other ways to contribute to the household costs, such as doing shopping in town for us and for the homes of her two daughters-in-laws within the compound every couple of weeks and contributing to school fees for one of her granddaughters who had lost her father the year before.

After a few months carrying out fieldwork in Akinda alone I asked Lily, who I had first met as a participant in one of our youth-group focus group discussions in the city, if she would like to become a research assistant. When she was with me in Akinda she shared my room in Mama Unita's house, usually heading back to the city at the weekend to go and help her mother and attend her church. I stayed in Mama Unita's house the majority of the time. Though I continued to rent my house in Kisumu City, and sometimes stayed in the city for periods of time to make use of the Internet and electricity for writing up notes and handling audio-files. The city, and especially, the roads between the city and rural Akinda which I travelled on by *matatu* (public minibus), therefore, maintained a presence in my

ethnographic fieldwork and fieldwork diaries during this second extended fieldwork period.

Mama Unita was concerned to make sure I felt part of her wider family. I was introduced to her brothers and sisters, visiting them in their natal home. Visiting Kisumu City also enabled me to sometimes visit Mama Unita's sister who taught in a school in the estate where I rented a house, and ran a bar in a nearby rural area, meeting her grandchildren who were growing up very much as town children. And when passing through the country's capital Nairobi on a journey from the UK I stayed with Mama Unita's brother, who was a High Court Judge, and whose children had grown up entirely within upper-class Kisumu City and Nairobi.

After I finished research, Mama Unita's brother and his family came to visit me twice in the UK. Her brother was notable for once suing a Kenyan supermarket chain for the indignity of refusing his credit card. On his visits, I found the difference between classes, lifestyles, and possibilities within one family startling. The juxtaposition between his ability to bring his family on these holidays and the fact that I often found some of Mama Unita's grandchildren chased from school due to lack of fees was sharp. It also acted as a reminder not to be too glib when describing life in Akinda, which often resisted easy categories, especially around ideas of poverty and class. All this helped me understand further the interrelations and circulations between village, and city and the vast juxtapositions and differences in class and wealth that could emerge even within one (extended) family.

***Ka' Mama Unita.* The home/place of Mama Unita**

Figure 16: House number 1: looking out from Mama Unita's home. The writing above the door represents the numbering of her home, compound, and village for the Akinda Health and Demographic Surveillance System.

The home of Mama Unita consisted of several dwellings. Firstly, there was the main home. This was a large house with brick walls, three bedrooms and a good-sized living room. It had been built by her late husband, a well-respected teacher. The home stood out compared to those around it, most of which had mud-thatched walls or were considerably smaller. This family had once been relatively wealthy. And, although fortunes had declined since her husband's death, Mama Unita was not dependent on subsistence farming alone. She still had income from her NCRO/CHA village reporter role, as well as remittance from her wealthier relatives and some of her children. But she could not afford to repair her house.

Outside the house were two concrete latrines. These were nearly full and collapsing. There was also a large concrete water tank which no longer worked. The water collected from the roof leaked straight out on the grass. So, Mama Unita either bought her water from the mission centre opposite, or depending on the price, sent her farmhand, Otieno, on a bicycle to collect from wells further away.

Behind the home was a substantial kitchen garden, where Mama Unita grew vegetables, and beyond this a large field where she planted maize and beans. There were also two cows, chickens, and a few goats. There was a small mud-thatched kitchen hut, where Mama Unita cooked her meals on an open fire.

Within the boundaries of the compound there were two *simbas*, or bachelor huts, belonging to two of Mama Unita's grown-up sons. The one belonging to Joe, who had died recently, was mud-walled and empty. The second belonged to Jack, who worked for NCRO/CHA in a different district where he rented a house with his wife and children. His simba was smarter, with plastered walls. Otieno, the farmhand, lived inside.

Outside the immediate compound, there were two other homes with their own entrances and maize fields. One belonged to a son of Mama Unita's who was currently without work, having lost his job as a caterer for an NGO project nearby. He lived there with his wife and two teenage children. The other was a more make-shift home, where Min Thea, a daughter-in-law of Mama Unita lived with three younger children. There had not been time while Min Thea's husband was dying to strike out a proper home and build a new house for him. A separate entrance had been made, but his rough, tumbling down *simba* still remained as the main dwelling. The door had been moved to signal the transition from his father's compound to his own before his death. His wife occasionally picked up small bits of work cooking for NCRO/CHA projects, but mostly relied on remittances from her relatives to scrape by.

Research activities

Observations

In Akinda I spent my days following the everyday routines of the compound members. This included Mama Unita, Min Thea and Min Bella. It also included several homes around Akinda that I regularly visited and built relationships with. This included the home of the Chair of the newly formed

Akinda Community Unit as part of the new Community Health Strategy, the home of two brothers in their early twenties whose family opted out of the HDSS, the home of Susan a subsistence farmer whose husband was bedridden with AIDS related complications, the home of a skilled birth attendant who delivered many babies in her village, and the homes of two young widowed NCRO/CHA *nyamrerwa*. Like Mama Unita's, all these homes encompassed extended families.

I drank a lot of tea, went visiting, attended funerals, shopped in the market, and spent hours chatting with those living around me. I joined a local youth group and a branch of the Anglican Mothers Union and attended their regular meetings. I also followed activities related to the introduction of a new Community Health Strategy, including community meetings, trainings and 'Dialogue Days.'

Figure 17: Taking the family cat for a rabies vaccine on World Rabies Day. Source: Gemma Aellah.

I accompanied Mama Unita as she did her research work for NCRO/CHA, walking slowly around her village offering pregnancy tests to all women. I also followed another 7 village reporters as they moved around their villages. I went out on a bicycle with one of the NCRO/CHA community interviewers to see how they collected health data from Akinda residents and

accompanied the entomologists on their checks on the human-landing catchers as described in the Prelude. I attended any public dissemination events that occurred in the villages, as well as the Akinda Community Advisory Board meetings.

Interviews

I conducted 20 formal recorded interviews with a range of NCRO/CHA staff working in Akinda. I also interviewed 15 *naymrerwa* and Lily interviewed another 21, exploring their personal biographies. Together we also conducted another 20 formal recorded interviews with Akinda residents. I also ran 8 focus-group discussions with the youth-group, HIV support group, several women's groups, and groups of community health workers. But, in Akinda, I tended to have more informal conversations than formalised audio-recorded interviews.

Figure 18: Interviewing a former human-landing catcher. The framed picture shows him shaking hands with the British Principal Investigator of a bed-net study in the late 1990s. Source: Gemma Aellah.

Figure 19: Attending a meeting of an HIV support group in one member's home. Source: Gemma Aellah

Field-diaries

I continued to keep a handwritten field diary, as did Lily, which she shared with me. Often, we did things together. Sometimes we went our separate ways, especially for in-depth interviews. I also sometimes asked her to go alone to the youth group meetings we usually attended together to see if things were different when I was not there. We quickly found it was hard for her (and me) to fully represent the complexities and mass of observations experienced in one single day in written form. So, in addition to our written diaries and the recordings Lily made of interviews she conducted by herself, I audio-recorded a long conversation between us every few days, where we went through and expanded on her written notes. If we had done something different from each other, I interviewed her about what it had been like. If we had done something together, I compared our observations, discussing the

different ways we had noticed things, as well as trying to get translations of things I had not understood well.

Piloting

In January 2014 I returned to Kisumu City and Akinda for 2 months to pilot the book 'Global Health Research in an Unequal World: Ethics Case Studies from Africa' (Chapter 8), which was to become one of the major outcomes of the RCS study and my doctoral project. This book brought together stories of ethical dilemmas observed during my research with stories emerging from other anthropological studies of transnational medical research within Kenya and in other parts of Africa. Each story was accompanied with an illustration and a facilitator's guide with questions and activities to provoke group discussion.

Piloting involved testing these stories and guides with several different groups: NCRO/CHA researchers, the Akinda Community Advisory Board, the Akinda *nyamrerwa* and medical staff at the Kisumu provincial hospital. This process was helpful for checking which stories caught their imagination the most, and for testing the anonymity levels for the material. But, through this process, I was also able to catch up with those people I could not easily stay in contact with by phone. I revisited the spaces of the city and rural Akinda, finding out what had changed and what had stayed the same. Doing this during an analysis and writing up stage, helped me reflect on what things might have lasting importance and resonance and what things had less.

In the lead-up to this visit via email and phone and then in person, I also worked again with the Kenyan clinical-officer/artist, Johnson Ondiek, who had earlier produced some visual representations of research for the RCS study. I wrote short descriptions for him of the fictive case studies planned for the book and described both in written and verbal form how I had

imagined they might look. He started painting some of these before I arrived, testing out the effects of painting on large sheets.

When I was in Kisumu, we then sat together, and he shared what he thought the rest of such scenes should look like, bringing in his own ideas informed by his wealth of experience as a researcher and as a Kenyan artist. Sometimes he agreed with my visual proposals, sometimes he suggested new ideas or changes, and in those cases I asked him to paint what he felt – within the rough confines of the stories. I tried not to dictate his artistic style in any way. Johnson then painted each scene on large pieces of cloth, which I photographed and digitalised for use in the book. Occasionally he repainted after a first draft and further discussion.

These paintings not only ended up as illustrations for one of the outcomes of the project and doctoral thesis. They – and the process of constructing them - also became ethnographic material informing my overall analysis, revealing new things, bringing to the fore others. Johnson's response to my scene proposals also became a way of checking my analysis, seeing if it, and my ethnographic sensibility, held.

I was also particularly struck by the way he decided to place me in some of the scenes, especially his use of visual cues to represent the constellations of my power/difference/similarity in relation to research participants. This was most apparent in the image below which depicts a life-story interview. In this picture, a research participant offers me a gift of a chicken as I switch on my tape recorder. I appear bigger, more dominant, and powerful than my interlocuter. In the picture, I saw what I looked like from Johnson's gaze. This came as a timely reminder for me, as I was in during the process of analysis and writing, to keep thinking about my positionality and responsibility when writing about/with/for/to others.

Figure 20: Painting by Johnson Ondiek (paint on cloth, 2014, jaoarts@yahoo.com

Ethics

'All protocols observed'

Data collection was governed by the ethics regulations of NCRO and CHA. This meant situating an ethnography which would otherwise follow the more flexible, responsive guidelines summarised by the Association of Social Anthropologists (ASA, 2011), within an interdisciplinary world of regulatory ethics. However, given one of my research questions concerned ethical challenges, this meant I had a chance to act as a direct participant observer of biomedical research practices such as informed consent, transport reimbursement, and decisions about when to intervene.

The regulations insisted on written, rather than oral, informed consent for recorded interviews and focus group discussions. For observations and informal conversations verbal consent was used. This ranged from a quick introduction to a more detailed discussion, for example if I was asking to shadow a community health worker. Obviously, it was not possible to constantly explain the study to everyone casually encountered during a day.

129

In Akinda, before I started research proper, I presented the study to the local administration and to the location and sublocation chiefs. Their permission was vital and counted for a lot in the area, as demonstrated by the chief's introduction of me at the funeral described earlier.

Audio-recordings and paper consent forms were kept securely. Names were removed from transcripts and the identifiers list was kept in a password protected file. Transcripts were also password-protected.

Throughout the thesis I refer to Kisumu City with its proper name and Akinda with a pseudonym. The nickname is a corruption of '*kindo*' meaning determined. I have also given pseudonyms to NCRO (National Clinical Research Organisation) and CHA (Central Health Agency), respectively the Kenyan parastatal and American government organisations that collaborated to create the NCRO/CHA field station. There are several transnational field-stations operating out of Kisumu and several HDSS sites. So, whilst this does not give full anonymity, it at least obscures a little. I have also used pseudonyms for all the people described in the stories in the thesis. Sometimes I have mixed up and created composite stories if I felt it was necessary. Where I have been able to, I have asked people involved to read the papers and check they are comfortable with the level of anonymity.

Ethical challenges

In Akinda, Mama Unita acted as a go-between between me and residents, perhaps more so than I will ever realise. Her respected status counted for a lot, and undoubtedly influenced people to talk to me. Sometimes she did 'behind the scenes' work to ensure things ran smoothly for me.

A notable example of this occurred in relation to Dave, a young teacher from one the Akinda villages. I had spent some time with Dave and his brothers. We often cycled around Akinda together and hung out in the evenings. I had helped with the building of his mother's new home, smearing mud on the walls as part of a local workforce. But one day, Otieno, who lived in Mama

Unita's compound taking care of the cattle, reported to Mama Unita that Dave had been shouting about me angrily in the market after I had not answered his mobile call. Mama Unita, unknown to me, then met with a man she knew from Dave's village. He was someone, like her, who was known to be good at 'talking to people'. She asked him to counsel Dave. She told me about this event several weeks later. During that time, I had not seen Dave at all and had wondered if he was avoiding me. Later we resumed a cordial relationship and are friends to date.

I am still not clear exactly why Dave was upset about that morning. He had recently been studying anthropology at university as part of a social sciences course and writing an essay on the colonial practices of anthropology. It is possible that we were treading a difficult line where the uncomfortable feeling of being researched and the realities/limits of friendship across inequalities of power and life-opportunities were coming sharply into view.

The situation with Dave demonstrates that ethical considerations in this context are not adequately covered by the bio-medical technologies of written informed consent, which formally governed the RCS protocol. My ethnographic fieldwork depended heavily on hospitality and on the kindness of those giving up their time to speak and spend time with me. My position as a white ethnographer, associated with the powerful institutions of NCRO, CHA and LSHTM – and the soft but powerful influence of Mama Unita - undoubtedly placed obligations on my research participants that are not alleviated by the signing of a form.

But generally, on a personal level, I feel mostly okay with how I navigated my research relationships, as well as those that became lasting friendships. I did not hide what I was doing and often had multiple opportunities to explain to people over time. I have also taken great care with how and what stories I chose to present. I sometimes was able to have honest conversations about the realities of the meaningful benefits of the research with research participants. I found people often perceptive and sceptical about the classic

consent form claims that my research might, in some vague way, benefit others like them in the future.

Decolonising research

But on a more structural level, I am much less confident. My research was essentially premised on a classic anthropological trope of a white anthropologist going 'out' to research others in Africa and then writing about this experience in academic contexts. Though the make-up of our team and working closely with Gertrude in Kisumu City did break this trope to some extent. But, really, my piece of work does not represent any significant methodological innovation towards recent (and not so recent) calls to decolonise both global health and anthropological research (Bejarano et al., 2019, Büyüm et al., 2020, Lawrence and Hirsch, 2020, Smith, 1999, Uddin, 2011). If I did this research again, I would probably do it differently. Although I am not, at this point, sure what this would look like.

Abimbola has summarised some of the concerns of calls to decolonise knowledge that apply across global health and anthropology and which I think are the most important. In particular, he reflects on the problem of 'gaze' in academic global health. This encompasses reflection on who we are as authors, who we imagine we write for and the stand-point from which we do so (Abimbola, 2019). Power asymmetries in the production of knowledge in global health are perpetuated through a structural preoccupation with/primacy of the foreign gaze, which acts to obscure the fact that the most important conversations about health policy, systems, and health experiences in many low-income or middle-income countries do not make their way into peer-reviewed journals. To make global health truly global, he argues 'is to make global health truly local' (Abimbola, 2019 p.3). At the very least, more open conversation on the power and limits of the foreign gaze is needed.

The open-source book of ethics cases studies we produced from the RCS ethnographic study could represent, arguably, one step towards this, because

it places some of the ability to define the meanings of the stories on to those using them in their work. But they were still largely produced through a foreign gaze, albeit one that tried to think locally. And in other parts of my writing, I have not broken down the problem of the foreign gaze in any substantial way.

What I have tried to do, however, is to find small ways of reducing othering a little, by keeping in complexity, writing in what I think of a 'subjunctive mood', and through small acts such as co-authoring one paper with JaKenya, and asking other research participants to comment on other papers.

Languages

Learning

There were three languages in use during my fieldwork: Dholuo, Kiswahili and Kenyan English. Dholuo and English were the most used, although Kiswahili words and phrases were often mixed into conversations. In rural Akinda, most conversation occurred in Dholuo. I tried to learn Dholuo in several ways. In Kisumu City, I had language lessons from three different people: a dedicated language teacher who operated a small school and gave private lessons, a Kenyan Catholic priest who I soon realised was teaching me a colonial version of Dhuluo from a church language guide, and one the NCRO/CHA researcher participants, Julie. Julie, one of the mothers in the EBS study who was also a primary school teacher, tried to teach me the Kisumu version *sheng*, a slang patois based on Swahili.

In rural Akinda, I took lessons from a retired teacher who lived close to our home. In between lessons he also taught me much about the history of the Catholic church in Akinda, and the way things 'used to be.'

I would say that I never became fluent in Dholuo. I was able to make myself understood and hold a conversation, but subtleties were often lost.

Depending on who I was speaking to, I tended to mix languages ('Eng-Luo', as some of those around me jokingly called it). In Kisumu City I only conducted interviews that could be conducted in English. I read the other interviews after they had been carefully translated by our team of transcriber/translators.

Translation

In Akinda, I relied on several different people to help translate. Lily conducted some interviews on her own in Dholuo and then transcribed/translated them for me. Sometimes, we conducted interviews together. On these occasions, I often let the interview flow, rather than constantly asking for translation if I was lost. I then picked up the details I had missed afterwards in the written transcripts. During interviews and conversations where I did not have help, the process of trying to understand each other was sometimes challenging, and sometimes actually quite helpful as it became somewhat of a joint project to reach understanding. I do not know the extent of what I have missed due to language. I suspect it is significant.

Although Lily's mother tongue was Dholuo, she had grown up in the city and did not always fully understand what was called 'deep' Dholuo. Therefore, when interviewing older men in Akinda, I asked my husband to assist. He had grown up in a rural village until his twenties and could speak in the right way to elders. I also asked Florence, the daughter of my language teacher in Akinda, to act as a second research assistant on occasion. As someone who was from Akinda she had a good understanding of some local tensions and ways of talking about difficult things. For example, I asked her to help with a focus group discussion with a self-help group for people living with HIV, as well as with focus groups with a women's group where one of the members was thought to be a witch. She helped unravel some of the hidden tensions or unsaid talk/double-meanings in these encounters. During my fieldwork, she got a 'chance' and started working part-time with NCRO/CHA as a

community interviewer so I also learnt about how it might be to become a new fieldwork from her.

Language as analysis

Because of my background training and interests in literacies, during fieldwork I was attuned to language(s)-in-practice. I was interested in how utterances, styles and shifts between languages were used for making shared meaning in the moments of speaking, and especially between identities and institutional practices, marked in speech. I became especially interested in the use of certain idioms or phrases that were dominant during fieldwork. Several of these – exposure, *okbichaloni, nyamrerwa,* and analogue and digital — became central theoretical concepts in my analysis.

In this, I am trying to follow the way JoLuo themselves use language, especially idioms, as 'codes' for their community's worldviews and philosophy of life (Miruka, 2001). What it notable here is the way that Dholuo idioms (or adopted English phrases such as 'exposure' and 'analogue and digital') are imbued with concealed meanings, ambiguities and multiple allusions (Amuka, 2000, Amuka et al., 2000).

Analysis

When fieldwork ended, I returned to the UK carrying a huge amount of data. I brought piles of notebooks full of stories and observations, transcripts of interviews, recordings of conversations with Lily, thousands of photographs, and electronic databases of newspaper clippings and other ephemera, as well as some of the material objects these electronic signifiers refer to.

My collection of ephemera included posters, leaflets, training manuals, letters; pieces of paper with handwritten notes or sketches by others; copies of pages from the field-diaries/personal notebooks of *nyamrerwa* spanning several decades; funeral programmes, certificates, CVs; copies of

memorandums of understanding, constitutions, and minutes of self-help groups; as well as t-shirts, paintings, CDs, expired condoms, discarded medicine bottles, mobile phones, sim-cards etc. Many of these were originally 'analogue' materials, often meant to be discarded after use. Most were given or shown to me by people, many of whom kept hold of such ephemera themselves somewhere in their permanent homes for generations, or in suitcases that moved with them.

These materials, when combined with my notes, transcripts, and audio-files, became a way I could access 'hard' evidence to return to and help orient me when deconstructing moments in the flows of time, place, and biographies, including my own. My appreciation of the true value of being able to remember, return, and reflect in these multiple ways grew exponentially as time passed — especially when I started to discuss my analysis and share my ideas for writing with some of my research participants; an activity intertwined with periodically re-remembering things together and learning how each other's lives were going; sometimes in person, often by voice mobile phone calls, or through platforms like Facebook messenger or latterly WhatsApp.[8]

My first act of trying to sort, organise and analyse this diverse material was to start by sketching out what I thought of as the 'stickiest' things. These were phenomena, categories of people, situations, events that had stuck out in my mind, either because they seemed unique or special, because they seemed to

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[8] WhatsApp is currently the most popular social media platform in Kenyans, used the most by people on mobile phones in rural areas, and across all lower income settings (SIME Lab Africa, 2019). Many of my participants started using it around 2014/5, among the multiple constellations of sim cards, platforms and analogue or 'digital' smartphones used to achieve the most communication at the cheapest cost. Prior to WhatsApp, Facebook messenger was popular, even on some basic phones without many smartphone features, or accessed in Cyber cafes. At many points in time, I have found some of my research participants to be far more skilled in navigating the possibilities of cheap digital communication than me.

be things that people cared about, or because they represented moments of absurdity or jarring that merited further exploration (Vohnsen, 2017).

In identifying this list, I was guided by one of my research questions in particular:

> What value and meaning does transnational medical research and intervention have to those who encounter it? What (other) things matter to people as they navigate their lives in this place?

I went through this process first without revisiting my written materials. At this stage I identified several ethnographic objects include the concept of 'exposure' in relation to the value of research (Chapter 6), which had already emerged as a guiding concept in discussions with my RCS team colleagues. The *nyamrerwa* was another sticky object, a category of person in Akinda which felt special, and seemed to encapsulate the multi-layered histories and relationships, of which research was a part. JaKenya's personal biography (Chapter 5) was a third. The changing meanings and experiences of HIV from something described as *chira* (curse from breaking rules) to *chalna* (My Status) was another. Other sticky things were smaller, such as the use of shipping containers as research clinics, or the grand plans of the youth-group, and a belief that life would end at 40, as described in Chapter 8. Taking these things as starting points, I considered them in their broader contexts, coming to realise that these were all forms of commentary on the temporary-permanentness of research and the lived experience of precarity/vulnerability.

I also realised that several of these concepts were words or idioms that had become linguistically 'keyworded': organisational focal points both within specific cultural/historical contexts, but also within institutional domains of practice (Apthorpe, 2012, Parkin, 2015). I realised that what I had been calling in my notebooks 'sticky things' or 'glosses' (certain acronyms, turns of

phrases, names for person categories) were of the same order of things as Parkin's use of keywording.

Initially, I had thought I would structure my thesis around different groups of people e.g., perhaps female research participants, young researchers, *nyamrerwa*, different groups of community members. I thought that by doing this I could describe and compare the places from different perspectives. But in this early sketch of themes, I realised that the structuring devices could rather be these ethnographic themes and keywords which sometimes cut across groups.

The next step was to move away from my 'head-notes' and go back to the material, using my field-diaries and transcripts to find the material that linked to these ideas. In many cases this involved pulling out stories, especially those stories where I had the 'thickest' material (usually because I had known the people involved for longer periods of time, or cases where I had multiple interviews, observations, and chances to talk through observations with them). I was concerned to identify the cases where I could expand people's narratives the most, as well as stories of social problems, which were most often the stories of avoidable deaths that open Chapters 5-10. In this sense, my approach has some resonance with the Manchester School tradition of extended case study analysis, that developed from the Rhodes Livingstone Institute (Evens and Handelman, 2006).

In pulling out these stories, I began grouping people and stories that fit with each other, as well as identifying those which were more singular. The story of JaKenya, for example, is one which is especially singular. He is an outlier. But I did not wish to discount his story simply because it stood out. I therefore ended up writing about it in a way that best fitted, in a paper written about largely about a single individual and celebrating what could be learnt from this, rather than down-playing it (Piette and Heiss, 2015). In other cases, I stopped some avenues of thought when I found I did not really have enough instances of something to make my points convincingly.

This process helped me organise the material into different packages. I began by writing out the histories of Akinda, and a chapter that focused on the life of Jakenya. But the focus of the other chapters shifted somewhat over time. I had a long writing up period, and I also stayed in contact with many people from Kisumu City and Akinda during this time. News from these places sometimes changed my course.

One of the early papers I developed was about strategies for getting ahead deployed by young men in rural Akinda. The youth group I had been a part of was a major component of the material I drew on. I planned to contrast their determined efforts and serious ambitions with the depiction of young men as dangerous, liminal, and lost in Kenyan popular discourse, and with anthropological studies of urban men living in precarious contexts. Precarity, I argued, was mixed with predictability in rural Akinda.

However, some months after returning to the UK, I learnt that the youth group, which I left on such an optimistic note, had collapsed. The chair had vanished, the group's micro-loan with him. My first reaction was shock. But I quickly realised that, actually, this was not surprising at all. And, furthermore, that I also would not be surprised that if I checked in again in a year or so, I would find it back up and running. In fact, this did happen. The event meant I abandoned the paper. But the youth group, and the theme of *okbichaloni* (You will be surprised. But you know that for sure), emerged significantly in other parts of the thesis. It also reminded me that the way 'the field' appears and is fixed is always dependent on when the ethnographer leaves. Yet of course, things continue. To try to mitigate some of the fixing effect that occurs when writing about places, I decided to include a Post-script at the end of the thesis, to remind the reader that things continue beyond my conclusions.

Writing

An analogue and digital thesis

To keep a sense of the multiplicities contained within the idioms deployed in my analysis, in line with my belief in the political power of storytelling (See Hurston, 1938, 2018, Jackson, 2002), and in agreement that anthropology can be form of 'theoretical storytelling' (McGranahan, 2015), the chapters and papers presented in this Research Paper Style thesis are heavy with stories – and stories within stories.

There is a long, albeit marginalised, tradition of story-telling within anthropology (Symons and Maggio, 2014). There is a strong history of beautiful, compelling experiments in literary anthropology, that have called again, - and again, and again - for the expressive elements of writing to be taken seriously, rather relegated to embellishments (Di Nunzio, 2021, Hurston, 1938, 2018, Jackson, 2000). For example, the collective that produced one such book of experimental ethnographic writing, 'Crumpled Paper Boat', describe how they: 'shared a sense that explanations came too quickly and easily in the social sciences, stripped of the dense and deeply mortal flesh of life' (Pandian et al., 2017 p. 4), and of desires to convey 'more elusive truths in experience' (ibid).

While writing my thesis I have been thinking carefully about three things. Firstly, how to balance accounting for the individual whilst analysing more general patterns (Piette and Heiss, 2015, Rapport, 2013), especially when individuals appear particularly singular and unique (See for example Plancke, 2015, Turner, 1967). Secondly, how to contribute less to objectifying and othering practices in social science research and presentation. Thirdly, how to best write at the messy interdisciplinary intersections where what gets glossed as medical anthropology meets what could be glossed as either 'public health' or 'global health' (Taylor, 2018), and trying to find useful ways to share what I have learned from the experience of doing long-term

ethnography with global health researchers. This is what many of the medical anthropologists who I have been inspired by and whose ethnographic projects are conducted around these margins do (Ahmadu, 2007, 2017, Hutchinson et al., 2018, Moyi Okwaro and Geissler, 2015, Reynolds Whyte, 2014, Siu et al., 2013, Zaman, 2008)

The form my resultant written thesis has taken is the result of these considerations and is an experiment in ways to convey the complexities and creativities of many-sided post-colonial African lives that sometimes get flattened in other accounts. I found the inclusion of multiple life-stories – and death stories – one way to achieve this.

I have also tried to find a way to express the analytical themes of my thesis through its form, structure, and style, as well through its content. My thesis could be described as one version of what has lately been referred to as 'multi-modal' anthropology (Dattatreyan and Marrero-Guillamón, 2019, Varvantakis and Nolas, 2019), or of 'writing otherwise' (Restrepo and Escobar, 2005, Stacey and Wolff, 2016). I have chosen to present my findings as a Research Paper Style Thesis rather than in a more traditional monograph style. The thesis is presented as a collection of papers, all aimed at different audiences, written in different modes, and produced through several different writing and authorship collaborations. Papers were reviewed through the various journals reviewing processes, but also by some of my research participants. One is co-authored with a research participant. They are annotated with stories of deaths inserted between the stand-alone materials, as well as photographs and captioned paintings of scenes co-produced by me and one of my research participants, who is also a Kenyan artist, clinician, and (now former) NCRO/CHA research study co-ordinator.

I used the flexibility the format of a Research Paper style thesis affords me because I wanted to find a way to produce something which retains some of the depth and holism that marks an ethnographic monograph, but which has some of the portability and wider readership of open-source journal articles.

I believe this represents the realities of practicing anthropology at the intersections of social anthropology and global health. The aim of the RCS ethnographic project was 'to improve the understanding of social relations within a community of long-term collaborative medical research'. Our collaborators were institutions involved in this medical research, and they had collaborated with us because they wanted to understand and benefit from a more anthropological perspective. Taking advantage of the flexibility of a Research Paper Style thesis offers a way of writing in different registers and of balancing writing for other anthropologists, and for those with other or inter-disciplinary global health backgrounds. In this, I agree with other anthropologists such as Thieme who argue that whilst reflexivity is valuable it:

> '..too often omits more vexing questions including 'who we are writing for', which means that one's own practice of humility within the field is not sufficient if our own written outputs are relegated to academic audiences alone, and the words of our interlocutors only become nice quotes interwoven in our academic theoretical prose' (Thieme, 2017 p. 227).

The disadvantage of this format is that it made it harder to find ways to insert the rich narratives of my research participants, which is why I included stand-alone stories between the papers.

The thesis can be read from beginning to end as a book. Or a reader might find one of the open access articles in a journal relevant to their specialism. They could (in theory), then, follow the journal article back to the thesis and contextualise it in relation to the other papers and stories placed alongside it. Each paper makes a different, self-contained argument but retains some commonality of theme.

I could describe this Research Paper Style Thesis, borrowing from the idiom of analogue and digital, as representing a somewhat 'digital' approach to presentation: breaking the data into little bits and recombining into different stories, producing multiple output for different audiences. Each paper presented represents a shake and a twist of a kaleidoscope; drawing on the same pieces of material but arranged differently, making different patterns, and telling a different story for a specific audience.

Yet, despite first appearances, the *chuny* (Dholuo for soul/heart/liver) of this thesis is a rather 'traditional' holistic ethnographic monograph, drawn from in-depth research carried out over time and grounded into two specific locales. The knowledge was produced in a way that Kisumu City and Akinda residents might describe as 'analogue.' It is underpinned by a foundation of hospitality, friendship, and personal relations. I learnt in an embodied, experiential way, and situated knowledge produced through more formalised recorded in-depth interviews and focus group discussions against a bedrock of ethnographic presence.

Writing in a subjunctive mood

By offering multiple ways of conveying my findings and interspersing stories between more generalising papers, I have also been trying to write in what I think of as a 'subjunctive mood', taking inspiration from Reynolds Whyte's depiction of the subjunctive mood of people dealing with health and uncertainty in post-colonial Africa (Whyte, 1997a, 2002). She describes the subjunctive as 'the mood of hope, doubt, will and potential...the mood of people who care about something in particular' (Whyte 2002, p. 172). Appropriating this idea and applying it to the process of writing about other people illuminates several points. Firstly, this has been a process of imperfectly trying, or trying out. Secondly, both ethnographic fieldwork and trying out how to write about it contains a lot of mess. In designing the thesis in this way and in combining different output styles, I subscribe to sociologist John Law's methodological philosophy on embracing 'mess', as illustrated in

the image below. Keeping a sense of mess within social scientific presentation can be one way to manifest 'a real that is not definite or singular (Law, 2004 p. 15).

If this is an awful mess . . . then would something less messy make a mess of describing it?
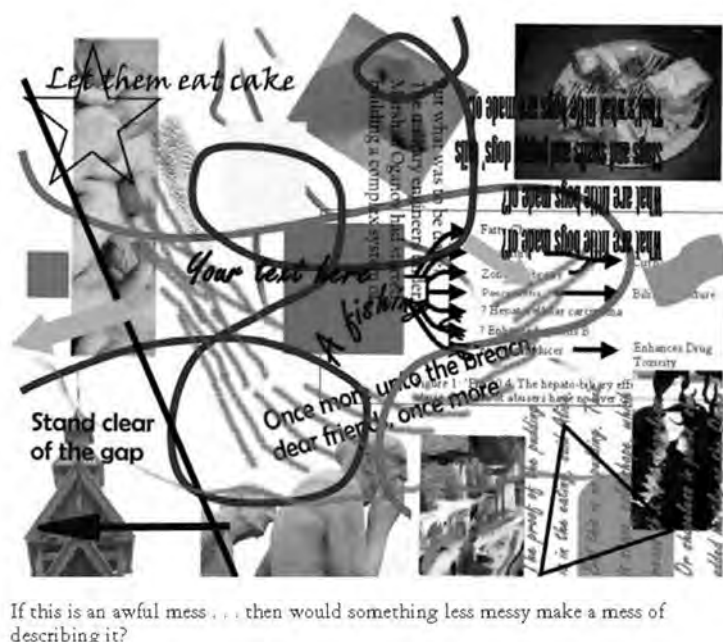
Figure 21: (Law, 2004 p. 1).

Thirdly, my process of trying out has been guided by caring about 'something(s) in particular'. The papers chosen are both a result of what I have cared about – tuned into – at particular moments, and what others within my study have expressed that they cared about. Including stories alongside papers is my attempt to also induce a sense of caring in the reader.

Thinking about subjunctivity also provides an important reminder that reflexivity within anthropology - understood here as paying attention to the contingencies of knowledge and the positionality of the researcher - moves beyond the process of the practice of ethnographic fieldwork. Contingency continues through the whole process, including thinking, narrating and the shaping of writing into different forms for publication, as well responding to

144

reviewers' comments. What emerges is very much dependent on what we tune in to, and out from at different times.

Chapter 4: Akinda and its histories:

Stories of magicians, missionaries, and scientists

Introduction

Nyanza is an administrative province in Western Kenya. Nyanza curls around the shores of Lake Victoria, or *Nam Lolwe,* 'the lake made by a giant called Lolwe.' It stretches from *Got-Ramogi* (Ramogi's Hill) on the equator where, Luo stories tell, *JoLuo* first settled after journeying from South Sudan before dispersing to other parts of Nyanza and Tanzania, and continues round and out encompassing Kogelo, the internationally-famous small village home of former United States President Obama's paternal step-grandmother (Madiega et al., 2008). It stretches onwards to the region's capital Kisumu City, with its ailing port, airport, growing Chinese investment, and ever burgeoning HIV and NGO economy (Aellah and Geissler, 2016, Prince, 2012). It continues further round the lakeshore, ballooning out to encompass Kisii City and the Gusii Highlands, homeland of the Kisii/Gusii people, and down along the lakeshores into 'deep' Luo country, rural Kadem in Southern Nyanza, the furthest distance from Kisumu City by road, merging into Tanzania.

This now defunct administrative demarcation, replaced in 2010 with a new county-system, contains 'Luoland'; the ancestral *dala* or 'home' of *Jo*Luo, (Atieno Odhiambo, 2000 p.247, Evans-Pritchard, 1950 p.132, Geissler and Prince, 2010 p.44, Shipton, 2007 p.40, Whisson and Lonsdale, 1975 p.44). For my own story, stating that 'I went to 'Luoland', the heart and homeland of *Jo*Luo' is the gloss that makes most sense. Luoland is a real place, a concrete map make-able and read-able by people from there. But it is also a dream of a community, one which extends beyond the borders of Kenya into

northern Uganda, the Mara Region in northern Tanzania and beyond to other linguistically-related Nilotic groups in Africa (Atieno Odhiambo, 2001, Cohen and Odhiambo, 1987, Geissler and Prince, 2010, Ogot, 1967, 2001, Ogot, 2009).

It is enacted within city enclaves in Nairobi and other parts of Kenya, and in continuing political dreams/caricatures of 'the Luo Nation' (Morrison, 2007, Parkin, 1978), not to mention the Luo Nation's Diaspora, and virtual communities (Ligaga, 2012). And not least within clans', families' and individuals' changing biographies as they move from, and between or back to, rural homes and urban houses to follow employment and shifting possibilities and dreams of what makes a good life (Geissler and Prince, 2010, Izugbara et al., 2013, Prince, 2006, Shipton, 1992, 1995, 2007, 2009, 2010, Smith, 2006).

Definition of a LUO

Special one for my brothers from the Lakeside. Omera, wot is!?
So, being a Luo is not a tribe (or a community), it is a lifestyle.
In fact, it is no longer just a lifestyle, it is a responsibility.
"When you tell a Luo to meet you at Ambassador stage, he arrives and informs you (over the phone that he is standing opposite the Hilton Hotel." – Phelix Jalang'o Odiwor

So, where do you belong? Here's the difference.

1. **Luoz** – are all over the world …*yaani* diasporic, highly educated and articulate. I mean Obama type of people… They will die supporting Arsenal FC, Brazil, All Blacks, Harambee Stars and Gor Mahia.
They also understand cricket.

2. **Luos** – are born and raised in Kisumu, probably went to Kisumu Boys/Girls High schools, then joined Maseno University or Kisumu Poly, work along Oginga Odinga Street in Kisumu and have never travelled past Ahero!
They adore *boda boda* and Guinness.

3. **Jeng'** – were probably born and raised in Nai (read Nairobi), lived in Lang'ata …or surrounding areas, have been to *shags* once or twice for *dani's* (grandy's) funeral coz *paros* insisted. Quotes his/her *shags* as being upcountry somewhere in Nyanza. You say "*amosi omera*" to them and they respond "*niaje jo vipi*". During football, they only attend Gor Mahia vs AFC matches played specifically at the Nyayo Stadium (which they insist is called 'The Brrr… arena' (Coca-Cola Stadium).

4. **Mjaluo** – was born in Mombasa , speaks swahili sanifu, broken English and no mother tongue. Full names are Otieno Abdalla or Anyango Amina… (you name it) Is a Muslim, lives in Ganjoni or surrounding areas.
They classify Kisumu people are "*watu wa bara*".

5. **Jaluo** – *Odhis ngima tek owada, we a bed e gweng' ka!! OMERA!!!!*

6. **Wajaka** – are born and raised in Eastlands predominantly Ololo, Okongo, Jeri, Salem, Bangla, Ofaro, Marish, Mbote, and Huruma. They have never gone past Ungem and they only know that they are Luos because of their second names.
They know Kisumu is a town near Nakuru, where you pass *ukiishiia kwa kina mbuyu…*

Figure 22: Kibao: Funniest jokes from Kenya and East Africa' from
https://jokeskibao.blogspot.com/2014/08/definition-of-luo.html

Akinda (a pseudonym) is a rural location in Nyanza, home to approximately 65,000 people, 95% of whom define themselves as belonging to JoLuo (Luo people). It is, according to the joke definitions JoLuo categories above, one of home-grounds of the 'real' Luo community – *JoGweng* ('the community').

It is locally famous for its seasonal sweet mangoes, fresh fish, and extremely high HIV prevalence. Its economic mainstays are subsistence farming, and the export of world-class global health research knowledge. For Akinda is also a collection of 77 numerated villages, made of compounds and households mapped by global positioning software for a longstanding Health and Demographic Surveillance System. It is a space of ongoing scientific endeavour and attention from the scientists of the Kenyan National Clinical Research Organisation (NCRO) who, in collaboration with an American Central Health Agency (CHA) and many other partners, have conducted transnational medical research in Akinda for more than forty years. Through this Akinda is connected to the NCRO/CHA headquarters on the outskirts of Kisumu City, about one hour away, and from there to the world.

When thinking about the history of this place, of how things have come to be a certain way, three overarching and intertwining strands or stories emerged most clearly during my ethnographic fieldwork. These are stories concerning the movement of people and ideas from three corners of the world, northeast Africa, Europe, and America, arriving in Akinda at different times and with different motivations. They are the stories of magicians, missionaries, and scientists. Or, in less dramatic terms, the stories of the slow migration of a group of Luo people beginning in the fourteenth century, of the arrival of a Dutch Catholic priest in the 1940s, the construction of a mission complex in the 1950s, a proactive Anglican Bishop in the 1970s, and of the extension of an American Central Health Agency's interest in health security within its own borders into an interest in global health security. This final strand of post-colonial scientific activity, in turn, was made possible by earlier British colonial practices and structures posited on a belief in the power of science as a means for the development of the colonies. Each of these stories and,

149

therefore, this version of a history of Akinda, are stories of arrival and intervention on the landscape and habits/bodies.

Of course, there are other histories and stories of the making of Akinda that could be told. For example, another potentially powerful narrative is that of the arrival of Indians in Akinda Bay who had migrated to East Africa with the construction of the Ugandan railway at the end of the nineteenth century, and who developed trade and changed culinary tastes in the region (Herzig, 2006). Or the intriguing origins of the group of staunch African Muslims living in a lakeside enclave in Akinda among the majority Christian population. But my particular fieldwork location happened to be in the compound of an Anglican NCRO/CHA village reporter, a few hundred metres from both the NCRO/CHA Akinda research field office and a Catholic missionary complex of schools, home-craft college, hospital, convent and cathedral. My home was surrounded by JoLuo neighbours that included clan elders and a direct descendant of Oracha, a famous pre-colonial *Jabilo* (powerful magician) and *Ruoth* (leader) of Akinda who had, it was universally agreed, inherited his *bilo* (magic). Therefore, these stories of magicians, missionaries and scientists were all around me, embedded in the biographies of neighbours and the construction of the landscape.

I could have also told stories of the historical and current pervasive influence of colonial categorisations and labour policies which, through the designation of Luoland as a labour 'reserve', mapped traditional/modern ways of life on onto urban/rural spaces, and created distinctive patterns of out-migration to towns and cities and later, for some, return to villages (Geissler and Prince, 2010, Shipton, 2007). Certainly, the biographies of one of the older male generation in Akinda that I will share in this chapter provides living documentation of some of these patterns. However, I did not manage to collect systematic data on this during my ethnographic fieldwork and my aim here is more to describe journeys *to* rather than *from* Akinda although, of course, these economic flows would be important parts of a more holistic history of this place.

In this chapter therefore, I will explore each of these chosen strands of history. I will show they are interdependent and feed into one another, and how they have produced layers of historical sediment, upon which the stories explored in later papers presented in the thesis play out. The first purpose of relaying these stories here is, on the one hand, to provide some background to deepen a reader's understanding of the papers that follow. It allows me to give more space to histories that are necessarily truncated by the word limits of journal articles. But, in doing this, I am also making some deeper analytical points, the framing of which I will now outline before describing the intertwining histories of Akinda.

Invasion or entanglement?

One reading of Akinda, as a site of transnational medical research activity with funding originating in CHA's headquarters in USA, positions Akinda at the far end of a trajectory spreading out from a high-technology epicentre in the States and down to the remotest rural outpost of global science. From such a position it can feel as if global health research is somewhat like an alien spaceship that has landed in this quiet place.

My first trip to Akinda, shortly after arriving from the UK by plane, felt a little like this landing of an alien spaceship. Kenyan medical researchers who lived in Kisumu city told us that by travelling to 'the field' in Akinda we were now 'going to the real ground'. Here they were referring to a perception of rural biomedical fieldwork as the most authentic, difficult, but also satisfying kind of biomedical research work. Something physically harder than work in either CHA's American headquarters, or Kisumu city's research clinics and labs, requiring energy, patience, and resilience to cope with long days, and strong legs and stomachs to cope with tougher terrain and 'natural/traditional' food. There were jokes that some of the Kenyan researchers who grew up in town (Luos, category 2 in the joke), along with *odiero* (white) researchers were too 'soft' to cope.

Furthermore, compared to most urban-based biomedical research which more often involved the researchers staying put and participants coming to them, during rural fieldwork researchers went deep 'into the community', entering homes where different, cultural, hierarchies of social relations might unsettle researcher-participant hierarchies. To do this well they needed to be especially respectful, patient, good at talking and at using the language registers of the rural. This was a manner/disposition sometimes described as 'being humble' or 'knowing how to talk to people'.

Rural realness

On one level such rhetoric around where the 'real ground' or 'real community' lies speaks, perhaps, to a persistence of an image within global health discourse, that of a remote, impoverished village community as the archetypal ground on which research happens and intervention matters (Jumbam, 2020). That global health research and intervention is tied to rurality is not surprising, given that the most deprived of health coverage and the most exposed to unnecessary suffering and death continue to be rural populations in Africa (Scheil-Adlung, 2015). It has also been argued that an ongoing imbalance between rural and urban health priorities is because global health has been historically intertwined with dominant development agendas that are 'rural health oriented' (Shawar and Crane, 2017).

But, more than this, ideas about Akinda as the 'real field' referenced in talk in Western Kenya perhaps also speak to the broader persistence of colonial ideas of the rural as a site for the making of a certain kind of African authenticity. An authenticity tied to land, ancestors, 'tradition' over 'modernity,' and gained through living in what is sometimes seen as a more authentic, organic kind of community. Although multiple ethnographic studies have taken apart this rhetoric, showing how what counts as tradition and what counts as community are historically contingent, debated and ever evolving (e.g., Edwards and Whiting, 2004, Prince, 2007, Watkins, 2000).

Nevertheless, rural living and rural life have been used as material for identity-making, as something to align with, or distance from and this is something which has historical/current resonance across the continent more generally. It is tied into patterns of exploitative world economic histories, dramatically intensifying during colonial periods, that moved groups of people – often men - either temporarily or permanently into new urbanised spaces for wage labour. Such migrations set up new economic, social, moral, and imagined relations and dichotomies between urban and rural locales and lifestyles (Apthorpe, 1968, Ferguson, 1992, Gluckman, 1940, Kabwegyere, 1979, Mayer, 1963, Potts, 2005, Thomas, 2002, van Donge, 1985, Wilson, 1941).

As a result of such uneven transformations, often, and in many places across the world, the rural was/is characterised as simultaneously a repository of tradition, nostalgia, and life less corrupted by the ills of modern life (Herzfeld, 1991) and as a place of backwardness, somewhere people have been left behind in, or forced back to, and do not wish to be (Li, 2010). There is a strong body of anthropological work showing how urban and rural connections, both material and imaginative, are invoked in both kinds of spaces, spaces which are entangled in multiple ways (e.g., Cheney, 2004, Cochrane, 2019, Englund, 2002, Piot, 1999, Troccoli, 2019).

Godfrey Wilson's 1940s ethnography of a mining town and rural labour reserves in Northern Rhodesia described how industry's demand for cheap labour depended both on the underdevelopment of rural agriculture and Africans becoming temporary residents in towns. He described uneven development, and the uneasy co-existence of spaces of subsistence agriculture with small, but rapidly industrialising urban development (Wilson and Wilson, 1945). In East Africa, Luoland, encompassing rural Akinda, was also designated as a labour 'reserve' during the colonial period. This naming still has some currency. I occasionally heard talk of going to 'the resaf for Christmas' articulated by JoLuo living in towns and cities. And, equally, I occasionally witnessed JoAkinda describe themselves self-

153

deprecatingly as '*Wan JoResaf*' (We are people of the Reserve'), used especially when referencing challenges in understanding 'tough' English used by non-Luo researchers presenting projects ('*Wan Jo Resaf*, talking to us is hard') or sometimes to differences in practices, such as during a seminar on how to use female condom which was met with scepticism by Akinda residents that it would be accepted by *JoGweng* (people of this community).

In the specific contexts of rural Akinda, therefore, it is possible that notions of what I have termed 'rural realness', for want of a better phrase, in transnational medical research practice, also has historical roots in the pervasive influence of colonial categorisations and labour policies which, through the designation of Luoland as a labour 'reserve', mapped traditional/modern ways of life on onto urban/rural spaces (Geissler and Prince, 2010b, Shipton, 2007). Although, again, this has an uneven history, which I will spend a little time outlining now.

The notion of Luoland, or more specifically rural Luoland as 'reserve' has its origins from 1895, when Britain declared the East Africa Protectorate, further solidified in the 1920S when Kenya became a settler colony, and the region was officially reserved to be a 'labour supplying district' (Berman and Lonsdale, 1992, Lonsdale, 1967, Shipton, 2007). Prior to this period, this region had little direct contact with Europeans or with coastal traders. Geissler and Prince have described the colonial experience of western Luoland as 'peripheral but intense' (Geissler and Prince, 2010b). Locally appointed administrative chiefs first aided colonial authorities in conscripting workers for road and rail building, porter services in the Carrier Corps and as soldiers in the two World Wars. Importantly, the official administrative classification of Luoland as a reserve meant tribal social structures and customary law was to be continued and economic development in the region was not promoted. Men were, therefore, drawn away to low-paid labour on Asian and European owned sugar plantations, highland tea estates, ports and other places of industry and wage labour

across East Africa (Geissler and Prince, 2010b, Ogot, 1963, Shipton, 2007, Stichter, 1982).

The period after the Second World War saw an increase in both living standards in Kenya, and the creation of an urban Luo 'working class', with many workers spending their whole working lives in employment away from rural homes, which became places to return to for Christmas and retirement. Conversely, rural economies further stagnated, with rural households supported by remittances from towns and cities. A study of life in rural South Nyanza in the 1990s showed that since 1963 roughly a third of men of working age have been away from their home districts at any given time, and that remittances contribute between 9 and 31% of incomes of rural homesteads (Shipton, 2007).

The 1960s and 1970s were seen as a hopeful time, with a future orientated towards the urban. But in the 1980s and 1990s, as urban unemployment and inflation rates rose, this changed. Geissler and Prince describe this a representing the crumbling of a 'expansive timeline' where:

> '...the connections, tangible or hoped-for, that the past had offered to the Luo traveller have been truncated. A road forward is hard to discern, and the predominant direction is back towards what used to be the reserve; to a 'home' that now, upon further scrutiny and under the shadow of HIV, no longer looks quite familiar' (Geissler and Prince, 2010a p. 51)

Thinking along these lines, one reading of references to 'going to the ground' when conducted transnational medical research in Akinda by Kenyan researchers are that these are acts of distancing, reinforcing such binaries between urban and rural, with its associated emotive qualities. These ideas were sometimes also drawn upon/celebrated in the post-colonial global research and intervention activities enacted by people from the global north that I encountered, although more often by fleeting overseas visitors than by

the longer-term overseas researchers who had gained more nuanced understanding of context. A vivid enactment of what I call 'rural realness', for want of a better term, was found in 2011 in a visit of a group of American 'Mommy Bloggers' who visited Akinda as part of a tour to 'see' and publicise the health-challenges facing fellow mothers in Africa organised by the ONE campaign.

ONE is a philanthropic lobbying organisation, co-founded by British musician Bono, funded by foundations, individual philanthropists, and corporate partners. It describes itself as a 'global movement campaigning to end extreme poverty and preventable disease by 2030' through, for example, 'world leaders' lobbying, advocating for official development assistance, and securing private sector funding https://www.one.org/us/. Most activity is concerned with sub-Saharan Africa. (RED), an 'ethical consumerism' brand targeting HIV by giving a percentage of profits directly to the Global Fund, which supports some of NCRO/CHA's HIV research and intervention activities, is one division of the campaign. The Mommy Bloggers tour tapped into ideas about leveraging the potential global collective power of so-called 'influencer' mothers writing about their lives on social media.

Akinda was the rural stop on a wider tour of Kenya. The stop was curated by CHA and included visiting a traditional healer, a children's clinic where mothers were getting their children tested for HIV, and visits to mothers in their homes, accompanied by local NCRO/CHA staff, thereby highlighting the vital importance of access to vaccines and community health care. When I first heard about the 'Mommy Bloggers'/ *'mummyboggers'* coming to Akinda from Mama Unita, the *nyamrerwa* who I lived with, it took a while to figure out what these strange creatures might be.

Searching for their highly publicised blogs about their trip while back in the UK, I found they included statements like:

'When our bus arrived at the site early this morning, we were greeted by a throng of gorgeous women in various iterations of elegant, colourful garb, who began singing and ululating a pretty exuberant Kenyan whoop.'

'We were able to speak to a traditional birth attendant. The wisdom on her aged face and in her voice was palpable'.
(Extracts reported on ABC News Luxenburg, 2011)

I also found an image of JaKenya, the NCRO/CHA fieldworker whose biography and forest home are described in the next chapter, amongst their blogs. He was strikingly photographed juxtaposed against the mud wall of a research participant and young mother's hut. In this image *Ja*Kenya is misnamed as a local 'village reporter', helping mothers access good prenatal care, and depicted as shiny-eyed and smiling, radiating a deep happiness and contentment, despite the poverty illustrated by the inclusion of the mud wall. His image is included alongside images of women dancing to greet the mommy bloggers bus, and an old *mama* famously known for her traditional medicine skills holding her potion up to romantically catch the light.

Finding these images on the internet in 2011 made me laugh, as I knew by then about the multiple identities possessed by JaKenya – and possessed by others depicted – that were flattened in these beautiful images of the poor and traditional. I also knew that the dancing women were *nyamrerwa* (village reporters) who had taken deliberate care to dress in colourful African cloth and that one of the 'traditional' *Dholuo* songs they had prepared and sung for these visitors was, as I will later discuss in this chapter, a re-hash of a layered, often reused, praise song for current and older interventionalists in/from Akinda. The question of 'what shall we sing to properly welcome our visitors?' had been much debated, and this song had eventually won out as the easiest option.

Later, I also came to realise that some of these cosmopolitan-seeming urban Kenyan researchers I met in the first few days of ethnographic research were

also, to borrow from Mbembe, talking in *multiplicities* when referring to Akinda as the 'real ground' (Mbembe, 2001) simultaneously distancing themselves from it at the same time as aligning themselves with it. For, Akinda (or places like Akinda) held an element of *real* home, in various ways, for some of them. In this cultural context, urban and rural are entangled in multiple ways. For many JoLuo, I found that the cultural idea that 'landscape means existence' still has deep resonance (Cohen and Odhiambo, 1989 p. 9). This, I think, is something *cultural*, influenced by but operating over and above the continuing structuring influences of colonial labour policies. And what 'landscape' means in this context is, partly, about trying to maintain some physical, and/or metaphorical connection with land that can be traced back to generations of ancestors (See also Geissler and Prince, 2010, Shipton, 1992, 2009).

Much of this (remaining) ancestral land is in rural places like Akinda. The environs of Kisumu City encompass some areas mixing rural ancestral homes with newer property developments. But in Kisumu City proper, such ancestral land is much harder to see having been sold long ago or completely built over and turned into estates (Geissler, 2013c). Yet I still, very occasionally, realised I was inside the traces of a truncated rural home even within the tightly packed spaces of a highly urbanised slum, marked by a particular layout of buildings and the presence of graves (See also Cooper, 2011b for a description of this within a peri-urban part of Kisumu around the airport).

At the very minimum, for those like many of the city-living Luo researchers, who were disconnected from 'original' land by generations of economic migration, land disputes or the effects of the AIDS crisis, connection to landscape remains in the acts of naming people. For example, in naming (and therefore properly 'knowing') a man as *JaX* (A person of a place) and a woman as *Nya* X (Daughter of a place) in conversations invoking such connections, such when Luo researchers living in the city went to rural areas

158

for research trips (See Cheney, 2004 for similar discussions about the rural as material for identity-making for children living in towns in Uganda).

Connections were also enlivened through practices such as keeping a subsistence farm going at 'home', having/supporting relatives living in rural areas, planning for future retirement to rural areas through initiating building projects on ancestral land for those that had some, or saving to buy a plot somewhere close to start a new permanent home for those that had no useable land. And, most importantly, planning to be buried in this 'real ground', *at home*, or as close as possible to something that feels like home.

Some members of the so-called 'working classes' which included more affluent NCRO/CHA researchers sometimes aspired - and even managed – to own/construct hybrid house-homes on compact plots of purchased land in peri-urban areas, through utilising loans. However, burial within these compounds would only ever be a very last option, though always preferable to the city cemetery. At the other end of the class-scale, to avoid the fate of the public urban cemetery for a loved one, NCRO/CHA fieldworker JaKenya (whose life is explored in the following chapter) created a simulation of a real home in rural Akinda in which to lay to rest an orphaned city-living friend, Ochieng, who had become disconnected from family and land of his own (See Cohen and Odhiambo, 1992 for more discussion of the politics of land, death and burying).

A case-in-point about urban/rural linkages among those city-based researchers in 2008 telling me I was now heading off 'to the ground' by leaving the city was Phyllis, a NCRO/CHA staff member living and working within the NCRO/CHA urban HIV clinic. She tended to dress in *kitenge* dress but overlaid with a smart jacket and office style high heels. Her husband worked in a senior position for Marie-Stopes Kenya. A year or so later I would drink coffee with her in an ultra-modern town house they owned in the centre of Kisumu City, near the private school to which she sent her sons. A year or so after that I found myself bumping through fields on the back of a

motorbike, deep into one of the most rural parts of Akinda to find her in her *real* home. This home mixed town and village living with an outside but white-tiled latrine block. They were in the process of adding a second storey to the home, which had an open veranda. It was full of trees, kitchen gardens, and maize fields looked after by caretakers when the family were away. I took tea with Phyllis' husband in the sitting room while waiting for Phyllis to return from paying a condolence visit to a friend within the village. He had travelled from Nairobi to oversee construction and was soon due to travel again to attend a conference in Uganda. Phyllis arrived, dusty from walking in flip flops. A few hours later, I left her in the grounds of her rural home, spreading groundnuts she had harvested earlier that morning on a mat to dry. Her home was visited every three months as part of the wider Akinda HDSS, although only her relatives living in the home and doing caretaking would be counted as regular Akinda HDSS residents.

The juxtaposition of Phyllis' relationship with urban/rural life and that of JaKenya's impoverished friend Ochieng also underscores the way that money and class intervene with the possibilities different people have for how such connections are or can be expressed. This also goes the other direction, heavily influencing how much JoLuo currently living in rural areas like Akinda can move from, or move between, villages, towns, and cities where, often, most houses need to be rented, rather than being *homes*. In fact, in Akinda in the first decade of the 2000s, although HDSS data showed substantial migration, with adults younger than 30 years being the most migratory, in-migration exceeded out-migration. Given that women migrated more than men, it is likely that this in-migration is strongly associated with marriage, and the tradition of women relocating to their husbands' homes upon marriage (reference withheld for anonymity).

I did not collect systematic data of my own on such migration patterns. But among those living closest to my host family, I found that many homes were headed by widowed women who had moved to Akinda on marriage and found ways to survive through subsistence farming and small business on the

160

death of their husbands. And of homes containing married men or multiple generations, all encompassed family members that lived, pretty much permanently, away for work, as well as members who had tried to leave but returned or 'in-migrated'. The stories of George and Peter, the human landing catchers described in the prelude who grew up in Akinda and migrated for a while but returned when things either did not work out, or they were needed at home, felt quite representative. The members of the youth-group in which I participated were also Akinda residents, both male and female, aged under 35 years who were thinking of Akinda as a place they might stay in indefinitely, and of how to make it more economically viable for them to do so. Although, most of them did not rule out future, nebulous opportunities that might take them somewhere else. Furthermore, as described in the next chapter, I also encountered (some) Luo NCRO/CHA fieldworkers who could have lived in the city but were determined to make meaningful rural lives for themselves in the village.

But I did not know or understand all of this complexity during the first days of ethnographic fieldwork in 2008. Then, my Kenyan colleague, our German Principal Investigator and I travelled in a Land-Rover from the urban HIV clinic, stopping for a while at the impressive well-built estate of the main NCRO/CHA field-station just outside of Kisumu City. After about 45 minutes, we moved off the tarmac onto a rocky earthen track, and eventually arrived to a run-down Ministry of Gender and Social Services centre, where NCRO/CHA has its Akinda field-office, where we were to interview village reporters seated on pieces of cloth on the grass. The juxtapositions of this journey reinforced an image of global techno-science arriving in (or perhaps invading) a rural, timeless Akinda village.

This feeling – a kind of jarring provoked by moving through and juxtaposition of seemingly vastly different places – is, I think, also shared in the thoughts of one of the American CHA ex-principal investigators who had lived in Kenya for 6 years and returned for a short visit to the children's clinic

in the mission hospital in Akinda. Writing after a pneumococcal conjugate vaccine had been successfully introduced, he blogged:

> 'Knowing something about the vaccine's complicated history – the technological sophistication of its design, the intricacies of its financing hashed out among high-level officials in meeting rooms in Geneva, London and Rome and the politics of its licensing – the tangibility of that diminutive vial in a cheap plastic cooler in a remote African village startled me somewhat. Yet, there it was, about to be injected into the chubby thighs of the babies waiting in the queue' (reference not given for anonymity).

Dichotomy in other ethnographies of transnational medical research

The feeling of worlds being apart has also been implied in anthropological studies of transnational medical research. Farmer states this explicitly when writing about bioethics in transnational medical research: 'researcher and subject are living in two different worlds' (Farmer, 2002 p. 1266). Fairhead et al's treatment of a Pneumococcal Vaccine Trial in The Gambia also sets up this imagined relationship, but more implicitly. They use the physical image of the medical research institution's compound fence to create a theorised image of the inside world of research and the outside world of the research subject, describing people as living 'in the operational *shadow* of a research station' (Fairhead et al., 2006a p. 1109 my emphasis).

Rajan Sunder's ethnographic description of the situation Patel, a former mill district in Bombay where the textile mills are torn down and new clinical trials infrastructure put up that the unemployed mill workers can only enter as research participants, also describes binary juxtaposition (Rajan Sunder, 2008, 2017). In these accounts the boundaries are both physical and

162

expressed through constellations of social relations and resources, as well as in clearly defined subject positions that delineate researcher from researched and powerful from powerless.

In the specific context of Akinda, such boundaries and juxtapositions between global science and rural African life do, of course, exist to some extent. But the shadow the research station casts here is much less sharply delineated from the everyday lives of Akinda residents. Many staff are from Akinda, living in their own homes or with their families. Some, especially the village reporters, who act as a bridge between research and community, have done a version of their jobs since before the arrival of NCRO/CHA and, I suspect, will continue afterwards. And often, as described above, many of Kenyan researchers who travel in from the city on research trips are already connected in other small (and sometimes big) ways to rural areas.

In Akinda, research inserts itself into everyday life, reaching inside residents' compounds, schools or embedded in their usual health dispensaries and clinics. And the health demographic surveillance system (HDSS) that overlays the villages with its impressive technological infrastructure of hand-held computers and satellite technology is, despite its high-tech appearance, essentially a mass of stories about individual residents' lives; their births, deaths, and movements in, out and around Akinda as they get married, move into their own compounds, or leave looking for work. Furthermore, for Akinda residents, the 'real' roots of the HDSS are in a much earlier locally driven census run by wives in the villages who numbered homes and visited women offering family planning services as part of a church community health and rural development programme.

The historical strands that I will describe in detail below, therefore, show that despite the first appearances created by the large permanent-looking, glossy field-station located on the outskirts of Kisumu City from which research activity appears to emanate, the past, present and future of research is patchy and contingent. Rather that entering like a huge, preformed machine landing

in Akinda, the form research takes now was created through the layering of individual projects, like a piece of sedimentary rock, through happenstance and individual effort, and allowed in only because of foundations laid in other older, and intertwining, stories. By providing a thick description of Akinda and some of its multiple histories, therefore, the various entanglements of the properties, rhythms and people involved in transnational medical research can be better understood.

Selecting a frame for a history of Akinda: shifting the kaleidoscope

Instead of setting up my thesis by telling a story that starts in Global North, moves to Kisumu City and then down to the village in Akinda (as I as an ethnographer first travelled) or even one that starts in the NCRO/CHA research clinic or headquarters in the city (as our Research Communities Study Protocol first did), I want to describe the creation of Akinda from inside, taking Akinda as the centring point. By doing this, I am not describing Akinda's history as I first learnt it, framed by the background descriptions provided in the Research Communities Study Protocol. By rather, as I *came* to learn it, over time, in conversation with various Akinda residents about what it was important to know to understand *'kaka JoAkinda odak'* (how people of Akinda live). Of course, my permission to do research at all was through NCRO/CHA, something well known by most Akinda residents I encountered. And this version of Akinda's history is equally as imbued with my positionality, as well my physical proximity to the source of these stories (as described above). But my guiding question was, at least, motivated by a concern to shift the kaleidoscope or frame a little.

My guiding question for the collection of material that informs this chapter was, simply, how did this unique place take its current form according to its residents? When asking this, it becomes clear that the history of Akinda does not begin with Health and Demographic Surveillance. Furthermore, it also becomes clear that the history of health and demographic surveillance in Akinda does not begin in the United States, where funding for the current

effort originates, nor in the organising, amorphous global assemblages around HDSS practices that include bodies like the World Health Organisation and the International Network of HDSS sites (see below for a visual imagining of this defined but nebulous structure). Or even in Kisumu City where the HDSS Principal Investigators work and reside.
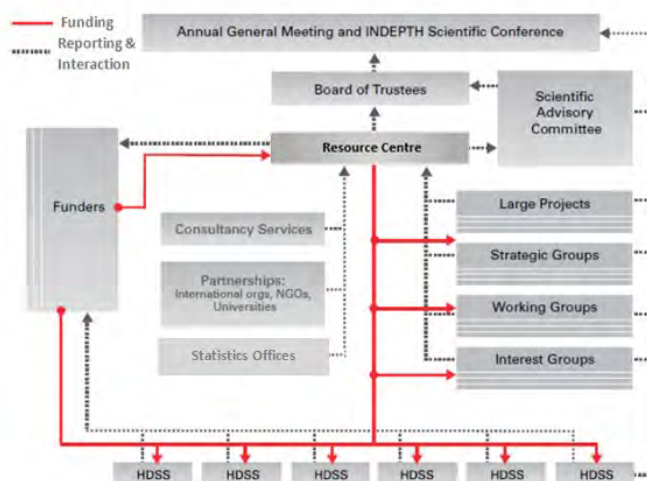
Figure 24: Image of governance structure of the INDEPTH Network, an International Network of field sites with continuous Demographic Evaluation of Populations and Their Health in developing countries, founded in 1998. Accessed 08.03.2020 http://www.indepth-network.org/about-us/governance. Public domain.

Rather, the history of medical research intervention in its current form begins in the journeys of Luo ancestors who populated the space, the colonialists and missionaries who also began setting certain orders upon it, and community efforts in the 1980s to organise homesteads grouped together around clan lineages into the 'villages' that structure the HDSS today (villages that are now sometimes misread as pre-existing communities) in order to improve their own health through home-visiting and monitoring.

Historicity and multi-durées

I will start here to relay the three different but overlapping stories that can introduce Akinda – of magicians, missionaries, and scientists - in conventional chronological order. However, anthropologists have cautioned us about too sharply delineating past, present and future when thinking

about history and history-making. Hirsch and Stewart, along these lines, prefer to think about 'historicity' which:

> '...describes a human situation in flow, where versions of the past and future (of persons, collectives of things) assume present form in relation to events, political needs, available cultural forms, and emotional dispositions.' (Hirsch and Stewart, 2005 p. 262)

Hirsch and Stewart's approach allows for a song, a dream, or a perception of a landscape to be classified as history/historicity within ethnographic research. In day-to-day Akinda life the stories of magicians, missionaries, and scientists, (or perhaps tradition, church and globalisation?) intermingle and co-constitute each other in ways considered perfectly coherent by Akinda residents.

This intermingling can be found in multiple aspects of life, but in this chapter, I demonstrate it particularly through three things. Firstly, the figure of *nyamwrera*, a category of person which includes, but is more than, the NCRO/CHA village reporters; secondly in songs sung by *nyamwrera* in praise of research and interventions; and thirdly, in one of the most interesting and concrete places where this intermingling happens, the compounds of the health dispensaries and the architecture of the spaces designated for improving life through public health. I will, therefore, conclude this chapter by bringing together these stories in a walking tour around one Akinda health dispensary, finding traces of the different histories in the architecture and shape the space takes today, as well as in the biographies of the people I met there using the space. I will contrast this with a description of the Kisumu City HIV research clinic which exists as much more of a separate enclave within the city.

The tour of the building, the *nyamrerwa* and the songs they sing are concrete material demonstrations of what post-colonial theorist and

historian Chakrabarty has described as the fundamental assumption that must be made when writing histories, that of a 'plurality of times existing together, a disjuncture of the present with itself' (Chakrabarty, 2000 p. 109). This chapter, therefore, gives attention to unfurling and depicting the *multiple durées* that Akinda residents have lived through and, importantly, continue to live in conversation with. The stories are presented as sometimes intertwining, sometimes diverting from each other. Generations of Akinda residents move through them and engage with them in ways that depend on their positionalities, such as when they were born, which families they are born into, and what both their relational and physical proximity is/was to a particular intervention or research project at any given time.

Mbembe characterised processes of transition and change in postcolonial Africa in his book 'On the Postcolony' as not moving 'in a closed orbit' but rather as pointing in several directions at once, and occurring at different speeds, on different time scales (Mbembe, 2001). There are two related points that I take from this in relation to Akinda: one concerning generations/generational time and one concerning progress.

The first is a rather simple point about recognising that, as in any place, the people living through one period of time together are made up of different generations who have other, different shared historical experiences. Such experiences may have been especially strong, usually if occurring during formative years around transitions to adulthood, such that they 'magnetise' consciousness and produce a specific generational consciousness that breaks in some ways from previous generations and continues to powerfully shape understandings moving forward (Mannheim, 1952, See Reynolds Whyte, 2014 for a discussion of this in relations to the AIDS crisis). Other experiences may be more or less affecting depending, to paraphrase sociologist C Wright Mills, on the intersections where personal and family biographies meet these histories (Mills, 1959). And, of course, this is all undercut as multiple anthropological studies have shown by debate and

conflict between different African generations about what things are important (e.g.Burton and Charton-Bigot, 2010, Kyaddondo et al., 2008).

This is something I felt particularly poignantly when interviewing the older men (80 -100 years plus) who provide much of the living stories for Luo, colonial, and missionary histories. For them, in the words of one, Andreas, NCRO/CHA 'came just yesterday!' And its' coming might not have been particularly significant against memories of the excitement of youth wrestling, the arrival of white missionaries, being sent to fight in for the British in Burma, Kenya's independence, struggles for Luo national political representation, famines, the AIDS crisis, the trials of raising families and many many other things. For others, such George the human landing catcher in his thirties described in the prelude to the thesis, seeing a previous generation of human landing catchers start work with NCRO/CHA in the 1990s when he was in school and then become 'big men' of science over the next decade *was* a special moment.

Yet for some of the *nyamrewa* (the village reporters who helped George get his chance of engagement with NCRO/CHA) the defining moment in this history was more than a decade earlier, and within in a rural development programme that met them in a transitional moment of their own lives, as young mothers. And, for yet others, such as the younger members of my host compound born into the HDSS programme NCRO/CHA has *always* been there. For them *nonro* (research) is nothing exceptional or exciting. In relation to this, I found it important to try to resist thinking about the past lives of my interlocutors as somehow *less* modern than their current ones.

This involved recognising that I, myself, also sometimes bought into the tropes of timeless rural African villages that I critique above. For example, I found myself taken aback to see a picture of a twenty-year-old Mama Unita, who I knew usually as a woman in her sixties dressed in a long skirt or *kitenge* dress, wearing high heels, a mini-skirt and beehive hair style. I was equally surprised, given her devoted attendance at the rural Anglican

Mothers Union, when she told me she was a 'life-ist', who loved dancing and drinking Guinness beer (a sign, if you cast your mind back to the joke categorisation of types of JoLuo of being a town *Luo*). It reminded me that someone like Mama Unita and other *nyamrerwa*, who might describe herself now, and be seen, as '*Ja*Analogue', was at one point someone who signified modernity. Moments like this, where I interrogated the assumptions I was making when I found things surprising, served as a reminder to resist easy binaries and categorisations of past, present and future. The older *nyamrerwa* I met in 2010-11, who were seen by the NCRO/CHA field-station as representing deep embeddedness in and understanding of their communities and their communities' traditions were, once, in the 1980s, the equivalents of the young 'Digital' Akinda community-interviewers now working for NCRO/CHA using the high technology of finger-print readers and palmtop computers. Especially, for example, when they had brought information to their neighbours about family planning interventions or introduced new concepts such as demographic surveillance in the 1980s, as will be described below.

Such 'entanglement' of *multiple durées*, and the conceptualisation of time as historical and simultaneously not linear is the condition of *all* human experiences, despite the linear 'grand metanarratives' of science, progress and history originating in Western Europe thought (and global north more widely) that might tell – or have told - otherwise (Lyotard, 1984, Tembo and Gerber, 2020). However, recognising this in Akinda is about more than a general recognition about the qualities of time and history as lived experience. It is also productive for thinking about how to understand the intertwining of progress with underdevelopment, exemplified in the overlapping and embedding in the landscape of failed, ended, or temporary projects with on-going hopeful ones.

Mbeme's provocative writing on 'entanglement' in the post-colony forces recognition of the (broad) *zeitgeist* of post-colonial experience across Africa where:

> 'as an age the post colony encloses multiple durées made up
> of discontinuities, reversals, inertia and swings that overlay
> one another, interpenetrate one another and envelope one
> another, an entanglement' (Mbembe, 2001 p.14)

This, he argues, (together with the simultaneous multiplicities of people and things), coalesces into a difficult to pin down, harmful exercising of power and situations of injustice, that he conceptualises as working through *arbitrariness*. Arbitrariness has its heritage in colonial regimes of power and their inherent lack of justice and othering practices. But when extending into what Mbembe and others gloss as 'the post-colony' it becomes ever more slippery to locate a centre or object/holder of power at which to lobby claims for redress, or a solid repository for ethical responsibility. In the kind of extreme situations Mbembe and others describe such as permanent African refugee camps, or abandoned conflict zones, or the treatment of African asylum seekers in Europe, this leads to *necro-politics*, the casting of 'others' at a population-level as less deserving of life with both dramatically violent (e.g. letting refugee boats sink), and slowly violent consequences (e.g. toxic dumping in vulnerable communities, or as felt within the complex unresolvable 'standard of care' controversies emerging around HIV research conducted in Africa in the 1990s, where African populations were given treatments considered not good enough for non-African populations, yet alternatives proposals of *not* doing this for ethical reasons would have left such populations with nothing at all (Bhutta, 2004, Davies, 2019, Davies et al., 2017, Mayblin et al., 2020, Mbembe, 2019, Wendland, 2013)).

Stories about Akinda are, clearly, not stories about these extremities of necro-politics. As I will show, by and large, they are stories of people – at multiple levels- working together with purpose and with ideas of improvement and new development in mind. It would be not be fair or accurate to characterise, for example, the form that transnational medical research has taken in Akinda as a type biosocial extractive and exploitative 'body mining' (Bruun, 2016), with necro-political side-effects of laying waste

to social relations and health-care landscapes in the long term. Nor to discount the multiple efforts of government, national and devolved ministries, missionaries, national/local church actors, donors, non-governmental organisations, and *Jo*Akinda themselves to address health and other vulnerabilities.

And yet, as the tour of the physical space of the Akinda dispensary at the end of this chapter will demonstrate within these histories are some of the kind of 'discontinuities, reversals, inertia and swings' that Mbembe describes; discontinuities that run alongside signs of progress progressing.

The physical spaces of an Akinda dispensary, as will be described, contains what could be thought of as a mix of monuments to earlier intervention innovation, monuments to projects started and abandoned, and monuments orientated to the future. The space projects an image of a constellation of interventions and projects that were once cutting-edge but did not become the (final) future. But their traces persist into the present, not least because in the dispensary I found Akinda residents busy re-purposing both old buildings and new buildings for their current efforts to serve the health and well-being of their community, as best possible within the limits placed by scarcity of resources and personnel. The Akinda dispensary, therefore, represents a powerful material example of the co-existence of progress with decline, and the inertia and swings of a time lived within *multiple durées,*

I have also found some resonance with the concept of *arbitrariness* outlined in Mbembe's philosophy when trying to think about whether it is possible to identify whose responsibility it is, or could be, for the ending of research and interventions, many of which were time-limited from the outset. Akinda residents have a sense that 'others' have come and intervened in Akinda (and should do so), but that one day these others 'will pack their things and go.' When they (inevitably) do, they will leave *Jo*Akinda, who cannot so easily pack their things and go, as the ones who remain and must see how to live.

Here, I have found it helpful to think further about both these aspects by drawing again on inspiration from the way that my participants used the flexible ambiguous metaphors of 'analogue' and 'digital' as ways of talking critically about, and overlaying, past, present and future, as described in the introduction. For, although 'digital life' as a metaphor is more intensely linked with the future or at least feels more like the future, it is not (at least by my interlocutors) automatically connected with meaningful, lasting development or progress. As I will show, what lasts through time in Akinda are the close-up and personal or 'analogue' social relationships that provide the scaffolding for each series of research activity or intervention that is/was seen as cutting-edge at any given point in time (or, in metaphorical terms could have been described as 'digital' if such metaphors were in operation then). It is their socialites that provide, borrowing from this productive metaphor, a continuous signal through time.

Furthermore, thinking about ambiguities of digital life which allows for more and faster, but perhaps less substantive, integrated, or co-ordinated outputs is also helpful for thinking about the ways in which transnational medical research in Akinda currently manifests itself as a plethora or multitude of studies.

Finally, using these metaphors in the multi-edged way used people living this social context also allows for the recognition that someone like Mama Unita could have been *digital* in the past, might be *analogue* in the present, and could be *digital* again in the future, if future innovation involves looking to the past to revive and revitalise older practices. Such oscillation, of course, also applies to the entire endeavour of transnational medical research activity and intervention.

Story 1: Magicians – the arrival of JoLuo in Akinda

'Josigana agannue? Ganuwa jasigana! Chon gilala....'
'People who like stories, can I tell you a long story? Tell
us storyteller! Long ago...'

(Traditional way of starting a storytelling of long-ago stories).

...or about the fourteenth century according to historians (Crazzolara, 1950, Ogot, 1967), the ancestors of the people known today as JoLuo slowly followed the course of the river Nile from Sudan into what is now Western Kenya. Wearing skins and carrying spears, ancestors of the Kale, Kanyigoro, Kanyikela and Omia clans and multiple sub-clans eventually arrived at the location of Akinda around the mid-eighteenth century.

In Akinda, asking to find out about the history of Akinda meant only one thing: talking to the oldest residents about famous ancestors, and things of 'long long ago'. My hosts and neighbours all directed me to the same people, namely three men, all at least in their 80s, one several years past his centenary, who were known as good storytellers and holders of history and clan genealogies. I spoke to these three men, Mr Okwama, Hermas and Andreas, at length with two of their wives chipping in details. I took my Luo husband, who had grown up in a rural area surrounded by grandmothers, instead of my usual younger translator because they spoke in a deep Dholuo with certain words and phrases that she found difficult, if not impossible, to understand. These taped conversations followed similar patterns all starting with the men locating themselves in place and their genealogies ('I am a person of Akinda, son of so and so, grandson of...etc...'). They described how *JoAkinda* (people of Akinda) had arrived in this place and fought for their boundaries. They recounted fond stories of their youth. They were pleasurable, ponderous, and nostalgic conversations. These men knew how to tell good stories. Much published Luo history-writing and ethnography of

173

'traditional culture', including that which I drew on to check some of histories, is also based on oral narratives of older people, especially men (Ayot, 1987, Malo, 1953, Mboya, 1983 (original.1938), Ocholla-Ayayo, 1976, Ogot, 1967). I was pleased to find some of the same characters appearing in both my interviews and written histories.

The pseudonym I chose for Akinda is a corruption of *kindo* meaning 'determined'. This derived from the story of arrival told to me by these old men. *JoKinda* (People of Akinda) Hermas (born 1917) told me, kept on pushing themselves on, gradually, like cattle being driven forward. They migrated from a nearby lakeside area called Uoyma after a fight over a girl (Ayot, 1987, Whisson and Lonsdale, 1975). According to Mr Okwama (born approximately: 1910), one of the local custodians of this mythic history, the fighting starting when the girl, Ojalgoro, a daughter of the Kanyikela clan was seduced by a man from the Uyoma clan and then abused by him and others for her ugliness. This was a major insult. By taunting her they were taunting the whole clan, implying they were too poor to produce beautiful daughters. After some fighting, people from the Kanyikela clan moved away to claim Akinda, followed by several other, larger and fiercer clans. Soon Oracha, Mr Okwama's great grandfather, from the Kale clan gained recognition as the overall *Ruoth* (leader) and *Jabilo* (powerful magician) of Akinda location. The land was not actually empty when they found it, requiring absorption of some, expulsion of others, and fierce defence of the designated borders. This was where Oracha's power as a *Jabilo* were felt:

> 'A most important medicine man with protective magico-
> medicine against destructive medicine is *Jabilo*....*Jabilo* uses
> his *bilo* in two main categories, the first and most traditional
> practice of *Jabilo* was that connected with prophecy: they
> can foresee the future, help the community against drought,
> plague and direct the course of wars in former
> days....Second, *Jabilo* possess *bilo* used as anti-Nawi, anti-

174

Mkingo, and many other forms of destructive medicine'
(Ocholla-Ayayo, 1976 p.158-9)

Andreas, Mr Okwama's younger cousin (born 1925) described how Oracha chose the strongest and bravest young men and sent them to the furthest corners to defend the land against encroaching enemies. Of which, it seems, there were rather a lot.

'*Seme wakedo go*. The people of Seme, we fought them.
Wakedo gi Uyoma. We fought with Uoyma
Wakedo gi Sakwa. We fought with Sakwa
Wakedo gi Alego. We fought with Alego
Wakedo gi Seme. We fought Seme again.'

(Mr Okwama telling stories about the early days of Akinda)

This all happened '*chon gilala',* long long ago before, as Mr Okwama says, '*higni ne pok occahki''* – years had started. According to Mr Okwama, *Jo*Akinda only started numbering years when *Bwana* (Mr) Oruko, the first white man arrived in the area. This was in the first decade of the twentieth century, Mr Okwama estimates, and it is possible that this Oruko was C.W Hobley (1867-1947).

Sent to Mombasa in 1890 as a geologist with the Imperial British East African Company with the formation of the British East Africa Protectorate, in 1895 C.W Hobley joined the British government and was posted to Kavirondo, now known as Nyanza, in Western Kenya as sub-commissioner (Matson and Ofcansky, 1981). He was also an ethnographer interested in Luo culture as well as the geology of the region, taking photographs and publishing an article in the Journal of the Royal Anthropological Institute (Hobley, 1903). In some ways, he was the first of a long series of researchers interested in this area.

175

Figure 25: Loch Mixed Catholic Primary school children visiting the University of Oxford Pitt Rivers Museum exhibition 'Paro Manene' (reflecting on the past) at Loch Church Parish Hall, February 2007. Many of the pictures in the exhibition were taken by C.W Hobley.

Mr Okwamo describes the coming of Bwana Oruko:

> *'Mmm ka obiro thuka to owachoni ...jaluo okone ni ...okone jaluo ni utiyo ang'o? Ere gima unyalo golonwa ukonywa godo? Ni wan wanego mana iyieyo ema wachamo.'*
> When he first came, he asked Luos "what are you doing? What can you give us?" Then Luos said, "We don't do anything, we only kill rats".
> *Ka Oruko aye duogo to oduogo ka okelo rupia mane iluongoni akidi.'*
> When Oruko came back, he brought with him Rupia (money) that we used to call Akidi (from the word for stone).

Oruko is recorded in an Dholuo-English Dictionary I bought in Kisumu City as both an adjective meaning 'He/she is busy (with work)' and a proper name, following linguistic traditions of male (usually) names starting and ending with O (Odaga, 2005). This tongue-in-cheek naming, therefore, fits

with the possibility that Mr Owamo is remembering C.W. Hobley as Mr Oruko.

Oracha, the magician, died just before the arrival of the British and the next Luo *Ruoth* (leaders) became uniformed chiefs in the colonial administrative structures. Adhola, the first chief in the colonial system apparently rode a horse around the land beating people who did not keep to the clan boundaries he had marked.

Shortly after C.W Hobley/Oruko's arrival, the completion of the Ugandan Railway in 1901 (so called because it connected the port at Mombasa to the port at Kisumu which connected the coast to Uganda) brought some new arrivals: Indians from British India to lakeside Akinda Bay. Around 32,000 Indians had been imported from British India to work on the railways and after completion they were free to settle (Herzig, 2006). A small number set up a small fishing trade centre by the lake. Akinda Bay quickly came to be known as *Ka'Mito* (now its official name) after one of the Indian businessmen who had set up a tea shop. He wanted to trade sugar, not yet known in the region, and sold tea and *mandazi* (doughnuts) to try and generate a taste for it. He was nicknamed '*Mito*' from *mit* meaning sweet and Akinda Bay became known as '*Ka'Mito*', place of sweetness.

All three men remember the tea shop with a mixture of excitement and fear, recounting childhood games of daring each other to get close to the strange new substance, which today is ubiquitous but then was feared amid rumours of causing sterility. In contrast, during my fieldwork, when the price of sugar rose sharply in 2010 the dormitory of the Loch Girls Boarding School was burnt down by angry students demanding more sugar in their tea. The Form 3 students of Sita Secondary school went on strike for the same reason. As well as tea and sugar, Mito used to trade in green-grams and sesame seeds. He brought a big boat to the bay and brought crops of finger millet and cassava to Akinda. *Ka'Mito* developed into a small but busy marketplace.

Today the Indian businessmen have left for the bright lights of Kisumu City but teashops – and the taste for sugar – remain.

Andreas, Hermas and Mr Okwama remember their youth and childhoods in the first few decades of the twentieth century with much nostalgia. Hermas was famous as a very good wrestler and dancer. He recounted stories of dancing competitions held between different clans and sub-clans where he would impress girls with his prowess, and of the first time he saw European clothes. Mr Okwamo owned two bulls so would work ploughing others' farms in exchange for goats. He was also a noted singer. He inherited the skills from his ancestors to become a powerful *Jabilo* for which he is still renowned. Though today, he says, his customers are mostly young men and women looking for love spells or people trying to identity a thief. He is trying to teach his youngest son his skills. Florence my 22-year old neighbour in Akinda told me that his power was still strong. She recounted how in in secondary school something was stolen from her group of girlfriends and they went to Mr Okwama to identify the thief. She was too scared to enter his hut but when the others left, subdued and shaking, the thief amongst them had confessed and the item was returned. Andreas, on the other hand, the most 'exposed' (to life outside Akinda) of the three, was at 17 years old nominated as one of his clan's representatives to fight with the British in Burma in 1941. It was a shock at first, especially the noise of the guns. Whilst there he leant carpentry skills which, on his return, he took to Tanzania for some years looking for work before returning home.

All three men, and their elderly wives, remember *'chon gi lala'* (long ago) as a time of plenty, of less people and more wholesome food:

> Mr Okwama: *"Ka apimo gi sani, sani piny onge"*.
> Mr Okwama: "Compared to now, the world is not there"
> [meaning there is nothing to look forward to or things
> have become worse]

178

This feeling of loss and of the world becoming more difficult became a common refrain in my fieldwork, not just amongst the older generation who talked about there being more love in the past, but also amongst younger generations who found it difficult to imagine living beyond 40 years. This is something I will come back to later in the paper presented in Chapter 5 on mood and adherence to HIV medication.

I recount these stories of long, long ago here not just due to their intrinsic interest but also because of their relevance for life today. Cooper writes about the development of a strong historiography particularly by Luo scholars, which celebrates *JoLuo* as a distinctive cultural entity (Cooper, 2011b). Beyond academic and political discourse, on a simple level, connection to land through genealogy as an organisational force for entitles like women's groups and claims for access to NCRO/CHA employment based on authentic '*JoAkinda*-ness' are still an important part of everyday life in Akinda. Where you come from still matters, as evidenced by the fact that at every homestead I visited with Lily my translator she was asked "where are you a daughter of?" As someone whose family had relocated from their rural land for work in Busia near the border of Uganda before she was born and who had grown up in an estate in Kisumu City this was an awkward question. Answering 'a daughter of Ugenya' she was frequently caught out when our hosts questioned her further about the exact place and people living nearby that she did not know.

I would also largely agree with the ethnographer Shipton's broad statement that: 'The Luo take pride in their past, and are widely reputed for traditionalism' (Shipton, 2009 p.40). This is not confined to older generations. The paper presented in the next chapter explores a reinterpretation of village-life and shows how certain 'youth' are trying to uniquely blend Luo-ness with cosmopolitanism, celebrating a nostalgic imagination of *chon gi lala* (long, long ago).

Story 2: Missionaries - the arrival of Father Ayot, the Catholic Mission and the Anglican rural health and development programme

Figure 26: Vincynthia at St Mary's Loch Girl's High School in Akinda, one of the oldest girls' schools in Kenya and started by the Loch Sisters. She is the daughter of Emma Dene, a neighbour delivered by Sister Emma Dene (the first Sister to arrive) in the Loch Mission Hospital and named after her. Source: Gemma Aellah.

The compounds of the old men whose stories are described above surround a Catholic mission complex which now dominates the Loch landscape (the market centre nearest to my compound in Akinda). The story of the development of the mission in Akinda that I relay here was largely obtained for me through scrupulous research by my neighbour and Luo language teacher, Mr Warinda, a 'child of the hope'; a mission child whose widowed mother was taken in and accommodated by the church.

Mr Warinda, a retired teacher, took a scholarly and enthusiastic approach to his assigned task. I asked him during a language lesson in his Akinda home for his thoughts on the best way to research the history of the mission. After my lesson he went and consulted with others in Akinda that he felt also knew the history well. He collated this information and produced a written document for me about the Loch mission and what he called the 'faith-bringers'. I then combined this document with secondary sources to produce the version outlined below.

Although European missionaries had arrived in Western Kenya at the end of the nineteenth century and the Church Missionary Society (essentially the mission branch of Anglican Church or Church of England) established a large centre in Maseno, a couple of hours from Akinda in 1906 (Ochwada, 2007), Akinda itself was somewhat neglected in early missionary activity. Writing about the 1930s period Whisson described Akinda as:

> 'a backwater…. It was over thirty miles from the Central
> Nyanza district headquarters at Kisumu, there was no
> mission station in the location. It possessed several bush
> schools, some small trading centres, a few acres of cotton
> and a fishing harbour on Lake Victoria.' (Whisson and
> Lonsdale, 1975).

But, in the 1950s this was about to change rapidly. Akinda might still have been classified as a 'backwater', but a substantial Catholic Missionary complex had now developed. Mr Warinda, the former mission child who collected data for me on the formation of the mission, when discussing this transformation with me exclaimed: 'do you see what Ayot (the first missionary) started? We began reed-thatched. Now Loch is not now a mission but a complex!'

According to the notes of Mr Warinda, and further verified by a book entitled 'The Way the Catholic Church Started in Western Kenya,' written by a Dutch

Mill Hill missionary who started working in East Africa in 1957 (Burgman, 1990), the first white priest came to Akinda in the 1940s. He was a Dutch priest called Father Bernard Verhej, known locally by the Luo name of Father Ayot. He had been the curate of a British priest, Father Franklin Bauman, who had started a large Catholic mission in a nearby place called Aluor in 1912 and wanted to expand to Akinda. His colleague Father John Odera came after two years to help. The first church initiated in 1946 was a simple reed thatched construction.

According to Mr Warinda's notes, the Akinda community were happy with the arrival of the priests. Father Frank Bauman had already been travelling over all the area with Father Ayot so:

> 'They [the Akinda community] were already familiar and when father Bernard Verhej came to establish a catholic mission, the Late Ojwang' the late Isaac Chwang'u, grandson of Oracha welcomed them because they had a spare round which Luo language calls '*gunda*,' a deserted home. They said: "let that white occupy that place."' (written notes, Mr Warinda 2010)

Andreas, one of the holders of Akinda history, is from the same clan as Ojwang who donated the *gunda* and, when we visited him in his home, he showed us a certificate he was given from the church when they celebrated its bicentennial. The letter thanked him and his relatives for their donation. Mr Warinda described how:

> 'In summary we revered them, we respected them, and we saw them in the image of faith bringers, so there was no discrimination, in languages like '*mano misungu odhi kucha a*' – 'that is a white let him go away'. No, they were welcomed. They felt at one with us and to prove to you this man Father Oudera, when we went with Father Oudera, he

182

ate with us *alot* (vegetables). He ate with us *kuon* (stiff maize porridge. He ate with us anything!' (written notes, Mr Warinda 2010).

Mr Okwamo, another elderly Akinda storyteller and a Luo magician, does not remember it quite like this. He remembers helping Father Ayot look for water boreholes for the church with other youth and that Oracha's snake hid in the boreholes. If you remember, Oracha was the famous *Ruoth* (leader) and *Jabilo* (magician) who died just before the British arrived in Western Kenya. According to Mr Okwamo, he had a very scary snake who continued to live in the Akinda bush. On apprehending this snake, Father Ayot simply shot it with his gun and skinned it. Father Ayot then took the skin back to Europe to show his friends, but whilst he was away his newly built house mysteriously burned down:

> Mr Okwama: "Oracha ne owachoni en owuon bade kora chiel nie lowo to kon chien ni oko, kane otho [silence] ne orito piny".

> Mr Okwama: "Oracha himself had said that his one hand is on the grave and the other outside [silence]. That even if he is dead, he is still in control of things".

In 1957 Bishop Hall promised 40,000 KES to any mission ready to build a convent in Kenya. An architect and technician, Father Ayot started building in Akinda with Father Oudera. Then, while on home leave in the Netherlands he called on the Sisters of Oudenbosch in Noord-Brabant, narrowly beating some fathers from Tanganika to it. Two of the Sisters came to visit and liked Loch the best as a location (Burgman, 1990). In 1958 five Sisters arrived in Loch and quickly got to work. Mr Warinda was one of the children serving the mass when they first arrived:

> 'They were paraded, from what we call now Loch market coming in style, Reverend Father, Sister Maktilde, Sister

Loice, Sister Emmadene, Sister Brigit, Sister Catherine, all five Dutch people. And we were so interested in seeing white sisters; we had never seen them.' (written notes, Mr Warinda 2010).

The sisters started preparing one of the first girls' high schools in Kenya in Akinda and:

> '...right from the beginning they opened their ranks for African girls to be candidates for the Sisterhood. In 1961 this began in earnest. At first the African candidates were to form a separate Society, but soon the policy changed. They were encouraged to integrate into one big community. In those days that was a novel and courageous step to take and they succeeded marvellously.' (Burgman, 1990 p. 258)

This action was particularly courageous given that Father Ayot was not a fan of Africans entering the Ministry. In fact, according to Mr Warinda, who was a child of 13 at this time and remembers the event vividly, Father Ayot behaved very badly at a 1958 visit of the Bishop. The visit involved a procession from the newly built permanent church to 'Od Ayot,' the original reed thatched church. But Ayot was jealous and:

> 'Chased the new Christians away, uttering abusive Dutch language. To us kids – what a day! To the older people – what a shame! The Bishop frowned and blushed; he resembled his dog who had a red stripe on his coat. But he was determined and still blessed the convent.' (written notes, Mr Warinda, 2010).

Ayot was given a penance by the Bishop of rations of tea with no milk, one slice of crusty bread and some hard work – the building of a bigger convent building.

At this time, medical facilities were scarce in the region. The only one around was Okello dispensary but this was an Anglican facility, so the Loch sisters endeavoured to open their own clinic. Sister Emma Dene was the first medical attendant in this clinic and became famous for her ability to deal with difficult births. The sisters offered an informal medical training scheme for young girls in the area. One of the current NCRO/CHA village reporters and my immediate neighbour in Akinda, Sabi, worked there in the early 19 60s as a young teenager, learning the rudiments of nursing and midwifery from the sisters. Later she took these skills to both the Saradidi Rural Health Programme (to be discussed below) and the NCRO/CHA research programme.

In the late 1970s the Sisters expanded still further creating a nutritional centre, once again on land donated by the Kolal clan. This became known as *Ka'Kwodi*, (Place of Swollen Stomachs) from the word *kwot* meaning to swell, referring to the swollen stomachs of malnourished children. Mr Warinda told me that this arose out of the difficulty the Sisters had with dealing with malnourished patients in the hospital:

> 'So again, this being something governmental they had to contact the Ministry of Social Services to give them permission to start a nutrition centre and they were given support and an ok by the government. That's why they began this nutrition centre, malnourished children, malnourished patients were brought there.' (written notes, Mr Warinda, 2010).

Their centre became part of the Family Life Training Programme, under the Ministry of Culture and Social Services which had existed since 1974. It became a residential centre where women and their children lived for 3 weeks or more for nutritional training and intensive feeding (Hoorweg and Niemeyer, 1979). Later it received funding from the Danish International Agency (Whyte and Kariuki, 1991).

The programme ceased in the 1990s and the complex became the property of the Ministry of Gender, Children and Social Development who now rents some of the buildings to NCRO/CHA. But it is still known as *Ka'Kwodi* and is associated with food notably because of a Walter Reed US Army research study on malaria prophylactics which had its headquarters there in the 1990s and was particularly famous for providing lavish feasts for its' participants. It was known as the 'chapati study' and Akinda residents recount seeing participants go every day (much like Ka'Kwodi women) for their trial drugs washed down with chapati, rice, chicken and soda, luxury items usually reserved for Christmas parties.

The 1970s also added a further dimension to the growing mission complex, a residential catering training institution called 'Home-craft' run by the nuns, which offered – and still –does – diploma courses to girls on cooking, sewing and cleaning skills. Still run by one of the same sisters who started it, the Home Craft computer room was where I had a small space for my computer during my fieldwork.

In 2008 when I first visited Akinda the dominance of the mission on the landscape was unavoidable.

Figure 27: St Peter church in Loch, 2009. Source: Gemma Aellah.

It is now a collection of a large cathedral, mixed primary school, national girls' boarding school, convent, mission hospital and catering college. Adult education classes are run out of the church and the Mission hospital's HIV clinic has a well-developed outreach programme. The Mission hospital is also the centre of much of the hospital-based medical research work by NCRO/CHA in the area, which I will come to later.

The main HIV treatment centre in the area is run out of the mission hospital under the domain of the Catholic Medical Services programme. Funding comes from the US President's Emergency Fund for AIDS Relief and Catholic charities. As a Catholic influenced centre, it will not provide any condoms to its clients. I organised a meeting between members of an HIV self-help group and an HIV activist from Kisumu City. We held the meeting on the steps of the church. When Erick, the activist, started demonstrating how to use a condom, members kept an anxious eye out for the mission sisters. I later found some of the free condoms we distributed discarded by the church fence.

The Catholics were not the only missionaries in the region. The Anglican Church also has a long history and presence in the area (Ochwada, 2007). Its presence, however, is much less physically obvious. The area around Loch, where I was living, only has small local Anglican churches. The one in our village, Sita, for example, seemed only to be attended regularly by ten or so people. However, in 2009-2011 I constantly encountered memories – in conversations, in songs and in practices – of the Saradidi Rural Health Programme, locally referred to just as 'Saradidi' or sometimes 'Minare' after its' satellite health clinic. This was an Anglican project initiated in the late 1970s, the director of which was called Dr P. I often heard his name praised in a song sung both at some NCRO/CHA meetings and meetings of community health workers working with the Ministry of Health. Mama Unita, my host, told me that the first Saradidi rural health programme volunteers composed the song lyrics. But the cadence and structure is reminiscent of more general praise songs.

187

Dr P's song 1980

Hawi malich nga wan JoAkinda

Ma wayudo ka oa e polo (x2)

Wakuongo wayude kuom Dr P ma oseriwo Akinda te

(x2)

Kaseje osebdo ma orikore chuth ma kelo konyo

Kendo Oseko kelo CMH ma thietho ji

Ochako otiego nyamweche tudo ma geng'o touché

Oseko kelo dongruok e Akinda te

Nonri kata in be ka ibende de thim

Ka pok iloko chunyi ka ingi'iyo jodala ng'at ma kama

(x2)

Sieme ng'at ma dipiem kode

East Akinda, West Akinda ka achiel kod Central gi

South

Wa kuanun gueth madongo ma nyasae omiyowa

Dr P's song

We have got blessings from heaven, the Akinda people

We first found it from Dr. P who united all Akinda

Dr P has been ready to bring help

He has brought CMH (Child Maternal Health) for treating people

He taught all the community health workers for disease prevention

He has brought development in the whole of Akinda

Look at yourself, if you could also do this, before you change your heart for your people.

Is there any other person like him?

Point to a person who could compete with him

East Akinda, West Akinda together with Central and South Akinda

Let us count a lot of blessings that God has brought us.

Mama Unita, who I lived with during fieldwork in Akinda was one of the first NCRO/CHA village reporters and also one of the first women trained by Dr P earlier in 1979. Through conversations with her and her friends, Dr P grew in my mind to a hero of mythic proportions. I never heard anyone say a bad word about him. It was very clear that this programme – and Dr P – had had a profound impact on the lives of these women, on their career trajectories, and the way they thought about and carried about themselves. In fact, when I went to meet him at the Tropical Institute of Community Health he had set up as part of Great Lakes University in Kisumu City I was surprised to find a down-to-earth person, much younger than I expected.

The Saradidi Rural Health Programme has its origins in a community development programme initiated country-wide by the Anglican Church of Kenya in 1975. 30% of Saradidi ACK congregations elected development committees through this programme (Kaseje and Spencer, 1987). As part of this, a church in Saradidi, a part of Akinda near the lake quite far from where I was based, began a small church-based pharmacy in 1975. Then in 1979 the Saradidi Rural Health Programme started as a result of intensification of this effort between Dr P, a community health physician and deacon, some medical students and community leaders.

In the bowels of the London School of Hygiene and Tropical Medical library archives I found a special issue of the 1987 Annals of Tropical Medicine and Parasitology which was a collection of 17 articles evaluating the programme. The main structure of the programme was the grouping of the scattered homesteads of the area (which eventually encompassed all of East and West Akinda, an area of 225 km²) into distinct villages which were given new names. Village committees were then established. In each village a 'village health helper' was appointed and trained to bring the health programme into the community. The programme activities included the development of a community cost-sharing clinic, a census, home-visiting and education by the village health helpers, and distribution of family planning, and of anti-malarial tablets by the village health helpers. The evaluation of the effects of

this distribution, among other aspects of the programme, became part of a research component conducted by Dr P in collaboration with the University of Nairobi and other outside agencies. But the organisers were very keen to express that this was, at heart, a local, community-based project rather than a research programme. The Chairman of the Committee of Village Committees wrote the foreword for the journal collection where he stated that:

> 'A community that was once poor, passive, sick and apathetic has, in the last five years, been able to mobilise its resources and become fully involved in the processes of improving its own health status...No activities were imposed from the outside...We are grateful that even researchers did not impose ideas or activities on us. The knowledge and skills planted in the community will remain evergreen for many years and may produce a new culture in which the norms include the practice of good health' (Kaseje and Spencer, 1987).

Initial seminars were held to educate the community on health and development. They were facilitated by people from the Ministry of Health District Health Team, a regional advisor of UNICEF, the Chairman of the Department of Community Health at the University of Nairobi and representatives from the international NGO the African Medical and Research Foundation. At these seminars, participants decided on the top priorities of the area: water, malaria, lack of health facilities and nutrition. Land was donated for the construction of the clinic – including land belonging to the father of the programme Director, Dr P – and fund-raising groups were created in Kisumu and Nairobi. Community members donated time, labour and materials. The Ministry of Health provided basic supplies and equipment. The few actual employees – a clinical officer and two community nurses were paid with money generated through external research funds and community development awards. British Voluntary

Service Overseas volunteers and a foreign water engineer came to provide additional technical assistance.

By far the most lasting legacy of this programme was the training and creation of the position of village health helper. Quickly their names were changed from village health helper to *nyamrerwa*, a term meaning, the programme says 'immediate helper in trouble' (Kaseje et al., 1987a p.3). But really, this term taps into a long-understood category of women skilled in child health and childbirth. The '*wa*' in *nyamrerwa* refers to 'our' which Dr P told me captured, for him, the essence of the programme which was trying to get the community to own their own development and health.

The *nyamrerwa* were expected to be mature in character, live in the village and to be respected. By the early 1980s 126 *nyamrerwa* from 56 villages covering 43,000 people had been trained. 96.8% were women, 99.2% were married, 75.4% were aged between 25 and 39 and 80.2% had at least 5 years of education. Most were housewives, mothers, and subsistence farmers. One, Mama Unita my host in Akinda, was a nursery school teacher (Kaseje et al., 1987a). They were recruited through church congregations and *barazas* (community meetings). Doreen, one of the original *nyamrerwa* who later joined the NCRO/CHA research programme described how those interested were asked to stand up and then the villagers were asked to stand behind the ones they felt fit the brief of 'being married, having children, being polite and not being a witch'.

After an initial intensive training period they were sent back to their villagers where they kept records of births and deaths and visited young mothers and pregnant women to encourage them to go for antenatal clinics and take their children for immunisation. The *nyamrerwa* carried out basic first aid in the community and distributed family planning and malaria treatment. A few days a month they assisted in the clinic pharmacy and, in the 1980s, many of them were sent for three months residential midwifery training at hospitals around Nyanza province.

After this training they were encouraged by the programme to offer delivering babies as an informal service in the village. Some of them continue this practice today despite a ban imposed by the Ministry of Health in 2000 due to fears about HIV infection. The *nyamrerwa* tried to charge 300 KES for a home delivery – a considerable sum but cheaper than the mission hospital at Loch at the time. Most of the time, they told me, they ended up doing it for free or for the gift of a chicken. This is interesting because when I first came to Akinda and heard the word *Nyamrerwa* associated with 'traditional birth attendant' I thought they would be women who had learnt their skills traditionally, perhaps from their grandmothers. Actually, these particular women had learnt in district hospitals and were proud of their technical skill and knowledge.

Figure 28: Layla and her husband in their compound in Ka'Mito (2010). Layla was one of the first batch of *nyamrerwa* trained at Saradidi in 1979 and one of the first to work with NCRO/CHA Researchers in 1984. She is shown here proudly dressed in her robes as an Anglican church teacher. The hut on the right-hand side is her kitchen which she enlarged to include a special extra room with a bed for delivering babies in the village. She says she no longer delivers babies – unless someone comes to her in an emergency at night.

The duties of the *nyamrerwa* were taught as not so much a list of responsibilities but as a *lifestyle*. When the *nyamrerwa* were assessed by

their supervisors during their training it was their own compounds and daily practices that were first evaluated. This included:

> '...family planning, breastfeeding and child rearing practices in her family. The presence, condition and use of a latrine, rubbish pit, plate rack and appropriate technology devices in the home. The presence of a kitchen garden and other personal development activities in the home. Cleanliness of her compound and whether she had planted trees. The use of maternal and child health services and presence of a clinic card if she had a child under 5 years of age or if she was pregnant. ...(Kaseje et al., 1987b p. 71).

Village reporters working for NCRO/CHA and Community Health workers working for the Ministry of Health under a new Community Health Strategy in 2012 also cited all these things as important ingredients for being a good *nyamrerwa*. In fact, Dr P was heavily involved in the development of the National Community Health Strategy, for which he drew heavily on his Saradidi experience. This new strategy is structured in a very similar way with voluntary community health workers responsible for the census and collecting health indicators of their 100 nearest compounds. Some of these new community health workers in Akinda are, in fact, the original Saradidi *nyamrerwa*.

The research component of Dr P's programme was supported by UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Disease. One of the main research activities was a trial of community-based malaria control. In 1982 anti-malarial drugs were provided in each village in two zones by the *nyamrerwa*, the third zone was a control. Several staff from the Government's Division of Vector Bourne Disease assisted (Spencer et al., 1987a). Another significant activity was an ongoing village census – an early forerunner for the NCROC/CHA Health and Demographic Surveillance System (Spencer et al., 1987d).

For the research components Dr P worked with a former CHA Epidemiological Intelligence Officer who had come from America to work in Kenya with NCRO as a physician, malaria coordinator and lecturer at the Department of Community Medicine, University of Nairobi, where Dr P was also a staff member. For the writing of research papers Dr P was sent on secondment to CHA in America where he was able to use their computers for data analysis.

Other organisations also tried to get in on the research opportunities the structures of the Saradidi programme offered. In an interview I carried out with him, Dr P recounted a story of a scientist from Queen Mary University of London coming to try and set up a project looking at the effect of salt on cholesterol. The researcher had noticed a difference in cholesterol levels between people living in towns and villages and wanted to feed salt tablets to Saradidi members to see the effects. Dr P was understandably against this project and told him he would have to get the approval of the community. The scientist bought and slaughtered a whole cow to tempt the villagers, but Dr P said proudly, they were educated about research and could not be tricked like that. Although they did enjoy the feast.

In the 1990s, with Dr P moving on to further education in Britain and America, wrangles amongst the clan elders, rumors of corruption and issues about the land the clinic was based on led the project to largely collapse, although more batches of *nyamrerwa* continued to be offered training at the Minare centre. Dr P had had a grand plan of turning Saradidi into a community university. But it was not to be and instead he set up his Tropical Institute of Community Health (TICH) in Kisumu. He continues Saradidi in a way though. Students on the community health diplomas courses offered through TICH are regularly sent to Akinda to conduct participatory rural appraisal research projects and work with communities on similar income generating projects and community health initiatives. Whilst I was there, for example, *nyamrerwa*, old and new, were called to participate in a research meeting in Akinda on the meaning of voluntarism run by TICH staff. This

was used to inform thinking about a new National Community Health Strategy which entered Akinda in 2010-201.

Story 3: Scientists – the arrival of CHA

The following narrative of the arrival of medical researchers in Akinda was gained through interviews, focus-groups, and observations. I also looked outside of Akinda to a world of academic databases and libraries. I relied heavily on the reservoir of hundreds of journal publications of the results of medical research endeavours in the area for a more concrete timeline.

In Akinda, I learnt about the slow introduction of NCRO/CHA activity from the perspective of Okello, one of the first Akinda residents to engage with NCRO/CHA scientists. In 2011 I conducted a series of in-depth interviews in his small tea shop in Akinda Bay, and his very smart new compound nearby. Okello was born in 1962 and educated at a local primary school. His father was a middle-class businessman who owned a shop and several lodgings in Akinda Bay.

In 1986 some entomologists arrived in Akinda doing mosquito work and looking for houses to rent. They ended up tenants of Okello's father. These were actually DVBD government men, the same ones who were also then on secondment to help with malaria research at the Saradidi rural development project a few miles down the road. Now some of them were also seconded to CHA. James Sande, one of the men attached to CHA described how this was the first time they were given per diems:

> "Then came that this hotel thing so that if we go for safari there is no need of going with a tent. We got one at 40 bob. I managed to stay in the hotel for ten years from eighty to ninety. Just staying in the hotel!"
>
> From interview transcript with James Sande, courtesy of Wenzel Geissler.

In my interviews, Okello described how he got a chance for employment when he heard about the research through his father's DVBD tenants:

> "Some of the DVBD guys said "oh Okello, there is a research that will be going on here. We need to hire some boys to help us." At that time, I was still very young: about 20. They had a land-rover, those days they used the land-rovers. Our work was to collect mosquitoes of the houses. Some mats were put on top of where the beds were, so after biting at night, during the daytime the mosquitoes rest on the mats. We went with the aspirator, sucking tube, to collect them. There was no office, so we met under a tree to give the samples."

Okello was paid 25 KES a day and worked 6 days in a month. A kilo of sugar at the time was about 14 KES so this was a substantial amount. The work was for a research study collecting mosquitoes from resting specimens to evaluate a DNA probe for identifying species (Collins FH, 1988). The research at this time only covered 4 villages, later extending to another 4, all in East Akinda. Okello remembers than when they started many people did not consider that mosquitoes could transmit malaria. They believed malaria was got from walking in the rain, so the research activity was very strange to people:

> "In one house the owner was very poor, he could not even afford a sleeping mat. At night he would sleep on our collecting mat. Dr Frank was very furious and started quarrelling. The man said it was raining and the mat had been causing the roof to leak. Dr Frank went outside and checked and said it was never raining. But Sexton, another colleague from America, told him 'let us not quarrel, he can refuse to let us in the house'."

Okello and his young colleagues were given a warm reception by their fellow villagers:

"...because we weren't drinking, we were very young, we were very polite."

At this time the research was not yet associated with CHA in the minds of Akinda residents. The research team were locally nicknamed '*JoMinare*' (People of Minare) after one of the satellite centres of the Saradidi project. This was partly because the DVBD men working on the research were also working for Saradidi and also because when NCRO/CHA started a cohort study looking at development of natural immunity to malaria in infants in the early 1990s they used the Saradidi *nyamrerwa* to help them.

Throughout the 1980s small-scale research, like a 4-month trial of treated nets in 2 villages around Akinda Bay, continued to be carried out in East Akinda. But in 1992 a larger research study was initiated, the Akinda Bay Cohort Study (McElroy PD, 2001). For more than two years pregnant women and their other children were followed through pregnancy and the first two years of birth in 15 villages. Two village monitors per village were appointed to collect data. But Okello remembers having problems locating the mothers when going to the villages. He described how:

"people coming here to do research from outside [i.e. America] did not know the way people living here know each other. There was this mzungu [white man] with a form written that this compound is north-west, south-west from this particular school. In this end we told him this was rubbish, just ask these women, these *nyamrerwa* know every pregnant woman!"

The Saradidi *nyamrerwa* really did know every compound, having already mapped them and written the numbers on their doors for their local community health programme. They knew every pregnant woman through their tracking of births and antenatal visits and because they also delivered many of the babies. Okello went to the Saradidi centre to request their

contact details and the first 15 NCRO/CHA *nyamrerwa* were recruited. Layla, pictured earlier, was one of them.

The Saradidi activities were winding down around this time and the *nyamrerwa* who had been volunteering since the beginning were very glad of the paid work. The *nyamrerwa* were to conduct a monthly census of births and attend the births of the women in the study (most of which they would have attended anyway in their other capacities). They collected blood smears, cord blood samples and placenta smears. Participants in the cohort study were a little more suspicious of the research than earlier studies, especially around the issue of blood taking. People were used to having malaria diagnosed symptomatically and did not see how it could be diagnosed through blood. They wondered what it was for and whether it was being sold. A group of elders were taken for the first time to the NCRO/CHA research field station near Kisumu City and taken on a tour of the laboratories to quell fears.

The relationship between rumour and medical research, especially in relation to blood-taking, has been much discussed within anthropological literature with compelling arguments made that rumours are less about misinformation and more about relationships of power and inequality (Fairhead et al., 2006b, Geissler and Pool, 2006b, Kingori et al., 2010, Stadler and Saethre, 2010). In Akinda rumours about the true motivations of medical research have periodically emerged, never strongly enough to threaten its continuation. One rumour that occurred during my ethnographic fieldwork is discussed in a fictionalised story presented in Chapter 6.

Around 1994 the issue of HIV was becoming more prominent. Okello felt that it was there before the 1990s, but it was not something that could be talked about in the context of research. But in 1994 it was being talked about in NCRO/CHA. There was a new CHA director who was asking "don't you think we can do something about HIV?" And already a few participants had requested testing.

This region of Western Kenya was particularly affected by the AIDS crisis. Akinda faced possibly the highest prevalence in the country, particularly for young men. In 2003-4 when a prevalence study was conducted in Akinda, rates among young men aged 23-34 were over 40%. In 2010-11 I found that Akinda residents would discuss HIV/AIDS relatively freely, mostly due to a large-scale home-based testing and counselling programme that had been recently introduced by NCRO/CHA. It was generally agreed that this programme had massively reduced stigma in the area. However, as I will show in Chapter 7 the experience of the AIDS crisis has had a lasting impact on how people understand life-time and death in this region.

In response to the CHA director's concerns about HIV, in 1996 an AIDS Resource Centre, kept physically separate from the research, was set up by NCRO/CHA. Some of the NCRO/CHA village monitors were trained in community education and testing, although no treatment was available at this time. It is likely that Akinda was ahead in this regard compared to surrounding areas. Geissler and Prince, who conducted ethnographic research in a village outside of the NCRO/CHA catchment in the same region in the mid-90s found that the word could not be mentioned in Ministry of Health circles and that it was not possible or allowed to do research on the topic (Geissler and Prince, 2010). In Akinda CHA completely changed this over the next decade.

The Akinda HIV resource centre was an early forbearer of the HIV Patient Care and Treatment Centres that CHA, through the Global AIDS programme with funding from the President's Emergency Plan for AIDS Relief, started setting up in the region in 2004. One of the first Akinda mosquito-catchers worked his way up slowly, financing undergraduate and master's studies through his employment, and became the eventual head of the NCRO/CHA HIV home-based testing and counselling programme operating across the area today.

But the biggest piece of research, and one that is still today the most synonymous with research in Akinda, was a massive trial of treated bed-nets, with a follow-up study looking at the effects of long-term exposure to the nets. It ended up encompassing the whole of Akinda population of 60,000 people as well as neighbouring locations (Phillips-Howard PA, 2003). Running from 1996 – 2002, for the first time *JoAkinda* were involved in NCRO/CHA research at all kinds of levels. The original village monitors from the cohort study were promoted as sector leaders and new monitors were sought in the new villages.

Nyamrerwa for the new research areas were recruited, many of whom were the original Saradidi *nyamrerwas*. There was a plethora of sub-studies attached to the project involving local schools. Residents were also temporarily employed to run spot checks in their areas at night to see if people were using the nets. Chiefs and community leaders were extensively consulted, drawing competitions were held in schools and every compound was given a calendar displaying the best drawings. Over 600 local staff were employed, and sector offices sprung up all over Akinda. One of the senior British staff members on the project I interviewed described the hard work involved in setting up the project: 'a lot of mud on the boots. I had pioneer blood' and the feeling of addressing thousands of people at the launch of the project: 'I felt a bit like a queen!'

The census taken for this project developed into a full Health and Demographic Surveillance System (HDSS) which is on-going to this day. The HDSS covers 217 villages in total (representing in 2002 134,990 people). 77 of these villages are in Akinda (representing 65,000 people). HDSS Community Interviewers on bicycles, aided by the villager reporters/*nyamrerwa* who keep track of births and quickly report deaths so that verbal autopsies can be done, routinely go house to house recording morbidity, mortality, fertility, migration, use of health facilities and malaria transmission. Quality Control and Assurance officers on motorbikes check their work and data is uploaded every night to the NCRO/CHA field station

in Kisumu City and to the CHA HQ in the USA. Data can also be directly downloaded in the field from the individual handheld computers instantly connecting rural Akinda to the CHA HQ across the world. In 2010 fingerprint readers were introduced, upping the visible display of high technology.

The HDSS is designed as a platform to aid and evaluate other public health research and interventions and more and more research projects have been set up using this platform. A massive programme of home-based HIV testing and counselling began in 2007, data from which has been combined with the fingerprinting to re-identify HIV+ patients.

In 2004 Kenya's International Emerging Infections Programme (IEIP) was introduced, working through several HDSS sites and surveillance was stepped up in a subset of villages, whose residents were now visited every two weeks and interviewed about their recent health. As part of this programme residents are entitled to free treatment for infectious diseases at the Loch Mission hospital where hospital surveillance and samples are linked to the household data. Participants visiting the hospital during day-time hours are seen by NCRO/CHA clinical staff working alongside the mission employees. This has created an IEIP zone in the 5km around the hospital, an area of extra intensive research. This is the area in which I lived.

The IEIP study employs 40 *nyamrerwa,* or village reporters, paid on a daily rate basis, to aid with community mobilisation, the introduction and recruitment to new IEIP related projects and to conduct pregnancy tests on all women in the area for an ongoing malaria in pregnancy study. Another additional 40 animal village reporters are employed on a similarly casual basis to report on abortions of cattle using smart phone technology for a Zoonosis project that, using the IEIP data, tries to link infectious outbreaks in the animal population to the human. Both the IEIP staff and the HDSS staff work out of offices based in Ka'Kwodi, the nutritional centre formerly owned by the Catholic mission and now run by the Ministry of Gender, Children and Social Development.

Figure 29: IEIP village reporters checking forms outside the Loch field office 2011. Source: Gemma Aellah.

The majority of the *nyamrerwa* working in the IEIP zone are Saradidi trained, either in the original cohort or in the later groups. They do not necessarily consider their work now as qualitatively different from their work before. I was particularly struck by this when I listened more closely to the lyrics of a song they sang for a group of overseas visitors. They had merely swapped a few of the lyrics of their original song for Dr P, which in itself may not have been so original. It shared similar patterning to the church praise songs I often heard in other contexts. I wonder, but could not ascertain for sure, if it was an echo of an older praise song, perhaps sung for the colonial or later missionaries.

NCRO/CHA song 2011 (30 years later after the song for Dr P*)*
Hawi malich nga wan JoAkinda
Ma Wayudo ka oa e polo (x2)
Wakuongo wayude kuom joka NCRO ma oseriwo
Akinda te (x2)

Kendo wayudo kuom joka CHA ma oseriwo Akinda te

(x2)

Ere research makama?

Ere research makama, sieme research ma dipiem kode

(x2)

West Akinda, East Akinda ka achiel kod Central gi

South

Wakwanun gueth madongo ma nyasae omiyowa

CHA osebdo maoikore chutho ma kelo kony

Kendo osetiego nyamweche duto mar geng's tuo

Oseko kelo dungruok e Akinda te

Oseko Sionotic yath ma thiedho dhok

Ochako kelo yath ma zinc ma thiedho diep.

NCRO/CHA song 2011 (31 years later after the song for Dr P.)

We have got blessings from heaven, we Akinda people

We first found it from NCRO which united the whole of Akinda

We also found it from CHA that united Akinda

Where is a research like this?

Tell me a research that can compete with this.

East Akinda, West Akinda, together with Central and South Akinda

Let us count the many blessings God has given us

CHA has been ready to bring help

It has also taught the nyamweche to prevent diseases

It has brought development in Akinda

It has brought Zoonotic medication for treating cows

It has also brought zinc that treats diarrhoea

Beyond the heroic figure of Dr P, in Akinda more widely, the memories of beginnings are held in the biographies of individuals and families who have

worked for, and participated, in intervention and research projects over the years. The most obvious is in the figure of the *nyamrerwa* many of whom worked for both the Saradidi rural health programme and later multiple NCRO/CHA projects. In my host's compound in Akinda, for example, the widowed head of the compound, Mama Unita, had been an original Saradidi trained *nyamrerwa*. When NCRO/CHA arrived in Akinda she continued her work as a village reporter, also locally known as *nyamrerwa*. One of her sons had worked as community interviewer on the HDSS and worked his way up to manage a research project in one of NCRO/CHA's other rural research sites. Mama Unita's widowed daughter-in-law was part of a team that occasionally providing catering for NCRO/CHA events. She became a volunteer community health worker – known as the next generation of *nyamwrera* - in 2010 under the new National Community Health Strategy, whose development drew inspiration from the original Saradidi community health programme. Another of Mama Unita's daughters-in-law ran a popular second-hand clothes stall, selling football shirts to the NCRO/CHA community interviewers who cycled past her stall on their way to the villages every-day. She also worked as animal health village reporter (or 'animal nyamrerwa', tracking births and deaths of cattle for a NCRO/CHA Zoonosis project. One of Mama Unita's sons, who was made redundant from his job as a caterer with a nearby NGO, sought temporary cash as mosquito-catcher for a malaria project. All members of the compound were enrolled in both the HDSS and IEIP programmes and received free treatment for infectious diseases at the mission hospital.

Mama Unita's family was particularly engaged in research because of Mama Unita's standing as one of the most respected *nyamrerwa*, but it was not at all unusual to find compounds in Akinda where family members had similar multiple connections to research over the years.

NCRO-CHA – a temporary-permanent common-law marriage

Over the years, the collaboration between NCRO and CHA has crystallized into a recognised feature of the landscape in Western Kenya. As more studies have been added, NCRO/CHA's 'base' on the outskirts of Kisumu City has developed into a large modern field station with central laboratories, Human Resource infrastructure and a transport service shuttling staff and samples back and forth between the city and rural Akinda. In additional to the two key collaborators, NCRO and CHA, the NCRO/CHA Research and Public Health Collaboration (as it is now known) works with a number of other organisations within Kenya and overseas, including the Kenyan Ministry of Health, the US Department of Defense, the Wellcome Trust, the World Health Organization, and the Gates Foundation. They work not just in the Akinda area but also other areas such as Kisumu City, and several other rural districts.

The importance of US domestic concerns in the NCRO/CHA research agenda is still crucial. All research conducted by CHA must, in some way, reflect US domestic concerns (according to a CHA technical advisor I interviewed). Sometimes this is not immediately obvious, and leaves a lot of room for maneuver to negotiate explicitly Kenyan concerns; for example the Kisumu Breastfeeding Study directly spoke to the needs of HIV+ women in developing countries to continue breastfeeding without infecting their babies, which is not so relevant to the US where formula feeding is the default for HIV+ women. But the study also provided evidence on the safety and effects of taking triple ART during pregnancy, highly applicable in the US.

The configuration of transnational medical research as a continuing agreement between a US Central Health Agency and a Kenyan parastatal research organisation rather than directly with the Kenyan Ministry of Health is typical of the way research tends to operate throughout the African continent today. According to the latest available figures, global medical research expenditures across the world by public and industry sources

originating in the United States, Europe, Asia, Canada, and Australia stood at $265.0 billion in 2011 (Moses et al., 2015). However, the landscape of the flows of resources related to medical research have been described as crystallising into an 'archipelago of a few high-powered and well-resourced islands of global science' (Geissler, 2013a), rather than dissipated throughout, and integrated into, national Ministries of Health and national universities. The 'islands' Geissler refers to are a handful of large field-stations with accompanying field-sites, mostly associated with parastatal government bodies, and existing in and through a convergence of collaborative agreements between overseas and local partners, such as the NCRO/CHA headquarters in Kisumu City. These 'islands' – especially in the case of NCRO/CHA with its large buildings, tended grass and air-conditioned corridors – appear, visually, as solid monoliths of modernity and of progress and permanence. But their foundations are fragile and contingent.

Geissler and others have shown how these 'islands' have evolved as a result of two inversely related changes – on one hand the increasing standards, technologies and possibilities of global science (think of the skills and resources required to continually transmit and transform the mass of health and demographic data garnered from Akinda residents into useable statistics; the networks and knowledge encapsulated in the 'diminutive vial' of vaccine to be injected into a chubby baby's thigh). The effort – and financial turnover – is immense, and the high standards set in place by the globalisation of health research means it must be protected if it is to become meaningful. On the other hand, economic and political crises since the late 1970s (privatisation, structural adjustment, compounded, in Kenya at least, by the AIDS crisis of the 1990s overwhelming national health services) have made it difficult for these standards to be achieved in local, national universities and laboratories without outside, overseas partners (Geissler, 2013a, Geissler, 2015, Ombongi, 2011). The handful of high technology islands, like NCRO/CHA, stand in contrast to other, abandoned, decaying and atrophying national centres of science across the continent (Geissler et al., 2016, Lachenal et al., 2016).

NCRO/CHA had, at its heyday in 2011 when much of the research for this thesis was conducted, around 1200 staff across its urban and rural sites administered from a human resource department based within its main city headquarters. Several more thousands were affiliated in some way, providing direct and indirect auxiliary services (transport, food, housing for staff), or sitting on community advisory boards, not to mention participating in research and intervention programmes. It was the largest employer in a region marked by little other major industry. In the surrounding rural areas like Akinda, the economic mainstay was subsistence farming. Previously a calm but important trading post, the region's capital city, Kisumu City, had entered a period of decline in the 1980s/1990s with reduction of growth in key industries like fish/cotton processing and breweries. Economic recovery has taken the form of an economy fuelled by HIV (Prince, 2012, Prince, 2013a, b). As I show in Chapter 6, 'being with' NCRO/CHA as research staff, research participant or provider of auxiliary services was, therefore, a highly sought after means of survival in precarious socio-economic conditions.

In the city, and especially in Akinda as a rural field-site, the acronym NCRO/CHA was understood as a proper noun. People in 'the community' were not able to specify its components, here glossed as National Clinical Research Organisation (NCRO) and Central Health Agency (CHA). But the acronym – and its forward slash - encapsulated something important: its existence as an agreement rather than an institution (See also (Brown, 2015) for a discussion of similar partnership configurations in relation to HIV care and treatment programmes). A visiting technical advisor from CHA tried to sum up for me the slippery nature of the temporary arrangement that birthed the seemingly permanent field station:

> "From the employee's point of view, they keep on talking
> about NCRO/CHA: "I work for NCRO/CHA" people say. But
> there is no such thing as NCRO/CHA. That is an illusion.
> There's no... well, my way of describing this to myself is that
> it is a common-law marriage. Now a common-law marriage

is a real thing. But there is no piece of paper that you can wave at us and say here this outlines the nature of this relationship and here are the terms and conditions under which it operates. A cooperative agreement is not a partnership. It is me giving you money and saying go and down and do what you are in the business of doing and by the way we are going to be looking over your shoulder very closely to check you are doing it the way you should be doing it. That's all we have with NCRO. But in fact, we are in their house with them, eating their meals with them, in some cases supervising their people. Which should we be doing? The US government is not responsible for the public health of Kenya. But we have a strong interest in making sure our investments are used wisely."

The same technical advisor went further to explain how part of the fuzziness of the existence of NCRO/CHA as an entity was also related to the linking of research and intervention, especially in relation to HIV care and treatment where, at the time, some of the public provision of services to people living with HIV was delivered under a programme attached to, and evaluated by, the field-station.

"This may be overstating it…. but say we are going to go study something, we have to create that something to study. The best example is HIV counselling and testing. We have the research in Demographic Health and Surveillance sites on the effect of all these things, but we also have teams of all these people who are actually doing the counselling and testing. Because we are really good at it…."

Another part of the fuzziness comes from the way, globally, in which priorities are set and research activities chosen.

There is no doubt that one of the central motivations of both the CHA and NCRO senior scientists and policy makers is scientific development and improved public (global and local) health. But it also cannot be denied that a market-like forces dictate activities to a large degree. The continued existence of NCRO/CHA as both proper noun and collaborative agreement rests on the abilities of its personnel to attract funding, or in company-speak to keep attracting new business, as well as cultivating existing relationships. Medical research itself is, naturally, periodic. Ideas are developed – sometimes in response to local disease needs, or donor country's disease needs; sometimes in response to other research results, or fashions, or a donor country's current political priorities, or philanthropic passions, and pitched. Funded, if obtained, is finite and specifically targeted to the needs of the particular research project. 'Core funds' are hard to come by. So, staff numbers and configurations of expertise, research clinics, vehicles, supplies etc. periodically expand and contract according to the precise needs of the projects that garner funding. But, equally, the ability of the field-station to attract projects in the first-place rests on its existence in a state of readiness, to be quickly mobilised as a space that can generate high quality research. And for this a core and history of staff, resources and expertise is needed. They need to be, in the words of the technical advisor already 'really good at it.'

In this configuration, the transnational medical research organisation exists in a state of permanent temporariness that permeates all layers of activity – from the contractual arrangements made with staff (kept on one year renewable contracts to try to find a balance between avoiding guarantees of permeance, and assisting staff, who are after all represent the Kenyan middle class, obtain the trappings of that class status such as mortgages and loans), to the ability of research projects to intervene in or impact on the landscape of health service delivery in lasting ways. The next chapter describes this in more detail.

However, though it might feel like something alien invading and potentially transforming a timeless African village from a certain perspective and exists as perpetually temporary, as this chapter has shown, in fact the shapes research has taken are (also) constituted from 'the ground' up. And, for many residents, it is one among many things: part of their multiple histories, and part of their multiple lives. In the final section of this chapter, I will further render this visible by examining the traces of these overlapping histories, relationships, and experiences within the physical spaces of one Akinda dispensary.

Histories embedded in buildings

A city research clinic: more of an isolated enclave

The way in which transnational medical research has become part of the landscape is quite different in Kisumu City as compared to rural Akinda. As described in the Methods chapter, the first part of my ethnographic fieldwork in the region centred on NCRO/CHA's HIV Research Clinic. This was a satellite clinic of the main NCRO/CHA headquarters which had a campus in a large compound on the outskirts of the city. The town clinic was purpose built and located inside the compound of the provincial hospital, inside its own dedicated walled compound. The research clinic compound was permanently guarded by a security firm and visitors had to sign in and wear badges. Research was the only activity occurring inside the compound. The compound contained both offices and two clinic spaces. Research participants, once signed in at the reception, waited on benches outside the clinics. It was a protected, exceptional and specialist space. Most Kenyan researchers, myself included, travelled into work along the highway on buses from an estate popular with science and NGO workers. This was not the most affluent estate in the city. Most houses were not on main water and had to buy water daily from vendors. But security was relatively good, and it was an aspirational estate. In comparison, most research participants travelled in by foot from the other direction, from the slummier areas of the city.

A rural space for health: sedimentary histories

In comparison, in Akinda, research found its way into the landscape in little nooks and crannies, layering itself on top of, and con-current with other histories of health and intervention. One of the best examples of this was found in an Akinda dispensary that I was taken to in 2011. Below I will take you through a walking tour of this space that brings together and embodies several of the stories described above.

I was invited to visit this dispensary, in a part of South Akinda quite far from my home and outside of the intensive IEIP research village zone (100 shillings by motorbike), after a chance meeting with Dom Willis at the home of one of the older IEIP village reporters nicknamed 'Pastor.' Dom and his wife, also a NCRO/CHA village reporter and an ex-Saradidi *nyamrerwa*, were somehow related to Pastor and Dom had come to visit another relative staying at Pastor's home. I was there early in the morning, planning to accompany Pastor on one of her pregnancy testing rounds of the village and we had a very smart breakfast together. Over tea, fruit, boiled eggs and shop-bought mandazi in my honour, I told Dom about my research. Dom was a very dapper man, I guessed in his 60s, dressed in a suit with a small briefcase. He told me that he had actually been the secretary of the Saradidi Rural Health Programme in the early 1990s and that they had brought some good development to his local dispensary in Nyagoko. We arranged to meet there in a few days.

I arrived a little before Dom Willis at the dispensary which was hidden from the road by greenery and a long drive cleared of bushes. It was not what I was expecting – the compound was large and it seemed to have several sections of buildings which looked like they had been constructed at different times. Dom arrived, gliding into the compound on his bicycle and proceeded to walk me around the buildings, explaining the history as we went. He first showed me the smallest building, with a rusty roof and two rooms accessed each by a separate door. We peeked inside and found, to my surprise, Kevin one of the

young local men working as a human landing catcher for a current NCRO/CHA malaria research project. He and his team had been up all night in one of their homes in a nearby village catching mosquitos off their bare legs by sucking them up through plastic tubes, drinking hot coffee provided by the project to try to stay awake. He had come to the dispensary to drop off their catches which would be later taken back to the temporary laboratory set up at Loch Nutritional Centre for analysis. Dom Willis recognised him; his mother was one of the original Saradidi-trained *nyamrerwa*. We also found Kenneth, a clinical officer working as a researcher for the NCRO/CHA Malaria and Entomology branch, as well as a young mother with her child both of whom were being tested for malaria by the researchers. Kenneth told me that NCRO/CHA had temporarily taken over the building as a South Akinda field office for both the Human Landing Catcher study and another study looking at the effectiveness of putting insecticide-treated wall linings in homes in the area.

Figure 30: The first building of Nyakogo Dispensary, originally constructed in the mid-1960s. In 2011 this building hosted researchers working with the NCRO/CHA Entomology/Malaria branches. Source: Gemma Aellah

Dom and I rested on a bench outside this building whilst he told me about its' original use and construction. Nyakogo dispensary, he explained, was started

in the early 1960s by 'the elders, the old men and women of the community. At the time the only places for medical treatment in the whole of the District were three hospitals, all unmanageable distances from Nyagoko. There were 'no roads and no means' (of transport). So, according to Dom, 'if the local (traditional) *nyamrerwa* could not help you, the only result was death.' So, in the spirit of *harambee* (pulling together) that was gripping the nation in the early years after independence, the Nyagoko community pulled together to take action. The Harambee movement, which the first Kenyan president, Jomo Kenyatta described as expressing 'the mood we want to create' after achieving independence and self-government in 1963 was a call for self-help, for coming together to build roads, water pipelines, schools and dispensaries. More than 2,500 facilities were constructed in the first 2 years after independence. (Ogot and Ochieng 1995 p.137).

Dom Willis was in primary school when the Nyagoko community started their harambee project and his mother was one of the project treasurers. He remembered so many 'well-wishers' getting involved; brothers and sisters working in towns brought money, villagers brought goats and sheep that could be sold and three churches –Hera, Catholic and Anglican – held fundraisings in their masses. Elders of the clan decided which piece of land would be donated for the dispensary and the first building was constructed.

As with most *haramabee* projects, the villagers built the building and then hoped and prayed that the government would recognise their initiative and bring them drugs and staff. For the first decade or so the dispensary was only staffed by villagers with some degree of medical background who had retired from government service. At the beginning they regularly collected money from harambees and travelled to Kisumu City to buy drugs from the city chemists to stock the dispensary. After some time the government took over the drug supply because, again according to Dom, 'they saw people were serious so they helped them.' Later a Ministry of Health Clinical Officer was brought to run the dispensary. *Harambee*, as a tool of both individual development (usually for school fees) and community development (for the

construction of bigger churches, orphan programmes, youth business enterprises etc…) is still omnipresent in Akinda, and Kenya more generally:

> 'The concept retains, almost three decades after independence, a very powerful appeal as a mobilizational force among all social classes in Kenya' (Ogot and Ochieng 1995 p. 138).

As does the idea that if a start, even symbolic, is made – a foundation stone is laid, land is ear-marked, uniforms are bought – help will follow, usually from international donors though, rather than the government. In fact, on later reflection about the composition of this specific dispensary it occurred to me that a missing element was an inscribed foundation stone for the next project, objects I sometimes observed in other community spaces across Akinda.

Dom then pointed out a large, decrepit looking concrete water-tank connected to the ramshackle guttering running the length of the building's roof. This, he told me was built by an NGO called Africa Now, although how they got interested in Nyagoko was a little complicated. In 1979 the Saradidi Rural Health Programme came to Akinda. The Centre itself was in Saradidi and was created in much the same way as Akinda, through donated land and harambee. Saradidi was a fair distance from Nyagoko but several women from the villages surrounding Nyagoko were trained as community health workers and birth attendants and in the 1980s a village project management committee had been set up, which Dom Willis joined as first as local treasurer in 1990, quickly becoming treasurer of all of West Akinda. Saradidi provided some 'small small help' for the community through providing chairs for the dispensary so people could hold meetings there. Then through connections with the Saradidi Project, in 1990 Africa Now, who had an office in Kisumu, constructed a large concrete water tank in the grounds of the dispensary.

Figure 31: The now defunct water tank built by UK NGO Africa Now in 1990. Source: Gemma Aellah.

Next stop on our tour was a more elaborate, newer looking building next door to the original dispensary. This building had a veranda full of waiting patients and posters on the walls. This building, Dom, explained actually came about because of a 'crisis' in the Saradidi programme. In 1993 the Saradidi programme Director Dr P said, according to Dom, 'this (meaning the centre at Saradidi) is not Saradidi. Saradidi is at your village. Go back to where Saradidi is.' Dom felt that very few people understood this statement. They felt they were being abandoned:

> "many people took it as if Dr P was sending people away
> from Saradidi. But me, I supported him. Saradidi had
> trained farmers, trained vets, trained social workers in the
> villages. Now he wanted to bring the services nearer to poor
> people and leave the centre for research.' So Dom, together
> with some of his committee members decided to visit the
> Chairman of the West Akinda Saradidi committee who also
> happened to be the brother of a former MP. 'We asked him,
> how do we start? But he said, "I don't know where to start

because we were sent away from Saradidi." So I decided we should visit Simba, which then was the District Headquarters so we can see how to connect with NGOs and get some development."'

Dom went to Simba with two other delegates and met with the District Commissioner who told him about a programme called IFAD – the International Fund for Agricultural Development. This was a UN agency established in 1977 as a result of the 1974 World Food Conference in response to a series of African food crises in the 1970s (www.ifad.org) . The District Commissioner explained that IFAD was working across several ministries and that there was funding available from some donors in Belgium.

Dom was introduced to Odech the programme officer and told him all about Saradidi, especially about how they had trained community health workers in the villages. It just so happened that Nyagoko was one of the dispensaries that they had been thinking about developing further and Dom arranged a visit. On the day Odech came to the dispensary, the local *nyamweche* met him on the road 'singing, dancing, doing all those things. They ate, they drank soda. We showed them the small building. We discussed. They understood and they took over development.' So, in the mid-1990s a new, bigger building for seeing patients, housing for the dispensary in-charge and latrines were constructed using IFAD funds. The government again responded to this improvement and added staff and medicine. So, as Dom says the dispensary was now 'government, international donors and the community.'

Figure 32: The building constructed through IFAD funds in the mid-1990s. The staff house can just be seen behind the tree in the background on the right-hand side. Source: Gemma Aellah.

Figure 33: A second water tank funded by IFAD in the 1990s. Both quickly fell into disrepair and are no longer in use. Source: Gemma Aellah.

We entered one of the rooms of the building and found the dispensary In-Charge Clinical Officer and several more NCRO/CHA staff, this time they

were nurses working on an Infant Diarrhoea study. In this study participants were told to come to the dispensary with any signs of infant diarrhoea. Because many patients were participating in the study, and the nurses were stationed there full-time, for the duration of the study they had taken over all paediatric treatment in the dispensary, freeing up the In-Charge's time to deal with adult patients. Some of the posters on the walls advertised other current NCRO/CHA projects, such as the *'Sir Jaodi'* (Support your Spouse) HIV Discordant Couple Study which recruited couples from HIV testing centres and a Pneumonia Vaccine project. This was a joint Ministry of Health and NCRO/CHA initiative. Country-wide the vaccine was offered to all children under the age of 1 year. In Akinda, a NCRO/CHA research area, the age-limit was extended to 5 years. The Ministry of Health and NCRO/CHA *nyamrerwa* were encouraging mothers to vaccinate their children by walking around villages inviting them to the clinics. Ministry of Health staff were vaccinating the children and NCRO/CHA staff were monitoring the effects of the age extension on overall pneumonia levels.

Figure 34: Posters advertising NCRO/CHA studies in the area. Source: Gemma Aellah.

The next stop on our tour was a large building behind the others which looked only partly finished. The concrete walls were unpainted, and piles of

bricks were dotted around. Yet Dom showed me a plaque attached to one of the walls showing it had been opened by the area MP in 2009. Dom told me, rather grandly, that this was the Maternity Hospital.

Figure 35: The unfinished Maternity hospital. Source: Gemma Aellah.

Figure 36: Opened three years previously and supposedly 'fully funded' by the Constituency Development Fund. Source: Gemma Aellah.

This Maternity Hospital was funded through the Constituency Development Fund (CDF), a devolved government fund set up in 2003 pledging that at

least 2.5% of government revenue would be channelled directly to the country's 200+ constituencies. Spending would be decided by local constituency CDF committees made up of the area MP and various community representatives. Between 2003 and 2012 the fund accounted for spending of 106,906,102,6511 KES (www.cdf.go.ke). In this constituency the fund was spent on, among other things the construction/extension of health facilities, covering school fees for orphaned children, the renovation of school classrooms and the mango processing industry.

In August 2009 the Nyakogo Maternity Hospital was opened by the MP. In August 2011 when I visited it with Dom it looked very much like it was still under construction. We entered a large hall full of plastic chairs where a HIV patient support group was holding a meeting and then walked through into the labour room. The whole place was dusty, plastered but not painted. The small labour room had a proper hospital bed in it, but the bed and the floor were covered with boxes of supplies and crowded with empty wheelbarrows. One of the support group members, Elizabeth, came over to us and introduced herself. She assured me that the hospital was indeed open, although no Ministry of Health staff as such had been allocated to work there. She, herself, was a Community Health Worker working voluntarily with the Ministry and she knew how to deliver babies which she said she had been doing since 1989 as a *nyamrerwa*. Only last week two women had given birth in the labour room (I could not work out where) and had now come for their first antenatal clinic visit in the main dispensary. I was pregnant at the time and she tried to demonstrate her skills by offering to check the position of the babies.

The state of this CDF-funded building was not too much of a surprise. CDF has not always had the best reputation, not just for corruption and nepotistic allocation of funds (especially school fees) but also for difficulties with strategic planning and long-term vision (see TISA report 2009). A second dispensary in Akinda also had a CDF funded maternity hospital. Completed in 2007, when I visited it in 2009 it had yet to see its' first birth. The building

was complete. But staff, furniture and supplies were absent. When I asked about this, one of the dispensary's health committee members muttered something about the MP wanting to make a statement before the December 2007 election and then 'forgetting' about the project.

The final building on our tour was entirely different. Compared to the brick, plaster and iron sheet roofs of the other buildings, this one comprised of two shipping containers. Placed opposite each other with a sturdily covered and paved reception area in-between, the containers had been adapted to resemble a series of treatment rooms. The whole construction was light and freshly painted. This, Dom told me was the PSC, or Patient Support Centre for people with HIV/AIDS. Three women were seated at a desk and benches in the reception area. They introduced themselves as Roseline, Janet and Mary and they were all peer educators with the PSC. Peer educators are a strong feature of much HIV Care and Treatment in Kenya. PSC Patients themselves, and often for a small amount of compensation, they not only educate and encourage other patients but also help with the running of the clinic, registering patients, doing simple tasks like weighing and taking blood pressure and tracing defaulters. This PSC had three peer educators who received a monthly monetary allowance and three peer volunteers who did not. There was one nurse in charge of the PSC, plus an additional nurse. The NCRO/CHA Clinical Officer I had met in the first building was sometimes called upon to test PSC patients presenting with severe malaria.

The women told me that the Nyagoko dispensary PSC had opened in 2009 with the drugs and staff provided through NCRO/CHA's Global AIDS programme (GAP) which received its' money from the US President's Emergency Plan for AIDS Relief Fund (PEPFAR). GAP had brought and set up the containers in 2011, but three months ago management of the PSC had changed over to ICAP, a programme from Columbia University's School of Public Health in collaboration with Indiana University (www.columbia-icap.org).

Looking in one of the treatment rooms I came across Fredrick who was a new Ministry of Health Community Extension Officer covering the Nyagoko and Akom Community Units. This position had been created under the new National Community Health Strategy, introduced into Akinda in 2010, and he was responsible for a number of new Community Health Worker volunteers who were to collect basic demographic and health indicator (number of births, latrines, mothers' attending antenatal care etc.) information from their villages.

Fred had done a diploma at TICH, the Tropical Institute of Community Health set up by Dr P of Saradidi fame, and the new Community Health Strategy was based, to a large degree, on Dr P's early Saradidi model. Fred did not have an office of his own yet so often borrowed one the PSC treatment rooms to collate his data and used the unopened maternity hospital for meetings with his volunteer community health workers.

Figure 37: The PEPFAR funded HIV Patient Support Centre Containers. Gemma Aellah

Dom and I started walking back to his home. On the way we tried to collate how many different agencies and types of people had been involved in constructing Nyagoko Dispensary, which functioned as a whole but was

223

really a contraption of aims and ideas from different time periods: *nyamrerwa*, harambee and community spirit, richer brothers and sisters and church members raising money, retired medical personnel volunteering their time, the Ministry of Health, the UN and international donors, the Saradidi project, transnational medical researchers, PEPFAR and peer educators, devolved government funding and CDF and, finally, the government's new Community Health Strategy and volunteer Community Health workers. We surmised that a common theme in the dispensary's history had been the involvement of the community as volunteers. Dom himself and his family had been involved in this from the beginning. These volunteers were, in fact, the thread that had kept the dispensary going through all its' incarnations and, Dom suggested, would be what remained after international donors like PEPFAR and CHA left or the Ministry of Health 'lost interest'.

As we were walking and talking a white Land-Rover slowed down to offer us a lift. It was a NCRO/CHA entomologist who had, by co-incidence, been heading to Dom's home. Dom, it transpired, was taking part in a small research study looking at light traps for mosquitoes. He had been sleeping outside for a few nights next to a light trap which now was to be moved inside for comparison. Once again, I wondered as I often did in Akinda, how many times in a day I would encounter biomedical research.

Figure 38: Setting a light trap in Dom's home. Source: Gemma Aellah.

Conclusions: The dispensary as entangled

Nyagoko dispensary could be thought of as a form of global assemblage, constructed by different actors, from different places connecting Nyagoko to overseas places and international agencies, as well as linking them to the national government. The collection of buildings are, perhaps a form of 'affective infrastructure' (Street, 2012) that could highlight inequalities through differences between levels of care as enacted in the buildings – for example in the contrast between the orderly, organised HIV treatment centre housed within a preformatted modernised shipping container, and the disorderly neglected space of the unfinished maternity 'hospital' (See also Berlant, 2016, Knox, 2017). The dispensary as a place in some sense does allow patients to 'travel' while staying still; to be within the field of transnational research and intervention one moment, to be in the domains of national health care or informal local *nyamrerwa* care the next, as has been

225

demonstrated in other post-colonial hospital spaces (Street, 2012, Sullivan, 2012).

But, despite these different strands represented in buildings, my embodied felt experience of the dispensary whilst walking around it was that it was somehow *cosy*. This is not a very academic word, but I have tried to think analytically about what might have been behind this feeling or affect that such potentially divisive 'affective infrastructure' provoked within me as an observer. For the entanglements of different historical moments of intervention as unravelled and exposed by Dom Willis for me on his tour, are for Akinda residents, I venture, probably not experienced as separate paths, but rather, in the moment are more likely encountered as one coherent experience. An experience which contains – as referred to earlier in relation to Mbembe's conceptualisation of the post-colony, simultaneous m*ultiple dureés*, *multiplicities*, and concurrent signs of progresses, reversals, starts and stops. This is not experienced as necessarily dislocating, exceptionally frustrating or confusing, but rather as simply how life is. Although this is not to say that frustration at the stagnation of projects, was never expressed, but rather that it was predictable/predicted and yet did not prevent optimism for new future interventions.

I venture this based firstly on the fact the different actors with their links – or not – to global networks were everywhere in Nyagoko, inhabiting all different parts of the dispensary and crossing architectural boundaries. The HIV support group was meeting in the unfinished maternity hospital, the NCRO/CHA researchers were working out of the oldest building built through community harambee in the 1960s, and I found the new Ministry of Health Community Extension government worker borrowing a brand-new office in the USA funded HIV patient support centre. And although these buildings were differently constructed, with different materials, the same style of open verandas, encouraging patients to sit together sharing the breeze, threaded across all.

226

Furthermore, because I was shown around the compound by Mr Willis, who was there at the beginning and throughout all the stages of the dispensary's development and considered it very much *his* and his community's dispensary I did not feel the jarring effects of juxtaposition. In every space we found known people and community volunteers - peer volunteers in the PSC, research participants in the NCRO/CHA office, volunteer community health workers in the pharmacy and a volunteer *nyamrerwa* in the maternity hospital. Not to mention Dom Willis himself, a consummate volunteer whose own home had temporarily been given up to light traps and entomological research.

Perhaps this feeling of cosiness also reflects something I discussed at the beginning of this chapter: how it might make better analytic sense to think of Akinda, with its multiple histories, as a profound part of what makes the NCRO/CHA research field station, rather than a place existing in its shadow or as simply its 'reserve' of research participants. Here, the dispensary is, in effect, the sum of its parts rather than a disparate collection of ideas, encounters and spaces. This is a sentiment which could be extended to Akinda as a historically contingent and constructed biomedical research fieldsite as well. What might tie Nyagogo together as a coherent place is found in its community-ness and its volunteers. This sociality, as suggested in the theoretical framing of this chapter, provides the continuous signal running through the *multiple dureés* physically represented in the monuments to various past and present health interventions displayed in the space. It is also such social relationships and social histories that have profoundly shaped how contemporary transnational medical research activity is understood in Akinda today. Again, whilst this activity, of course, has powerful points of origins and orientation (especially in terms of funding and priority-setting) that are located outside Akinda, and outside Kenya, in Akinda these meet and intermingle with other, different kinds of origin stories. And, furthermore, even despite the current omnipresence of transnational medical research activity in the area, to its residents

NCRO/CHA is not necessarily or has not necessarily been, for everyone, always the main event.

This chapter has offered a detailed look at how things came to be in this place, Akinda. It offers several, intertwining histories of arrival and intervention on its landscape and habits/bodies of residents: early *Jo*Luo fighting off their enemies to claim the land, Indians bringing sugar and trade, missionaries bringing new belief systems, schools and medicines and scientists (and a myriad of development organisations including a seminal one formed from 'within') bringing technologies to change practices and bodies (like bed-nets, vaccines, zinc supplements). In doing so, I invite reflection on the recognition that history does not start (or stop) with one particular moment of global health, which are always (as exemplified in the rehashed songs sung by Akinda *nyamrerwa*) folded into other stories. I also show how while often some of those instigating the intervention may have left after a while, they have left their stamps on the landscape. Such histories of intervention are tidal-like, ebbing but leaving marks on structures – in composite buildings like Nyakogo dispensary - and on the biographies of the people involved, a little like the creation of sedimentary rock.

Chapter 5: "Living honourably and independently": Dreaming of a good village life in an African rural Health and Demographic Surveillance System Site.[9]

Figure 39: "'My hut is going to amazing!" thought Jessie. "I wonder when he'll bring all these new things?". Painting by Johnson Ondiek (paint on cloth, 2014,jaoarts@yahoo.com). Created for Case Study 10: '*They just come and ask questions': participants' understandings of the purpose of research* (Aellah et al, 2016, p.10).

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[9] The published paper of this chapter should be referenced as follows: Aellah, G., & Okoth, A. (2019). 'Living Honourably and Independently': Dreaming of a Good Village Life in an African Rural Health and Demographic Surveillance System Site. *Etnofoor,* 31(2), 103-120. doi:10.2307/26856488. Reproduced here with permission of the journal.

About the Death of Ochieng

In 2015 I visited my friend Ratwar ("Rat") in his forested compound in rural Akinda, nicknamed '*West-point, JaKenya, yawa!*' I had watched him labour over this miraculous and playful forest construction for eight years. He had struggled to achieve his dream on a modest research fieldworker salary, and the transformation of the land was astonishing. While we drank soda in an outdoor mock-up of a 'soda shop' he had tucked away amongst the trees, I noticed a freshly dug grave towards the edges of the forest. This, he told me, belonged to Ochieng, a close friend of his from a youth spent largely in a slum in Kisumu City.

Figure 40: Left: Before the trees, Rat building his first hut in 2009, with the assistance of *Jo*Akinda residents. Source: G. Aellah 2009. Right: After the trees, JaKenya standing in front of the same hut, which can be seen peeking through the trees in 2015. Source: G. Aellah 2015.

Ochieng had died in his thirties in a fatal *matatu* (bus) accident on the road between Kisumu City and Nairobi earlier in 2015. He had not known his father. His mother had never married. Ochieng's grandmother often stayed with Ratwar's grandmother in her compound in Kisumu City. When Ochieng's mother died she was buried at Rat's grandmother's place. But when Ochieng died there was no one left to claim him. Rat, a Luo medical researcher living and working NCRO/CHA in rural Akinda, decided to step up for, as he said, 'you cannot rest forever in the morgue'.

Rat decided to bury his friend in this cool, shady place that he had made in Akinda. In doing so he gave Ochieng a mock ancestral home in which to rest. Friends and relatives were invited for the funeral. And on that day Rat's home was Ochieng's. Ochieng was given a funeral to be proud of and so he did not die 'lost'. Rat's wife was unhappy and worried about 'the Luo culture part of it.' But some of the 'old folks' living around Rat's Akinda home told him not to worry. According to them Rat said, this 'was something Luos used to do long ago. It's a symbol of having a big heart.' 'Sometime', Rat told me, 'I will tell my grandkids [yet to be born], "you help your friends even when everyone else has run away." I will look back [at Ochieng's grave] in twenty years and know this was something honourable that I did.'

Figure 41: Rat holding my son in 2015, next to the grave of his friend Ochieng; bedding into and becoming part of the forest. Source: G.Aellah, 2015.

Theoretical contributions

The paper in this chapter was published in a thematic issue of the journal *Etnofoor* entitled The Village. It looks at the way transnational medical research figures in everyday life in rural Akinda through the biography,

actions, and dreams of Rat (referred to as 'JaKenya' in the paper, and by the names Aloice Okoth in the paper's authorship).

In doing so, the paper primarily addresses the first two of my research questions.

1. How is transnational medical research understood and folded into the broader lives of those living within its midst?
2. What value and meaning does transnational medical research have to those who encounter it? What (other) things matter to people as they navigate their lives in this place?

It also touches on the fourth question:

4. What ethical challenges emerge in the everyday practice of transnational medical research, and how can we best talk about them?

The material I present in Chapter 8 about using ethnographic case studies to create spaces to talk about relational ethics offers one possible answer to question 4. But in this chapter, I find Rat contending with, perhaps, a more macro-level ethical challenge: how to live a good, ethical, and sustainable life, and how to confront, and live with (in his words) the recognition that the transnational medical research activity he engages in daily 'is not a permanent thing'.

This paper builds on the material presented in Chapter 4 by homing in on one biography to reveal some of the m*ultiplicities* and *multiple durées* that are being simultaneously lived and lived through in Akinda. In the process, the specific fragilities of life in this Analogue and Digital time are laid bare. It also reveals something of the myriad connections between urban/rural places and people in Luoland, and how post-colonial transnational medical research practices weaves through and animates these.

For, Rat/Jakenya is not *Ja*Akinda (person of Akinda). His ancestral *dala* (home) is in a location not too far away, but one that is vastly richer in food

and tree biodiversity partly due to access to water sources, but also because it contains the Millennium Villages project[10], from which he takes much inspiration. But, as a son brought into a family by his mother when she married her husband, Rat can only develop himself and his land in this ancestral *dala* headed by a non-biological 'father' up to a certain point[11]. He was largely brought up by his maternal grandmother, Ratwar, whose name he proudly carries alongside other names[12]. He spent his early formative years in his 'Granny's' compound in Kisumu City, a compound which was traditional/analogue within itself, but also located within an-ever growing modern/digital 'slum' area. In Kisumu City, he stayed in and looked after an absent uncle's house. The surroundings of this plain concrete house are also touched by Rat's creativity, unusual compared to its city surroundings for an abundance of flowers and decorated inside with the vibrant paintings of Rat's (now late), artist brother.

Yet, Rat also qualifies to work in rural Akinda as a 'local' fieldworker, accepted by both NCRO/CHA definitions and the definitions used by *Jo*Akinda. He got his 'chance' to come because he can draw on other kin connections through a different well-respected uncle living there. This uncle, Mr Warinda, the 'child of the mission', who provided oral history and research for me on the story of the arrival of missionaries described in Chapter 4, also underwent a much earlier process of belonging to be accepted as *Ja*Akinda. This chapter shows Rat following his own path in this long history of creative belonging, one further embedded by his action of marrying

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[10] A demonstration project of the Earth Institute at Columbia University, the United Nations Development Programme, and Millennium Promise (2005-2015), aimed at proving that its integrated approach to rural development could be used to achieve the Millennium Development Goals. See: http://mv-aid.org/mv/sauri.html
[11] See for example Geissler and Prince (2010b) and Cooper (2011) for further explorations of love, traditions and land pressures.
[12] See Geissler and Prince (2004) for explication of love and care-taking between grandchildren and grandmothers in relation to the AIDS crisis in Western Kenya.

a *Nya*Akinda (daughter of Akinda) along the way, and all largely made financially possible by a NCRO/CHA contract and salary.

Precarity

This paper also offers a contribution towards the broader anthropology of precarity by showing how one individual responds to the precarities of economic, environmental and health uncertainties by bedding into land and the promise it holds. Rat knows well that his fate could have easily been the one of Ochieng (or of his own brother, or of one of his own young children. Both of whom have died since I took the picture of his hut in 2009). In the paper, Rat/JaKenya wonders about the future of NCRO/CHA research, questioning its' existence in a state of perpetual temporariness. When he wonders 'why we still have these deaths under five when we have all these interventions' this question is framed in the specific context of his NCRO/CHA fieldwork activities in Akinda. It is also framed in the context of the death of his young child from a first wife, who was living elsewhere and not resident in the Akinda HDSS, but who is dead, nonetheless, of a brain tumour misdiagnosed as TB. I have chosen to start by making this paper About the Death of Ochieng. But it is, of course, about all these deaths and all these lives.

Yet, Rat's recognition of the fragility of life does not mean he lives in a state of suspension or waithood, as sometimes described in literature on precarity earlier discussed in Chapter 2. Rather, Rat channels his futures down multiple paths simultaneously: forest, family, friends, NCRO/CHA employment. He is prepared. And, above all, his creativity and joyfulness is irrepressible.
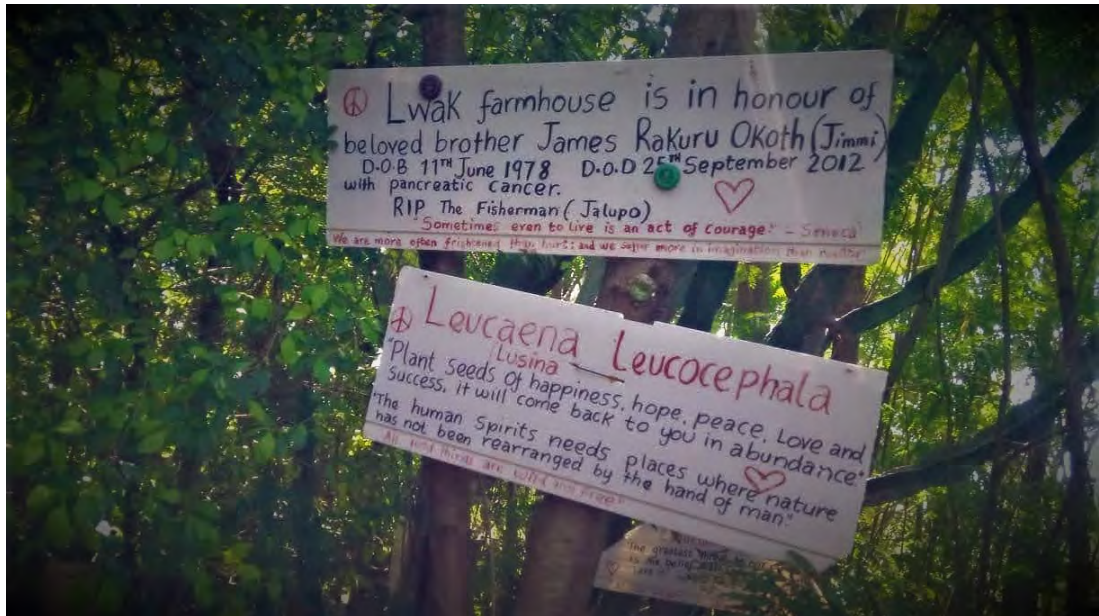
Figure 42: Memorial and tree species identification signs fixed to trees in Rat's forest. Source: Okoth (2020). The top sign reads: '[Peace symbol (originally from the 1958 British civil society campaign for Nuclear Disarmament)] Lwak Farmhouse is in honour of beloved brother Jaems Rakuru Okoth (Jimmi). Date of birth 11th June 1978, Date of Death 25th September 2021 with pancreatic cancer. Rest in Peace The Fisherman, JaLupo (Dhuluo for Fisherman). "Sometimes even to live is an act of courage", "We are more often frightened than hurt; and we suffer more from imagination than from reality"' (Lucius Annaeus Seneca, Roman Stoic philosopher, born circa 4 BC). The bottom sign reads '[Peace symbol] Levacanea Leucocephala (scientific name for tree species), Lusina (Swahili name for tree species), "Plants seeds of happiness, hope, peace, love and success. It will come back to you in abundance" (Steve Maraboli, American motivational speaker, born 1875), "The human spirit needs places where nature has not been re- arranged by the hand of man" (author unknown), "All good things are wild and free" (Henry David Thoreau, American naturalist, born 1817 and author of 'On the Duty of Civil Disobedience' (Thoreau, 2014 (1849)).
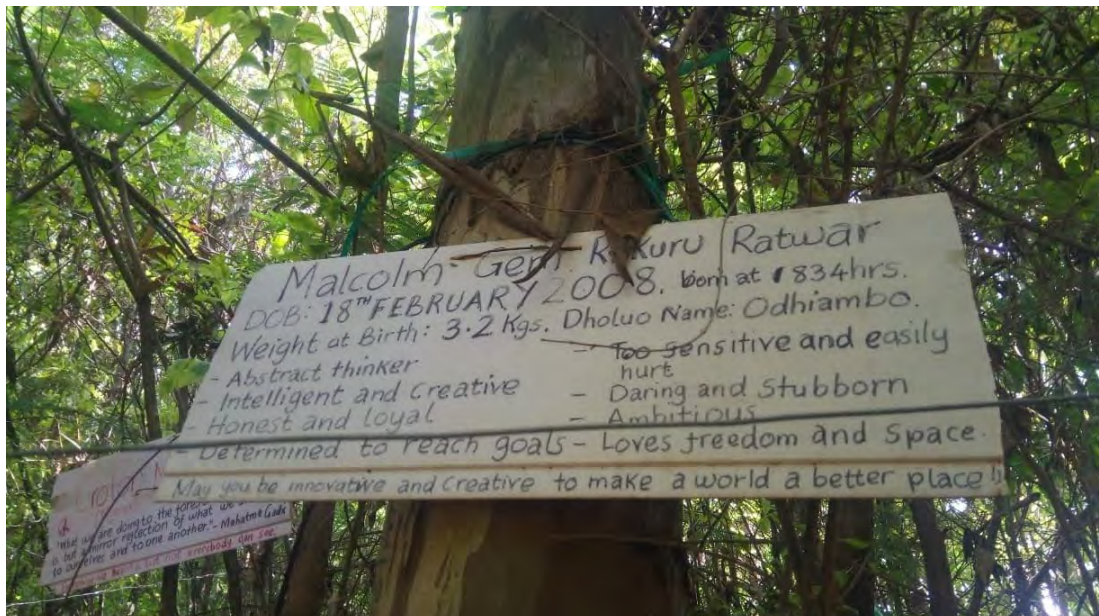
Figure 43: Here Rat uses his tree signs to celebrate the new lives of his children.

Rural realness

This paper offers some points of comparison with the paper in Chapter 6, which follows it. Chapter 6 focuses on the flexible idiom of 'exposure' through participation in transnational medical research in Kisumu City. It describes conversions of scientific knowledge that, by and large, were moving in more of a cosmopolitan, globalised direction. JaKenya, with his flamboyant

embrace and love of Luo cultural life, stood in marked contrast to some of the city-based researchers I met whose ambitions looked to travel beyond Kenya. In fact, travel is something JaKenya hopes to do only for leisure in a 'retirement' stage of his life. Compared to some city-based researchers who were sometimes rather reluctant to work in the villages, JaKenya spent as much time as he could in Akinda. He took out a loan to buy the land there that would become his 'West-point, JaKenya, Yawa!' rural idyll, and was committed to finding a way to belong in the village. Eventually he hardly returned at all to his uncle's house in the city, claiming the rural was 'the real' place.

Figure 44: JaKenya at a NCRO/CHA city headquarters' Christmas party. Participating in a fashion show with a rare funeral headdress borrowed from an Akinda elder. Source: Okoth

The Etnofoor thematic issue on the village argues anthropologists have long been associated with the village as the ideal site for ethnographic fieldwork (Gupta and Ferguson, 1997). But in recent years the village as a primary field

site has increasingly been exchanged for urban, institutional, or 'digital' sites of ethnographic research. It raises the question: has 'the village' lost its relevance to anthropology? My paper offers a case study that argues the village is still highly relevant to contemporary life in Africa. In transnational medical research the idea of a rural field-site or 'the field', 'the ground', the 'real community' is central to the machinery of global health. Akinda may be one of the most remote, rural outposts of Global Health, but it is essential to the endeavour.

But, beyond this, in JaKenya's biography an imagined idea of the village is central to his own subjectivity. He consciously works to create a certain Luo identity, grounded in rural living. I think this paper, therefore, offers a contemporary ethnographic case study that resists popular post-colonial narratives casting the village as backwards-looking place, both in terms of nostalgia for a time now lost, or as a place of political and economic marginalisation (Herzfeld, 1991, Li, 2010, Sorge and Padwe, 2015). The very things from both spectrums of this narrative – slower pace of life, connection to land, state abandonment, political marginalisation etc. – which are often taken as symbols of looking back are here re-appropriated by JaKenya to dream of a different future. In this way, this case study is a reminder that villages are, always, 'historically contingent processes, never inert, always becoming' (Sorge and Padwe, 2015 p. 241).

Figure 45: JaKenya's feet walking in rural Akinda. He is wearing his own version of *akala* flip flops, made from old tires. Usually considered a marker of poverty, his are shaped like fish to represent *Jo*Luo's connection with the lake, and their intelligence gained from eating fish. Source: Okoth.

Methodological Contributions

A long-term following approach

The paper in this chapter is only possible because of the long-term following approach to fieldwork I was able to take. I first met JaKenya on a trip to rural Akinda in 2008. He took me to visit a local chief in a village where there had been some opposition to a new NCRO/CHA HIV home-based testing programme. We exchanged phone numbers and he invited me to visit him in the city at the weekend. We gradually became friends and involved in each other's lives. He introduced me to his wife-to-be, who worked in her father's hardware shop in rural Akinda. He took both of us together on what he thought of as a mission for us to gain needed 'exposure' to the more disreputable dance clubs and parts of the city. When his wife delivered their first baby in the city hospital, he asked me to go and see if she was okay as he was stuck in the village. This son carries my name. When I lost my own babies in a private city hospital, he was one of the first to come. He came bringing food and solace.

I often sought Ratwar's advice on how to live well in Akinda. He introduced me to Mama Unita, whose home I lived in for the duration of my rural fieldwork. His Uncle, Mama Unita's neighbour, taught me Dholuo and colonial mission history. And throughout all this time, Ratwar had been working to realise a dream; to create a fresh, wild forest in Akinda. Over the years I witnessed him transform a former maize farm into a lush nature reserve, often finding him cheerfully digging in his garden in the early evening. He loved to do this after completing his day job of performing quality control checks on the data collected by community fieldworkers working on the emerging infectious disease programme in Akinda. Yet I was/am still surprised to see how this garden has grown.

Accounting for individuals

Ratwar is someone who stands out. There are others I encountered in Akinda and within Kisumu City whose stories do align in some ways. But Ratwar is especially visible, not least in his dress, oratory style, and in the creativity he expresses in the ways he shapes his landscapes.

There is a long tradition in anthropology of encountering individuals in fieldwork, but then (with notable exceptions e.g. Muchona the Hornet (Turner, 1967)), disappearing them in analysis and presentation through the processes of identifying patterns, structures, and generalities:

> 'At every step of our inquiry, then, we observe individuals;
> yet step by step our analysis also leads us away from the
> individual to something else' (Nadel, 1951p. 92).

The structural anthropology of Levi-Strauss represents perhaps the most extreme example of this (Hénaff, 1998, Lévi-Strauss, 1969).

How to account for individuals within generalities has been an enduring concern of anthropology, producing multiple experiments (e.g, among many others, Appadurai, 1988, Hurston and Walker, 2018, Pino, 2018, Rabinow et

al., 2007). Piette and Heiss argue that one dominant technique has been the collection and representation of life-histories, but that in these cases the object of study becomes not the individual themselves, but their life histories constructed through sitting with the subject and asking questions. Therefore, although the individual is addressed, it is at the same time somehow circumvented (Piette and Heiss, 2015).

This paper is not the product of life-history interviewing as such. Much of what I learnt is from observing actions over time, and through discussing things within an ethnographic research relationship with Ratwar that spans more than a decade. What I have tried to do with this paper, therefore, is to produce an account of an individual that demonstrates how individuals 'creatively 'write', narrate, and animate cultural and social life' (Rapport, 2002 preface). This is especially visceral in the case of Ratwar because his animating acts have literally changed the landscape around him. The paper is co-authored by Ratwar because I wanted to acknowledge his centrality in the writing, not in putting pen to paper (although he did read and comment), but in writing the story through his own life-course over ten years. It is probably the clearest example of how my thesis is part of an academic tradition that embraces narrative ethnography or 'doing things with stories' (Maggio, 2014, Symons and Maggio, 2014).

This piece is also co-authored by its subject because its' critiques are both of ours. The critical reflection is not mine alone. Within Ratwar's actions, I found an important critique of the state of transnational medical research in Western Kenya. In this paper we use his dreams to, in a roundabout way, perform a critique of its current form of fictive perpetual temporariness. Such a state enables it to stay and continue without the complications and obligations of acknowledging its permanence (which after thirty plus years is somewhat self-evident). Ratwar, to me at least, also stands as a figure who questions, parodies, and quietly contests such a difficult state by firmly attaching himself to, and working on, a rural landscape.

241

Research paper

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SECTION A – Student Details

Student ID Number	226397	**Title**	
First Name(s)	Gemma		
Surname/Family Name	Aellah		
Thesis Title	Everyday life in a site of transnational medical research in Western Kenya: an ethnographic study		
Primary Supervisor	Clare Chandler		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	Etnofoor		
When was the work published?	2019		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	**No**	Was the work subject to academic peer review?	**Yes**

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Stage of publication	Choose an item.

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	The authors are: Gemma Aellah and Aloice Okoth. I am the lead author on this publication. My co-author is the person whom the article is written about. He was the inspiration, advised on the content and added comements to the final version. I conducted all the research and wrote the text of the article

SECTION E

Student Signature	Gemma Aellah
Date	01/03/2020

Supervisor Signature	CIR Chandler
Date	01/03/2020

ETNOFOOR

The Village

Contents

'Living Honourably and Independently'

Dreaming of a Good Village Life in an African Rural Health and Demographic Surveillance System Site

Gemma Aellah
London School of Hygiene and
Tropical Medicine

Aloise Okoth

I belong here. That is why kids around call me JaKenya [Person of Kenya]. I would like to see this place in twenty years, even if I am not working for NCRO/CHA [a transnational medical research organisation]. While waiting for those twenty years to come I want to put a landmark. I have that dream

Photo 1. 'Westpoint JaKenya Yawa!'. JaKenya next to his tree farm sign: an affectionate reference to a US Army researcher, now friend; 'JaKenya Yawa!' means 'Citizen of Kenya oh yeah!' Yawa is a stereotypical Dholuo exclamation used for emphasis in a tone that is both self-mocking, proud and filled with emotion.
All photos © Aellah

in my mind. I want to live in a place close to nature. I want to live honourably and independently. Right now, if I'm at the field office, I can rightfully tell somebody, 'If you want to see me, see those trees? That's where I stay'. And as the years are coming in, the trees keep growing.

- JaKenya, fieldworker, describing the creation of his forest home in Akinda, rural Western Kenya, 2013.

When we plant some flowers around it, it will look like a real building. But it can easily be taken away.

- Contractor discussing plans to use a repurposed shipping container to house a research clinic in Akinda.

This paper considers some of the possibilities for life lived and, most importantly, imagined in a late-modern East African village. It focuses on two parallel, inter-linked stories that unfold in Akinda, a group of villages in Western Kenya.[1] One is the story of how a quiet rural location became a Health and Demographic Surveillance System (HDSS) site; an abstracted statistical construct of a poor African village, networked to other HDSS sites around the world; a place existing in journals, meetings, statistical analyses and international conferences. The other is a more personal story. It is about how a local fieldworker, JaKenya, who was invited into this landscape through employment with a transnational medical research organisation, has transformed a piece of Akinda into a forested rural idyll; a place for – in his words – 'living honourably and independently'. Both stories are about the flexible, loaded meanings of

Photo 2. A container clinic in Akinda.

'village' in Kenya today and the ongoing entanglements of African rural lives and global health research. They are also about the challenges of transforming visiting into staying and belonging.

Both stories demonstrate an interplay between local and global connections in the construction of village identities. Akinda's very localness and permanence makes its global abstraction possible. The intimate data collection that enables Akinda to operate as a global health research rural outpost relies on the work of local Kenyan fieldworkers and their deep knowledge of, and connections to, its villages. Both stories also feature different kinds of fabrication, although the dreams encapsulated within each activity operate under differing ideas of time, future permanence and commitment. In the first, a shipping container is deposited in Akinda to be repurposed as a temporary transnational medical research clinic. Bedded in with flowers, over time this clinic provides an illusion of permanence and

modernity with clean, metallic lines. Yet it could still easily be transported elsewhere at the end of the project's lifecycle. In the other story, a cosmopolitan version of a traditional mud-thatched home is constructed from local materials amidst a forest painstakingly grown by a fieldworker, alongside the carrying out of his employment activities. This home, created with reference to the fieldworker's global connections, but seeking also to revive a nostalgic traditional past, was designed explicitly to set in motion the continued improvement of the rural landscape beyond its creator's lifespan.

Neither stories are possible without the other. But JaKenya's small personal story helps illuminate some of the binds of global health research activity carried out in rural outposts. In Akinda, research employment has created a new middle class (there is no other source of formal employment apart from teaching or healthcare). In turn, it depends on the hard work, creativity and independence of members of this class, like JaKenya, to continue and successfully negotiate permissions from villagers. Yet, as will be shown, it also exists in a state of perpetual temporariness. Research has been conducted in the locality for over thirty years now, but there is always the potential for it to leave at the end of the next project. It is always only observing and never (officially) interfering with the landscape and infrastructure. Placing the story of research next to the story of an individual fieldworker allows for an exploration of the effect of this state of existence on the subjectivities of those involved.

Most ethnographic work on transnational medical research fieldworkers in Africa has focused on the ways in which local fieldworkers grapple with the differences between bioethics conceptualised in formal globalised protocols and those experienced in the field (Chantler et al. 2013; Kamuya et al. 2013; Kingori 2013; Kingori and Gerrets 2016). This includes things like balancing expectations, dealing with research participants' poverty and data falsification. In Akinda, such things are, of course, important. However, the starting point of these anthropological critiques of global health research has been to focus on the emergent properties of research and to ask how it could better achieve its goals (for instance, how it could be more ethical or locally engaged). In such accounts, the village simply provides the backdrop to global health research. Consequently, the richness, idiosyncrasies and creativeness of local lives are underplayed.

This paper takes a different starting point. It focuses on the wider, more diffuse entanglements between transnational medical research and everyday life that permeate rural identities and subjectivities. Akinda could be considered something of a 'company town', with the town being a village, the 'company' a complex alliance of international parastatal and university collaborations, and the industry the production of world-class global health knowledge. Global medical research expenditures by public and industry sources originating in the United States, Europe, Asia, Canada and Australia stood at $265 billion in 2011 (Moses et al 2015). Therefore, although somewhat unique, Akinda is not alone. There are over 30 HDSS sites in sub-Saharan Africa, with many other villages involved in not dissimilar programmes run by international non-governmental organisations (NGOs) (Crane 2013). It is therefore important to understand Akinda in its own right, rather than just as an example of global health practice. Akinda, as the 'company village' of a transna-

tional organisation, represents one possible version of contemporary East African village life.

To evoke everyday life in this place, this paper draws on ethnographic fieldnotes, interviews and photographs collected between 2008-2012 in Akinda, Western Kenya, as well as continued visits and correspondence to date. Written informed consent was obtained for the interviews and verbal consent for observations and conversations. The first author initially conducted fieldwork in Kisumu City, exploring the everyday lives of those involved in the medical research and intervention emanating from a transnational medical research station (NCRO/CHA) headquartered on the city's outskirts.[2] In 2010, she moved to Akinda, one hour away, to compare rural and urban experiences.

During this time, Western Kenya, like many places in Africa, was experiencing the profound impact of large-scale biomedical research programmes, intertwined with much larger transnational HIV/AIDS interventions (Rottenburg 2009; Crane 2013; Prince and Marsland 2013; Geissler 2015). Following the destruction and inflation brought about by post-election violence in 2007, decades of diminished industry and no significant rural commercial agriculture, the region could be described as having an HIV-based economy (Prince 2012, 2013; Aellah and Geissler 2016). Four transnational medical research organisations were operating in the city and 117 NGOs also had their headquarters there, fifty percent of which reported HIV as their main activity.

NCRO/CHA was at that time the largest private employer in the province, with over one thousand staff. Running multiple clinical trials in the city and nearby rural areas, several HDSS sites and HIV treatment programmes, the station touched the lives of several hundred thousand people. Transnational medical research provided the most visible reference for economic or health opportunities, either as a prospective employee, a research participant or the receiver of an intervention.

A paper that the first author wrote about the impact of medical research on everyday life in Kisumu city describes how research participants and staff sought to convert the knowledge gained through involvement in transnational medical research activities into strategies for securing their futures (Aellah and Geissler 2016). It describes a metaphor used by research staff of a process of 'exposure', like a film being slowly exposed to the light, becoming solid and visible. Research participants and staff tried to capitalise on the nebulous new relations, networks, styles and ways of life to which they were 'exposed' in order to move forward in life under conditions of extreme economic uncertainty. In that paper, the orientation described was towards an outward-looking cosmopolitan way of life provoked by exposure to global health research networks and practices beyond Kenya. City-based researchers dreamed of PhDs from overseas universities, conference travel and new lives in the United States, much like other 'aspiring elites' described in comparable African settings with intense transnational medical research or international NGO activity (Swidler and Watkins 2009).

This paper offers a counter narrative to such dreams of moving 'outside', in the story of JaKenya, a local fieldworker attached to NCRO/CHA but living in one of its rural HDSS sites. JaKenya's dreams were of forests, of reclaiming Luo traditions, and of creating possibilities for a life lived, in his words, 'close to nature'

and 'honourably and independently'. His engagement with transnational medical research took the form of a more rooted and locally-orientated version of the 'exposure' we described among city residents, one which reclaimed the village as the centring reference point of a good life.

Crucially, JaKenya's dreaming is bound up with the ways in which transnational medical research operates in the village. For, in direct contrast to the relative anonymity of city clinic-based research, in Akinda data collection is woven into the fabric of daily life and neighbourly relationships. 'Exposure' here, at least for JaKenya, who was brought up in the city, means exposure to a sense of rural community (or a selective version of it). It also means exposure to the contradictions of global health research, notably its current state of fictive perpetual temporariness that enables it to stay and continue without the complications and obligations of acknowledging its permanence (which after thirty plus years is somewhat self-evident). JaKenya, at the same time as embracing the opportunities offered by transnational medical research, stands as a figure who questions, parodies and quietly contests this style of existence by firmly attaching himself to, and working on, the rural landscape in much more lasting ways.

Story 1: Welcome to Akinda, home of Health and Demographic Surveillance

Akinda in Luoland, Western Kenya, is a rural geographical location, a collection of small homesteads and subsistence farms mapped out by generations of kin relations spreading away from the Great Lake. It is known variously as *dala* (real home) to its residents and diasporas, *resaf* (reserve), a linguistic echo of its colonial designation as a place of backwardness far away from the political and commercial centres, and *shags* (a slang term meaning 'hood) to those younger people who leave for the capital city in search of economic opportunity and only return for Christmas. It is also a place referred to as 'the ground' (as in 'we need to go to talk to people on the ground') or 'the real community' by city-based global health researchers who travel out, down and into Akinda along the highway from the headquarters of NCRO/CHA, ferrying samples, overseas visitors and medical technologies to and fro.

For Akinda is, as well as being the true centre of many of its residents' lives, a rural HDSS site: one of the remotest, most peripheral outposts of the machinery of global health science. As one of over 30 HDSS sites across the continent, Akinda is a 'global village' (Cid Aguayo 2008) where the movements, births and deaths of 60,000 residents are updated quarterly by fieldworkers on bicycles with handheld computers. Data is downloaded and transmitted by satellite to institutions in the Global North, where it is cleaned and transposed into trends, shedding its localness and the deep personal relationships that made its extraction possible.

A group of 33 villages within the HDSS are also part of an international emerging infectious disease programme. Residents are visited fortnightly, their temperatures taken and questions asked about their health in exchange for free treatment for infectious diseases at the local mission hospital. Numerous research projects and interventions hang off these interconnected platforms. In 2010/2011, this included

Photo 3. Home Number One. Designation on the door of the *nyamrerwa* (village health helper) whom the first author stayed with in Akinda, and who started the mapping of her 'village' in the late 1970s.

studies of early pregnancy, diarrheal disease, HIV, influenza and TB.

The history of how Akinda came to represent such an intense nexus of transnational medical research is rooted in a locally-driven rural development programme initiated by the Anglican church in the 1970s. Led by a young Akinda deacon and community physician, the programme grouped the scattered homesteads into distinct villages which were given new names. 'Village health helpers' were asked to number the 100 homes surrounding theirs for a census. This shaping of homesteads into villages provided the mapping for the HDSS that was to come in the 1990s.

In each village, village health helpers were trained to bring the health programme into the community. Activities included creating a clinic, conducting a census, making home visits and the distribution of family planning. In the 1980s, a research component of community-based malaria control was conducted by the local physician in collaboration with the University of Nairobi and other outside agencies. He was invited to complete data analysis in the United States, making the first connections with CHA. But the most significant legacy of this programme was the creation of the role of the village health helper, which quickly changed to *nyamrerwa*, a local term encompassing child health, midwifery and a person known and respected by all. When the first NCRO/CHA study on immunity to malaria in infants arrived in the late 1980s, outside researchers found it difficult to find and gain pregnant mothers' trust. In this they were helped by existing *nyamrerwa* who already knew and regularly visited everyone in their villages. A bed-net trial and the beginnings of the HDSS followed in the 1990s, which further allowed additional projects to utilise the statistics already known about the Akinda villages. The *nyamrerwa* soon became essential to every new project, as they were easily able to monitor births and deaths in their villages, and the trust villagers had in them was transferred to NCRO/CHA projects. As subsequent projects required more technical skills, their roles in routine data collection were replaced by school-leavers like JaKenya. But each NCRO/CHA village still retains a *nyamrerwa* to serve as a community liaison between transnational research and the villages. They introduce new projects, disseminate findings, help handle tricky situations, and are called upon to do sensitive work like

pregnancy testing or entreating parents to bring their children to the hospital for nasal swaps.

Caught in a state of perpetual temporariness: the meaning of a clinic inside a shipping container

This crystallisation of medical research into a permanent fixture in Akinda occurred through a series of consecutive short-term projects – where the next was never guaranteed – underpinned by the existence of the HDSS, which in turn is dependant for its continuation on funding generated by the shorter-term interventions that come to Akinda because of it. In the eyes of residents, these temporary activities blur into one continuous existence, held together by the familiar faces of staff like the *nyamrerwa*, themselves kept on temporary zero-hours contracts. In this way, transnational medical research activity has managed to continue for more than three decades.

Akinda is one location in an 'archipelago of a few high-powered and well-resourced islands of global science' (Geissler 2013). Not dissimilar to industrial enclaves, these are highly serviced small areas dotted across the continent, rather than dissipated throughout, and integrated into, national ministries of health and universities. Such islands have evolved as a result of two inversely related changes. The first involves the increasing standards, technologies and possibilities of global science (think of the skills and resources required to continually transmit and transform the mass of data garnered from Akinda residents into useable statistics). The effort – and financial turnover – is immense, and

the high standards set in place by the globalisation of health research means that it must be protected if it is to become meaningful. The second change relates to the crises that have occurred in Kenya since the late 1970s (such as privatisation and structural adjustment, compounded by the AIDS crisis that began in the 1990s, overwhelming national health services), which have made it difficult for these standards to be achieved in local and national universities and laboratories without overseas partners.

The foundations of these islands, formed through collaborative agreements between overseas and local partners rather than cemented in national ministries, are fragile. They are governed by politicised and projectified funding cycles and underpinned by ideologies of observing and testing in a scientific field, rather than interfering in a national space. Research activity in Akinda therefore struggles to put down deep roots in the villages it continuously statistically constructs. Staff numbers and configurations of expertise, clinics, vehicles, supplies and so on periodically expand and contract according to the projects' needs. Criticism of this short-term approach is met with the comment that this is, after all, *research* and not a public health intervention.

In this configuration, NCRO/CHA exists in a state of permanent temporariness that permeates all its activities. Staff are engaged on one-year renewable contracts, to try to find a balance between avoiding any guarantees of permanence while assisting staff, who after all represent the Kenyan middle class, to obtain various class trappings such as mortgages and loans. The ability of research projects to impact the infrastructure of health service delivery in lasting ways is also chal-

lenged. A good example is an Akinda research project that required a new clinic and ended up with one in the form of a shipping container, as mentioned in the opening of this paper. The container was placed on the grounds of a dilapidated Ministry of Health dispensary, and was bedded in with the planting of flowers around its base. When these flowers grew, the designer assured the delegation of researchers, dispensary staff and community representatives who gathered to agree on the plans, it would look just like a 'real' building.

Widely used in HIV programming activities in Africa, shipping container clinics are valued for their low cost and speedy set-up, and their capacity to be taken away and re-used elsewhere at the end of an epidemic (or funding cycle). In Akinda, the use of a container also avoids the conundrum and tricky negotiations of a donor country exerting its sovereignty and exceeding its remit ('we are not responsible for the public health of Kenya') by building on Kenyan land. The clinic was deposited, not built.

The best example of this constant balancing act between states of permanence and temporariness is found in the International Emerging Infectious Disease Programme (IEIP) run on the bones of the HDSS in Akinda. When the IEIP was first set up, the facilities needed to run the hospital arm of the study were not available in the local government dispensaries. Time pressures, resources and the ideology of research rather than intervention therefore led the researchers to make an agreement with the matron of the private mission hospital instead: every month, the NCRO/CHA field station would be billed by the mission hospital for services provided to its study participants. Furthermore, nearly all of the hospital staff are in fact field station employees. Over time, this arrangement, initially conceived of as temporary, has become more permanent, as the IEIP study has been granted extension after extension. From the perspective of participants, care at the mission hospital is permanently free. Researchers worry what will happen, however, when, inevitably, no more extensions are given, the hospital reverts to being understaffed and fee-charging, and residents must turn to increasingly neglected government facilities.

What effect does this situation have on the subjectivities of those living in Akinda? It could be argued that Akinda residents relate to transnational medical research in a somewhat 'subjunctive mood' (Whyte 2002). Min Unita, for example, whom the first author stayed with during fieldwork, has been a *nyamrerwa* since 1979, when she was one of the first to join the rural development project. She has worked continuously on a 'casual' temporary basis with various researchers ever since. Her work biography – always working on small projects, never knowing for sure if a new one will follow – has crystallised into a career spanning 30 years and a rock-solid self-identity: 'We are *nyamrerwa* for life'. Yet she always answered questions about new upcoming projects and her future in a tentative tone: 'God knows'. With no pension and a zero-hours contract, she continues to work and walk around the villages in her late 60s, despite her painful hips. Equally, in many interviews with residents across Akinda, concern was raised about the possibility that the field station would one day 'leave us', placing research in the same category as other nonspecific 'donors', perceived as sometimes helpful but invariably transient. Concerns also flourished when people spoke

of the negative side of 'being with' the field station, such as the 'money shock' that was perceived to hit youths newly recruited as fieldworkers.

Underlying these stories were fears of something both participants and researchers termed 'dependency', borrowing from development parlance. Fears about dependency were invoked when researchers raised concerns as to whether Akinda was becoming 'over-researched', an idea that encompassed participants becoming too familiar with study routines (such as the filling of consent forms) for them to be truly meaningful, and irritation when participants made demands, such as youth wanting to be employed as HIV testers in their own villages. This represents an eternal conundrum: villagers need to be primed and receptive to research, but not so receptive as to bias findings. Dependency was also something feared by participants. An extreme example was a rumour spread by a young man when talking about a non-NCRO/CHA research study which included Akinda in its catchment. This study was, in his view, giving HIV drugs as prophylactics to at-risk HIV negative women, 'confusing them with cash' as a way to make them have sex with HIV positive men. 'In the old days', this young man claimed, people with HIV just died and the disease did not spread.

> But now these ARVs that [President] Bush gave us freely means people are living with it unseen, infecting us all. … It is part of a conspiracy to make us Kenyans dependent and obedient to the US, as without these drugs all would die. We have become a child dependent on its father for food. Why do you think there is no British research? Because Britain is no longer the superpower.

More often, the fear of dependency was milder and was connected to the recognition that they, the villagers, were the only permanent elements of Akinda. A retired teacher summarised a focus group discussion about the issue:

> Let me explain what we are saying clearly: If [the field station] carried their things and goes, and the government also carried their things and goes, and we are from here, do we also carry our things and go? No. We are not going anywhere. We remain here. Life has to go on. If they go, then the people they have been treating in the study will just die. So, as this is the case, we must see how we can live.

In this focus group, the pervading feeling that emerged in relation to Akinda as a researched village was not a sense of being opened up to global connections, but rather a recognition that Akinda residents were, or would one day would be, ultimately alone.

The next section turns to the second story mentioned in the opening of this paper, which looks at the activities of one fieldworker, who, whilst working for NCRO/CHA, was also engaged in a personal attempt to create a space for himself in the village. Brought into a rural landscape through research employment, he ended up turning visiting into staying and belonging. JaKenya's story is orientated towards the future and, as such, is a counter to other, more temporary, stories of transnational medical research activity in Akinda. His lively and rich sense of self also acts as a counterpoint to the flattened descriptions of fieldworkers' lives in other anthropological accounts.

Story 2: Welcome to 'Westpoint, JaKenya, Yawa!', home of a fieldworker in Akinda

A few minutes' walk from the collection of rented concrete single-storey buildings that house the local field office of NCRO/CHA in Akinda, and surrounded by parcels of land divided into maize fields and small rectangular iron-roofed homes, a once bushy patch of neglected land has been transformed into a forest in miniature. Crossing the threshold into JaKenya's compound in 2013 is like being transported into a lush secret garden. A blue-painted iron gate – normally an indicator of a modernised dwelling – marks the beginning of a path through a tangle of trees and flowers. An artful hand-painted wooden sign nailed to a tree and decorated with Tusker beer bottle tops announces that you have entered 'Westpoint, JaKenya Yawa!' (Westpoint, Person of Kenya oh yeah!). Beyond, hidden among a veritable forest of acacias, pines and indigenous trees, stands a group of small structures, their composition following the layout of a traditional Luo homestead. First, we come to the *dero* (granary) for storing the maize, on whose cylindrical woven reed wall hangs a weather-beaten inspirational poster declaring that 'Man can live about forty days without food, about three days without water, about eight minutes without air, but only one second without hope'.

Peeping through the acacias, we can see an uncut ceiling pole poking proudly through the grass-thatched roof of JaKenya's *abila*, a traditional hut belonging to a compound's patriarch, a place for relaxing and meeting friends, as well as the mud-plastered rounded walls of the *od yueyo* (kitchen), *od welo* (pit latrine) and *od budho* (main house). Inside this rounded hut, one of the few

still constructed like this in the village, Norwegian, US, British and French flags, and posters of Malcolm X and Bob Marley, hang from the ceiling. Cartoons and sketches by JaKenya's deceased artist brother adorn the walls. Traditional gourds for drinking sour porridge and catapults for hunting hares hang off nails tacked into the wall posts.

Beehives dot the edges of JaKenya's forest and, in a shady clearing, he has replicated a cool outdoor soda shop, complete with plastic table, chairs and a Coca-Cola branded umbrella. From this vantage point, with a soda in hand after a long day traversing the rural landscape by rugged motorbike, with his laptop plugged into a solar-powered battery, JaKenya can watch over a small earthen grave beyond, a quiet monument to a dear friend from the city slums who departed too young and with no ancestral or acquired land of his own in which to rest.

Every day, JaKenya leaves his forest haven and rides around the thirty or so villages involved in the IEIP on a rugged motorbike doing quality control checks. He greets everyone he comes across with an emphatic greeting of *'JaKenya!'* (Person of Kenya!), which in turn has become his local nickname. The nickname is a typical Luo-English hybridisation, his attempt to recognise and emphasise shared citizenship, albeit with a Luo designation.

As he travels around Akinda assisting in the collection of biomedical and demographic knowledge about its population, JaKenya collects additional things of his own: a traditional headdress borrowed from an elderly traditional dancer to help him win this year's Christmas fashion show held at NCRO/CHA's city headquarters; inspiration from a nearby NGO-run model

Photo 4: JaKenya's *abila* (patriarch's hut). From top left: a mock post box; JaKenya and family in the forest surrounding the hut; flags adorn the ceiling; gourds and catapults on the walls.

farm for tree-planting techniques; a sweet, rare taste of ghee prepared by a friendly lady farmer; as well as a feel for what 'the community', as local residents are known in research parlance, thinks about a new TB study.

In the evenings, JaKenya stays late in the small field station office to ensure that the handheld computers, which connect the data collected from the villagers to a virtual global research network, are fully charged for the next day. At night, he returns to his wife and two young children, both named after international researcher friends, who live with him at Westpoint. On the weekends, he works hard on his tree farm, as

well as on other small parcels of land nearby that he has bought for his children and future generations and has planted with tree seedlings. A phrase he is fond of repeating goes: 'The true meaning of life is to plant trees under whose shade you do not expect to enjoy'.

Financing for what has now become JaKenya's Westpoint forest and its expansion came from slowly accumulated savings from his modest fieldworker salary, as well as loans, with progress often suspended by the various family crises of sickness and death which periodically draw away funds and energy. It has been hard, slow work. But to an outside observer, who has watched for the better part of a decade, the growth of JaKenya's Westpoint from a small collection of prized saplings to a fully-fledged secret garden hideaway feels like a miracle.

Becoming a rural person

JaKenya, unlike many of the 'local' fieldworkers working for NCRO/CHA, was not born in Akinda. He was born in the Rift Valley, where his mother worked for the National Cereals Board and his father was an army officer. His parents were busy and his grandmother felt he was being neglected, so at the age of five he was taken to live with her in one of the lower-class estates in Kisumu City. For the latter part of his primary schooling and for all of his secondary schooling, he was sent to boarding schools in North-Eastern province. After school, he took a diploma in electrical engineering. He hated it, feeling he was 'more a human person than a machine person'. After completing the diploma, he 'tarmacked' for a while (an expression for walking around looking for work), while staying at his grandmother's place. One day, he was ambling along the street and he caught sight of Robert, a Scottish Voluntary Service Overseas worker. He describes the encounter as follows:

> It was crazy, you know when you are still in your teens, you don't behave so well! I was just walking along the street and I decided to make fun of '*odiero*', the only white who was resident then in Manyatta. [Putting on a funny nasal voice] 'Hello! How are you?' Robert was like, 'I'm Okay'. I said: 'You look like an American'. He said 'Nope, I'm a Scottish'. And conversation started. It was as simple as that.

This chance meeting was a turning point in his life. Robert was conducting a survey on children with disabilities, but was having trouble locating them. JaKenya suggested asking children if they knew any, since unlike adults, children are always free to come and go in other people's compounds. The strategy paid off and Robert employed JaKenya for six months, inspiring in him an interest in development work and, perhaps more importantly, writing him a glowing reference letter which JaKenya took to Research International when they were recruiting for fieldworkers. As a Research International fieldworker, JaKenya had the chance for further 'exposure' and travel, working on projects ranging from enquiring into the soapiness of soap to the quality of mobile phone reception.

During this time, JaKenya continually applied for positions at NCRO/CHA, at least fifteen times, and always in rural areas. He was keen to experience rural life, because he had been brought up in town and longed for

a change. Eventually he got lucky when he responded to an advertisement for community interviewers for IEIP in 2005. During the interview, he had to demonstrate some connection with Akinda. Fortunately, his mother had been born there, so he could truthfully say that he had relatives in the area. Having been brought up by his grandmother, he could also speak deep, rural Dholuo and so was able to pass the translation tests. He moved to Akinda, first staying with his uncle's family and throwing himself wholeheartedly into rural living: 'They said, "We can't believe you are one of town". I told them, "Life is how you take it"'. He soon moved into a one-room rented rowhouse behind the market. His forest home was then only the beginnings of a dream contained in the promise of fragile saplings, lovingly nurtured in cut-off plastic bottles, collected as samples from various village homes and arranged in neat lines outside his house.

When asked about what had drawn him to rural living, JaKenya argued that it was more 'real' to him:

> Down here, the place is becoming wilder and wilder. In the morning, birds wake me, people greet me. People live more outrightly, not hiding around. Urban people tend to pretend and be more cosmetic. I'm touched when a kid or an old man says hi to me. I feel part of it. Some old men told me you are now *JaKinda gi WuodYala* (a person of Akinda, who is also a son of Yala, JaKenya's ancestral home) because I have stayed without issues and brought something unique.

Making as performing

Jakenya's Westpoint farm, with its careful consideration of style and substance, is, arguably, a form of performance art, a deliberate and imaginative construction of a heterotopic space. It is an act of wilful thinking, a mapping of a real yet utopian place (Bloch 1995 [1986]). It is an artistic creation reflecting a desire to be somewhere, and shaping that somewhere. Sitting in his traditionally constructed *abila* hut contained within a compound that takes its nickname from a US military academy, in a nod to an army researcher friend, JaKenya looks up at the flags that he had entreated numerous overseas researchers to bring him. His place in the world is made meaningful through reference to these other faraway places that he plans to tour in his retirement, as well as in reference to Luo traditional practices of herding and hunting, brought into view through the gourds and catapults displayed on the walls. For JaKenya's constructed space reaches across time as well as place. Or more specifically, across ideas of time – of dreams and longing for the future and dreams of the past (Piot 2010). JaKenya's Westpoint looks across the world to the United States and elsewhere, but is firmly embedded 'on the ground' of Luoland soil. Similarly, it looks forward to a cool, shady utopian future protected by trees and self-sufficiency (one which also connects him to a global network of other committed environmental activists through his active social media accounts) and simultaneously backwards to a Luo past that may or may not have really existed. A pre-colonial, pre-AIDS time when Luo patriarchs contentedly shared stories with friends in their cool *abilas*, made like JaKenya's out of

mud-thatch, surveying their wealth contained in cattle, land, produce, wives and children.

It is fruitful to think of JaKenya's work as a performance, or performative, not least because of his beautiful labelling of the components of his compound, which call to mind a living museum. JaKenya has surely not labelled aspects of his dwellings for the benefit of his Luo neighbours, who know without being told how a traditional Luo homestead should be constructed. Although mostly designed for his own future generations and the improvement of, in his words, 'the community around' in impoverished Akinda, JaKenya's Westpoint is also partially created with a different audience in mind. For the researchers from the Global North that JaKenya regularly meets or invites into his space – to eat a 'traditional' meal of brown, unbleached *ugali* (a rough, unprocessed maize grain) porridge and tilapia freshly caught from Lake Victoria, for instance – JaKenya's celebratory, nostalgic version of a traditional, rural life improved by global connections and relationships is a compelling, joyful representation of a 'remote African village'. It offers a counterpoint to simplistic representations of the village as a place of poverty and of local researchers as only desiring to become Westernised. JaKenya works hard to maintain this. He often takes it upon himself to act as a tour guide for visiting overseas researchers, taking them to visit the village of Mama Sarah Obama or sites of Luo cultural significance.

At NCRO/CHA's annual Christmas fashion show, in contrast to his colleagues who wore outfits made of condoms or *kitenge* cloth in modern cuts, JaKenya confidently strode down the runway resplendent in a historic feathered headdress borrowed from an elderly

Photo 5. JaKenya, a loving sartorial parody of a Scottish hiker, taking the first author on a cultural fieldtrip to Kit MiKayi, tourist landmark and pilgrimage shrine for followers of Legio Maria, a Luo-initiated church. He is wearing socks with battery-powered leg warmers. 2008.

village dancer. In his day-to-day attire, he prefers to wear *akala* flip flops. Made of repurposed tires, and usually seen as a marker of dire poverty, JaKenya shapes his into fish, a creative reinterpretation that celebrates the association of JoLuo with Lake Victoria. This has led to more than one overseas researcher taking these lower-class items home as a cultural gift.

JaKenya's joyful performance of Luo identity moves beyond his sartorial choices. He has been strict with the upbringing of his children. Malcolm Gem, his young son, has tasted only brown *ugali* and takes no sugar in his tea. He spent the first few years of his life mainly living with JaKenya's grandmother so he could speak only Dholuo and learn the right ways to be from an elder.

Although in a minority, JaKenya is not alone in his commitment to finding conscious value in village living and celebrating Luo identity. There are others who, in perhaps less dramatic ways, carry with them this joyful spirit of reclamation. Chacha, for example, a young Luo man brought up in Nairobi, came to Akinda to intern on a development project. After a sharp period of adjustment to village living, he described a new-found sense of self and purpose, learning how to speak proper Dholuo and developing a deep connection to the place. Nine years later, he is still there and engaged in a tree planting project of his own. Other Kenyan fieldworkers who had relocated from urban areas also made efforts to place the village at the centre of their lives. One veterinarian working on a zoonosis study opened his own permanent veterinary clinic in the market, and another choose to hold his wedding in the village. JaKenya and these others are perhaps part of the seeds of a turn towards a new ruralism

among a particular group of educated young people in Kenya (Mwaura 2017). A group that does not see the 'village' as a necessarily backwards-looking place, but a potentially fertile space to creatively dream of a different future and independent living. The 'village' is continuously parodied in Kenyan popular discourse, but there are attempts to encourage a re-interpretation of the possibilities of rural economies, especially in Kenyan TV shows like 'Shamba [Farm] Shape Up' and 'Don't Lose the Plot'.[3]

Conclusions: making as dreaming

JaKenya's creation of Westpoint is about more than the performance of a rural cosmopolitan neo-Luo identity, of which an idealised hopeful version of rural life is a key ingredient. The space that JaKenya has laboured to create can also be read as both a product of and a counter to, or perhaps even an explicit commentary on, the anti-permeance of transnational medical research. When asked about the future of his home, JaKenya is confident: 'I would love to see it in 20 or 30 years'. But when asked about even the short-term future of research in Akinda, JaKenya, like other Akinda residents, is much more tentative: 'The future with research is so tricky. It really depends on the goodwill of NCRO and CHA. I cannot say it will be here in even two years. It is not a permanent thing. And I question why we still have these deaths under five when we have all these interventions'. At the time of writing, fears of temporariness were finally being played out, starting with a drastic reduction in the number of villages included in the HDSS.

117

For JaKenya, his family's future economic survival lies in the land rather than research. He cites the honey that his bees produce as a future income generator. He also has plans for some commercial farming, ironically planning to sell produce to Akinda youth who want to work rather than farm. Like city-based researchers, employment for JaKenya is not the end of his financial struggles, but more a chance to access loans and begin to build a real economic future through business or farming (Aellah and Geissler 2016). In this sense, JaKenya's Westpoint is an opportunistic by-product of employment with transnational medical research. Employment has enabled JaKenya to access loans. But it has also had its limitations, and the potency of JaKenya's desire to change the future has been thrown into sharp relief by some of the tragedies that have occurred along the path towards the creation of his forest. Along the way, he has lost a friend, a child and a brother. His child died of a brain tumour, misdiagnosed as TB. The cost of specialist treatment surpassed the private medical insurance cover provided through his employment. His friend died in a traffic accident and his brother of pancreatic cancer, in a country with no affordable cancer care. The protective effect of working with a transnational medical organisation, and of years of experimentation in aid to improve public health, can only stretch so far. Here it is possible to see in JaKenya's forest something bigger than a personal dream.

In terms of thinking about the specifically temporal and visceral qualities of dreaming through a space like Westpoint, Foucault's writing on heterotopia is helpful (Foucault 1997 [1967]; Street 2012). Unlike utopias, which are sites with no real reference places, dream-sites, like JaKenya's forest garden, are realised through

activity in intensely real and intensely physical places. JaKenya digs, waters and labours in his garden, acting to concretely dream of a future where his forest will become a local permanent 'landmark', and a habitat for birds, insects and small reptiles. His forest dream-site stands next to, and in contrast with, the temporary rented offices of the field station nearby and the light-footed, preformatted research clinics in their shipping containers dotted about the landscape, as described in the first story.

Recent literature has explored the importance of dreaming as a way of trying to actively work on the future in contexts where gaps between the techno-logical promise of global health and the realities of access have grown even further, due to the exponential growth of private health services across Africa and the continued neglect of national health facilities (Geissler and Tousignant 2020). Dreams can be 'a form of work through which people make the world they live in and the world they live for, through which they constitute themselves and trace possible futures' (ibid.). The papers in Geissler and Tousignant's upcoming collection tend to focus on larger-scale dreaming with future-looking visions more directly related to health programming, but there is also space for thinking about the work of dreaming within the seemingly small, everyday actions of fieldworkers like JaKenya. JaKenya's personal dreams, which are ostentatiously not about global health, nevertheless create space, through contrast, for thinking critically about the conduct of transnational medical research in rural locations like Akinda.

The work JaKenya has done on his tree farm is about creation and production, a celebration of concreteness. It is hard not to avoid comparing this labour to the

labour JaKenya puts into the data he collects during his day job, which disappears into a digital ether, leaving behind no real changes in infrastructure. Both activities are tiring, but one is about movement and circulation and the other about grounding and centring. Both are also about building relationships, yet within transnational medical research the relationships are there to serve the creation of an abstract statistical concept of a village. Within JaKenya's forest, the relationships celebrated are the health and good life of his future generations. The trees he plants remain, the food he produces is eaten, the bees pollinate, and the landscape is continuously visibly changed. With his art installation of a globalised forested Luo homestead, a playful reinterpretation, bounded and full of nostalgic love, JaKenya re-centres the village as key to what it might or could mean to be Luo today.

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Acknowledgements

Notes

1   Akinda is a pseudonym.
2   National Clinical Research Organisation/Central Health Agency (NCRO/CHA). This is a pseudonym.
3   See for example newspaper articles like: Kale, E. (2008) Hell Has No Fury Like a Villager 'Conned' by Consultants. *The Standard*, 5 October, p. 40; Malanda, Ted (2008) Death of the village dating service. *The Standard*, 17 November, p. 4.

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Chapter 6: Seeking exposure: Conversions of scientific knowledge in an African city[13]

Figure 46: 'A Research Class System'. Painting by Johnson Ondiek (paint on cloth, 2014, jaoarts@yahoo.com). Created for Aellah et al (2016).

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[13] The published paper of this chapter should be referenced as follows: Aellah, G., & Geissler, P. (2016) Seeking exposure: Conversions of scientific knowledge in an African city, The Journal of Modern African Studies, 54(3), 389-417. doi:10.1017/S0022278X16000240. Published under Creative Commons https://creativecommons.org/licenses/by/4.0/

About the Death of Willis

In 2010 my friend Gladys invited me to the funeral of her cousin, Willis, held in one of the peri-urban slums on the outskirts of Kisumu City. Willis was in his early thirties and had been living with Gladys and her mother for a few weeks when he died quietly in the night. The funeral was in a small, impoverished compound in an area difficult to reach by vehicle. There were many drunk men. Gladys was smartly dressed, sad, and uncomfortable. We did not stay long.

Gladys was a Luo medical researcher working with NCRO/CHA in their HIV research clinic in the city. She had a master's degree from the University of Nairobi in data management. She hoped to return to live in the capital one day, perhaps pursue a PhD. Her stepbrother had been an MP. Her mother held a senior position in the administrative department of the provincial hospital. They lived together in a safe, secure compound near the centre of the city. Gladys could be described as 'exposed' and middle class. Yet, her family history was one of struggle and tragedy. She had adopted her two nieces as young children after both their parents died of AIDS, and within her extended family there were stark differences in the socio-economic status of some members.

Gladys and her mother had taken Willis to live with them after finding him desperately ill at his home. He had recently spent some time in the district hospital and had been diagnosed with TB. But fearing the mounting hospital bill he had discharged himself and was languishing at home alone, unable to do his usual work unloading lorries for a supermarket. On Gladys' insistence, he had eventually attended an HIV treatment clinic in the city. It was a Friday. The clinic was busy. Experienced patients had arrived at dawn to join the queue outside the clinic gates. Willis left at the end of a long day sitting without being seen. After the weekend he had returned. This time he was seen, but told he needed to attend 'defaulter training' before being re-initiated on the HIV anti-retroviral therapy, prescribed elsewhere, which he

had taken intermittently. That evening, Gladys had intervened, sensing the urgency of the situation. She spoke to one of the HIV clinicians at her research clinic who in turn spoke to one of the clinicians at Willis' new HIV clinic. Willis was then told he could come back the next day to start his medication straight away. He died that night in Gladys' house.

Theoretical contributions

This chapter consists of a paper that was co-authored with the RCS team Principal Investigator, Wenzel Geissler, and published in the Journal of Modern African Studies. It is an exploration of multiple conversions of scientific knowledge, gained by research workers and research participants, into practical knowledge. We explore its value to sustaining precarious livelihoods in an economically fragile city – Kisumu, referred to in the paper as 'an African city'.

The paper, therefore, addresses my first 2 research questions:

1. How is transnational medical research understood and folded into the broader lives of those living within its midst?
2. What value and meaning does transnational medical research have to those who encounter it? What (other) things matter to people as they navigate their lives in this place?

But, like Chapter 5, it also touches upon a third in its concluding sections (See the section on Futures):

4. What ethical challenges emerge in the everyday practice of transnational medical research, and how can we best talk about them?

This is because, like JaKenya working in his forest in rural Akinda, some people engaging with transnational medical research in Kisumu City are also imagining and trying for more certain futures while wondering about the place of transnational research in them. This includes reflection on things that could, on the one hand, be categorised as macro-level research ethics, such as other possible ways of being a 'researched city,' or how to become a

centre among centres, rather than a periphery to a centre in the Global North. It also encompasses the struggles of those staff who, like JaKenya, are concerned with, in the words of a NCRO/CHA supervisor quoted in the paper, keeping hold of the capacity to 'think like an African.' Such moments of ethical deliberation occurred among NCRO/CHA employees but also among others, such as Community Advisory Board members, community group members and some research participants, who I found to be just as reflective.

On the other hand, such deliberations speak to more general concerns about how to manage life and its vulnerable moments, within this hot spot of disease and intervention. Regarding my first two research questions, therefore: in this paper we were also interested to consider what it might mean to think of transnational medical research and intervention as a broader feature of modern life in certain parts of sub-Saharan Africa. In our ethnographic context of Kisumu City, we found there was no clear separation between science and sociality. As our paper argues, 'life science and everyday life are co-constituted.'

To better understand this, we drew on a flexible multi-edged idiom that all the RCS team had noticed was in use in everyday talk during all our fieldworks, that of 'exposure'. This idiom is a specific way of talking about opportunity, personal development, or growth e.g., 'it's like how you expose a chemical to sun.' In other kinds of talk, such as in the technical language used in HIV research and interventions, 'exposure' holds more dangerous meanings.

Exposure and precarity

The paper reveals the many dimensions of the vulnerabilities that put city residents in a position where exposure to transnational medical research offers the best chance for aspirational and healthy futures. Gladys, as a NCRO/CHA employee, represents someone able to gain a foothold within this kind of situation. She was able to capitalise on her exposure to scientific

knowledge to find ways to move forward in life. As of 2019, she has moved on from this employment into a senior position at an International Non-Governmental Organisation in the capital. She frequently travels overseas, rents a nice flat in Nairobi, and is constructing a modern permanent home for herself and her dependents in Kisumu City.

Willis, on the other hand, worked within the '*jua-kali*' (hot sun) informal economy in Kisumu City. He waited around the loading bay of the city's increasing number of supermarkets catering to the changing tastes of those able to capitalise on their exposure to international organisations, hoping for a few shillings in exchange for his help unloading lorries. His 'exposure' was mainly to some of the risks of the city: exhaustion and HIV infection. When he became sick, he was no longer strong enough to work under the hot sun. With no private medical insurance, he relied on the limited provision of a public hospital. Gladys' 'exposure', which precipitated her intervention on his behalf at the HIV treatment centre where treatment was provided free through the US Presidents' Emergency Fund for AIDS Relief, could have saved him. But his body was too tired by then.

Gladys and Willis show, within the same family, the double-edged meanings of 'exposure' in this HIV city. Together, they show the opportunity and limitations city residents are exposed to when they engage with the outside agencies that have flooded to Kisumu City in the wake of the AIDS crisis. The lines between success and failure are easily crossed. I chose to entitle this introduction to the published paper About the Death of Willis to stress that, similarly to Ratwar and his friend Ochieng (Chapter 5), Willis' tragic fate is not far from the minds of those who manage to move ahead in Kisumu City. It gives a sense of urgency to their efforts. Gladys' deep despondency at Willis' death is heightened because even with her willingness to help, premium city contacts and networks, intervention was still too late and too little.

Anthropology of transnational biomedical research

This paper demonstrates some of the *porosity* of global health research, offering a case study that cautions against assuming too sharp a distinction between research workers and research participants. We do recognise that research workers are, or become, a different socio-economic class to many participants. However, as the example of Gladys and Willis demonstrates, lines demarcating the experiences of these groups can be made, crossed, and recrossed within the same extended family.

Importantly, this does not only happen in ways that serve to underscore a sense of some shared vulnerabilities between groups. There is also a sense of some shared optimism. The paper shows how, in some (albeit much more limited and rarer) circumstances, even the most vulnerable-seeming research participant can use their exposure to 'make it', and eventually become a research worker, potentially as successful as Gladys.

Methodological contributions

This paper is drawn from research material collected collaboratively by the RCS team. In the analysis process I reviewed all my own notes, as well as the transcripts of the interviews individually conducted by Gertrude, Wenzel, myself, and earlier team members, searching for the literal use of the term 'exposure' to check the linguistic strength of the idiom, and for other mentions that could be categorised as representing its many dimensions and limitations. In the drafting process, I gave a presentation on the paper to NCRO/CHA staff, hearing from them whether it felt right.

Interestingly, it was an expatriate CHA staff member who first noted the other, negative connotations of the term 'exposure'. Her attention as an experienced HIV clinician accustomed to the specific technical language of exposure to disease, and as a person from elsewhere, was drawn to the health risks of the city. The NCRO staff, and research participants, tended to use the term specifically to talk about opportunities for growth. Her insightful

271

comment helped me better understand the potential of this fertile metaphor for conveying the complexities of life in Kisumu City to external audiences. As Abimbola, the editor of BMJ Global Health, has noted in ongoing discussions about the challenges of trying to 'decolonise' global health knowledge production, it is important to be attuned to and render visible to readers the moments when a 'foreign gaze' is being applied, and to what ends, i.e to interrogate 'what we mean we say we' (Abimbola, 2019, 2020). Abimbola focuses mainly on authorship/writing practices in global health. The paper adds an additional layer to this insight, being an exercise in how to incorporate and account for moments of 'foreign gaze' across the whole process of ethnographic learning and writing.

The on-going connections I have kept with a few of my own research participants, particularly being able to bring them back into discussions periodically about these things, has also helped act as a litmus test for the durability of the potentials of 'exposure'. They have also shown how the 'gaze' of both a NCRO/CHA research participant *and* an ethnographer's research participant can change. Or, rather, following my earlier discussions of multiplicities: multiply. The story of one of the research participants included in the paper is that of Min Favour. My engagement with her story starts when she was a research participant trying to manage unemployment, single motherhood, her own HIV diagnosis, and preventing passing on HIV to her baby. By the time of final reviews of the paper, she was more 'exposed', being a degree holder, had studied a bit of anthropology, and was working as a social science interviewer doing similar work to what I had been doing when we first met. When she read a draft of our paper she commented, among other things, that 'Actually, I didn't really get what you were doing back then. Now I see.' If I were to re-write this paper again now, I could/should author it with her as well.

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<u>**SECTION A – Student Details**</u>

Student ID Number	226397	Title	
First Name(s)	Gemma		
Surname/Family Name	Aellah		
Thesis Title	Everyday life in a site of transnational medical research in Western Kenya: an ethnographic study		
Primary Supervisor	Clare Chandler		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

<u>**SECTION B – Paper already published**</u>

Where was the work published?	Journal of Modern African Studies		
When was the work published?	2016		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	No	Was the work subject to academic peer review?	Yes

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273

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	The final paper is a revised and expanded version of a paper I wrote (sole author) and presented at an earlier conference. Both authors were involved in data collection. The text of the final paper was developed equally. I took the lead on the sections on Seeking Exposure: Staff (p.400-408) and Seeking Exposure: Research Participants (p.408-415). I am the corresponding author for this paper.

SECTION E

Student Signature	Gemma Aellah
Date	17/09/2019

Supervisor Signature	Clare Chandler
Date	21/09/2019

*Seeking exposure: conversions of scientific knowledge in an African city**

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A B S T R A C T

Transnational medical research has become a common feature in many parts of
Africa. This paper explores the contribution such activity makes to the social
and economic lives of those involved, including both trial subjects and local
staff. By considering the value of the 'exposure' that involvement brings to
staff and research participants, we reflect on the conversion of scientific knowl-
edge into practical knowledge and its value to sustaining precarious livelihoods
in an economically fragile city. We consider the interplay between science and
sociality and argue for a need to take seriously the circulation of scientific knowl-
edge beyond the confines of expert spaces.

INTRODUCTION

December 2009. In an African city two women prepare to leave their houses for the day. Emily,[1] a single mother and nurse working at a transnational medical research centre, packs the second-hand clothes she bought at the market and is planning to resell to her colleagues. She says goodbye to her daughters, reminding her house-help that she will return late because she wants to use the office computer to study for an online diploma course. Emily leaves her rental flat above a shop, taking her employment ID card. Avoiding rubbish strewn across the road, she boards a public minibus. The blaring bus radio promotes male circumcision as HIV prevention, reminding listeners that this city has the highest HIV prevalence in the country.

Meanwhile, in her mud-walled bedsit, Jennipher, a research participant in an HIV prevention trial, prepares breakfast for her husband, who does roadside radio repairs. The charcoal briquettes she makes from coal dust and clay to sell to her neighbours are piled in the corner. Jennipher packs a bag with a cloth and flask of porridge for her toddler who is freshly bathed, powdered and wearing a frilly dress. Today Jennipher is taking her daughter to the research centre for their final visit. She plans to ask the doctor to write her a recommendation letter for a peer-education position she has seen advertised at an HIV Treatment Centre. Jennipher did not complete school and hopes a note from the doctor describing her knowledge about HIV, acquired through her trial participation, will suffice. She grabs her research participant ID card and walks to the centre. Roadside billboards advise her to carry a condom, call abroad from 10 bob a minute and invest in shares. She passes signposts for various HIV-related NGOs and tents used for mobile HIV testing. She enters the 'Obama Gate' to the public hospital compound. There she passes Emily, the study nurse, alighting from her minibus. They catch each other's eye and smile, as both display their ID cards to gain entrance to the guarded research centre within.

Emily and Jennipher live, work and plan for their families' futures in uncertain situations in an African city. In doing so, they both engage with scientific knowledge involved in the practices of HIV/AIDS research. One is a research participant in a trial to reduce mother-to-child transmission of HIV conducted by a parastatal National Clinical Research Organisation (NCRO) in collaboration with a Central Health Agency (CHA) from the Global North.[2] The other is a former government nurse working for the same trial, forging a new career in medical research. Drawing upon the narratives of research staff and participants like these, and ethnographic observations of HIV research work over several years, this paper explores the, sometimes unexpected, movement of scientific knowledge around a 'trial community' (Geissler 2011) and its relation to the identities, imagination and ambitions of people involved.

Many parts of Africa are experiencing the profound impact of large-scale biomedical research programmes, intertwined with much larger transnational HIV/AIDS interventions (Crane 2013; Prince & Marsland 2013; Geissler 2015), both premised on a broadly 'experimental' logic, generating knowledge as they go along (e.g. Nguyen 2009; Rottenburg 2009). By focusing on the production and use of scientific knowledge, our paper aims to reflect on the interplay between science and sociality in an African city today, contributing both to our understanding of post-colonial science and the conditions of precariousness that shape 21st century urban life across the continent (Cooper & Pratten 2014). We draw on a metaphor of 'exposure', which emerged directly from the narratives of our interlocutors, to explore the movement and remaking of scientific knowledge in this exceptional, but not singular, space of hyper-medicalised development. Using this fertile metaphor, we follow the energetic radiation of knowledge through, outwards and back to the 'trial community', knowledge that often changes on its journeys, sometimes doing good, sometimes not, but always intensely productive.

Scientific knowledge in a researched city

We use 'scientific knowledge' as shorthand for knowledge that results from scientific work in a given place, and that retains connections or reference to its scientific origins. We are not focusing here on the abstraction of 'Science' as in the making and circulation of scientific facts in a global scientific community. Anthropology already has a strong tradition of prising open the sociality of making scientific facts (Latour & Woolgar 1979). Instead, we look at a more obviously localized circulation of knowledge; the epistemological 'spillage' or 'radiation' of scientific work itself. This may include 'proper' scientific end products like statistics and publications, but much of it consists of practical knowledge created through production processes: technical procedures, habits and behaviours as well as social strategies, modes of self-presentation and of relating to co-workers and others. It also includes career ambitions and lifestyles. Such knowledge is not necessarily aimed for, nor always formalised, as an outcome. It is not always recognised or made explicit as significant. But its production is evident across all the spaces in which medical research takes place. In our ethnographic field-site, for example, we witnessed the 'radiation' effect of scientific work in a form of self-knowledge referred to as 'positive living', vital for HIV+ workers' success as peer-educators, or in the intercultural

communication skills national staff developed to accommodate trans-national collaboration, and their adaptation to specific workplace styles – technical, linguistic and social. Epistemological 'spillage' radiated out even further, beyond the clinic into the everyday lives of re-search staff and participants, where we saw research participants draw upon trial benefits (such as transport reimbursements, trial participation certificates and new personal contacts in local health systems) to nego-tiate better lives for themselves. We witnessed it in the struggles of poten-tial participants to navigate the landscape of medical research and intervention to secure the best possible healthcare in a fragile, uncertain system. We also saw it in the biographies of staff; in the choices they made regarding where they lived, how they lived, what they studied and what they aspired to. All of this, we argue, constitutes vital 'scientific knowledge'.

Rather than excluding this type of knowledge from what is properly 'scientific', we consider it here in a continuum with more obviously 'scientific' knowledge of facts, technologies and apparatus. We explore the contribution that doing medical research makes to the broader lives of those involved, what scientific knowledge does for them, and what they can do with it in their lives in an African city. This means attending to the circulation of scientific knowledge beyond the confines of expert spaces and scientific production.

Common sense understandings of such extension of knowledge, as a transfer or transmission, diffusion or dissemination of knowledge, imply a movement of knowledge between places and people – global to local, experts to laypeople, science to everyday. In such renderings, knowledge remains (ideally) the same, while its 'context' shifts. If the knowledge does change along the way, this reflects simple distortion due to insuffi-cient communication (e.g. Fitzgerald *et al.* 2002) or external factors, as in the case of misconceptions and rumours.

More sensitive studies of epistemological extension look for creative shifts and unexpected effects of mobile knowledge, questioning the idea of continuity in extension (Fairhead *et al.* 2005; Stadler *et al.* 2007; Simpson & Sariola 2012). We too explore the somewhat less expected knowledge that arises from trial participation. Our interest is directed at social and political-economic processes, and on the value of knowledge in the moral economy of HIV intervention (see Prince (2012) for a discussion of HIV and political economy). The question about extension is then less about the *transfer* or *translation* of knowledge from one group to another than about the *conversion of* knowledge from the operation procedures of a clinical trial and the scientific protocol

into other forms of value, beyond that of universal scientific truth. Hereby, the problem of knowledge cannot be separated from that of social differentiation and economic practices – focusing on the clinical trial not as a matter of cognition but a site of value production (Cooper 2008; Kelly & Geissler 2011) and on knowledge not as a property but an asset continuous with, and convertible into, material conditions of life.

Ethnography of an experimental community

The observations presented below were gathered during ethnographic fieldwork (2007–10) at the NCRO/CHA field-station, one of the largest and most prolific sites of bio-scientific production in sub-Saharan Africa. Located in a city with a population of *c.* 400,000, it is the largest private employer in the region with about 1200 staff. Running multiple clinical trials, epidemiological and observation studies and a health and demographic surveillance system, the station touches upon the lives of several hundred thousand people.[3]

The city

With at least four other major transnational medical research organisations in addition to NCRO/CHA, as well as numerous smaller operations and university research departments, medical research activity permeates this city.

Transnational collaborative research began here after World War Two. NCRO/CHA collaboration pre-dates the HIV epidemic by 20 or so years – malaria is another of the region's disease burdens – but has rapidly intensified and professionalised since. This also reflects a wider HIV economy. By 2011 there were 117 NGOs with headquarters in the city. Fifty per cent reported HIV as their main activity.[4] Previously a calm but important trading post, the city entered a period of decline in the 1980s/1990s with reduction of growth in key industries like fish/cotton processing and breweries. Today economic recovery has taken the form of an economy fuelled by HIV, as well as a major oil depot and new airport. Investment is evident in new hotels and shopping malls, but precariousness is still a feature of everyday life. The city's uneven history is reflected in its physical landscape and city spaces (Geissler 2013).

Methodology

Our anthropological study was referred to as the 'trial community study', reflecting the idea that all those connected by science work – academics, funding agencies, policymakers, government doctors, researchers, participants, their relatives and the wider public – constitute a 'community', albeit a shifting, heterogeneous community bound together by multiple over-lapping networks across levels of scale (Geissler 2011). Our ethnography of this 'community' involved observation, conversations, individual and group interviews. We attended clinical and laboratory procedures, staff meetings, training and conference travel, as well as informal visits and social activities with staff and participants.

Our team consisted of ethnographers and assistants from Africa and the Global North, involved at different times. We lived in various city suburbs, including gated communities popular with expatriates and estates popular with science workers and participants. From these spaces we observed not just the specificity of NCRO/CHA in which we were embedded but also the wider landscape of HIV research and intervention in the city.

We interviewed over 100 staff involved in NCRO/CHA HIV research projects and conducted extensive, repeated, interviews with 89 HIV+ women participating in a study to prevent mother-to-child HIV transmission. The trial involved over 500 women recruited from antenatal care centres upon HIV diagnosis and followed for two years after delivery. We began interviewing these participants towards the close of the study, when some were still attending the clinic, and others had already 'exited'. We followed several participants after the end of their participation, visiting them at their (often shifting) homes, and joining them during their visits to public HIV treatment centres.

EXPOSURE AND EXPERIMENT

Developing oneself

Being here [NCRO/CHA] I consider a step forward. It's a kind of an exposure; I am able to develop myself. (Male senior staff member)

Our interest in the movements of scientific knowledge, linking people's daily life in the city, personal and professional biographies and scientific work, found an apt expression in a term oft-cited by our informants: 'exposure'. Many informants described how participation in medical research provided them with exposure to new knowledge, including

medical, pharmaceutical and technical expertise, as well as exposure to organisations and places, people and lifestyles, processes and connections.

For staff, this included opportunities for formal higher education, but also access to less formal knowledge: exposure to new ways of thinking, technologies, practices and networks, and imaginaries of futures engendered by this exposure. A third of staff directly cited 'exposure' as a key benefit of working in this leading transnational research organisation. Others used different words to portray their exposure to formal and informal knowledge through their employment. They spoke of meeting new kinds of people and of learning how to interact with them (e.g. foreign scientists). They referenced previously unseen connections and procedures (e.g. grant mechanisms), hitherto inaccessible places (labs, hotels, international conferences) and objects and resources previously out of reach – such as computing, internet or state-of-the-art laboratory equipment.

'Exposure' thus offers itself as a broader cover for this much coveted mode of partaking in scientific knowledge. Working with NCRO/ CHA – the leading research organisation in the region, as well as a key site of HIV policymaking and intervention – afforded staff the ideal setting to get exposed, partly because of the cutting-edge knowledge that research work produced, and partly because of the extraordinary power, resources and expertise invested in this collaboration. Exposure, as a rather nebulous form of knowledge-making, is particularly sought after and indeed vital in the contemporary post-HIV economy. In this new economy, formal professional training and higher education are somewhat devalued, and rapidly shifting knowledge-clusters, shaped by particular institutions, funding trends and fashions (e.g. HIV counselling and testing, 'family life training', male circumcision, peer education) are vital for finding employment and sustenance.

However, being 'exposed' also echoes older local meanings, sharing connotations with a term common since colonial occupation in many parts of Africa: 'enlightened' (Mayer 1963; Meinert 2009). Linking schooling with church and the production of modern upstanding citizens, 'enlightened' refers to being versant in modern technologies, able to handle wider connections, and, in consequence, better equipped for modern society and labour markets, as well as morally superior. One could say that 'exposed' has to some extent replaced the use of 'enlightened' between the educated post-independence generation (now retired to the countryside) and contemporary urban youths such as the NCRO/CHA staff. The encompassing connotations of exposure,

like its predecessor term, referring to the whole person's betterment, is captured in the analogy of developing a photograph, sometimes made explicit: 'it's like how you expose a chemical to the sun!' Or in the words of a female laboratory technician: 'I feel like I am almost fully developed.'

Exposure was not confined to staff. Research participants also sometimes deployed this term to describe knowledge – particularly around HIV self-care – gained through trial participation. But becoming exposed is somewhat different to the notion of being 'empowered' prevalent in HIV policy narratives about self-care (Prince 2013; UNAIDS and the African Union Joint Report 2015), which has a narrower focus on inner selves and individual rights. Exposure has a wider reach and, importantly, is a term with a chancier and more unstable quality. This is both its value and its risk.

The value attributed to exposure in the narratives of research staff and participants, therefore, cannot be divorced from concrete material concerns with making-a-living in a city with one of the highest HIV prevalences in Africa, a widening gap between the few in employment and the many outside and an ever-present sense of precariousness. When we look at how researchers and participants, such as the two described in the opening of this paper, make use of scientific knowledge we are also asking about what it is that makes a life. How do the people whose lives we have caught a glimpse of in our fieldwork imagine a meaningful life for themselves, their dependants and fellow citizens? What is it that drives them forward against the odds?

Another kind of 'exposure'

Securing a relatively stable existence in this city is challenging for many. So far we have referenced 'exposure' in relation to opportunity, but there is another kind of exposure faced by people: exposure to uncertainty and danger. Poverty, hunger, accidents, violence, illness and particularly, in the parlance of HIV research and interventions, 'exposure' to HIV infection. HIV prevalence is double the national estimate. Many people depend for their daily survival upon antiretroviral treatment, which has been provided free since 2005 through public facilities but which still reaches only part of the HIV+ population, and has important limitations in terms of organisation, diagnostic facilities and drug availability. Risk of exposure to HIV is a felt presence for everyone, as well

as, of course, the motivation and precondition for the high intensity of
HIV research.

Daily efforts to live in spite of HIV epitomise a wider economy of un-
certainty: an economic order in which life has to be sustained day-by-day
and where it never is certain whether needs – medical treatment, food or
housing, children's school fees – can be satisfied the next day. Regular
jobs as industrial workers or government employees – once a safe
option for every school leaver – have become an exception for
younger people, while school leaving certificates have lost much of
their former value. Most people work in the informal or 'jua kali' (lit.:
exposed to the hardship of the 'fierce sun') sector without a regular em-
ployer or stable income, and with minimal capital turnover or overheads.
'Jua kali' work was originally associated with making and repairing
cheap, useful products outside traditional factory settings, usually
along the roadside, but has grown to include all those 'hustling' for a
living by, for example, hawking clothes, selling small quantities of vege-
tables or otherwise creatively trying to find something to do when locked
out of formal employment structures (see Lourenço-Lindell 2010).

In our city this kind of unstable work is not only the province of the
very poor or uneducated but also comes in professional-looking guises –
 at times celebrated as the new African entrepreneurial middle-class –
that belie profound instability: itinerant computer repairers, insurance
agents, self-employed pharmaceutical representatives etc.

Most of the female trial participants we interviewed lived such precar-
ious lives. They were recruited from government antenatal care facilities,
suggesting they had low incomes and no private medical insurance. Of
the 89 women we interviewed, two thirds (67%) supported themselves,
or were supported by husbands, through 'jua kali' work, such as tailor-
ing, 'mobile' hair plaiting, or selling vegetables in minute quantities.
Husbands' work involved unskilled construction or touting for buses.
All these 'small small business' activities tended to be short-lived and
shifting.

Of the few trial participants not involved in such work, three were
supported by relatives and six were living off their domestic farms.
Five had husbands with more regular employment: as drivers, a shop as-
sistant and a printer's assistant. None of these involved regular pay-
ments. There were two nursery school teachers and one school
secretary, all in low-status private schools, receiving inconsistent cash-
in-hand payments. One mother was enrolled in teacher-training, and
one a government primary school teacher. This mother and another
who was a government driver were the only mothers whose families

had any contractual link to a formal organisational structure and accessed a regular salary paid into a bank account.

Many mothers also experienced social insecurity. Few could describe their marital situations as stable and not infrequently marital arrangement changed during trial participation: there were many widows, second or third wives, women describing themselves as separated from their husbands, single mothers and wives out of formal wedlock, who could not count on husbands. Understandably, these mothers valued what study participation could offer them in terms of free, good quality healthcare, occasional material benefits such as water pots, transport reimbursement and generally being taken care of.

These small-value transfers are part of a range of new opportunities available to poor, especially HIV+, people within the local HIV economy. Boundaries between research and intervention are porous, since many scientific and academic institutions have expanded from clinical trials into implementation and evaluation. NGOs and 'Community Based Organisations' have become a dominant entrepreneurial model providing diverse economic opportunities. Some of these involve short-term contracts creating new specialisations in novel forms of expertise like community mobilisation and representation, quality assurance, participant retention etc., which in turn have generated high demand for training and certificates from new educational institutions providing certification in 'HIV Counselling and Testing' or simply 'Community Work'. While employment in the non-governmental HIV sector is limited to those with formal education, high motivation and some good luck – and connections and access to information ('exposure') – many other people try to benefit from the HIV funds that circulate through today's urban economy through even less stable, 'jua kali'-style activities, including providing services, housing and transport, as well as various forms of 'volunteering' such research participation (for more on the wider African volunteer economy see Prince & Brown 2016), and the formation of self-help groups for the sake of 'income generation'. In 2011 there were 10,172 registered Women's groups, 16,353 Self-help groups and 1,105 Youth groups in the city[5] – an unlikely one group per 15 residents.

Perhaps more important to this economy than immediate material gains are the potential, imagined, possibilities of finding an inroad into the success associated with NGOs and large research organisations– big cars, smart dress, private healthcare, sponsored education and travel. When we asked younger people in the city without links to NCRO/CHA whether they had ever applied for work with NCRO/CHA and most

answered 'yes' accompanied by resigned laughter. Many applied numerous times, sometimes for jobs beyond their educational credits.

Working class

Those who do manage to enter the sector formally become members of what is known as the 'working classes' (those working for a regular salary). The staff we interviewed are leading representatives of this class. They are all secondary school graduates and include medical doctors, nurses and laboratory technologists, and others with more specific skills such as trial mobilisation, or HIV testing and counselling. Competition for positions is high – with 50–100 applicants even for menial jobs. Previous experience in research or NGOs is an essential asset, documented in candidates' thick portfolios of certificates. In comparison to many city residents, staff are already 'exposed'. Their employment provides them with a degree of security, including written contracts, salaries paid into bank accounts, and health insurance.

However, in some respects they are in a very different position to the original, post-independence 'working classes' of teachers and civil servants; their parents' generation (the 'Enlightened'). While these had spent most of their lives working on permanent pensionable contracts with government ministries, NCRO/CHA staff have at best one-year contracts, with higher perks but without lasting tenure and secure retirement, and their salaries and promotion depends upon foreign institutions with shifting expatriate staff and changing policies and budgets.

Fundamental uncertainty therefore applies thus to everyone in the city. In some respects, the line between an HIV researcher and a woman surviving on ARVs and selling tomatoes by the piece is porous; both lives are contingent on the vagaries of international donors. Even those who, from a poor participant's perspective, have 'made it' into employment remain 'exposed' to uncertainty. Transnational medical research exists in a state of permanent temporariness – or ongoing boom and bust – dictated by the politics of international funding, project cycles and of course the science and urgency of the disease burden itself. Staff, thus, expressed considerable disquiet around the time of the annual renewal of one-year contracts and the completion of research studies. If a contract ends or a new study does not immediately follow a completed one, private medical insurance is stopped, cars are sold and children's school fees are at risk. To enhance stability

and diversify options staff, like participants, run (as noted in the opening vignette) businesses on the side. These range from the substantial or skilled, investing in shops, farmland and rental properties, to the same 'small small' businesses as their participants, i.e. hawking clothes, vegetables, soda and mobile phone scratch-cards to colleagues.

'Just trying'

What most current economic activities in this city have in common, then – including even HIV research employment – is short-term temporality, dependency upon outside funding sources and resulting uncertainty. As a common expression in the city puts it, one is 'just trying'. While direct, literal struggle for survival certainly is not the condition of life for everybody, this extreme – and the spectre of death as the ultimate certainty underlying it – affects almost everybody's life. Everybody has relatives living under such conditions, and fulfils attendant responsibilities, and in the absence of social security, many are at risk of sinking to the level of mere survival. Life is a constant process of trying, of pursuing possibilities without knowing their outcomes (see Whyte 1997); an 'experimental' life, exploring uncertain, innovative ways forward, that at least as often fail as succeed.

In this African city, then, 'exposure' takes two very different meanings – danger and promise – as does 'experimentation', which can refer to the externally controlled clinical trials that provide the frame of this ethnography, and to daily attempts by inhabitants, including those collaborating on clinical trials, to move forward, ascertain sustenance and create some security in an uncertain terrain. It is against this background of exposed lives and everyday experiment that we now explore specific ways in which both research staff and participants 'convert' scientific knowledge into strategies for moving forward in life.

SEEKING EXPOSURE: STAFF

Pursuing degrees

Obtaining further formal education was an important part of seeking exposure for staff. NCRO/CHA is a scientific institution, where workplace hierarchy reflects academic degrees. Certificates, diplomas and Masters degrees featured heavily in future plans and as reasons for joining NCRO/CHA, which had an educational sponsorship programme.

Often future plans were expressed in terms of reaching somewhere distant, e.g.: 'my aim is to be a Principal Investigator! Ha ha!' (female community fieldworker) or 'I got really inspired and said "I want to be an international policymaker!"' (male nurse). Although such statements tended to be accompanied by ironic laughter there was an idea, supported by widely narrated rags-to-PhD biographies within the organisation, that such distant places could be reached through careful step-by-step planning and effort.

The field station offered some limited funding towards diplomas, Masters and even PhD studies. However, relatively stable wages and a yearly gratuity, made self-funding an option and many staff were enrolled in privately paid academic evening courses. NCRO/CHA also provided invaluable infrastructure for distance learning: high speed internet, new computers, professional mail addresses, subscriptions to literature databases that few African university students can access, and research data for thesis work. To utilise these resources for their 'schoolwork' and other assignments, staff often stayed late at their offices. Beyond material support, this international, high-aiming workplace also provided crucial exposure to knowledge about courses, their content, reputation and employability potential in a rapidly shifting market of HIV expertise, application procedures, deadlines, styles and references. NCRO/CHA thus provides a good *placement*, a position that opens up future opportunity, and provides an overview of networks and the terrain of possibility, as well as contact with others who could provide strategic and academic advice. This sort of learning is not simply a matter of '*who* you know', but knowing *where* to look, and when, and also of how to make oneself known, visible to opportunity, potential supporters and gatekeepers.

Learning on the job

Some directly research-relevant knowledge, such as computer skills, lab techniques, technical terminology or clinical handling procedures, was conveyed as part of institutional 'capacity building' by senior staff or external experts or, in the case of laboratory equipment, by the manufacturers. Other skills, notably in scientific dissemination, were acquired through paper-development workshops or conference presentation rehearsals.

Most staff's scientific knowledge, however, was gathered informally, through conversations, or observing others. Here, the concept of 'exposure' with its connotations of learning through being somewhere is particularly apt. Large organisations, notably transnational ones, develop their own sociality and work-related cultures; and working for such organisations impacts people's lives through formal and informal learning processes and habitual inculcation to work ethics (Wright 1994). In NCRO/CHA this involved knowing how to be a good researcher – in the sense of proper scientific conduct, and adequate discursive frames, such as the bioethics rhetoric of 'autonomy' or 'confidentiality', or the idiom of 'going the extra mile' to achieve valid scientific results and satisfy senior staff. Staff learned routines such as daily work rhythms and meeting procedures, and, not least, appropriate styles and manners of self-presentation. They described for example how they, in their interactions with expatriate management, had learnt to reference authority without appearing deferential, make their voice heard in professional meetings, and display personal initiative and independent thinking, which they found more highly valued, or expressed in different ways, than in their earlier experiences, e.g. in government institutions. Skills in intercultural communication and adaptation to the idiosyncrasies of a Global North government institution also extended from the workplace into the private domain – involving exposure to party behaviour, leisure and sports activities, or gift giving. Significantly, staff often helped each other, sharing and discussing ideas, reading each other's university coursework as well as offering support during family tragedies and – for those with clinical skills – sometimes providing informal expert advice and treatment to colleagues and their relatives.

'Being with' NCRO/CHA therefore involved habits and connections, ranging from preferred social venues and shopping places, gained and lost friends and social networking, to the embodied dimensions of speech, posture, hairstyle and dress. Some of these aspects remained implicit, others were consciously experienced, and either valued as exposure, or registered with some irritation; thus, some staff recalled how, during the initial days of their employment, their dressing styles and comportment had made them feel out of place among the well-groomed staff: 'I could hear my flip-flops in the staircase, among all these high heels' (female nurse). The same staff member likened the totality of the experience of entering the new work culture as: 'You feel like you are in another world, you are in another country.'

Pushing this analogy further, informal learning within this workplace also involved getting to know new people at the workplace and beyond –

globally and locally: 'I have exposure. I have met so many people that I never knew that I could meet in the world of HIV/AIDS. I have talked to them. I have shared with them. I have learned a lot' (male community technologist).

The pleasure that this staff member – who otherwise was particularly critical of the inequalities and shortcomings of transnational collaboration, even evoking its 'colonial' continuities – took in making connections across continents, national boundaries, race and class, was reflected by his screensaver displays, depicting him in various exotic locations, sharing moments of conviviality and touristic experiences with world-leading HIV scientists at international conferences.

'Fitting into the world map'

Thus exposure to scientific knowledge and attendant modes of being – in conferences, seminars, planning meetings and discussions with senior staff and overseas experts – implies a process of becoming part of a larger world: 'We have access to literature materials about youth intervention, about research work that is being done in many places, we are in a sense being fitted in the world map of adolescent sexual reproductive health' (male doctor).

Sometimes exposure to the wider world was through literal *mobility* as in the case of staff given the chance to travel to international conferences. Such opportunities were highly valued, not just for the chance to mingle with experts but also to see and experience more of the world and exchange ideas with others in similar situations. Under wider conditions of globalisation, mobility itself is often associated with the realisation of value. Some of the value realised or, we could say *converted* through scientific knowledge, was less lofty than the exchange of scientific ideas. One staff member for example, was initiated to the global clothes trade when talking with colleagues at a conference in Thailand, enabling her subsequently to set up a successful clothes shop in the city. A few staff even 'got lost' overseas, using temporary visas obtained through international conference participation to start new, potentially just as uncertain, lives abroad.

For the many who remained within Africa, these wider spaces and collectives, beyond the immediately accessible, were demarcated by senior staff's teleconferencing and international travel, data-faxing to research network headquarters, equipment supplies and maintenance by multinational firms, international technical standards and guidelines and

reliance upon foreign grants and funders. It was present, for example, in the common reference to the CHA's Northern headquarters, as in 'we are waiting for [HQ's] response', and related turns of phrase like 'back there', 'out here', 'coming down/out', with implications of a global, hierarchically structured space, or in the disembodied voice of a foreign 'principal investigator' emanating from a mobile phone at the centre of the meeting table. The imaginary of other (better, higher) places combined with the value placed on further education, noted above, into a specific vision of moving forward in life, out of one's present condition towards new places.

CHA has a particular place within African HIV and bioscience land-scapes – conducting not only large-scale, world leading research, but also shaping health policy across the continent, and implementing HIV care and treatment through government institutions. Attachment to NCRO/CHA provides an opportunity to work and learn in an environment that represents, like no other in Africa, the cutting edge of scientific – as well as clinical – expertise and possibility. It is the best place to get reliable information on the latest global scientific developments, and develop new ways of thinking about the world – a site from which both the world and one's place in it, and oneself, are transformed.

The recognition of the state of the art, inherently influential positioning of NCRO/CHA's scientific knowledge was not simply a matter of personal career advancement, good salaries or per diems. It also speaks of a search for innovation, potency, trustworthy knowledge and global standards, and reflects staff's curiosity and yearning for job satisfaction: being able to do what one knows one could and should do (see also Wendland 2012; Aellah *et al.* 2016). This was particularly the case for clinicians who, equipped with drugs, diagnostic equipment, laboratory facilities, and sufficient time for clinical encounters, felt able to perform their clinical commitments to their full potential and generate and engage clinical knowledge:

I've learnt about good clinical practice, about how to do certain things in research… Research is very strict in the ways that they do things. So, actually it builds discipline in you, I think I have loved that. (Female clinical officer)

Comparing research work to his previous government work, another clinical officer described how he now had the chance 'to think about patients differently', having the time and resources to get to the bottom of difficult cases, including the time to talk to patients' spouses and understand their social situations. Although these

possibilities were partly due to the need for valid clinical trial data, the situation also afforded this clinician a valued chance 'to treat clients so nicely'.

Satisfaction with doing good work – and doing good – also applied to other professions among the staff. A laboratory technologist described with pride how joining a research project exposed him to the newest technologies and techniques – 'we always know the latest things'. As well as pride in being on the cutting edge, he spoke of research as instilling in him a desire to want to do things with scientific rigour, contrasting this to working in the government and private health sector.

On this note, the exposure to new 'worlds' through work as discussed earlier also included exposure to different realities on a local scale and changed sensitivities. For some staff who had grown up in more privileged circumstances, exposure to other local communities, social classes and social experiences was as enlightening as exposure to leading HIV scientists and experts. This was more pertinent for community-based staff working outside the lab or office: 'I have got a lot of experience from this study, it has actually made me know that human beings have different needs and everybody is unique. I have come to socialise with the community. I have known a lot of places within the region.'

The promise and challenges of graduation and conversion

Staff drew analogies with graduation when describing their time at NCRO/CHA: 'This place is just a High School; we are moving on … Once we get through the High School we leave CHA and go to a different organisation in a different capacity, we go very far out there; so this is a learning place, a school until you get there' (female supervisor).

The metaphor of 'graduation' – a particularly sought after social occasion in this part of Africa, immortalised by photographs displayed in every living room – underlines the forward-moving nature of knowledge, and it implies a vision where NCRO/CHA is a step on the way rather than a final destination. Employment with research is time-limited and will end, the positive outcome of which is to move ahead to a more permanent or at least even better paid job. The particular attraction of this knowledge, then, lies in its convertibility and transportability. It is of value in the city's HIV economy, which involves related organisational structures and similar procedures and idioms, such as notions of participant autonomy, voluntarism, standard operating practices, evaluation,

participant flow, consent etc. which have travelled within the organisational networks of the HIV economy.

However, like the future after graduation, conversion is not always straightforward. The success of such movement depends upon the market situation, and upon the nature of the knowledge. In spite of the booming HIV economy there are increasingly many knowledgeable workers and competition among them is getting harder. When this is coupled with the ongoing boom and bust nature of project-based HIV research work, there were times when the harder, more painful, edges of the search for a better life revealed themselves in competition for roles in new projects. When some staff lost out mutters of patronage, sexual favours and corruption surfaced and the ethos of conviviality was harder to maintain.

NCRO/CHA's staff's pursuit of scientific knowledge in their city's leading institution for knowledge making and dispersal, and their emphasis on the value and marketability of such knowledge may, therefore, seem individualistic and self-serving. This recalls other ethnographic descriptions of African donor-funded AIDS programmes, which according to their Northern authors are inhabited by 'aspiring' elites involved in 'hunting and gathering in a terrain of AIDS NGO projects' (Swidler & Watkins 2009: 2), in order to 'remain buoyantly suspended above the froth of projects and donor interests through good contacts and placements' (Swidler & Watkins 2009: 10). However, the pleasure taken in good work and skill development, described by staff above somewhat runs against a depiction of utilitarian 'hunter-gatherers'. Moreover, staff's social conscience and civic commitment are also expressed through doubts held by the staff concerning connections between research and society, and between global standards and technologies, and local possibilities (see also Feiermann 2011). Some staff – especially in the laboratory – expressed doubt of ever returning to government work and circulating their newly gained knowledge in the public health sector, because of lacking resources to utilise their knowledge: 'Government is frustrating for many, many reasons; you don't have things to work with … and if you are someone who is lazy and you just want to pass time … you can get away with it' (male laboratory technician). But, importantly, this was often phrased as an uncomfortable thought. One supervisor, for example, emphasised that the technological and pharmaceutical possibilities within NCRO/CHA work were such that one was at risk of 'forgetting' about Africa:

But sometimes I say CHA can cheat you until you forget that out there in the world, everything is not like CHA. It makes you feel so comfortable in your work, that it might even hamper your creativity; you might start thinking like a non-African and look at the world like a non-African. But my own perspective is, that if you are in Africa and you are dealing with Africans you have to think like an African.

This quote illustrates a characteristic yearning for civic responsibility. Indeed, some staff, notably clinicians, developed, though their work experiences, a critical outlook towards social injustices and their health system, shaped by exposure to institutional inequalities and by facing the discrepancies between medical possibilities in transnational research and their inaccessibility to most Africans (see Wendland 2012).

Exposing others, opening futures

Another form of further extension and conversion of scientific knowledge is visible in staff members' attempts to convey their own exposure to their children. Drawing upon their relatively stable financial resources and awareness of educational opportunity, many staff prioritised the education of their children in their future hopes: 'I have so many dreams, [laughing] I want my boy to go to the best school' (female administrator).

In addition, most staff have taken on responsibilities for orphaned children of their kin. Thus, one nurse described how she is 'pulling' family members 'up behind her' as she progresses within medical research. Her family was decimated by HIV leaving many dependants in her rural home. Her aunt sponsored her secondary education and certificate in nursing, hoping she might become a future stabilising influence in the family. After experiences in mission hospitals she was employed by NCRO/CHA and after initially self-funding her further education, she eventually received sponsorship for Masters studies. Using her salary, the annual gratuity, and per diems saved from conferences, each year she gradually built up the number of relatives whose education she sponsors. Underlining the value of education, she compared herself to her brother who stayed home, married young, and now has several children. Yet she convinced even him to go back to finish school and start this process for himself and his own dependants. Other staff, too, talked about this social conversion of knowledge with pride: 'I can be proud because I am now furthering my education, and then I am supporting some other people, and I also intend or plan to support a pupil next year, who is joining secondary. So of course I account those as achievements' (male records-keeper).

Often, like in the above case, this process of conveying knowledge starts as soon as one earns a salary. This is a tough and uncertain effort. It involves careful budgeting, saving and triage, as well as facing unreasonable expectations and the possibility of educational failure. Working at NCRO/CHA is particularly useful, not just because of the higher wages, but because staff know what knowledge counts where and where best to attain it.

Peer-educators

As discussed earlier, the increase in HIV funding and the associated growth in income opportunities has created a generalised imaginary of possibilities among all city residents. The HIV+ mothers we interviewed represent – in the most part – a distinctly different economic and social class to the staff discussed above. Possibilities open to them for exposure and career development are, therefore, markedly reduced. However, there was one area where study participation, in conjunction with one's biological status as HIV+, was an entry point to a form of employment, albeit often as inconsistently paid 'volunteers'. This was the field of 'peer-education'.

Peer-education is the use of HIV+ 'peers' for counselling, care and general assistance in both research and treatment. Peer-education with HIV treatment centres represents a particular kind of 'voluntary' labour in this city. While officially 'volunteer' positions, most of the time volunteers receive a regular monthly payment and sign contracts. More significantly, volunteers are exposed to the formal workings of the organisation. They have to adhere to specific working hours, attend staff meetings and, to centre clients, appear as regular staff. In their day-to-day encounters with clients, they are holders of expert knowledge on HIV. Occasionally chances present themselves for some training or additional paid work, such as mobilising during mobile VCT sessions. Some peer-educators can make the transition to a formal contract as community health worker with the treatment centre, although this does require a school leaver's certificate.

Seven of the 91 mothers we interviewed became peer-educators in HIV research or treatment programmes after they exited the study and before the end of our fieldwork. Three were employed on temporary contracts by the study itself to act as peer-educators to other participants. They were later absorbed as regular staff on other studies or

moved on to better paid positions in external organisations. Others were working in various HIV treatment centres in the city and beyond. Peer-education as an economic opportunity for this group takes on significance in terms of both numbers and imagination when it is noted that this was, aside from one teacher and one government employee, the *only* actual employment held by any ex-study participants we interviewed.

Study peer-educators were generally valued for providing tender care, and spoken of lovingly by other participants: 'they were encouraging our hearts'. They also held a somewhat iconic status for both staff and participants – as a representation of what could be achieved and the potency of exposure. When one ex-study peer-educator who had obtained a car was spotted driving, both another participant and a doctor remarked on how well she was doing: 'She is even driving a car now!'

This particular peer-educator had used her salary to gain various counselling certificates and eventually applied for jobs in other organisations. In the time that we knew her she moved onwards and upwards several times, dropping 'peer' from her job title and developing a career trajectory indistinguishable, from that point on, from other staff. By 2016, when we shared a draft of this paper with her, she told us she was now a degree holder and social science interviewer herself with 8 years of experience working with various transnational research collaborations, commenting 'It's amazing. I really never thought that I was a source of encouragement to many. I mean, it is just totally amazing.' This peer-educator thus represents an imaginable but idealised and infrequent endpoint that creates a continuum between staff and participants in the circulation and conversion of scientific knowledge.

Placement

The study peer-educator described above seized upon her physical placement within the research organisation as an opportunity to capitalise on her exposure to people she might normally have not met:

I used to say to myself: 'God, when my boy reaches six months I don't want to be here and I want the study to give me a job so that I can be able to give him formula.' So that time I shared it with the (trial) doctor. She encouraged me to go and see the Principal Investigator. So I carried my baby, I carried my umbrella and I was so tiny. When he was called, he came in the reception. It was so nice. He carried my umbrella and my bag. Then I

explained to him what I wanted. He looked at my CV. There was a project I had done for a CBO and it really excited him.

This action – and subsequent changing trajectory of placements – was a source of inspiration that also, ironically, created some distance between her and some participants who couldn't make the same use of their placement in the trial:

We used to share the [waiting room] bench … but it sometimes happens to many people that when somebody is employed she changes. I found out we can't rhyme together [anymore] so I just kept away. She was picked to be a peer-educator because she was suffering. I felt bad because everyone is in need. Should I also go and say my problem so I can be employed? But my legs were just heavy for me to go.

The importance of placement as a way of opening up further opportunity was also experienced by participants who became peer-educators in HIV treatment centres after the study ended. Like staff, by virtue of being in a space of activity in the field of HIV, they had occasional chances to gather useful information. Sometimes this worked in rather refracted ways. The study had created a self-help support group for participants and encouraged them to join both for emotional support and as an opportunity for talks and small training sessions (safe water, memory books etc.). This inspired one mother to join a similar support group attached to her HIV treatment centre after exiting the study. There she became friends with one of the centre's existing peer-educators. When an advert was placed on the wall in the centre for new peer-educators, it was he who told her when and where to look.

Acquiescence of nomenclature and skills

Study participants received no formal training in HIV knowledge. But informally, in the process of being a study subject, undergoing clinical procedures and receiving counselling, learning the rules of the study and sharing with other participants and study peer-educators, they did gain specific knowledge that was not only of lasting use as an HIV positive person, but also convertible into social advancement for those that became peer-educators. One of these participants described how she had been asked to explain the terms 'adherence' and 'opportunistic infections' when she interviewed for a volunteer job, terms she knew very well because the study had been strict on adherence and had encouraged participants to come to the clinic frequently to treat opportunistic infections. A treatment centre coordinator, in turn, told

us that she had specifically asked another participant to become a peer-educator because she saw from her referral letter that she had taken part in a study and would therefore be 'knowledgeable and disciplined'. The use of the term 'discipline' is important here. As role models for others peer-educators are expected to be experts in their own self-care.

Certification

The convertibility of implicit study knowledge was made explicit when participants asked their study doctors to confirm their knowledge in writing. When one mother who later became a peer-educator at her treatment centre responded to an advertisement for community health workers shortly after the end of her study participation, she went, like several of her fellow hopeful ex-participants, to visit her study clinician because: 'I wanted the doctor to write for me at least a certificate to say I am from the study and know something about HIV, because they wanted a school certificate and I don't have one.'

Similarly, one of the ordinary study participants we visited proudly showed us her file of certificates, including a copy of her study referral letter (issued at the end of the trial to refer her for post-study HIV treatment) and her study ID card, side-by-side with her school records, letter of reference for a job as a petrol station attendant and the certificates for workshops on 'HIV Home based care and nutrition', 'Memory book making' and 'Taking care of the elderly' that she had participated in as a volunteer community health worker with a church-based NGO. This folder was a visible representation of her own valuation of the place and convertibility of scientific knowledge gained through study participation in her life.

ACCUMULATED EXPOSURE

Research participants' opportunities to convert knowledge are small and unsteady, compared with those of staff. But they can accumulate, as in the following case of a participant-turned-peer-educator:

In school Maureen had dreamt of training as a nurse. But when her parents died she was left to look after her sister, forcing her to leave school. Rejected by relatives, she struggled to find somewhere to live. After telling a shopkeeper her life story, she got a job but was often sick. She informally married a 'jua kali' man who paid her hospital costs.

When she became pregnant she found herself to be HIV+ during her first antenatal visit, where a NCRO/CHA staff recruited her for the trial. When she joined the study she knew nothing about HIV. Described as a 'good participant' by staff, after exiting the study she went to continue treatment at a donor-funded centre, where she joined a support group and befriended a peer-educator, who alerted her when they advertised for peer-educators. At interview she described her experiences in the research study and, as she proudly recalled, was able to answer confidently questions such as 'Do you know the work of Septrin?' She got the position and was paid the equivalent of one day's informal domestic cleaning work per day. Later, international funding was stopped but she continued working voluntarily because she thought this better than sitting in the house where she 'might be forgotten', invisible to other opportunities.

She continued to learn the work of the centre, being deployed in the pharmacy, the records department, and helping in drug adherence training for HIV clients. She also benefitted from improved quality of medical care, having direct access to doctors and her patient file to make sure her lab results were returned in a timely fashion.

She continuously hoped for employment: 'So we thought maybe these people the way they are appreciating us they will just employ us.' When she applied for a job tracing drug defaulters she went back to a NCRO/CHA study doctor to get a letter of recommendation based on her study participation. But she was eventually told by the treatment centre human resource manager that any employment would require a school leaver's certificate. She thus started secondary-school education at an evening school, partially sponsored by an expatriate researcher she had met during the study. Today she dreams of eventually getting her school certificate, becoming a community health worker or researcher and ensuring her dependants can go to school and beyond. This dream is a long way off. She is still working unpaid.

Maureen's story shows the diffuse and fractured nature of exposure and conversion of scientific knowledge, but also the potential of its cumulative effect – Maureen has moved on, at least a little, from where she started. It also shows its limitations and barriers, particularly related to socio-economic inequalities, captured in the following encounter between Maureen and a client at the treatment centre:

A smartly dressed client came to rearrange her next visit because she had a higher diploma exam in the capital city on that day. She encountered Maureen who, during the in-charge's absence, was registering clients and addressing queries. Carefully, and with quiet authority, Maureen told her this would not be possible. She explained the importance of the two-week visit after initiating ARVs, checking that drugs were working and monitoring side effects. She suggested the client should come early in the morning before travelling to the capital. Upset, the

client tried to negotiate, but Maureen stood firm. Eventually the client left in a huff, saying that she might fly to the capital to get there in time for her expensive exams. In contrast Maureen, who walks to the clinic to save the bus fare, returned to work, her books for the first year of secondary school in a bag under the desk. 'She probably won't come back', she told us, 'she doesn't understand the importance'.

Beyond Peer-Education

Some of the processes of exposure and conversion described in relation to the peer-educators were also experienced by the participants who did not achieve such status. The most obvious is the exposure to knowledge about one's HIV status and self-care developed through study participation. One participant described this process – of despair when discovering her HIV status to learning that there was treatment, and that she could have an HIV-negative baby – within a terminology of moving from darkness to light: 'By then I didn't know anything. I only knew that once you fall positive yours is only death. I was still in darkness. But they explained to me the benefit of taking the drugs and the study, now I just thought I could help the life of my unborn.'

Much of this knowledge was circulated not through direct teaching or dissemination but through the social experiences mothers gained whilst waiting on the clinic benches. Here, mothers learned that there were others in their situation, and felt encouraged that they were not alone and could live a normal life.

Producing an HIV-negative baby at the end of this HIV transmission prevention study could be seen as the ultimate conversion of scientific knowledge that participants could gain through study participation. In dissemination meetings the scientific results of the study – the very significant reduction in HIV+ babies – was thus celebrated as a scientific triumph but also a personal one, achieved through hard work, steep learning and strict adherence to the new knowledge. It was notable that when we visited those mothers whose babies had become HIV+ during the study, we generally did not find, as we had expected, scenes of despair and tragedy, but rather scenes of quiet hope, organised effort and loved children. These 'exposed' HIV+ children were being looked after by 'exposed' mothers, armed with new knowledge about how to make a life for themselves in this uncertain city.

There was a myriad of other, small, ways that study mothers found to take something of value from study participation and use it beyond. A few mothers, for example, opted to join other studies when the chance arose, having seen the benefit; others used their experience of

high quality care, as well as discussions with other mothers to make informed decisions about which post-study HIV treatment centre to attend, even occasionally changing centres or coming back to consult with study doctors over issues in their care. Here, the importance of making use of social connections in a healthcare system perceived as contingent on relationships and placement is highlighted (see also Reynolds Whyte & Etyang Siu 2014).

FUTURES

What kinds of futures are imagined and imaginable by the different trial community members? Concerns about maintaining lifelong access to donor-dependent life-saving HIV drugs as well as meeting their families' basic needs in a precarious economy continue to infuse day to day life for trial participants. However, the value placed on exposure to scientific knowledge reflects ways of trying for, and dreaming of, more certain futures. Trial participants' carefully collated folders of trial participation certificates invite us to consider what it would mean to take seriously the yearning for knowledge among all members of the trial community – including those whose participation at present is of a purely somatic nature. Could one utilise the opportunity for scientific and medical extension work afforded by medical research participants' attachment to knowledge-producing institutions (for periods that are equal to, or even exceed, the duration of common higher education courses)? Could one imagine then that transnational research programmes – many of which now look back at decades of local clinical trial work, and consequently generations of 'exposed' populations – actually become formal sites of public engagement with and teaching of science?

Other trial community members have their own ideas about how to move forward and stabilise the effects of their exposure to scientific knowledge. During our time with NCRO/CHA a suggestion that the community advisory board, made up of representatives of city subcultures (motorbike taxi drivers, religious leaders, commercial sex workers, women's groups, government doctors etc.), should register itself as an independent body and act as a permanent filter between the city and any research project that wanted to work in it was repeated again and again in meetings. And in the concern of the supervisor who struggled to retain the capacity of 'thinking like an African', we see an ideal future dreamed as one where science in

this city could/should be a centre positioned among centres, rather than a periphery or satellite of a centre in the Global north (see Moyi Okwaro and Geissler (2015) and Lachenal *et al.* (2016) for discussions of African scientists' perspectives on international collaboration in the context of asymmetric relationships).

<div style="text-align:center">CONCLUSIONS</div>

Our interviews and observations with African research workers and participants bring to view the value of 'exposure' to scientific knowledge in its broadest sense to those whose day-to-day labour and mutual collaboration are the foundation of transnational medical research. These effects are not limited to the long-term social good of scientific progress or to the immediate material benefits of trial participation, but extend to subject formation. Although we recognise that the structures of both global and local inequality and injustice within which medical research and healthcare operates exclude and stagnate as well as include and energise (see Sullivan 2012; Aellah *et al.* 2016), we argue that informal extension of knowledge from scientific work processes is explicitly valued and sought after by participants and staff alike, and we illustrate how such exposure, despite its chanciness, is convertible into better lives, ranging from gaining formal employment to much smaller movements in the daily search for a better life.

It needs to be stressed that these conversions of scientific knowledge between different productive settings in the lives of the staff and participants are vital *both* to the lives –sometimes the survival – of those working on the trial, and to the maintenance of the scientific production itself: without this process of extension, labouring for science – be it technical work or bodily participation – would be a lot less attractive to people living in the city. Without the benefits of exposure, the scientific production process would lose much of its privileged status among the employment opportunities in the city. Life science and everyday life are in this sense co-constituted, and the flows of scientific knowledge across the city link it all up and keep it alive. In African cities like this one, there is no clear separation of science and sociality. Transnational medical research has become a part of everyday social and economic life. In this city, it is no longer something new, imposed from outside, or somehow separate from 'national' everyday life. To staff and participants, it is, simply, part of life.

NOTES

1. We used pseudonyms and representative composite stories. Direct quotes are from interviews but surrounding information has been changed. Verbal informed consent was obtained for participant observation. Written informed consent was obtained for interviews and focus groups. Our research protocol was approved according to the ethical review processes of both our then employers and all collaborating research institutions: NCRO, CHA, and a third overseas institute for tropical disease who was also partnering on HIV research and intervention work during our fieldwork.

2. The local 'Centre for Global Health Research' of the National Clinical Research Organisation (NCRO) was mostly financed by its collaboration with the overseas Central Health Agency (CHA). The NCRO Centre consisted mainly of the CHA 'field station' although it had several smaller collaborative projects in operation, independent of the CHA.

3. The total number of people contributing to, and living off, medical research is hard to determine. In addition to staff, research depends upon a corona of 'volunteers', working in return for casual payments and 'reimbursements' e.g. peer mobilisers, women's and youth groups involved in recruitment and education efforts, interns etc. The total number of people contributing work to the medical research endeavour and gaining knowledge and material benefits from it, would thus be several thousand, even before considering the trial participants' somatic labour.

4. According to the local Non-Governmental Organisations Co-ordination Board.

5. According to the District Officer for Social Services.

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Chapter 7: "The earth does not get full": Understanding men, mood and avoidable deaths from AIDS in Western Kenya[14]

Figure 47: 'After a long day at the conference, I think I'll have a dip in the pool.' Painting by Johnson Ondiek (paint on cloth, 2010, jaoarts@yahoo.com).

About the death of Zeiki

I met Zeiki in 2008, shortly after moving to Kisumu City. We sat next to each at a volunteer workday at the NCRO/CHA city HIV research clinic. The researchers were planning a medical camp as part of World AIDS day and our task was to divide painkillers into individual doses in little plastic bags. Zeiki was volunteering because he, like many others, valued the potential opportunities 'exposure' to medical research might bring. He knew one of the study co-ordinators and sometimes helped introduce the HIV cohort incidence study team to community groups in his neighbourhood. Zeiki was relentlessly upbeat. He came to visit me in my office in the city centre and walked with me around the city, pointing out different NGOs. He often dropped by our office, and I tried to teach him how to type. Zeiki had a young daughter who he stayed with in a rented one room hut. He was estranged from his daughter's mother, who lived in Nairobi. Zeiki's small, ad hoc income came from the various informal services he offered to researchers and NGO-workers. At the time we knew each other he was helping an NGO set up their headquarters in a house in one of the upmarket suburbs in Kisumu. He had helped connect the NGO to estate agents and oversaw obtaining the office furniture and supplies. He also introduced them to several youth-groups to source their beneficiaries. In his spare time Zeiki managed a youth football team. He had named them the 'Flying Emirates' and he was looking for sponsorship for their football kit.

Towards the end of 2008 I realised I had not heard from Zeiki for a while. I found him in the District Hospital, next door to our office compound. He had been in hospital with gastrointestinal tuberculosis. He was cheerful when I visited him and thought he might be out of hospital soon. I met his sister, Mary, at the hospital. A week later she called to tell me he had been transferred to a national referral hospital. He died the next week. Mary came to visit me at my office. She told me that Zeiki had not been very good at taking his antiretroviral medication. Mary was HIV+ herself and told me she could never miss a dose. Together, we wondered why Zeiki could. It was

certainly not a case of lack of knowledge. He was exposed to the knowledge through his connections to HIV research and intervention. Zeiki was buried in an empty plot of land in his rural home. His parents and older brothers had all already died. Only his four sisters remained to mourn him. His daughter's mother came and collected his daughter. She did not take her to the funeral.

Zeiki's death was the first of several, similar avoidable deaths from AIDS related illnesses that I tried to make sense of during my fieldwork. The son of my host, Mama Unita, in Akinda, also died from multiple opportunistic infections when I first went to stay with her. This paper opens with the death of another man who died in his thirties, Atomic. In the paper I try to capture the aspects of the mood, or affect, that might contribute to difficulties in taking medication. I feel particularly passionately about this paper. I wanted to find a way to write about these deaths and to write in a respectful but useful way about them. It is easy to slip into writing with overtones of individualised blame. All these men had negative impacts on the lives of others. There is a version of this paper that could be written from the perspective of the women in their lives which might look very different. These men certainly despaired at times and behaved badly. But my experience of them was, equally, of joyful, energetic people who were, above all, trying.

I wanted the audience of this paper to be those directly involved in policy and intervention. But I struggled to find a policy orientated journal that would accept this paper in this form and was advised by editors that it belonged in an anthropological journal. But I felt that the inclusion of at least some ethnographically informed story telling was important. I feel there is a gap that needs filling with stories of complex, multi-dimensional lives. In this version published in Culture, Health and Sexuality, I hope to have found a balance.

Theoretical contribution

This paper addresses the things that matters to people as they navigate their lives in this place (my second research question). It addresses a matter of key concern to both transnational medical researchers and communities: young men struggling to adhere to their life saving HIV medication. But it also looks at what matters to these young men, their situated concerns, and shows how these concerns can outweigh concerns with adherence. As such, it shows that adherence needs to be understood in a broader context than acceptance (or not) of medication.

Transnational medical research as a field of practice is not foregrounded here. However, the paper offers insights that could inform future HIV research and intervention. In fact, HIV research conducted by NCRO/CHA researchers in collaborations with others in HDSS sites across sub-Saharan Africa after my fieldwork grapples with similar issues. In a recent paper entitled 'The Rebellious Man', researchers explored next of kin accounts of the death of male relatives from AIDs related complications (Skovdal et al., 2019). They were motivated, like me, by a concern with gender disparities in engagement with HIV services, and wanted to 'uncover the stories surrounding the most vulnerable group of men, namely those who die' (Skovdal et al., 2019 p. 1253).

In these next-of-kin accounts the men were depicted as rebellious and impossible to support. These despairing descriptions reminded me, somewhat, of conversations I had had with Zeiki's sister, and with Atomic's relatives. But the authors wrote that their qualitative interviews also served as occasions where kin relinquished any form of responsibility for the premature death of their relatives, and downplayed structural explanations. Their paper, therefore, provides valuable information about the way kin might explain the deaths through individualised psychologies, positing this may be because the interview encounters unintentionally subjected the participants to a perceived moral judgment, which they responded to. But it

offers little to help meaningfully explain the deaths. The Rebellious Man paper highlights both a need and a gap for ethnographically informed accounts, like the one I provide in the following paper.

In the Rebellious Man, kin described a 'lack of will to try to survive'. My findings show there is much more nuance to this. The men described in my paper never fully gave up hope and were often engaging in 'future-thinking' at the same time as neglecting their health. But their future thinking was undercut by unshakeable beliefs that they would not live to see 40 years. This belief, as I will show, was heavily influenced by earlier experiences of life amidst an HIV epidemic.

It is worth noting that attempts have been made within HIV research to operationalise hope as a measurable, quantifiable indicator of HIV risk, turning hope into an epidemiological variable (Barnett et al., 2015, Desmond et al., 2019, Hansen et al., 2020). As, I argue in this paper, I strongly advocate for the inclusion of mood into health policy considerations. I am less convinced that it is possible to turn it neatly into an epidemiological variable.

One of these papers on hope examines the applicability of a hope scale developed and validated on US populations in Uganda (Barnett et al., 2015). They convincingly demonstrate that the Snyder scale they use does work in Uganda in the sense that it is understood and has meaning when used in a Luganda-speaking population. Presumably, these means future interventions could potentially be assessed in terms of their impact on hope. But it still does not answer fundamental questions of hope for what? Or what brings hope, what blocks hope and why, sometimes, hope is not enough or (in the case of the young men in my paper) channelled in directions detrimental to healthy life.

This paper, therefore, also speaks strongly to the theme of living with precarity and the impact of this on future-thinking. It contributes to

anthropological literature addressing the felt experience, rather than concrete conditions of precarity. The young men described in the paper live in several historical conditions at once, carrying memories of earlier times with them in the present, and thinking of the future as they live.

Research paper

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311

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Understanding men, mood, and avoidable deaths from AIDS in Western Kenya

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ABSTRACT

A person diagnosed with HIV today might never experience AIDS, nor transmit HIV. Advances in treatment effectiveness and coverage has made the UN 2030 vision for the 'end of AIDS' thinkable. Yet drug adherence and resistance are continuing challenges, contributing to avoidable deaths in high burden African countries, especially among men. The mood of global policy rhetoric is hopeful, though cautious. The mood of people living with HIV struggling to adhere to life-saving medication is harder to capture, but vital to understand. This paper draws on ethnographic fieldwork with a high burden population in Kenya to explore specific socio-economic contexts that lead to a potent mixture of fatalism and ambition among men now in their thirties who came of age during the devastating 1990s AIDS crisis. It seeks to understand why some HIV-positive members of this bio-generation find it hard to take their life-saving medication consistently, gambling with their lives and the lives of others in pursuit of a life that counts. It argues that mood – here understood as a shared generational consciousness and collective affect created by experiencing specific historical moments – should be taken seriously as legitimate evidence in HIV programming decisions.

Introduction

Omondi and Atomic[1]

'HIV has really changed', Omondi, a hustler in his thirties living in Kisumu City, Kenya, wrote to me in 2014. 'Back in the early 1990s it was perceived as a curse in the backwaters where I was born. My first understanding of HIV/AIDS was grim and foggy. Tales of local men of repute in diapers and the huge cost of medication that left even well-off families in poverty before the death of breadwinners was hard to imagine for 14 year old me. As the number of orphans soared, we called it 'the life gobbler that clears all'. If you had AIDS, yours was only death. But now young people call that medicine [anti-retroviral therapy] *andila* - meaning it is just like swallowing kernels of corn.'

A few months after Omondi wrote passionately about changes in everyday experiences of HIV, he found himself in the city morgue. He had come to collect the body of

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his cousin Atomic, a lively computer-repairs freelancer, for the long drive to Atomic's final resting place high on a hill overlooking the Great Lake and the small homes, maize farms and many graves of their relatives. Over the last five years Atomic's life had oscillated between periods of crisis and fantastic effort towards big dreams and energetic entrepreneurial hustling. At one point he became the repair man for most of the city's internet cafes; the next he was arrested for participating in a scheme to illegally resell national telecommunications connections. He moved house often, depending on his fortunes. He trained to become a Pentecostal pastor and developed a heavy alcohol addiction. He married, and acrimoniously separated. His mood was unpredictable.

Atomic's eulogy, composed by Omondi, read:

> Born in 1980, Atomic flourished, healthy and aggressive […] But after surviving bouts of depression mid-2013, Atomic's life took a worrying turn. So did his hope, career and health. Several times Atomic tried unsuccessfully to pull himself up. Sometimes he would commit himself to prayer … He tried so hard to play his role as father, husband, brother, contractor and neighbour. He really tried. In the early hours of the 29th December, Atomic succumbed to TB. Atomic had his high roads and low moments. Some will praise him, others will vilify him.

In this setting a death like Atomic's at the age of 36 is not a surprise to friends and family, mourned with sadness tempered by resignation and the refrain 'not again. We are tired.' Such quietened anguish is most achingly captured in the words of Atomic's younger male relative, Bro:

> Uwwwwii … the earth does not get full. Death never tires or takes a break. Death has no sympathy for youth. How long, people of our home, since we buried? Are we, the youth, not to achieve anything in life?

Atomic's unnecessary, avoidable death, hurried along by alcohol, despair and not taking his life-saving and, by that time, widely and freely available once-a-day anti-retroviral therapy [ART] serves as a poignant reminder that even now AIDS remains, as a common refrain in East African school songs stresses, 'a killer disease'.

This paper uses the stories of Atomic and others, gathered during ethnographic fieldwork in Western Kenya between 2008 and 2012 and followed to date, to highlight the importance of unravelling the social, economic and historical contexts of a generational mood, or affect, that influences the life-choices and chances of HIV-positive men. It offers insights as to why men like Atomic struggle to continue living with HIV despite living with the disease at the most promising time in its history. I consider the shaping of life chances beyond conventional risk factors, bringing into view both individual biographies, collective histories and wider socio-economic structures.

AIDS after ART

Atomic, Omondi and their peers were living with HIV at a time where universal treatment access has, largely, been successful. People can describe anti-retroviral drugs as corn kernels because they have access to free medication in a single tablet formulation with lowered initiation criterion and reduced journey times to clinics that were unimaginable a decade ago. Yet, there is compelling evidence that maintaining the

rates of diagnosis, treatment and, crucially, suppression of viral load required to keep HIV a manageable, non-transmittable condition remains challenging. Analysis of mortuary-based HIV surveillance data in Nairobi shows that although 73.6% of adults living with HIV are on treatment, which should be leading to a palpable decrease in mortality, their risk of death is still more than four times higher than those uninfected (Young et al. 2017). This is somewhat unexpected given that ART has been shown to dramatically increase life-expectancy in lower-income countries (Nsanzimana et al. 2015). An inference can be drawn that some clients may be struggling with taking medication consistently. Another study in Kenya indicates that the rapid scale-up of treatment since 2010 is being undermined by high rates of treatment failure, with poor adherence a key factor (Ochieng-Ooko et al. 2010).

Men as a blind spot

HIV-positive men are particularly at risk of AIDS-related death and treatment interruptions (Ochieng-Ooko et al. 2010; Dovel et al. 2015). Reducing prevalence among young women has been the focus of global policy (UNAIDS 2014), with male mortality described as an 'HIV blind spot' (Shand et al. 2014). The two, of course, are intimately linked. The stories of HIV-positive men who struggle with adherence are also indirectly stories about younger women's increased HIV risk, especially in contexts where intergenerational relationships, domestic and sexual violence are accepted cultural norms (Gust et al. 2017). Often studies have argued that certain constructions of masculinity are a barrier to men's adherence and testing (Bwambale et al. 2008; DiCarlo et al. 2014), although it has been suggested that such explanations implicitly blame men and side-line more sophisticated structural explanations (Dovel et al. 2015).

Beyond blame and individualised risk factors

It can also be difficult to write about such things without, as has been argued, reducing complex lives to generic 'barriers to adherence' or individualised, decontextualised risk factors (Owczarzak 2009). Most work on risk has focused specifically on sets of discrete, sometimes correlated, behaviours. Here, I am interested more in the common thread that lies behind such actions - especially when seen over the course of a life - what has been described as 'affect' (Gregg and Seigworth 2010). Studies of affect explore the intuitive, hard to articulate forces or feelings beneath conscious knowing and actions. They move beyond ideas of individual emotions to think about how feelings are generated in dialogue with the world (Stewart 2007; Rutherford 2016). Within the HIV literature there has been some focus on feeling with discussions of the importance of hope and hopelessness (Bernays, Rhodes, and Barnett 2007; Kylmä, Vehviläinen-Julkunen, and Lähdevirta 2001). The causal links between poor adherence and hope is posited such that certain environments do not engender hope or long-term planning which, in turn, weakens self and community regulation of risk (Bernays and Rhodes 2009). But hope itself as a concept has been left relatively uninterrogated; considered simply as 'a positive expectation of the future' (Bernays, Rhodes, and Barnett 2007). For example, the study of barriers to adherence above listed

'hopelessness' and 'bad feeling' as reasons clients gave for non-adherence (Ochieng et al. 2015). What does this actually mean? There is a dearth of narrative between such descriptors that make it hard to extrapolate into meaningful policy action.

Furthermore, the feelings expounded in the stories of Atomic and others that I have followed over time resist simplistic bounded concepts like hope and hopelessness. Atomic could be both cheerful and ambitious, as well as driven to such pits of despair that he carried a rope to the fields thinking of hanging himself. And, although he did not envision himself living to see old age, he never stopped - in economic terms at least - planning for the future. A close examination of the specific socio-economic context can help understand such seemingly contradictory oscillating affects, and the correspondingly impact on his life chances.

In taking such an approach I am following anthropologists who have explored the social conditions of complex collective feelings or moods. For example, Scheper-Hughes unravelled the historical production of indifference to child death amongst mothers in a Brazilian shanty town, an indifference born out of social, economic and cultural logic, but one which contributed to the premature deaths of babies viewed as born 'wanting to die' (Scheper-Hughes 1993).

Anthropologists have also paid attention to collective mood among people living with HIV (Halkitis 2014; Morris 2008; Sagar 2013; Reynolds Whyte 2014). Writing about youth in pre-ART South Africa at the turn of the millennium, Morris (2008) reported a collective, inflationary assumption of imminent catastrophe; namely, that everyone will die. She asked about the effect of this inflation on 'the capacity of those who believe such statistics to orient themselves toward a future horizon' (201), noting that economic deprivation and employment concerns were equally, if not more, pressing, and that this assumption of catastrophe was expressed not as panic, but as rush – with risk 'now utterly internalised as the nature of life in the new South Africa' (229).

In contrast, Reynolds Whyte (2014) wrote movingly about the 'second chance' generation in Uganda. They draw on the work of Mannheim on the formative of generations to look at how shared historical experiences, especially events occurring at the time of coming into adulthood, 'magnetise' consciousness and produce a specific generational consciousness, representing a break in behaviour, feeling and thought to past generations (Mannheim 1952). They focus on the experiences of those people who contracted HIV before the global treatment scale-up, yet survived long enough to be initiated on ART. Describing this cohort as a 'bio-generation', whose consciousness was magnetised by the introduction of ART, they argue that the 'experience of a second chance adds a dimension of intensity and reflection to many aspects of life' (Reynolds Whyte 2014, 20). Such a consciousness or collective force provides this generation with a will to continue and to access treatment.

This is not necessarily the case, however, for the men aged 25–40 in Western Kenya in this ethnographic study. They experienced ART at a different time, and in a different social, political and economic context. Bringing together ideas of generational consciousness with affect theory, I now will explore the conditions that generate complex feelings among these HIV-positive men that make it hard for them to adhere to their medication. Like Reynolds Whtye (2014), I trace historical events like the 1990s AIDS crisis and introduction of ART that have had a formative impact on this generation's

consciousness. I combine this with a consideration of their role models and ideas of what makes for a good life, notably the joy and promise of the successful entrepreneurial hustler. When this playful, energetic and fast lifestyle is situated against a far-reaching hangover of being part of the first post-AIDS generation in Kenya and an unshakeable feeling that their life expectancy will be curtailed, I argue this creates the context for an affect swinging between ambition, indifference and despair, and an accompanying lifetime trajectory of action oscillating between industrious and suspect. Rather than feeling ART is a second life chance, this generation's collective heightened aspect of perception is the concept of (life) time as something experienced as always about to run out. Pinning down these feelings into one articulated emotion is difficult. Perhaps this is the reason that participants in the barriers to adherence to study mentioned above were only able to talk about 'bad feeling' (Ochieng et al. 2015). Here, the concept of affect is particularly useful as it describes feelings, moods or impulses beyond and beneath conscious thought and action (Gregg and Seigworth 2010). Ethnography involving following people's everyday lives over time can help explicate the layered dimensions of collective affect.

Methodology

In 2008 I, a white British woman then in my late twenties, moved from the UK to Kisumu city, Western Kenya, to work on an anthropological study of the practices of a burgeoning HIV economy made up of HIV science and intervention workers, receivers of 'intervention' and others trying to make a living from flows of international funding into the area. Estimates of HIV prevalence ranged from 15% overall to 40% among men aged 30–34 years in one rural location in the province (Amornkul et al. 2009). Ethnographic fieldwork involved observation, conversations, individual and group interviews, first focused on the networks emanating from a HIV transnational medical research clinic in Kisumu (2008–2010) (Aellah and Geissler 2016) and then continuing through doctoral research in Akinda[2] (2010–12), one of the rural field-sites for the transnational medical research organisation which hosted the study. In Akinda, I lived with a host family, following everyday experiences including joining youth and self-help groups. I participated in the daily routines of rural life, as well as conducting in-depth interviews and focus group discussions.

In accordance with the requirements of the ethical review boards of the London School of Hygiene and Tropical Medicine and the organisations involved in the transnational medical research collaboration that hosted this study in Kenya, written informed consent was obtained for interviews and focus groups, and verbal consent for participant observation. Omondi, Bro, and members of the friendship gang to which Atomic belonged reviewed this paper, giving permission to write about his life and death.

Following life trajectories

I first met Omondi, Atomic, and others with similar stories in 2009 in Kisumu City. They had moved from their villages in their twenties to attend college. In 2009, six

years before his death, Atomic was unmarried and cheerful. He soon made enough from his unregistered computer repairs business to improve his mother's rural home and construct a small, smart bachelor hut.

When I moved to rural Akinda in 2010, I met and followed several counterparts to Atomic and his peers; men mostly in their thirties who had not (yet) moved away to the city. I joined a 'self-empowerment' youth group which started off well. All members directly linked economic success with HIV prevention and dreamed big, talking of multi-storied chicken coups, fantasy hotels and securing government tenders. But by 2012, like Atomic, the lives of several of these men had also taken a turn for the worse, with one member chased out of the village at night on suspicion of harbouring 'bad people', leaving behind his girlfriend and baby. The energetic group chair, who by then had five young children, was also gone, the group's micro-finance loan with him.

In this paper I consider these rural and urban-based men as a cohort. They are from the same tribe, generation and region, and it is not uncommon to find rural-based youth spending periods of time in the city trying to 'make it', or for urban-based youth to return to their rural homes when things get tough. Doing ethnographic research over a longer period of time helped me follow their life trajectories through several cycles, observing changeable fortunes and, in the case of several of the young men, their early deaths.

Generational consciousness of AIDS

The men whose stories I draw upon here were aged 25–40 in 2011. Many were born when Kenya's average life expectancy reached its highest peak in the 1980s. Unlike people born later, some could remember funerals as relatively rare, special events. But many were also less than twenty years old in 2001 when Kenya's life expectancy started to plummet, and AIDS was a taboo, the word rarely spoken out loud (Geissler and Prince 2010). A cross-sectional study in 2003 found extremely high HIV prevalence in some of Western Kenya's villages, with around 40% among men in the generation above Atomic and Omondi's (Amornkul et al. 2009). This generation would have been their role models: older brothers and uncles, as well as their teachers and respected businessmen, then aged 30–34 years. Omondi recalled the first moment AIDS became a reality for him:

> I was walking at home in the bush and I saw my favourite teacher passing. By then I had finished school and was just at home, farming a bit and waiting to find what to do next. This teacher, I really admired him. He let us borrow his novels and we learnt about the world outside. He was always dressed so smart; he had these nice shirts from [the capital]. But that day he was so thin and slow. I nearly did not recognise him. He had soiled himself – that uncontrollable diarrhoea. I had heard of this scaring sickness, and of AIDS, by then, but I had not thought about in relation to me.

In 2006 the roll-out of PEPFAR in Western Kenya meant that ART was suddenly more widely and freely available, although with complicated regimes, severe side-effects and rationed to only the sickest in major centres (Brown 2015). By 2010/11, ART had become available in once -a-day, less toxic formulation, criteria for treatment initiation was relaxed, although still at much lower CD4 counts that in the Global

North (Brown 2010; National AIDS/STI Control Program 2011). Life expectancy was back to pre-AIDS crisis levels.

These men, therefore, had the dubious honour of directly experiencing, at a formative time in their younger lives, the effects of the greatest dip and then recovery in life expectancy in their community's history. This is a truly transformative shared experience. They lost parents, siblings, aunts, uncles, friends and role models to AIDS. They were now able to refer to taking HIV drugs as something as ordinary and easy (and, perhaps, as careless) as swallowing kernels of corn. But unlike teenagers born post-ART and the future 'AIDS Free Generation', they could not distance themselves from knowledge that death is still there and, in Bro's words, 'has no sympathy for youth.'

Post ART, although the notion that everybody with HIV will die is not anymore evidentially supported, a broader acceptance of the expectedness of early death per-sists and affects ideas about lifetime and a necessity for speed of transition through life stages. A hangover of doubt relating to the robustness of ART provision and the unreliability of donors and government continues and affects orientation towards a lifetime spent on ART. Such expectations are situated in a context where semi-legal hustler economic action is seen as the best chance of economic success for young people in an uncertain, neo-liberal economy. The idiom 'Get Rich or Die Tryin' popular in the rap songs listened to by Atomic and his youthful friendship gang at the turn of the millennium takes on a particular salience against their earlier experiences of HIV diagnosis as inevitable death in the 1990s and a continuing background expectation of early death today.

Expectations of early death

Throughout my fieldwork, a striking theme was an expectation of early death affecting people regardless of HIV status. In 2014, a Kenyan newspaper article stated that residents of 3 counties, including Akinda and Kisumu, – which are not the poorest, or furthest from health facilities - can 'expect to live a mere 40 years under today's social, economic and health conditions, a staggering 16 years shorter than [the country's] average of 56.6 years' (Okewo and Mungai 2014). My interlocutors agreed with this statement. It sup-ported an expectation that had already been frequently expressed: that life is likely to end by 40. In 2011, I had queried one father in Akinda about the literalness of this inter-pretation of demographic data: '40? But you are 39 now and healthy. So … next year you will die?' 'Well,' he laughed ruefully, 'that is our life expectancy.'

The article also quoted a professor who said the outcome of this expectation is a thought process of 'let me capitalise on time; I never know when this disease will strike me.' The potential impact on decision-making among men considered 'youth' is shown in a conversation I observed between Dave, a rural -based 35-year-old, who earned his living from co-ordinating a network of youth groups and his father, a retired teacher in his 60s. Talking about the difference between 'youth today' and 'our fathers', Dave's father lamented that Dave and his peers lived in a hurry - they weren't interested in adding to their homes and building wealth slowly but surely. Their philosophy of wanting everything at once was dangerous. Dave argued life today was different. Senior 'fathers' (at least those who had gone to school and got

the chance of government employment) looked forward to retirement as a time of growth and a chance to do business. 'Now', Dave explained 'not only do we not have the chance to get those jobs, we don't have time. We must hustle in a rush. We are not looking to our 50s to do our things. We only have now.'

The chair of the Self-Empowerment Youth group reiterated these sentiments when I asked why he and his wife had 5 children in such quick succession. He explained he wanted to get that part of his life done quickly: 'Now, I am finished with [that], I can do my things. I have plans.' The chair's need to rush through life stages brought friction with his parents when he wanted to build his permanent rural home before his older brother, breaking with custom, saying 'I don't have time to wait for him to organise himself.' The tension led him to destroy his bachelor hut and move his family out of his father's compound into a rental house. This was an unusual and economically problematic move as he found himself struggling to make rent each month. It also threatened the chance for his family to seek shelter in his bachelor hut should he meet an early death.

Doubt in drugs, donors and the state

Expectations of early death are intensified for people living with HIV in their thirties; by their memories of AIDS, the side effects of HIV drugs and doubts about the dependability of international donors and the government. Although Atomic and Omondi's generation do, sometimes, see that HIV is now liveable on ART, they also have memories of dozens of people who have died, despite going to a clinic.

Some of their older relations were initiated on ART at sub-optimal times and on drugs with more serious side-effects, when initiation criteria and regime choices were behind the gold standard of the Global North. Their bodies and faces might now have significantly changed, and they might be on second or third-line treatment regimes. Furthermore, Efavirenz, one of the drugs used in the main first line treatment combination (TDF/STC/EFV) between 2010 and 2017 has a well-documented side-effect, especially in the first month, of 'serious mental health problems'[3] including 'feeling sad or hopeless', 'not being able to tell the difference between what is real or unreal' and 'not trusting other people.' Niehaus has collected narratives of 'bizarre and frightening' intense ART-induced dreams among South Africans in a context where dreams are seen as portentous (Niehaus 2018). More research is needed to demonstrate the impact of this side-effect on the ability of already frightened people to maintain adherence, especially when dipping in and out of drug-taking. But anecdotally some of HIV-positive research participants talked about how taking ART was too 'heavy' and needed to be taken at an optimum time before ending a day's activity and sleeping to avoid a night that blurred nightmare and reality. This challenge is especially pertinent for those working at night, wanting to socialise, drink alcohol, or concerned about the night-time security of their homes, things more often associated with men.

This feared side-effect of Efavirenz was compounded by a more generalised doubt in the quality of drugs and the motivations of donors. Doubt was not expressed directly but manifested in conversations such as with a young man in Akinda telling me about a research study paying women to deliberately expose themselves to HIV, or

with an HIV activist, working with - and supportive of - a transnational medical research station who nonetheless felt there must be a parallel secret military motivation for their involvement. People often expressed the idea that a cure for HIV already existed in the West or that a cure invented by a national scientist had been deliberately shut down to increase Africa's dependency on its donors (Ankomah 1996). Concerns about the quality of HIV drugs and the national supply chain circulated, validated by newspaper stories and evidenced by research studies on the prevalence of fake drugs in-country, as well as corruption of global health funds scandals.

The pressure to feel grateful

As has been demonstrated in other contexts, the projectified nature of HIV care and treatment in countries dependant on donor involvement or where HIV treatment is rationed means that there can be a tendency for HIV-positive clients to be expected to be excellent, active patients and furthermore, to feel grateful for their salvation through medication (Bernays, Rhodes, and Janković Terźić 2010; Reynolds Whyte 2014; Nguyen et al. 2007).

Certainly, despair followed by heart-felt gratitude was the emotional experience of many HIV-positive pregnant women I interviewed. Less so for men. A requirement of being a good patient is patience. In 2010–11 the process of obtaining medication at HIV centres was arduous, with long queues and a need to carefully 'do as you are told' (Prince 2012). Those deemed not be taking their medication properly had to undergo 'defaulter training', the quantity of drugs released to them reduced until they were deemed responsible patients, requiring more frequent clinic visits. For those feeling a need to rush through life to hit goals like markers of financial success and respect before death, the degree of waiting and admonishment required to obtain drugs could feel insurmountable, with visits to the clinic a painful reminder that they had already 'messed' their lives. In the words of one participant: 'It makes me feel like a child back in school.'

Despite reduction in HIV stigma and discrimination in recent years, people still talked about the felt experience of stigma – especially what has become known as 'self-stigma'. Omondi, for example, would not share his status with his family despite his elder sister already having disclosed hers with no ill consequences. 'I just can't. They will think of me differently. I need to be the strong one for them.'

Get rich or die trying: the lure of the hustle

Against these expectations of an early death and lack of faith in HIV care and treatment, what is seen as a good life for men like Atomic? Earlier, I indicated that for men of Atomic's generation, a hustler lifestyle was seen as both the most accessible and as the most aspirational. During my fieldwork, most men in both the city and surrounding rural areas, were not able to access formal employment, following a period of economic and infrastructural decline in the 1980s/1990s. Now, the major sources of employment were offered by the HIV economy: NGO and research activity which limited opportunity to the few (Aellah and Geissler 2016). The rest relied on informal

Figure 1. The Starkuzz in 2002. Source: Omondi.

entrepreneurial hustling activities like Atomic's semi-legal telecommunications activities in the city, or combining subsistence farming and fishing with 'squad' motorcycle taxi services (occasional hire of motorbikes from owner-friends for single fares) in rural areas where opportunities for hustling were reduced (Aellah and Geissler 2016).

Hustlers, according to a self-proclaimed one 'live by the streets and know the streets.' They might resell products in different locations at inflated costs, provide transport services, rent out their electrical equipment or connect suppliers to customers – probably all at the same time. What they have in common is their ability to quickly change their activities and creatively adapt. Another hustler explained 'doctors they know how to treat people, lawyers know the law. We don't have any skills - except we know how to hustle. And you can hustle with anything if you have that heart.' In the case of the Self-Empowerment Youth Group this included hustling micro-financing loan organisations, leading to the Chair's quick departure from Akinda.

It is important to recognise that the hustle is more than an economic activity. It is lifestyle. It has a draw because of its joyful, creative energetic edge, as well as sinister capitalist drivers. Figure 1 above shows Atomic and Omondi with their youthful friendship gang – 'the Starkuzzs' – in 2002 when they were living at home by the lake, doing a bit of fishing and trying out ill-fated business schemes. They were waiting for a chance to be taken to college and dreaming of making it as hustler global rap-stars.

Their nickname was a play on 'starkers' (naked), and cousins (kuzz). They listened to Tu Pac and sang along to 'Get Rich or Die Tryin''. The picture was taken on the eve of the first free election since the country's independence. Using pocket money gained by clerking for the election they had thrown themselves a party. In that moment, they felt *unbwogable* (unshakeable and indomitable), a hybrid word made popular by the song 'Who Can *Bwogo* me? by musicians GidiGidi MajiMaji and adopted as the anthem of soon to be President Kibaki's whose National Rainbow Coalition, supported by Luo opposition leader Raila Odinga, successfully challenged 24 years of de-facto single party rule. Although Starkuzz had witnessed many deaths from AIDS, none of them were – or knew they were – HIV-positive at this time. Their fathers suspected their dreams of hustling, rap and shady business would soon reshape through college and marriage and merely represented youthful rebellion. Shortly after this picture was taken Atomic was sponsored by an older sister to go to college in Kisumu city.

Five years after the Starkuzz posed together by the lake, following a tumultuous contested election at the end of 2007 and the violence and inflation that persisted into 2008, the StarKuzz's rebellious global rap-star hustler role models began to crystallise in popular discourse into the figure of the 'hustler' as a more mainstream aspirational figure; an African entrepreneurial character associated with hard work, creativity and seizing opportunity, as well as shady dealings. The figure is placed in opposition to staid post-independence politicians with overseas education and impenetrable networks. The hustler as a 'digital' rather than 'analogue' caricature, with a resonance beyond East Africa (Di Nunzio 2012; Thieme 2013) offered a possible way to move forward in life when it seemed all others are blocked.

Post 2007, there have been many such hustler biographies to motivate the dreams of young men unable to access more traditional routes to success, not least vice-president Ruto, who markets himself as someone who came from 'the village,' as opposed to the president with his privilege and family political power. In 2013, the 'rags to riches' Ruto, then under suspicion at the International Criminal Court, declared himself the ultimate hustler. His 'Hustler Jet' grabbed a contract to transport politicians. Popular songs alternately praised the sweet VIP life of entrepreneurial hustlers and bemoaned the *kigeugue* or constant and unreliable 'turn-about' nature of people and circumstances in the current economic and political climate. Such popular self-proclaimed big hustler role-models like Ruto, Nairobi city governor Sonko, whose wealth is suspected to be amassed from illegal drugs, and musician Jaaguar, who later became an MP, and then was imprisoned, offer youth the promise of economic success and an aspirational, consumerist lifestyle that the route of formal education and formal employment cannot afford them. They also offer danger and slippage into illegality, as well as dramatic falls in fortune. Atomic's 'low road' moment of illegal entrepreneurship is a demonstration of this.

The dangers of the hustle

The Self-Empowerment Group was also touched by the lure of hustler dreams. By forming a group, individuals could access micro-financing and generate capital to invest, something they would otherwise be denied. In 2013, I heard that the group's

chair had disappeared with some loan money. He had earlier confessed to me that he formed the group as part of a hustle - a way of accessing quick loans for several business schemes because he had no other avenues to generate investment capital. A combination of big dreams of successful hustling, a feeling of *kigegeu* (that people could never really be trusted) and a sense of a need to rush partially contributed to the collapse of activities. Youth who had started off with good-ish intentions started to cross the line between good and bad hustling. I was reminded of the experiences of Omondi, Atomic's cousin, who had been part of a group specifically created to fight HIV after attending an HIV conference at church. They decided to grow immune-boosting vegetables to distribute freely to the needy, selling the surplus to a hospital. At first this ran well. Members farmed together and distributed money equally. But soon the group began to be offered more opportunities, including cement to build an office. Issues arose among members about who was accessing the benefits. Omondi, frustrated with being side-lined for some training events, oversaw accepting the cement. He had been saving the money from his part of the vegetable profits to buy a motorbike. His ultimate plan was to use the motorbike as a taxi to gain enough money to buy a car which he could then rent out to NGOs at a large profit. Together with another member he hatched a plan to 'lose' the cement but secretly sell it to a builder. With the profit he planned to buy his motorbike, reasoning this would quickly allow him to get enough money to replace the cement. But of course, the motorbike business proved slower and more precarious than in his dreams, the lost cement was never replaced, and he had to go into hiding. 'I really believed I could do it,' he told me wryly. 'I had a positive attitude!'

The impact of hustling on ART adherence

These cycles of trying, collapse and trying again can have a seriously destabilising impact on the lives of those also struggling with their commitment to ART. Such oscillations in fortune create breaks in routine, often involving moving away from home for a time, which make it hard to continue consistently with HIV treatment and the commitment needed to ensure regular care at a clinic. They also damage relationships with wives and girlfriends which could otherwise have been supportive of treatment adherence. But, perhaps more importantly, they create highs and lows in fortunes leading to highs and lows in mood and producing periods of stress where motivation to continue with the everyday effort of routine treatment is threatened, as well as periods when the most important thing in life is the pursuit of a new hustle, rather than attention to health, which anyway might feel a little like a less important and lost cause.

Towards an anthropology of avoidable deaths

This paper offers an exploration of the social, economic and historical contexts that help generate a collective affect among the 'bio-generation' of Atomic and his peers. Memories of the devastation of the peak of the AIDS crisis, experienced as teenagers, and an expectation that even now life is likely to end at 40 is coupled

with modern expectations of a fast-paced hustler life and tempered by doubts in previously trusted others like donors, governments, role models and friends.

Atomic and his friends live in a world where anything feels possible: a simple village hustler can become Vice-President and own a jet. But they also live in a world where this is not the experience for most. Experiencing the gap is painful. The affect, or force, unconsciously underlying their actions, could be described as the feeling of balancing on the edge of an abyss, below which lies alcohol, fatalism about the future, doubts in politicians, role models and international donors, as well nostalgia for the seemingly more predictable past of their elders, and the trauma and horrific deaths of the AIDS crisis experienced by their younger selves. It is not surprising that here some get lost and find it hard to believe in, and regularly take, their 'andila.' To describe this simply as 'hopelessness' does not give credit to the rich, complex depth of feeling involved. Capturing it requires writing in a way that evokes some of the flow and rhythm of life, what has been called 'evocative ethnography' (Skoggard and Waterston 2015).

It is important to take seriously complex emotions or socially and economically constructed moods, affects and bio-generational experiences into HIV policy decisions. It involves moving beyond a consideration of discrete risk factors to try to understand a common thread or impulse (here glossed as a mood or affect), that influences men's responses to challenges and experiences over a lifetime.

There are recent innovations that offer potential for taking such things into consideration. Social network interventions perhaps offer as a way forward (Salmen et al. 2015). Based on a theory that 'HIV infection too often falls solely and silently on the shoulders of infected individuals' (Salmen et al. 2015, 333), there have been interventions that assume collective responsibility for care and create treatment management collectives of friends, neighbours and kin whose aim is to support the emotions of those struggling with treatment. It is also worth considering the positive effect that more actively promoting Undetectable Equals Untransmittable campaign messages could have for those who find it hard to believe that HIV is no longer death, giving them a feeling of more time to live lives compatible with good treatment adherence.

Notes

1. People's names, and some surrounding contextual information, have been changed to maintain a degree of anonymity/confidentiality in accordance with the research protocol, as approved by the ethics review boards of the London School of Hygiene and Tropical Medicine and the organisations involved in the transnational medical research collaboration that hosted this study in Kenya.
2. Akinda is a pseudonym used to maintain a degree of anonymity/confidentiality, in accordance with the research protocol, as approved by the ethics review boards of the London School of Hygiene and Tropical Medicine and the organisations involved in the transnational medical research collaboration that hosted this study in Kenya.
3. www.aidsinfo.nih.gov (last accessed 28 September 2018).

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Chapter 8: Talking about ethics in transnational medical research[15]

Figure 48: 'David first learnt about the research study from his friends'. Painting by Johnson Ondiek (paint on cloth, 2014, jaoarts@yahoo.com). Created for Case Study 20 *Husband out of town: gender relations and decision making* (Aellah et al, 2016 p. 111).

About the death of Janet

In 2014, one of my research participants, the study co-ordinator of the IEIP in Akinda wrote to me to tell me that Janet had died. Janet was one of NCRO/CHA's two community liaison officers working in Akinda. She worked closely with the *nyamerwa* and, as such, was one the people seen to have the deepest understanding of the Akinda community. She had worked with NCRO/CHA since the 1990s, when she was involved in the creation of its AIDS resource centre. Her death in her 50s was a loss for many reasons. But one of these was the loss of a wealth of knowledge about concrete, everyday realities of conducting medical research. Janet was the one who the *nyamrerwa* turned to discuss the daily challenges and ethical dilemmas of working in their villages. Many of these stories I knew would never feature in discussions of ethical practice either at the NCRO/CHA field station level, or in global discussions of bioethics.

This chapter contains extracts from a book I co-authored with Wenzel Geissler and Tracey Chantler. It focuses on the kinds of things that Janet knew about conducting transnational medical research, things she shared with me, and things that I also observed during my ethnography. Here, I present the introduction to the book and three of the case studies that are drawn from stories collected during my fieldwork.

The Wellcome Trust provided funding for this book, which is available both as a hard copy and an open-source download. All of us involved conducted ethnographic research related to transnational medical research and intervention in Africa. And we all found ourselves encountering ethical situations that were often hard to talk about with our medical researcher colleagues. We wanted to find a way to communicate insights from our fieldwork to people working directly in transnational medical research.

The book is a collection of 42 fictionalised case studies of everyday ethical dilemmas and challenges often encountered in the process of conducting

global health research in Africa where the effects of global, political, and economic inequality are particularly evident. Our aim was to create a training tool which can begin to fill the gap between research ethics guidelines and their implementation 'on the ground'. The case studies, therefore, focus on every-day or 'relational' ethics: ethical actions and ideas that emerge through relations with others in context, rather than in universal principles or abstract regulations.

The fictional case studies are based on stories and experiences collected by the three authors, as well as contributions from colleagues working in other sites of intensive medical research across Africa. The stories have been anonymised, combined with each other, and substantially altered in order to provide 'stumbling stones' to start discussions, without naming real places or situations. I took the lead on the introduction to the book, the introductions to each section and overall editing of the content. I also did the layout and design work. I wrote more than half of the case studies, drawing on my PhD research. I worked with Johnson Ondiek to develop the illustrations that accompany each case study. I piloted case studies with researchers and hospital workers in Kisumu City, the community advisory board and village reporters in Akinda and with staff at the London School of Hygiene and Tropical Medicine.

Theoretical contributions

This material presented in this section directly addresses the research question: What ethical challenges emerge in the everyday practice of transnational medical research, and how can we best talk about them? The case studies offer a synopsis of the kind of ethical dilemmas that arise in everyday practice. The collated stories show that transnational medical research activity moves forward through a constant negotiation of relationships. Therefore, we organised the stories into several sections: those concerned with researcher-participant relationships, with community and family relationships, with staff relationships and with institutional

relationships. Keywording the stories showed they encompass a wide-ranging series of issues, including but not limited to: consenting, confidentiality, capacity building, data-sharing, clinical responsibility, corruption, friendship, north-south relationships, money, memories of past research, long term engagement, research versus care, standards of care.

The format that the book took is an attempt to address the second part of the question: how can we best talk about such dilemmas? As a collection these stories offer a flexible resource for training across a variety of contexts, such as medical research organisations, universities, collaborative sites, and NGOs. We hope they will encourage global health researchers to think – and talk – about their everyday experiences and practices, and about ethics, in a new light.

Providing material for training was a core objective of the Research Communities study from the beginning. What became more apparent during fieldwork, however, was that we needed to find a better way to talk to researchers about our findings than traditional journal articles. Our collaborators were not thrilled with articles a colleague wrote on some of the ethical challenges of conducting research across inequalities. The formal articles shut down, rather than opened-up discussion. Yet, they found in-person presentations on the same topics illuminating. Such presentations led to thoughtful engaged discussion. The idea of creating a collection of 'fictive' stories to act as stumbling stones to open the way for such discussions was born out of this.

I also feel committed to finding a way to inject people and their everyday struggles directly into such discussions. In a conversion between ourselves and an epidemiologist a complaint was made that anthropologists focus too much on individuals rather than the big picture. This might well be a valid concern. But here I am trying to show this audience how sometimes small stories can lead to discussion of big issues, and how a grounding in personal descriptions can give such discussions a much-needed sense of urgency. This

workbook is by far the most well received of the outputs of the Research Communities study among our collaborators and global health researchers more broadly. We used it as a basis for a symposium at the 2017 ASHTM meeting co-chaired with Professor Ogobara Doumbo from the University of Bamako. In this forum the stories were able to be used to provide a space for talking about awkward economic and political inequalities in the conduct of global health research right in the centre of that activity in the United States.

The case studies I have chosen to include here are drawn from sections in the book that cover researcher-participant relationships, community relationships and staff relationships. The first case study represents a reflection on positionalities and navigating boundaries between research and friendship. It encourages debate around what knowledge should be incorporated into findings. The second case study reflects on the meanings of inclusion criteria to research participants. In this sense, this case study also speaks to the meaning and value of 'exposure' that both researchers and research-participants take from transnational medical research activity. Here, you see a research participant creatively engaging with research as a way to access the best healthcare within a precarious landscape of care.

The final case study focuses on the inequalities in scientific collaboration across continents. It is inspired by the first time I went with NCRO/CHA researchers to an academic conference in Nairobi. This experience threw into sharp relief inequalities in global health research on several inter-relating levels. The conference was held in one of the most luxurious hotels in Nairobi. The previous day I had been in a research participants' impoverished mud thatched home. The next day, this research participant's life was data presented on a state-of-the-art LED screen in an international conference. The cost of the venue must have been immense. On another level, who travelled to the conference by air or road and who stayed where revealed inequalities among the NCRO and CHA staff. My expenses for the conference were covered directly by my research project. I was expected to provide receipts for the hotel and could have chosen to stay in the conference

venue. I chose to stay with a friend in her house for sociable rather than financial reasons and could afford a taxi there. The researchers I travelled with, however, saw conference per diems as a vital way to supplement their employment income. The cash influx paid for dependants' school fees or contributed to their masters' courses. They shared four to a cheap hotel room in order to maximise on their per diems. I am as painfully aware now as I was during that conference that I am part of this system of unequal access to opportunity in global health research.

Book Extracts

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Student ID Number	226397	**Title**	
First Name(s)	Gemma		
Surname/Family Name	Aellah		
Thesis Title	Everyday life in a site of transnational medical research in Western Kenya: an ethnographic study		
Primary Supervisor	Clare Chandler		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	As a book with CABI		
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SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	The material in this book is drawn from research conducted by all three authors, as well as case materials provided by the additional contributors. I took the lead on writing the introduction and authored more than 50% of the case studies. I also had overall editorial responsibility, edited some of the materials provided by contributors, created the workbook design, layout and structure and keyworded the cases. I worked with the artist to develop all the images used in the book and wrote the image captions.

SECTION E

Student Signature	Gemma Aellah
Date	17/09/2019

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335

GLOBAL HEALTH RESEARCH IN AN UNEQUAL WORLD

ETHICS CASE STUDIES FROM AFRICA

Gemma Aellah, Tracey Chantler, P. Wenzel Geissler

PREFACE

Conducting good, ethical global health research is now more important than ever. Increased global mobility and connectivity mean that in today's world there is no such thing as 'local health'. How we experience the effects of disease may be shaped by our particular social and political-economic circumstances, but the sick in one part of the world and the healthy in another are connected through economics, politics, media, and imagination, as well as by the infectiousness of disease. Global health research carried out through transnational collaboration is one crucial way in which people from far-flung geographic regions relate to each other. Good global health research, and the relationships it creates, therefore, concerns us all.

This book is a collection of fictionalized case studies of everyday ethical dilemmas and challenges often encountered in the process of conducting global health research in Africa where the effects of global, political and economic inequality are particularly evident. Our aim is to create a training tool which can begin to fill the gap between research ethics guidelines and their implementation 'on the ground'. The case studies, therefore, focus on everyday or 'relational' ethics: ethical actions and ideas that emerge through relations with others in context, rather than in universal principles or abstract regulations.

The fictional case studies are based on stories and experiences collected by a group of anthropologists who have worked with leading transnational medical research organizations across Africa over the past decade. The stories have been anonymised, combined with each other, and substantially altered in order to provide 'stumbling stones' to start discussions, without naming real places or situations.

As a collection, these stories offer a flexible resource for training across a variety of contexts, such as medical research organizations, universities, collaborative sites, and NGOs. We hope they will encourage global health researchers to think – and talk – about their everyday experiences and practices, and about ethics, in a new light.

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We would like to thank the institutions, researchers and research participants across Africa who generously allowed us to learn from their experiences. Although the case studies are fictional, we hope that they all recognise the kind of situations described and see them as fair representations of their experiences.

We greatly appreciate the feedback that we received from scientists, ethicists, clinicians, fieldworkers, technical and administrative staff, community advisory board members, students, ethicists, and others, when we presented this project and piloted some of the stories with audiences in Kenya (Kenya Medical Research Institute, Ministry of Health), Norway (University of Oslo), Tanzania (National Institute for Medical Research), and the UK (London School of Hygiene and Tropical Medicine).

ASANTE SANA, THANK YOU, TAKK

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INTRODUCTION

REGULATORY VERSUS RELATIONAL ETHICS

RESEARCH IS ABOUT PEOPLE

Global health research is not just about blood samples, laboratory technologies, data capture and translating evidence into health policy. It is about people. More specifically it is about relationships between people. It is the relationships between funders, government staff, local and international scientists, fieldworkers, research participants and communities, which facilitate the conduct of essential health research. A concern with 'relational ethics', simply put, means thinking carefully about these relationships.

It also means thinking beyond and outside of the wealth of regulations which have sprung up in the field of transnational medical research. Relational ethics are the complex and spontaneous momentary pursuit of morally right actions in personal interactions with other humans. They are guided not so much by formal rules as by individual and social conscience, and by particular overlapping identities and relationships. Good clinical practice guidelines will tell you what you need to include in

RESEARCH IS ABOUT RELATIONSHIPS

SATANISTS AT WORK

a participant information sheet for a research study. But they won't help you think through what to do, for example, if members of your team are labelled 'Satanists' by the community, if a participant says her child is hungry during a research appointment, or if one colleague makes a derogatory comment about another because of their gender, faith or ethnicity. Guidelines and regulations do not account for the 'messiness' of everyday encounters involved in global research practices.

ANTHROPOLOGY AND RELATIONAL ETHICS

Anthropologists, on the other hand, have made the messiness of life their subject of enquiry.

Anthropology is the study of human behaviour and human relationships. Anthropologists learn about this by spending long periods of time living in, and observing, different communities around the world. In our case, these were the communities of people involved in medical research in Africa.

For the past decade we have been involved in, and conducted studies on, transnational medical research in

RESEARCHING RESEARCH

different parts of Africa, in many cases at long-established, large-scale research sites. Our aim is to explore how medical research works in practice, and what ideas and hopes actors pursue through their work in their relations with others.

To collect data on 'relational ethics', we shadowed fieldworkers, sat in on senior staff meetings, and lived in the homes of research participants. We paid close attention to mundane practices and tacit knowledge, as well as hidden tensions, subtle cues, and complex moralities. We did this

ANTHROPOLOGY: LEARNING BY BEING WITH PEOPLE THROUGH ALL ASPECTS OF THEIR LIVES

over long periods of time so that we could understand individual encounters and incidents in their wider contexts. At the same time, we also engaged ourselves in research collaborations, sought our informants' consent, underwent ethical review and faced ethical dilemmas – much in the same way as our colleagues in the medical sciences do. We tried to learn from the ethical reflections that arose from our own research too and, needless to say, we more often than not failed to achieve definite, satisfactory solutions to the challenges that, ultimately, stem from the unjust distribution of wealth between the world's peoples, as well as between academic and scholarly institutions.

During this process, we gathered many stories – some we were part of, others we followed as they unfolded, or were about told by colleagues. These stories have been fictionalized for the training case studies, but they are not hypothetical. They represent live encounters between researchers, participants and communities, and they show that ethics in medical research is complex and fluid, involving more than regulations and rules. Personal, cultural, professional, and community moralities and perspectives are all brought into play in specific contexts and situations.

RELATIONAL ETHICS AND INEQUALITY IN AFRICA

INEQUALITIES ARE SOMETIMES HIGHLY VISIBLE IN RESEARCH

Reflecting on relational ethics is important in any medical research context, but particularly crucial in Africa where global health research invariably involves major economic and political inequalities. The vast majority of health research conducted in Africa involves partnerships between countries, populations, institutions and staff from the global 'North' (the former European colonial powers and their North American successors), and their counterparts in the global 'South' (roughly speaking the formerly colonized areas of the globe). This means medical research in Africa operates across huge differentials in power, resources, and knowledge. Both the current reality of these differences, and historical memories of colonial relationships and post-colonial attempts at redress, affect how people involved in research today relate to each other. We found that these differences were an underlying theme to many of the ethical dilemmas we describe in this teaching resource. With this in mind we encourage both facilitators and training participants to read and engage with the material presented in the second half of this book which explores the current and historical context of transnational medical research and ethics in Africa in more depth.

Such things are often hard to talk about. Being explicit about inequality – and its many small practical effects – can be embarrassing, even humiliating. It can also highlight irresolvable differences in opinion, and therefore seem futile. This is why this workbook uses stories, rather than real cases. It is our hope that discussing the stories will give global health researchers the opportunity to think about how they manage dilemmas and uncomfortable research encounters across power divides.

PATIENTS NOTICED THE SUBTLE DIFFERENCE BETWEEN THE GOVERNMENT CLINIC AND THE RESEARCH CLINIC

Our aim is to create a training tool which can begin to fill the gap between ethics guidelines and their implementation. The stories are designed to encourage practical thinking within constrained conditions, in order to improve the immediate conduct of medical research. But, at the same time we aim to raise awareness of the underlying, more challenging, issue of global inequality and how it affects global health research. The case studies are set up to encourage ethical deliberations on the stories to move between three distinct arenas of debate and action: debate over individual choices and behaviour, debate over institutional practices, and debate over wider 'structural' issues. An awareness of all three of these 'levels' operating in global medical research is, in our view, essential for all involved to move forward with a wider and more empowered understanding of ethical dilemmas.

RESEARCHER-PARTICIPANT RELATIONSHIPS

TRAINING CASE STUDIES

EVERYONE WAS WONDERING: WHO WAS CARO'S SMARTLY DRESSED 'FRIEND' WITH THE BIG CAR…?

RESEARCHER-PARTICIPANT RELATIONSHIPS
CASE STUDIES

How can we best categorize the relationship between researcher and participant? One is paid; the other is not, yet is not a customer or receiving a service. One seems more powerful, yet cannot function without the other; he or she cannot proceed in the relationship without the other's explicit consent. They are not friends, yet often share intimate details – albeit one-sided – about their lives. Their relationship is at once highly technical and sometimes deeply human. Furthermore, it is one which, while at first glance – in the moment of drawing blood or obtaining consent – seems to be a relationship between two individuals, in reality stands for relationships between whole populations, countries, governments and institutions.

COLLECTING INFORMATION, CONNECTING WITH PEOPLE

FURTHER READING

Special Issue: Fieldworkers at the interface between research institutions and local communities. *Developing World Bioethics* 13(1)

The stories in this section concern this unique relationship. They explore standard ethical concerns such as the informed consent process, coercion, and transparency. They also explore less commonly talked about issues such as friendship and kin-like relationships between researchers and participants, as well as the emotional struggle researchers sometimes deal with when faced with the conditions of abject poverty experienced by some participants. The stories look at relational ethical dilemmas, such as when research clinicians faced with sick participants are forced to decide whether to be foremost researchers, or clinicians.

FIELDWORK AND FRIENDSHIP:
WORKING IN YOUR OWN COMMUNITY

FACILITATOR'S NOTES

This story focuses on the blurred lines between fieldwork and friendship when researchers are employed in their own communities.

Many research organizations rely heavily on the unique expertise of local community interviewers (also called 'villager reporters', 'community health workers', etc.), who are valued for their local understanding and their ability to negotiate both individual and collective consent. However, the personal position of such a worker is delicate, as they may feel pressure to represent the interests of both the research organization and the trial participants. Many conflicts and misunderstandings between organizations and their target communities are related to competition for limited employment in an already challenging economic environment. Paid interviewers often have to deal with resentment of their own economic good fortune, at the same time as working to encourage community members to participate in projects for free. Local staff may also be working directly with research participants who are friends or relatives, which adds extra pressure. How do they handle this?

This case study is designed both to encourage staff members in similar situations to express their personal challenges, and to help senior staff better understand these challenges. As such, care needs to be taken when setting the ground rules for this discussion. The facilitator needs to think carefully about the possible consequences of encouraging staff to open up about this topic. Many research organizations have strict rules governing conduct between researchers and participants. Will

LEARNING OBJECTIVE

To consider the challenges of working for research programmes in one's own community, especially when competing for limited employment opportunities, and to identify possible solutions

KEYWORDS

Informed consent

Community-based fieldworkers

Friendship

Employment issues

there be any consequences for staff if you encourage them to speak freely? The range of the discussion should be made clear at the beginning and this may involve extra preparation to create a 'safe space'. For example, if possible it would be helpful to be able to assure participants that there will be no disciplinary action if they discuss personal experiences that may have violated regulatory ethics. If this is not possible, we recommend you steer the discussion carefully away from areas where disclosure could lead to staff being disciplined later. The final discussion should include a discussion and comparison of different types of ethics – regulatory, and relational or individual.

FIELDWORK AND FRIENDSHIP:
WORKING IN YOUR OWN COMMUNITY

THE TENSION WAS PALPABLE AS JENNY READ MAGGIE THE CONSENT FORM

THE STORY

Jenny is a community interviewer for a transnational research organization, and is employed on a casual contract to work in her own marital village, where she has a long history of community work. As well as casual work for the research organization, she provides voluntary home-based care for people living with HIV/AIDS. She is also the secretary of a local network of women's self-help groups, and a church teacher. She has helped the research station on a number of projects over the past ten years, and has gone on numerous training courses.

At the moment, Jenny is working on a project looking at the feasibility of distributing condoms to women door-to-door. Her role is to visit women in their homes, explain the study to them and obtain their informed consent. Today she visits Maggie, a younger woman living with her husband and child. Maggie is a teacher working in a nearby school so Jenny visits her on the weekend when she knows she will be in. Jenny and Maggie have known each other for a long

time. Before Maggie trained to be a teacher, Jenny organized for her to assist her as a village reporter on a research project. But, after that project finished, Maggie was not asked to assist again. Jenny says that this was because Maggie 'didn't know the right way to talk to people'.

When Jenny arrives at Maggie's home she is greeted cordially and invited to sit. After exchanging greetings and some local news, Jenny starts to explain the new study to Maggie. Soon, however, the atmosphere becomes a little awkward. Jenny stumbles over her words when reading the form and Maggie corrects her disdainfully. Maggie's husband arrives when they are still going through the consent form, and stays to listen. When they get to the end, Jenny asks Maggie if she is happy to be visited and given the condoms every month. Maggie says loudly, 'No, I do not consent. It is my right. Look here, it says I can say no. You need to say that it is my right to say no. Say that first.'

Jenny is a bit taken aback at Maggie's tone, but agrees that of course Maggie can say no. She looks for her pen. 'Look,' says Maggie, 'this lady is not prepared, where is her pen?' Maggie's husband is clearly uncomfortable. He asks Jenny to tell him what the research is about. But before Jenny can answer, Maggie tells him, 'Why are you asking her? I know what it is about.' Maggie and her husband start to bicker, and now Jenny is uncomfortable. She tells Maggie she will come back later for the consent form and leaves quickly.

Walking away, Jenny is clearly upset. A researcher accompanying her on the visit asks her what went wrong. 'I don't know,' replies Jenny, 'we used to be such good friends, and now look at the way she talks to me. She has become so arrogant since she became a teacher. I won't be able to do good work in that home again. Last month, she promised me she would take her child to the clinic for that vaccine study. She kept saying she was going to and then she didn't. In the end I arranged for a motorbike to take them. Then she left me to pay for it!'

'Do you think it was because I was there?' the researcher asks. 'Perhaps,' Jenny replies. 'I don't know. I think she is also having some problems with her husband. He has been staying away a lot. I did hear he might be getting a second wife.'

QUESTIONS

- ❓ There might be several reasons for the awkwardness that has developed between Jenny and Maggie. What might these be?

- ❓ Do you think Jenny's employers should know about what has happened? Why (or why not) might it matter to them?

- ❓ What should Jenny do, if anything?

- ❓ What should the research organization do, if anything?

I COULD BE A SEX WORKER:
MEANINGS OF EXCLUSION AND INCLUSION CRITERIA TO PARTICIPANTS

FACILITATOR'S NOTES

Sometimes researchers complain about participants being dishonest or lying in order to 'greedily' get into trials, and participants' motives are labelled as 'good' or 'bad'. However, the poor quality of public healthcare available in some places and the wider context of global health inequality make it difficult to pass judgment on participants' attempts to obtain treatment. Inclusion criteria for trials matter to researchers from the point of view of funding and scientific rigour, but for participants, they can be a matter of life or death.

This case study asks training groups to put themselves in the shoes of a participant who is keen to get onto a project. Whatever their final verdict on her actions, hopefully discussing the case will help them to understand her. You may want to emphasize how confusing the various options for care might seem to participants, and how they often need to become adept at representing themselves and their condition in order to navigate this complex landscape. The story is about accessing post-trial care, but from a patient's point of view, this is not particularly important. The same issues could arise around recruitment to a research project.

The story also points towards several wider issues which your group may like to reflect upon: what is 'fair' in the context of global health inequality; specific cultural attitudes towards what counts as 'sex work'; and the potential dynamics between researchers and study participants.

LEARNING OBJECTIVE

To reflect on differences between how research participants and study coordinators may view inclusion criteria, and to appreciate the reasons behind this

KEYWORDS

Recruitment

Post-trial care

Inclusion and exclusion criteria

Standards of Care

Money

I COULD BE A SEX WORKER:
MEANINGS OF EXCLUSION AND INCLUSION CRITERIA TO PARTICIPANTS

MAUREEN THOUGHT, 'OK, IF I GET MYSELF SOME TIGHTER CLOTHES I COULD BE A SEX WORKER...'

THE STORY

In this busy African city there are several large transnational medical research organizations, and many NGOs providing a range of care and treatment services for people living with HIV/AIDS.

Maureen is an HIV positive woman who has just exited a research study looking at the progression of HIV and Hepatitis B co-infections. During her time in the study she received her HIV care and treatment at a study clinic. She felt she received excellent care, as well as having her transport to the clinic reimbursed. She also enjoyed being a member of an active self-help group, and attending several training sessions for which she received certificates. Before exiting the study Maureen and the other participants are advised to think carefully about where they would like to receive their care and treatment post-research.

Maureen has done her research well on the options available to her. She has visited the various clinics and spoken to other research participants who have already exited the study. She decides that the best place for her is a clinic run by a Swedish organization which caters specifically for commercial sex workers. One of the friends she made during her time in the

study, a sex worker in a local bar, has told her that if she 'gets a spot' in the clinic she'll continue to get her transport reimbursed, and that there may be employment opportunities there for her as a peer educator. The only problem is that Maureen has not considered herself to be a sex worker before now. She has had a number of boyfriends and concurrent relationships, but actual money has not changed hands. Her sex worker friend tells her this shouldn't matter. She advises her to say that she is a sex worker with a number of 'long-term clients' or 'sugar daddies', rather than short-term engagements. She also tells her to say that one of her boyfriends (or 'clients') pays the monthly rent on her house. This, she advises, will help her qualify.

Maureen goes for an interview at the sex workers' clinic. She wears a little more make-up than usual and copies the dressing style of her friend. Her friend gives her a 'peer referral' to the clinic as well. Maureen is accepted at the clinic and also joins the self-help group. A few months later, Maureen applies for, and gets, one of the highly sought-after peer educator positions. Her certificates and training from the former study, as well as her ambition and commitment, have impressed the interviewers.

QUESTIONS

- ❓ What do you think about what Maureen does? Why does she do it? What do you think the consequences might be for Maureen, and for the organization?

- ❓ Why do you think the Swedish organization is only open to 'sex workers'? Do you think this is important from the point of view of people living with HIV/AIDS?

- ❓ Do you think it is important to Maureen that the first organization she receives care from is a research project and the second an NGO?

- ❓ Do you think Maureen will make a good HIV peer educator?

- ❓ Can you think of anything that could help avoid this type of situation?

- ❓ If you were a member of staff in the Swedish organization and you found out that Maureen does not think of herself as a sex worker, what would you do?

- ❓ Is it always clear what 'sex work' is?

- ❓ Is this situation also applicable to participation in research studies?

- ❓ What do you think this story tells us about how the presence of overseas organizations may be interacting with local culture?

❓ What could you say about the wider issues behind this situation? Do you think the overseas organizations are doing a good job?

❓ 'Sex work' suggests making a living from your body. Do you think this story can tell us anything about the interaction between medical organizations and research participants?

REFLECTIONS ON YOUR OWN EXPERIENCE

❓ Have you ever been in a situation like this where boundaries have been blurred (either as a member of staff, or changing the way you represent yourself to get something you need)? How did you approach the situation? What happened?

❓ Have you experienced similar situations in recruiting research participants for studies?

FURTHER READING

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STAFF RELATIONSHIPS

TRAINING CASE STUDIES

THE STAFF TURNED IN THEIR BADGES SADLY. "ANOTHER SHORT TERM CONTRACT…" THEY SIGHED.

STAFF RELATIONSHIPS

CASE STUDIES

CONNECTING WITH THE WORLD

The majority of global health research in Africa is conducted through transnational organizations. These are collaborative partnerships between one or more in-country national research institutions, and the overseas arms of one or more government or academic institutions from other countries. The situation is further complicated by the involvement of global non-governmental bodies, usually through the provision of funding. Often, specific research projects are multi-sited, connecting institutions and staff in multiple sites and countries. Project-specific funding also means that whilst some staff are employed on a more permanent basis, others are employed on a contract or even daily basis.

The nature of research and its requirements means that the staff population may include people with a wide range of educational backgrounds, from highly skilled and educated scientists to community mobilizers with less formal education, chosen for their knowledge of their local communities.

> **FURTHER READING**
> Redfield P. (2012) The unbearable lightness of expats: double binds of humanitarian mobility. *Cultural Anthropology* 27(2), 358–382.

Medical research, therefore, brings together staff from different national, cultural and educational backgrounds. It also means that in one research field-station there may be groups of staff employed under different salaries, conditions and regulations – and exposed to different opportunities for educational and professional development. The stories in this section look at some of the issues that might arise in these circumstances when staff from these different backgrounds relate to one another.

Some of these stories explore the relationships between 'expatriate' researchers from the North with African researchers. The chance to experience different cultures is often a motivating factor in seeking employment in medical research on both sides. However, the differences between their socio-economic situations are difficult to avoid.

Expats are often employed on short-term contracts, their children attend international schools, and they frequently travel to international meetings and conferences. Security issues can mean they are housed in gated communities, with special guards and secure vehicles. They

MEETING BY THE CLUB POOL

may have to follow certain rules about where they can go and what they can do whilst living in Africa. What difficulties does this pose for relationships between expat and African staff? Other stories in this section look at experiences and allegations of nepotism and corruption in medical research institutions in Africa. Perceptions – and often realities – of corruption in the public sector in Africa are high. How do these perceptions affect employment issues and staff relationships in medical research, when held by staff and communities?

PER DIEM:
PRACTICAL INEQUALITIES IN SCIENTIFIC COLLABORATION

FACILITATOR'S NOTES

This case study demonstrates how the economic circumstances of different staff shape their professional positions, and determine the practical choices they make. In this story, economic inequalities affect staff participation at a national conference. Some effects are subtle, like authorship positions, and others are more evident, like differences in accommodation and levels of physical presence at the conference. Different actors experience this situation very differently, and draw different conclusions from it.

The main aim of this case study is to think about how these inequalities emerge, sometimes in unanticipated ways; how this might affect collaboration; and how a more equitable situation could be achieved. It is important to remember that some inequalities have historical, political and economic roots, and that trying to redress the balance is not straightforward. Nonetheless it is important to engage with and discuss these inequalities in a constructive manner, to work towards lasting change. In this particular case, the discussion might lead to both simple practical changes in the way the conference is organized, and a more general consideration of long-term issues like discrepancies in salaries.

In exploring this story, students could reflect on the ways that equality is often taken for granted in professional scientific engagements. Inequality, however, persists in many ways, material and immaterial – and inequalities are perceived in various ways, filtered through different stakeholders' everyday life experience and historical memory. The ways in which we see or don't see, and engage or don't engage with, material inequalities shape how we live and work together.

LEARNING OBJECTIVE

To think about the various practical effects of inequalities between different types of staff, and to brainstorm both short-term and long-term solutions towards equality in the workplace

KEYWORDS

Employment issues

Money

North-South relationships

PER DIEM:
PRACTICAL INEQUALITIES IN SCIENTIFIC COLLABORATION

'AFTER A LONG DAY AT THE CONFERENCE, I THINK I'LL HAVE A DIP IN THE POOL…'

THE STORY

A workshop on HIV care is held in an international 4-star hotel, which offers well-equipped conference rooms, excellent catering, and pleasant garden and pool areas around which scientists can meet and talk between sessions. Rooms and meal prices are expensive, but the delegates' employers – international NGOs and their collaborators – pay a substantial per diem which covers all the costs incurred in attending the workshop, so this does not affect participation. Delegates include international policy advisors, scientists, local civil servants, and health facility personnel.

Most workshop presentations – well-prepared slide sets embossed with the relevant organizational logos – are given by African clinicians, policymakers and scientists, on behalf of co-authors who are predominantly overseas colleagues. Proceedings are carefully timed,

allowing for animated and friendly discussions after each paper. The conference chairs seek to involve and elicit views from all participants, regardless of their status.

Over dinner, a leading international NGO representative states how impressed she is by the large number of African presenters at this workshop, but wonders why so few of the local healthcare staff attend dinner and evening activities. The director of a large NGO consortium which sent many staff to the conference points out that all his staff, irrespective of their nationality or seniority, receive the same per diem for their conference visit, and that it is up to individuals to decide where they stay. But, he adds, 'Maybe next time we should just pay for the hotel for everybody.'

While international visitors and most managers from larger international NGOs (local and expatriate), as well as some Northern HIV care volunteers, stay at the conference hotel, most Department of Health staff, local clinicians and civil society representatives have chosen to stay elsewhere in town, in cheaper accommodation or with relatives. Due to traffic and long commuting times, many arrive late and leave immediately after the last presentation. They receive the same per diem regardless. The same evening, some delegates including a group of local HIV activists and junior health professionals from the regional hospital have gathered at a popular music venue. Over a drink they start to discuss their respective per diem rates, and jokingly compare how much they can save from this three-day conference. Based on her US$70 per diem, one nurse calculates that she will be able to take home almost her monthly salary after tax – just at the right time, before the school fees are due. She stays with a relative, and her two hours' local transport costs less than US$2.

Two Scandinavian student volunteers tagged along on this outing, preferring the lively music venue to the hotel pool. The evening gets late, and when everybody leaves, their new friends, who are familiar with the city and its dangers, take great care to find a safe taxi driver to take them back to the hotel. The volunteers depart, slightly embarrassed, as their friends jokingly point out, 'We must take care to get you safely back home from the ghetto!'

The next morning, everybody is assembled to listen to an honorary address given by one of the host country's most eminent doctors, who is well known for his advocacy of traditional medicine. Looking at his young colleagues, he praises the progress African medicine has made since the 1960s, a time when he had to leave Africa to obtain his degree. He starts by acknowledging the achievements of the international organization hosting the conference, and then recounts his research into herbal medicines, drawing attention to the achievements of African traditional doctors. Finally, he calls for more emphasis to be placed on local resources to tackle HIV/AIDs, warning against dependency on drugs manufactured by powerful global pharmaceutical companies. After that, a young woman from the international organization which sponsored the workshop thanks the speaker, joins in his praise of African doctors, thanks the sponsors, and closes the meeting.

QUESTIONS

❓ Inequality appears at many different points in this account. Try to identify different forms of inequality, taking note of who is involved and how the power differences become apparent.

❓ Equality, as a value and intention, is also present throughout the observations presented above. Explore where and in what ways equality is emphasized.

❓ Why is the manager of the expatriate NGO proud of their policy regarding per diem rates? What is made equal by them (and what is not)?

❓ What do you think junior local doctors would say if next year their hotel bill was paid for and they received no further per diem? Would this be more equitable? Why?

❓ Why are the two expatriate volunteers embarrassed by their friends' joke?

❓ What concerns over equality and inequality are expressed in the senior doctor's honorary speech? How might this be perceived by different members of the audience?

❓ How does the way we engage or don't engage with material inequalities shape working relationships and research practice? Why is it difficult to talk about hidden inequalities in a situation like this? What do you think should be done?

REFLECTION ON YOUR OWN EXPERIENCES

❓ Which inequalities are present among staff and collaborators in your own research setting?

❓ Which of these inequalities are spoken about and directly addressed, and which are not?

❓ Are there social settings or groupings in which inequalities can be discussed, and others where one does not take them up?

❓ Are there practices or situations in which equality, as a moral value, is emphasized or followed through on, within your research organization?

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Chapter 9: Okbichaloni (things aren't always what they seem to be. Know that for sure): Hustling, HIV and hope in Luoland, Western Kenya[16]

Figure 49: Painting by Johnson Ondiek (paint on cloth, 2014, jaoarts@yahoo.com).

About Gemx

In 2008 I left the UK and travelled to Luoland, and at the end of 2011 I returned home to try to write about it. Given that in ethnography, the researcher themselves is the research instrument, it became impossible to disentangle my own story from the stories of many of my research participants, especially those who became friends and where we became more involved in each other's lives. For me this was an especially formative time, a time when I made new and lasting friendships, where I got married and experienced the loss of children, as well as the joy of their surviving followers.

One of things I noticed most when trying to analyse and write about life in these places was the intangible but emotive rush of feeling accompanying the acts of remembering involved in analysis. To me, this was underscored by memories of music and the shared experience of dancing, especially in Kisumu City but also in Akinda, as well an underlying affect or rhythm to the everyday life that I had participated in. This 'rhythm' represents a mixture of joy with despair, and a particular approach to handling and feeling the effects of precarity. It is best captured in the Dholuo phrase '*okbichalni*'. There is no direct translation for this, but essentially it means that things might take you by surprise, but this experience of surprise is a predictable and knowable one. Over time, observing and participating in the ebbs and flows of life-events, I started to understand why this phrase resonated so much with people living in Luoland. It is also a good description of the process of doing ethnographic fieldwork and slowly gaining an ethnographic sensibility towards the flow of life in this place.

Theoretical contribution

I want, therefore, to end this thesis with a kind of song that I wrote for a special issue of the Irish Journal of Anthropology. This is my attempt to find

a way to capture on paper something of this feeling, whilst still keeping hold of the complexities and multi-layeredness of people and ideas.

Others have characterised this, and comparable African contexts, as representing situations where uncertainty is the dominant mode of being (Cooper and Pratten, 2015). Ethnographic work has described uncertain lives and risky futures in African contexts characterised by rapid urbanisation, absence of functioning national welfare states, the rise of neo-liberalism, increasing juxtapositions of massive wealth and abject poverty and, in some cases, extreme security crises and conflicts (Archambault, 2013, Cole and Durham, 2008, Di Nunzio, 2012, Honwana and Boeck, 2005, Mains, 2013, Thieme, 2013). In Western Kenya, however, I found that uncertainty is not quite the right word. Uncertainty was experienced as something entirely predictable and familiar. In the song I will present here, I have tried to capture this sense of predictable un-predictableness and the accompanying mix of optimistic-pessimistic spirit that people move forward with in life.

It is within this broader context that transnational medical research and intervention is situated. Understanding it helps explain the value placed on exposure to medical research. It underlines why, for example, JaKenya invests in both medical research employment and his forest garden and why the men described in Chapter 7 struggle to take their medication but continue to creatively seek new livelihoods.

The act of academic writing simplifies and fixes the rhythms of both long-term ethnographic fieldwork and the many-side lives that ethnographers try to represent. Finding ways to retain and meaningfully convey complexity is challenging. But it is also vital if we, as anthropologists, aspire to contribute less to objectifying and othering practices. This piece of writing is a commentary on the limitations of ethnographic writing genres and an experiment in 'writing otherwise' (Stacey and Wolff, 2016). It also aims to convey the intangible zeitgeist of this time, while making transparent that this is experienced second-hand by the ethnographer. To do this I use the

format of song lyrics to evoke the rhythm of life during this specific time-period in Luoland, a rhythm punctuated by a poignant mix of optimism, pessimism, vitality, and apathy, and underscored by the certainty of knowing that you will always be surprised by the turn of life-events.

Departing from more conventional ethnographic genres, my piece is presented in three parts: 1. The written form of a song, each stanza representing a different story from my fieldwork, and composed using a bricolage of fieldnotes, Luo puns, snatches of song-lyrics popular in Kenya at the time, even a biblical verse. 2. An explanatory academic commentary annotated with images and 3. A glossary which provides contextual understanding to the phrases used in the song. The glossary can be consulted to reveal some of the double-meanings and deeper contexts in the phrases used. But, equally, I want the reader to be able to first read the lyrics without it, in the way you might listen to a song, picking up on the feeling, and then only later getting the layered meanings. By encouraging this I celebrate the 'elasticity of the idiom' (Nyairo and Ogude 2005) as used by my research participants.

Research paper

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RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed <u>for each</u> research paper included within a thesis.

SECTION A – Student Details

Student ID Number	226397	**Title**	
First Name(s)	Gemma		
Surname/Family Name	Aellah		
Thesis Title	Everyday life in a site of transnational medical research in Western Kenya: an ethnographic study		
Primary Supervisor	Clare Chandler		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	Irish Journal of Anthropology		
When was the work published?	2019		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	**Yes**	Was the work subject to academic peer review?	**Yes**

*If yes, please attach evidence of retention. If no, or if the work is being included in its published format, please attach evidence of permission from the copyright holder (publisher or other author) to include this work.

SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	
Please list the paper's authors in the intended authorship order:	
Stage of publication	Choose an item.

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	]

SECTION E

Student Signature	Gemma Aellah
Date	01/03/2020

Supervisor Signature	CIR Chandler
Date	01/03/2020

364

OKBICHALONI

(THINGS AREN'T ALWAYS WHAT THEY SEEM TO BE. KNOW THAT FOR SURE): HUSTLING, HIV, AND HOPE IN LUOLAND, WESTERN KENYA

GEMMA AELLAH

LONDON SCHOOL OF HYGIENE AND TROPICAL MEDICINE

You can't *bwuogo* (shake) us
We are hustlers in a rush
Not a ninja
We don't wash-wash.

Life is sweet
We are Digital
Old Boys are Analogue
Migration is over
The signal is off.

Dar *mpaka* Moro
We will ride Boda, ride Boda Boda
Mikono Juu (Throw your hands in the air).

Sweet life.
Kazi va Vijana!
(Work for Youth!)
Or is it:
Pesa Kwa Wazee?
(Money for Elders?)
Where's my jet?

Ling. Okbichaloni
(Hush. Things aren't what they seem to be)

Pressure

Niki hustle juu chini ili nuvke border,
Wanaigeukia
(While I hustle up and down to cross the border
they turn against me).

M-Pigs, MPesa
Priests
Pressure

Ocampo
Only the Bachelor Can.

Not again. We are tired.
How long, *JoDalawa* (people of our home), since we last buried?
The earth does not get full
Death never tires or takes a break
Are we, the youth, never to achieve anything in life?

We hear you Bro. But:

Ling. Okbichaloni
(Hush, Things aren't what they seem to be)

Take heart, God is in control.

Hey Bush.
We're so happy you're growing up strong.
Your parents repented, left the way
Yet you swallow your *andila* (maize/HIV medication), every day.
Thank you, Mr President
Though Obama *Wuod* (son of) Alego is Our Son.

It's *Otonglo* (Money) Time!
Presha

I do not like to brag:
In Nairobi I had three jobs
I was the Human Resource Manager in Accountability in External and Internal affairs – a sweeper
I was the Official In-Charge of Mobility Implementation – a wheelbarrow servicer
I was the Chief Inspector and Attorney General of Light Arms and Light Weapons – a watch man.
But do I say?

Hey, Mr President – tweet me, *yawa*! (surely!)
Thank you, Our Father
I appreciate.

Ling. Okbichaloni
(Hush. Things aren't what they seem to be)

Presha.

But this is a big joke
Look at this house!
Cracks and semi-permanent,
Why is that officer at State House playing tricks?

Happiness of a father
Is no longer
Mor Dhiang (Happiness of a cow).
Ling. Okbichaloni
(Hush. Things aren't what they seem to be)

Repent and prepare the way
Sweep the streets with green leaves
I've rented the penthouse
HIV/AIDS Healed!

Or, if you prefer:

Give and it will be given to you
A good measure, pressed down, shaken together
Running over,
Poured into your lap.

You're a Winner!
The Chapel is a Citadel.

Ling. Okbichaloni
(Hush. Things aren't what they seem to be)

We are just trying.
Know that for sure.

Things Aren't What They Seem to Be. Know That for Sure.

Figure 1: Football and happiness of the cow. Playing football with friends from the city after a rural funeral, amid a grazing herd. ©GAellah 2009.

In 2013 Kenyans were on the verge of electing a new President, Uhuru Kenyatta, who was simultaneously facing charges at the International Criminal Court for suspected involvement in the 2008 post-election violence that had thrown the once stable country into turmoil. A new Dholuo saying was coined in 'Luoland', in Nyanza, Western Kenya, the home and heart-land of political opposition leader and Luo figurehead Raila Odinga: *'okbichaloni'*. Meaning 'you won't believe', it captured,

broadly, the wry experience of being thoroughly convinced your understanding of a situation is clear yet finding in the final reckoning that the tables have turned. It referred to the certainty of knowing that you would always be surprised. Originating among Nairobi fans of Luo football team, Gor Mahia, as a way of chatting about their team's changeable fortunes, its' use quickly extended into domains of political talk (Jones and Omondi 2013) and beyond, becoming a more general commentary onthe nature of life at this historical juncture.

Post-millennium, anthropological work on African youth as a social and historical category hastended to focus on uncertain lives and risky futures in contexts characterised by rapid urbanization, absence of functioning national welfare states, increasing juxtapositions of massive wealth and abject poverty and, in some cases, extreme security crises and conflicts (e.g Archambault 2013; Di Nunzio 2012; Cooper and Pratten 2015; Mains 2013). Youth are portrayed as surviving, gambling, hustling, chancing and constantly balancing on the edge of an abyss. But the Dholuo saying *okbichaloni,* touches on something other accounts of uncertain lives do not: that at least in Western Kenya over the last ten years, the felt-experience of such a state-of-being in the world can be one of predictability. Uncertainty does not have to mean situations are opaque or unreadable. And, moreover, the certainty of knowing you will always be surprised or let down in the end does not prevent people from feeling hopeful and energized in the moment.

Ethnography in an In-between and After World

In 2008 I moved to Nyanza, Western Kenya, to work on a study of the everyday practices and experiences of the HIV science and intervention workers, medical research participants, receivers of intervention and their wider networks that characterize the current economic mainstay of this region. It has one of the highest HIV prevalences in Africa and its regional capital, Kisumu City, has been termed an 'HIV city' (Prince 2013). When I arrived in March 2008, the

Figure 2: A home fit for a president. GAellah as seen by Bush helping construct Bush's grandmother's home in Akinda ©Bush, age 7, 2011.

region was struggling to get under control both its HIV epidemic and the excesses of destruction, insecurity and inflation that accompanied post-election violence on an unprecedented scale following a contested general election in December 2007. In 2010 I moved out of the city to a rural area 'Akinda,' about an hour away, living with a widow in her sixties as an honorary unmarried daughter in a rural home.

Figure 3: Digital Life: Slogan of pay-tv company StarTimes, Kisumu City ©GAellah, 2014.

During my most intensive period of rural fieldwork (2010 – 2011, with return visits over the next few years), inflation reached a new peak, evidenced by the doubling price of sugar. A perceived famine in 2010 was nicknamed *Misumba Nyale*,meaning 'TheBachelor Can', as in, only a bachelor could manage to live in town where, according to Akinda youth, 'life is all money.' My fieldwork was demarcated by elections. It occurred during the time immediately after the post-election violence of 2008. It included the promulgation of Kenya's new constitution in 2010 leading to the beginning of national devolution, as well as campaigns for the 2013 election of a 'Digital Boys' President, then under indictment at the International Criminal Court, who promised to replace the 'Analogue Vanguard' (despite his being the son of Kenya's first President). It was also punctuated by the two landmark campaigns and elections of United States President Obama in 2008 and 2012, claimed as 'Our Son' in Luoland (Madiega et al. 2008).

Through positioning first in the city then in the rural area, I was able to step, albeit very partially, into the practices and spaces of a distinctive Luo component of the so-called 'digital' generation of Kenyan 'youth'. These 18-35 year olds were busily engaged in trying to cross the border between abject poverty and economic stability by entrepreneurial means, here glossed as the Kenyan-English word 'hustling'. They were thinking of a bright future, without being able to quite shake the feeling they would not live to see past 40 (in this cultural context age 40 is generally seen as the cut off for being classified as 'youth'). Such youth have become, since the rapid scaling up of free anti-retroviral treatment in this region between 2008 and 2013, Kenya's first post-AIDS generation. They lost parents, grandparents, siblings, aunts, uncles and friends to AIDS but are now able to refer to taking HIV medication as something as ordinary and easy as swallowing *andila* (maize kernels). Though this idiom also has a double edge. Maize is the staple food and subsistence crop. It is also famine relief food, with associated fears of corruption scandals and worrying dependency on donors (Ochieng 2016).

Figure 4: Looking for hope. Shopping mall noticeboard, advertising HIV 'wonder drugs' in Kisumu City ©GAellah 2013.

Figure 5: HIV medication – as easily as swallowing pieces of maize? Sorting andila (maize) in Akinda © GAellah 2010.

I became interested in finding ways to describe the everyday experiences, fortunes, struggles and dreams of this generation who transitioned into adulthood during a devasting HIV epidemic at the turn of the millennium and who experienced the greatest rapid dip and then recovery in life expectancies in their country's history.

These youth often took inspiration from the iconic political and social figures of serious or successful hustlers that dominated Kenya's media; musicians like Jaguar who sung in 2011 about hustling to cross the border from poverty to riches and later became an MP in 2017, or flamboyant politicians like the first Nairobi city governor 'Sonko' (*sheng* for boss), or Vice-President Ruto, a former rural youth who hustled his way up to owning his self-named 'Hustler Jet.' Although, of course, explicit dentification with these famous members of the 'Hustler Nation' was something close to an abomination, given they were fierce political rivals of politician Raila Odinga, 'Baba' (father) of the Luo Nation. And as proudly Luo youththey also continued to feel strong connections to their Luo ancestors, even if they could no longer trace all of them; their ancestral land *(dala)* even if they could no longer live off it sustainably; and to their traditions, even as they broke them. Their spirits were alternatively crushed by political events in Kenya and raised by the election of a 'relative', Obama, to the US statehouse.

My piece of writing above is a song; an ode to a particular Luo generational group, caught between being 'analogue' and being 'digital', who were/are trying to make a living and a good life in difficult times. They live in a time of *okbichaloni* where they have the potential to get lost in the cities and turn into 'ninjas' (city street boys), or they could be political revolutionaries. They could end up in 'wash-wash' (fake money), set up a Tech Hub, hack a bank's ATM, or dominate the Forbes list of most promising young entrepreneurs in Africa. They are football hooligans and vigilantes, and they are anti-corruption and community policing. They could be lynched, or accidentally shot by police. But they could equally take local government to court for misuse of powers. Such youngish people might still anticipate dying at 40 but they are carefully planning for the future of their children's children. They embrace male circumcision as a HIV prevention tool, even though it is explicitly not part of their cultural tradition. But they do not always take their medication. They are serious and determined. And they are jokers. Economic hustlers trying to make a living in

Figure 6: You can't bwogo us. Teenage dreamers in 2001 post-election celebrations in the rural by the lake ©Star-kuzz.

difficult circumstances and social tricksters who use endlessly inventive wordplay as a form of social and political commentary.

Figure 7: The earth does not get full. Mourning a life cut short, concrete grave of a father and the fresh grave of his 30-year-old son in Akinda ©GAellah 2011.
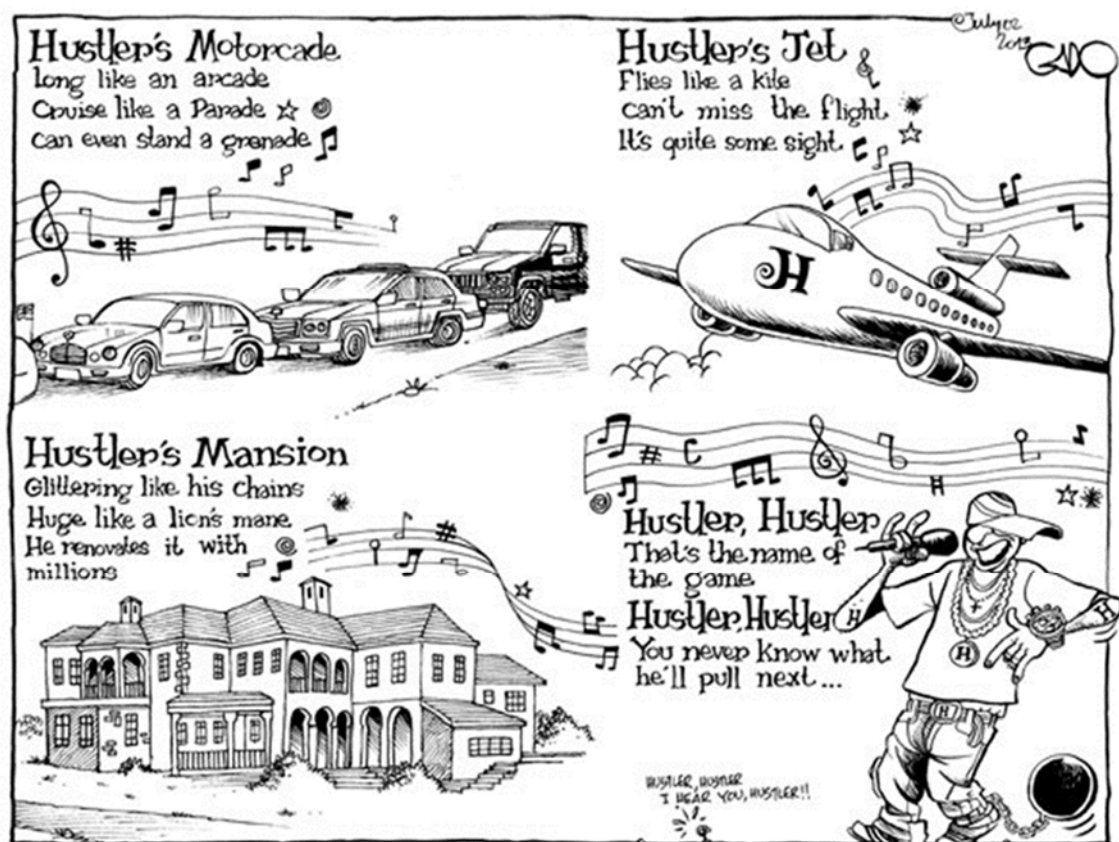
Figure 8: Where's my Jet? 'Hustler, Hustler you'll never know what he'll pull next'.
Political Carton in the Kenyan Daily Nation newspaper © Gado 2nd July 2013.

Writing in Rhythm

In my more traditional academic writing about my research (Aellah and Geissler 2016; Aellah and Okoth 2019; Aellah 2020), I've found it difficult to convey the *okbichaloni* nature of day-to-day life convincingly. How to convey the co-existence of joy, vitality and optimism with despair, apathy and pessimism? Especially as these aspects don't seem to be experienced alternatively, but rather altogether as the general flow of life. The piece of writing presented above is one attempt to do this. It is an act of bricolage, constructed by bringing together direct quotes from my fieldwork interviews or jotted in my fieldwork diary, together with fragments of popular Kenyan phrases, song lyrics, Dholuo puns, newspaper quotes, and even a Biblical verse. I wrote this piece in frustration after trying – and failing – to find the 'right' way to write for a public health audience about the mood of the 'analogue to digital' generation described above, particularly men living with HIV in their thirties who were struggling to adhere to their life-saving medication and sometimes acting in ways dangerous to those around them. I wanted to explore the more 'measurable' or actionable aspects of mood, and, also, convey the urgency of taking mood seriously in HIV policy decision making. In the process, the mood itself slipped away.

I have constructed this piece of writing to read like lyrics to a song, each stanza representing a different story from my fieldwork, alternating optimism and pessimism, but held together with the common refrain of *okbichaloni.* I'm trying to portray the rhythm of life during this specific time period in Luoland: life in an in-between and after world. Song lyrics felt an apt choice because both music and dance are central to the fabric of day-to-day life in Luoland, and are a popular form of social critique (Njogu and Maupeu 2007; Prince 2006). They were also were very much part of my experience of ethnographic research. Popular music blared on the radios of the buses I took between the city and the rural, and on the sound systems in the night clubs I visited with friends I made. Phrases from popular songs quickly entered general discourse. My song shares familiar patterning and rhythms with music popular in Luoland at that time, and appropriates echoes of *ndombolo* (Congolese) *ohangala* (Luo),

Bongo Flava (East African hip hop) and, towards the finish, a little of the aggression of Afro-trap, which was starting to take hold at the tail end of my fieldwork. But it needs remembering, of course, that this is the song of the city and village as heard through my particular ears. In the words of one member of this generation on reviewing the piece for me: 'Flows like

Figure 2: We will ride Boda Boda. Boda boda Daily Nation newspaper seller in Kisumu City captured while driving through ©GAellah 2011.

river Nile. I just wonder if they will understand the flow because these are pieces of your experience'.

Here, I am also trying to capture something of what Kenyan scholars Nyairo and Ogude have called 'the elasticity of the idiom' as used by Kenyans in this setting, something which I found so compelling, skilful and joyful when encountered in conversations during my ethnographic fieldwork (2005, p. 225). The accompanying glossary (below) can be consulted to reveal some of the double-meanings and deeper contexts in the phrases used. But, equally, I want the reader to be able to first read the lyrics without it, in the way you might listen to a song, picking up on the feeling, and then only later getting the layered meanings.

With this song, I'm following a creative line I started developing with fellow-anthropologists with the publication of a book of ethics case studies for Global Health researchers (Aellah, Chantler, and Geissler 2016). This was a book created for those working on the front-line of transnational medical research in a part of the world where the effects of global health and economic inequality are most evident. The book is a collection of fictive stories of ethical dilemmas, informed by our own ethnographic fieldwork in various countries but reshaped and transposed into anonymity. The stories are accompanied with facilitator's guides and questions for discussion, and with captioned drawings by an African medical researcher/artist. Piloting this workbook with colleagues in Kenya, I found that using multiple alternative ways of portraying the essence of a situation enabled us to provoke much more discussion and consideration of the ethical themes we wanted raised than our more conventional academic presentations of findings had allowed. We could convey the 'mood' through the stories and drawings and this, in this context, was what was needed to create space for open discussion with transnational medical researchers. I think, perhaps, in other contexts a song could do this too.

Figure 10: We are just trying. Know that for sure. JoNam (people of the lake) catching dreams. Kisumu City Homes Expo poster ©JOmondi 2010.

Okbichaloni Glossary

Andila (Dholuo) – Pieces of corn. Slang for anti-retroviral drugs used to manage HIV. There are several readings of the idiom. Firstly, nowadays, that taking these drugs is something as ordinary and easy as swallowing pieces of corn – which has special emphasis in rural Western Kenya where maize is the staple food. A ess optimistic reading is that HIV prevalence is so high as to be normal, or that the free HIV drugs are like famine relief food, creating dangerously dependent relationships with outside donors and a susceptibility to corruption (See also Ochieng 2016).

Analogue – see **migration**

Boda Boda (Swahili) – Heavy imported bicycles often used to provide taxi services, especially by young men. 'Ride Boda Boda' refers to a song lyric from a popular song 'Boda Boda' by Kenyan musicians Madtraxx (2008). The music video featured bicycles, considered lower class, interspersed with scenes of men wearing sunglasses at night, expensive cars, night clubs and cash.

Bwogo (Eng-Luo) – To frighten/shake. From 'Unbwogable' (a Luo-English hybrid word meaning Unshakeable), the title of a rap song by Nairobi hip-hop duo Gidi Gidi Maji Maji. The song was adopted as the anthem of Mwai Kibaki whose National Rainbow Coalition party, then supported by Luo opposition leader Raila Odinga, triumphed in the December 2002 election, ending Daniel arap Moi's oppressive presidency (See also Nyairo and Ogude 2005).

Bush – Refers to Bush, a 7-year boy I met during fieldwork in 2010. His parents were devoted followers of Pastor Awuor, a Luo prophet whose Ministry of Repentance and Holiness offers miracle cures for HIV. After their deaths Bush came to live with his grandmother in Akinda. She took him to the local HIV treatment centre, where he was initiated on anti-retroviral therapy and transformed from desperately sick and emaciated into a healthy, happy child. She nicknamed him 'Bush' after US President Bush, under whose presidency PEPFAR (The President's Emergency Plan For AIDS Relief) was created and facilitated the provision of free HIV drugs in Luoland.

Dar mpaka Moro (Swahili) – A song by Tanzanian Bongo Flava artists TMK Wanaume (2008). The song tells the story of two male hustlers making a journey from Dar es salaam to Morogoro. Very popular in 2008 and later in clubs, public transport and radio in Western Kenya. One of the group, YP, died in 2014. His death was mourned as another East African life cut short.

Digital – See **Migration**

Hustle – Informal, adaptable, entrepreneurial activities, sometimes semi-legal. Could include buying and reselling at inflated prices, connecting people with service providers at a price. 'Doctors they know how to treat people, lawyers know the law. We don't have any skills - except we know how to hustle' (Self-proclaimed hustler, field-diary quote).

Kazi va Vijana! Pesa Kwa Wzee? (Swahili) – Work for Youth! Money for Elders? A national government scheme, Kazi va Vijana, was launched in 2009 supported with funding from the World Bank. It was designed to build moral character and boost declining infrastructure through short-term intensive group work projects like road-building and litter picking, that would ultimately leave entrepreneurial youth with a small pot of honestly earned cash held in a bank account, that they could leverage to boost their own hustler activities. Quickly renamed as Kazi va Vijana! Pesa Kwa Wazee? (Work for Youth! money for elders?) the project rapidly collapsed in 2011 amid valid claims of corruption and the withdrawal of World Bank support.

Migration – The so-called 'great migration' from analogue to digital television, a national pun on Kenya's most famous tourist attraction, the Great Wildebeest Migration across the river Mara, began in December 2009 when then-President Mwai Kibaki launched the digital signal. The initiative, branded as 'Digital Kenya', quickly became a powerful metaphor for visions of political, ideological and economic change. As well as a critique of such. The migration was regarded a flagship project of Vision 2030, Kenya's national development plan. Current President Uhuru Kenyatta's Jubilee party utilized it in their campaign slogans, dubbing themselves 'digital boys', versus the 'analogue old boys vanguard'. 'Analogue' and 'digital' firmly found their place in sheng, a popular slang patois that constantly mixes and reinvents Kenya's multiple languages. In rural Akinda people made subtle, layered jokes about being '*Jo*Digital' (Eng-Luo) or 'digital people'. The terms, a little like the earlier 'dot com' become playful and imaginative linguistic short-cuts referring to perceived modern versus traditional ways of acting, thinking and being. But, reflecting the experience of the migration itself which was marred by corruption scandals and stand-offs between the government, and Chinese and local television companies, such terms were not considered either unambiguously good or bad. (See also Nyabola 2018)

Mikono juu (Swahili) – Throw your hands in the air. A joyful phrase often used in East Africa pop music, especially in the chorus. This phrase was used in conversation with a Kenyan from another part of Kenya to describe the irrepressible attitude of JoLuo: 'Even when everything is going wrong and life is really hard, they still dance in the clubs like *Mikono juu*!' (despairing tone. Field diary notes).

Mor Dhiang (Dholuo) – 'Happiness of a cow', a traditional delicacy. A kind of ghee made by leaving a gourd in place over a cow's teat for some time. This treat is nostalgically remembered from childhood by some JoLuo of the generation described here who grew up in, or regularly visited, rural homes in childhood. It is associated with a rural way of life that is seen as being lost. It is also a reference to the earlier importance of cattle both as bride-wealth and a marker of riches and a good, healthy life.

M-Pesa – Mobile phone money platform launched in Kenya in 2007, which rapidly transformed the flows of money (See also Maurer 2015).

M-Pigs – Reference to greedy Kenyan MPs, after they voted to increase their salaries in 2013.

Ninja (sheng) – Street boy. Nimble, shadowy, quiet, surviving (barely). In Kisumu city, they can be found sleeping in the bus station ditches, sniffing glue, playing football. They do not

exist in rural Akina, where they are, instead, 'orphans' sleeping in the kitchens' of their distant relatives or struggling with their older siblings in dilapidated homes.

Obama Wuod Alego (Dholuo) – Obama, Son of Alego (a place/clan). US President Obama was claimed in Luoland as 'Our Son'. His grandmother's village is close to Kisumu city. His first campaign in 2008 offered some measure of hope in the region after the 2007 Kenyan election was 'stolen' from Luo opposition leader Raila Odinga (See Madiega et al. 2008).

Ocampo – A 2011 famine in Luoland was nicknamed Ocampo, after International Criminal Coirt prosecutor Luis Moreno Ocampo who summoned six prominent political figures to the Hague for their part in Kenya's 2008 post-election violence, including current President Uhuru Kenyatta. The famine's nickname referred to the financial drain these suspects' attempts to evade prosecution were having on the country's economy.

Okbichaloni (Dholuo) – Things aren't what they seem to be. Know that for sure. Originally derived from a saying by supporters of Luo football team, Gor Mahia, about controversial football match results. Took hold in Luoland in 2013 in reference to political machinations around the aborted Orange Democratic Party nominations in the run up to the national elections. Now used more generally.

Otonglo (old or 'deep' Dholuo) – Money. 'Otonglo Time' is the title of a song by pioneering Luo rapper Poxi **Presha** who died of TB, an AIDS related opportunistic infection in 2005 at the age of 34. In 2013 a secondary school drama student had President Kenyatta and the nation in hysterics in a schools' competition with his witty, charming narrative 'Otonglo Time,' (Money Time), which used the parts of the original song as a chorus. He told the story of a Luo boy who travelled from HIS village to Nairobi in search of big dreams, but instead found himself forced to return to village life after living in a slum, where he had to pay even to 'make long calls, short calls and SMS (the notorious Kibera slum flying toilets). Aptly, the student proved to be a skilled digital hustler, ending his performance with 'Mr President – tweet me, *yawa*!' In fact, musician Jaguar offered to sponsor his remaining education and the President then awarded him a full scholarship to university. The next verse is a newspaper quote from the mother of a different school boy who also performed in a drama competition a year later in 2014 and to whom the President promised a family home as a prize. In 2019 the house was finally gifted but rejected by the mother as not being of fit enough quality for a presidential gift. This has resonance because homes and home-construction are important markers of identity and debate in Luoland. And, as I was writing this piece in 2019, Bush's older brother, now a teacher, was complaining bitterly to me about the automatically deductions taken from his salary to finance the government's affordable housing scheme; especially galling as he had constructed his own rural home, and rebuilt his mother's before even joining college (see image).

Pressure/Presha – Song popular in Kenya by Tanzanian artist Hafsa ft Banana Zorro (2007). The music video featured scenes of stressful love and relationships. Pressure also refers to the emergence of a new colloquial medical condition in recent years known as 'pressure' and encompassing, variously, stress/high blood pressure/hypertension/diabetes and connected with stressful modern lifestyles.

Repent and prepare the way – A reference to the slogan of Pastor Awuor, a Luo prophet of the Ministry of Repentance and Holiness, who preaches miracles and prophesies. His rallies are attended by thousands and are preceded by devoted followers sweeping the streets to make them ready for his presence. His CV includes claims of an overseas PhD in bio-chemistry and he regularly announces miracle healing for HIV. Sweeping roads with green leaves is a form of celebration, which was also used in Kisumu City during Obama's victories.

Sweet Life – Sweet Life ('La vie est belle') is a song recorded by Congolese singer Fally Ipupa, from his third studio album, Power 'Kosa Leka' (2013). Congolese music is very popular in Kenya and this song was ubiquitous on public transport, nightclubs and the radio throughout 2013. *Mit* (Dholuo) meaning sweet, is also used to describe the pleasurable feeling of sex without a condom. The use of Sweet Life here is also a reference to concerns about the rapidly rising price of sugar and sugar stock-outs in both Akinda/Kisumu documented in my field-diaries in 2010/11. Tea without sugar was seen as marker of poverty, and a way of talking about inflation and economic crises.

Wanaigeukia (Swahili) – 'They turn against me'. From 'Kigeugeu' a 2011 song by Kenyan musician, Jaguar. *Kigeugeu,* derived from the Swahili verb *geuke* (to turn about) means a person or a character, usually one who is supposed to exemplify trust, responsibility and goodness like a church leader, government official, medical professional or friend, but who is inconsistent, every-changing and undependable. In the music video, Jaguar, an archetypal hustler, decked out in a uniform of jeans, t-shirt, white trainers and heavy bling – gold chains, bracelets and ear-rings - drives his BMW through the capital city's highways interspersed with scenes where people described as *kigeugeu* try to get between him and his attempts to, in his words 'hustle up and down to cross the border.' He sings about his frustration and where to find a role model in a world where doctors to put patients already dead on life support, babies are switched at birth by midwifes, politicians make promises of development but deliver only increase in their own girth, pastors offer wise counsel then sleep with your wife, and even street beggars shake off their crippled demeanours after a day's work and walk home as businessmen. *Kigeugue*, his song claims, is endemic; a feature of modern African life that the serious hustler has to grapple with. In 2017 Jaguar became an MP.

Wash-wash – Making counterfeit money

Winner's Chapel – Winner's Chapel is an evangelical organisation with branches worldwide. During my fieldwork a new huge church building was constructed opposite the then biggest mall in Kisumu City. This is also a reference to the popularity of the 'prosperity gospel' in Western Kenya, where church goers are entreated to donate cash and possessions in order to receive them back ten-fold. As well as a further pun on concerns about the rapidly growing popularity of online and mobile phone betting as way to trying to earn money in Kenya, especially among youth. The biblical verse quoted is from Luke 6, versus 38. Citadel in this context refers both to the enormity of the new church and Citadel, the transnational business organisation and leading investor in the world's financial markets.

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Acknowledgments

And an extra verse for the Star-kuzz:
But hey yo!
Donge ok bi chaloni
Sama wandiko PHD papers to waoroni
Ok bi chaloni.

Chapter 10: Conclusions

The papers presented in this thesis have explored different aspects of, and possibilities for, life lived in a place that has experienced the profound, albeit waxing and waning impact of large-scale biomedical research programmes, intertwined with much larger transnational HIV/AIDS interventions. My starting point was to consider what it would mean to think of transnational medical research and intervention as part of everyday life in this region in Western Kenya, rather than as something exceptional.

This thesis argues that transnational medical research in this context needs to be understood as part and parcel of 'how people of this place live.' Therefore, an approach that conceptualises researched communities as temporary experimental publics (Montgomery and Pool, 2017) does not work well here. Equally, my thesis also highlights how the behemoth, or global assemblage of transnational medical research activity is scaffold by intimate everyday relationships. Furthermore, transnational medical research is both a contributor to, and a resource to creatively draw on to mitigate, the effects of precarity.

In Kisumu City, and especially in rural Akinda, transnational medical research activities were diffused into broader lives. This is because its history and current shape is not just folded into, or understood in reference to, other histories of intervention but also made possible by them. I learnt that it makes more sense here to think about the co-constitution of things, and have drawn on Mbembe's notions of *multi dureés* and *multiplicities* to help conceptualise this (Mbembe and Nuttall, 2004, Tembo and Gerber, 2020).

For, when I first went to ask Andreas (then age 80 or so), one of the holders of local Akinda history whose narratives I described in Chapter 4, to tell me the story of how things came to be in Akinda, I told him I wanted to ultimately get to the point of understanding the arrival of NCRO/CHA. He laughed and told me 'NCRO/CHA? but that came just yesterday!'. We were

sitting in his home, on his ancestral land, close to the Mission hospital where he could receive free treatment for emerging infectious diseases by dint of being enrolled in the NCRO/CHA IEIP programme, the routines of which were described from the perspective of JaKenya in Chapter 5.

Andreas's land bordered *Ka'Kwodi* (Place of the Swollen Stomach), which was at one point a deserted home belonging to his ancestors, then donated to the Italian Mission Sisters who used it to run as a nutritional centre, later incorporated into Ministry of Culture and Social Services, and now housing the Akinda NCRO/CHA field station. As he made his point about generation, time and simultaneity, Andreas reached for a certificate from his sideboard, that he had been given by the Catholic Church when they celebrated their bicentennial. It thanked him, and his relatives, for the land donation.

So, when Andreas says 'NCRO/CHA came just yesterday' this is not a trivial comment, but rather a profound recognition of two things. Firstly, that history did not/does not begin with whatever post-colonial global health interventions are most prominent at the time. And secondly, that the viewing-points of both Akinda residents and ethnographers are contingent. As such, Andreas' comment can take us into conversations about post-coloniality, about multiplicity, about co-existence of modernity and tradition, and about the experientiality of time.

The profundity and playfulness of Andreas's comment — as well as the fullness of the intertwining of NCRO/CHA's city spaces with its rural field-sites, and the city with the rural in Western Kenya more generally — is further reinforced when I also tell you the following: Andreas has a granddaughter working with NCRO/CHA in the city; several grandsons who have carried on his carpentry trade, learnt when fighting with the British in Burma in 1941; and another grandchild who was a research participant in the Akinda arm of a globally multi-sited HIV discordant couple study, administered in Akinda by NCRO/CHA staff, most of whom travelled in daily from Kisumu City.

Thinking about Andreas' *multi-side life*, and the *multiple lives* of his descendants, takes me back into thinking about *multiple scales,* as it did in the Prelude of this thesis. NCRO/CHA's HIV branch was called to add its expertise and pool of potential participants to the globalised network and study population of the HIV discordant study couple in which Andreas' grandchild participated, when the study had been running for several years. Through this, the life trajectories of a handful of Akinda research participants meeting inclusion criteria at exactly the right moment — like Andrea's grandchild — and their families, were potentially radically transformed by a chance to be initiated on HIV medication earlier than otherwise possible in their local treatment centres. Shortly after talking to Andrea, the overwhelming success of the global study meant all participants were offered this chance. In Akinda, this accounts for only a dozen people. But many twists and turns in the story of changing criteria for access to HIV treatment followed (see Chapter 5), to the point at which the latest Kenyan Ministry of Health Guidelines states, in bold, that:

> '**All individuals with confirmed HIV infection are eligible for ART, <u>irrespective of […] any other criteria</u>, provided that the individual is willing and ready to take ART and adhere to follow-up recommendations**.' (NASCOP, 2018 p. 4)

From my perspective as a long-time observer and, I feel, from the perspective of others living with the daily realities of HIV infection in Kenya, this achievement has a miraculous quality, albeit a miracle hard-won, worked at by many determined research workers, participants, and activists, and won too late for many. And yet, again, as I pause to marvel at this in a moment of writing and finalising my conclusions in 2021, a direct Facebook message with a link to a YouTube video comes through from Oki, the 58-year-old Kisumu HIV activist who reads what I write about things to do with HIV. He has been living with HIV for decades and is the very definition (now) of someone 'ready and willing to take ART and adhere to recommendations. A

383

clip from a National TV broadcast labels him as an 'HIV survivor', showing him organising the many bottles of drugs he takes daily to continue surviving, with the strapline: 'Looming ARV Crisis'. At a recent HIV clinic visit he only received a six-week supply of his complex drug regime.

 A consignment of specialist supplies worth 2.1 billion shillings is stuck at Mombasa Port, embroiled in a tax row between the government and the donor agency, US-AID. Wearing a disposable facemask to protect against Covid-19, and fore-grounded against posters with curling edges fixed to a wall in the shade of turquoise associated with government dispensaries across East Africa, Oki outlines the impact of the daily realities of rationing even in the short term for those, like him, on more complex treatment regimes. He points out the implications are even more pressing for children born with HIV, who 'must eat their ARVs every single day' and rely on others to bring them back to clinics or navigate pharmacies. Oki's reaching out through a *digital* link brings me back into an *analogue* world where relationships, relatedness, and your ability to walk to a local clinic matter.

It takes me to the concept of e*xposure* as resource and opportunity, within its counter-point interpretation of risk and danger, and through to the lived experience of precarity as encompassing extreme vulnerabilities, which are also knowable, and somewhat predictable. Oki knows what to do when facing this new, destabilising, predictable precarity, or 'okbichaloni' moment. He uses his exposure, and he uses it well, on his own behalf, and on behalf of others who cannot. He, and others, move forward and gains are made.
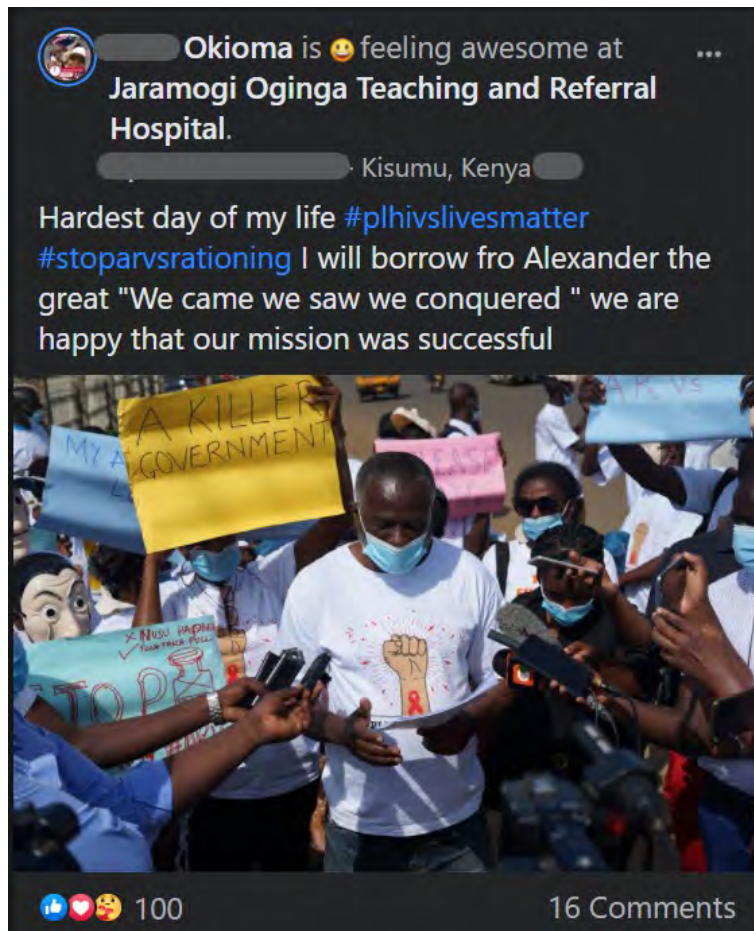
Figure 50: Okioma at the centre of things, for a moment. This image, shared with me through his Facebook page, shows him speaking outside the Provincial Hospital in Kisumu City. This location is geotagged by its proper name but locally known as 'Rassia (Russia)' as the original hospital construction was funded by the Soviet Union during the Cold War). Facebook post reproduced here with permission.

Yet, even as collective action somehow works and the consignment is released, Okioma remembers that:

> '[this scene] reminds in mid-2000 a number of HIV activists were arrested here for staging a sleep-in in protest about access to medicines and other diagnostic services. Many people were dying as they could not afford, yet there was support from Global Fund, and someone was busy collecting money for desperate poor and vulnerable people, hence Nothing4UsWithoutUs was the rallying call. **We are back here today in a worse situation** [my emphasis]. We need a sustainable solution.'

A week or so later, the victory of releasing the consignment is superseded by another realisation by HIV activists, HIV Treatment Centre clients and researchers: that the anti-retroviral drug, Nevirapine, officially phased out in Kenya by December 2019 and replaced with Dolutegravir, a drug with less side-effects, potential for liver-damage and eventual treatment failure, is back in circulation. Nevirapine was trialled, then later withdrawn, and replaced in the HIV Prevention of Mother-to-Child Treatment study whose mothers and babies I followed a decade ago. One of the many multiplying afterlives contributions of this study was evidence that helped in a small way to get future mothers, babies and children living with HIV in all high-burden countries in African onto this WHO recommended best-available first-line regimen. Its return to HIV treatment centres in Nyanza may be a short-term emergency fix for a political-economically driven crisis. But for a person living with HIV/AIDS, especially for a child, the impact on their body and lifeline will last a lifetime. As Oki eloquently sums it up:

> 'Living in Kenya should be included in a thousand ways to
> die.'

Contributions of the thesis

Through the papers in this thesis, I have been interested to consider how transnational medical research relates (or sometimes how it is less important than other things) to the biographies, relationships, and dreams of those involved. In other words: how such practices, which are tangles of multiple transnational collaborations invoking multiple power dynamics, are part of how life is managed over and beyond the production of 'scientific knowledge.' For, as the paper on 'Exposure' I presented in Chapter 6 shows: there is a 'radiation effect' of scientific knowledge production practices (Aellah and Geissler, 2016 p. 167), that those involved experience and contribute to. And these 'radiating' scientific knowledge production practices, have deep, historically layered, sedimentary foundations as shown in Chapter 4: perhaps

most apparent in my description of the walking tour of an Akinda dispensary. As well as in the biographies of the *nyamwrerwa*. This is also seen in the past and present and future hopes encapsulated the familiar patterns of the Dr. P and NCRO/CHA praise songs composed 30 years apart (and probably referencing and mixing older missionary and cultural praise songs).

In relation to existing social sciences studies of biomedical research carried out in the global south my case study highlights four vital, related points. Firstly, my findings make it clear that history(s) in these places does not begin – or end – with the current moment of post-colonial global health intervention. Any current version is made possible by, played out against, and situated within, a series of other, overlapping histories of responses to ill-health.

Related to this point, secondly, even the most intensively researched communities, such as the two described here, are not defined by research, but rather fold research into their lives. The stories that infuse this thesis show clearly that research is but one part of many-sided lives. It is, therefore, important to understand both fieldworkers and research participants as multi-dimensional persons. This involves moving beyond addressing them only as the 'experimental subjects of global biomedicine' (Rajan Sunder, 2009).

Thirdly, my findings show that the global assemblages or configurations of biomedical technoscience through which transnational medical research operates are scaffolded by intimate, everyday research relationships, which are folded into, and understood through, already existing communities. The fragile techno-scientific activity of transnational medical research is imbued with residents' creativity, expressed through their existing relationships, and held together by human connections.

Finally, the thesis demonstrates the porosity of global health, global science, clinical trials and, by extension, global academic knowledge. A long-term

following approach allows me to show how some participants in biomedical research interventions can potentially become (or already are) researchers themselves. Therefore, lines between researcher and researched are somewhat diffuse. My approach of following biographies as they changed over a long period of time has enabled me to contribute an analytical description of this, and its limits. This ethnographic observation has not been made in much other literature (for an exception see Bruun's description of transitions between research participants and researcher in Lusaka (2014)). It may be that my study locations are relatively unique in this regard. Or it may be that the length of time of my ethnographic fieldwork rendered this more visible.

A further central aspect of my findings is a demonstration of the many dimensions and dynamics of vulnerability, underdevelopment and injustice that situate people in such ways that engagement - as participant or as worker - with the perpetual temporariness of transnational medical research activity can sometimes contain the best promise for hopeful futures for themselves, their families, and their future dependants. In this sense, my findings are in conversation with other anthropologists studying clinical trial socialities who worry about the logics of techno-scientific regimes that, despite often producing radical life-transforming health improvements, at the same time participate in, and perpetuate, exploitative economic modes sustained by precarity (see for example Alenichev and Nguyen, 2019, Crane, 2013, Monahan and Fisher, 2015, Rajan Sunder, 2005, 2008, 2017).

In both Kisumu City and rural Akinda, transnational medical research and intervention related to HIV and other diseases is one of the biggest providers of material resource and aspiration in places otherwise characterised by informal, entrepreneurial, and/or fishing and subsistence farming economies. Residents creatively utilise it, seeking exposure to help navigate their lives. However, despite a powerful presence for several generations, such activity still exists in a state of permanent temporariness. It is always underscored by the fundamental understanding of all involved that 'one day',

in the words of an Akinda resident Timothy, a retired teacher and subsistence farmer living with HIV, 'they [the field station, overseas donors, international non-governmental organisations] will carry their things and go.'

But, interestingly, this high level of uncertainty and vulnerability is experienced by those living through it as relatively predictable and knowable, and in the same order of things as many other of life's challenges. To continue with this Akinda resident's philosophical reflections:

> '[and if that should happen] do we also carry our things and go? No. We are not going anywhere. We remain here. Life has to go on. So, as this is the case, we must see how we can live' (Focus group discussion, 2011).

Or, in the words of Landhie, an experienced local clinical officer and biomedical researcher who found himself suddenly – and precariously – without an income after more than fifteen years of project-based employment with the NCRO/CHA field-station in both Kisumu City and rural Akinda:

> 'We are all fine here. My contract ended and was not renewed. But those are just changes in life, for change is the only constant in life.' (email correspondence, 2020).

In this sense, my findings also critically speak to the broader literature on precarity and precariousness, beyond the clinical trials literature. But my particular analytical contribution speaks more to those discussions concerned with precariousness as an ontological condition or 'structure of feeling' (Reynolds Whyte and Etyang Siu, 2014).

I take seriously the philosophical orientation of Landhie and others towards the idea of 'change as the only constant in life' and the poignant mixture of lament and sense of belonging expressed in Timothy's statement that 'We remain here.' By doing so, I explore how the felt experience of such a

389

precarious state of being-in-the-world can be one of predictability. I try to represent the non-contradictory co-existence of joy, vitality and optimism with despair, apathy, and pessimism evident in everyday life and in plans made by people living in these places. Because, unlike in other places, uncertainty has not placed people into a suspended waithood. The life-stories presented in my thesis offer a counterpoint to arguments that uncertainty/precarity is necessarily the only 'dominant trope' in the subjective experience of life in contemporary African societies (Johnson-Hanks, 2005 p. 366).

I have presented my thesis as a collection of papers written with different audiences in mind; from those concerned with theoretical ideas about the flows of scientific knowledge, to those working in sites of transnational medical research and struggling with daily ethical dilemmas. Across all the papers, I have been committed to the importance and power of storytelling. The papers contain stories within stories, and these stories are not finished. And, so, I would like to end here with a Post-Script, or coda to the song of my fieldwork presented in the previous section and tell you a little bit about what had happened since. This Post-script also makes even more explicit the *okbichaloni* nature of the precarities experienced here, and ongoing co-existence of optimism with pessimism, vulnerability with perseverance.

Post-script

Elections

My fieldwork was bracketed by landmark national elections in Kenya. At the time of writing this post-script another had occurred. In August 2017, a general election was held and 'Digital boys' President Uhuru Kenyatta was re-elected. Raila Odinga, the Luo opposition leader, claimed the election was rigged and appealed to the Supreme Court. In an unprecedented turn of events the Supreme Court ruled that the election had not been conducted in accordance with the constitution and ordered fresh elections. This was the first time a court had overturned the results of a presidential election in Africa.

Yet, in a further surprising turn of events, opposition leader Odinga then withdrew from the new elections claiming there was still no prospect for a credible election. So, on 30th October 2017 Kenyatta was declared the winner of the new elections.

Okbichaloni!

Analogue and Digital

The analogue signal in Kenya was finally switched off in June 2015. Yet the relevance of the metaphor persists. In April 2019, Kenyan Daily Nation commentator, Sunny Bindra, wrote a newspaper article describing his experience of driving home through Nairobi. Bindra portrayed the co-existence of the digital countdown on traffic lights with hand signals of old-fashioned traffic police and seeing Uber drivers move along the roads next to water vendors pushing handcarts. He described receiving both twitter updates while stuck in traffic and a knock on the car window from a blind beggar, and, finally, the process of completing digital electoral registration. After completing the form online, he found it still needed printing out and taking in person to a government officer for a stamp. He wrote:

'The new digital part is just a layer on the old analogue process. Africa is going digital rapidly, while remaining intensely analogue.' (Bindra, 2019).

He, like me and undoubtedly many other commentators, continues to find 'analogue and digital' a useful way of thinking about continuity and change that reaches beyond its technological applications.

Bindra continues:

'Could we get real and see the actual world around us? Yes, huge progress has been made with mobile money and digital apps. Yes, artificial intelligence and blockchains and big data could yet power some dramatic changes in healthcare, education, and service delivery. But the analogue world has not gone anywhere. It must be tackled, accommodated, and addressed first. Anyone looking at a digital answer to old problems must understand the old problems first. At the moment, digital is colliding with analogue — sometimes explosively. The two will have to play hand in hand, not side by side. That will take some doing.' (ibid).

Transnational medical research

In Kisumu City and Akinda there has been much change in terms of transnational medical activity. I can now look back and see that 2010-11, when I did most of my fieldwork, may have been the heyday of NCRO/CHA. In 2013 NCRO was mired in a corruption scandal after more than $80 million of CHA funds sent to NCRO went missing. NCRO Staff did not receive their salaries for several months and their most prized benefit, private medical insurance, was cancelled. It was a difficult time. Some staff went on strike. The NCRO director was removed from his position and has since died. CHA decided to administer all its future funding through a third-party auditor. More recently, in early 2020 in Akinda, the size of the HDSS

was dramatically halved to only include the IEIP villages. JaKenya tells me he is doubtful about the future of transnational medical research activity in Akinda. Perhaps the fears of Akinda residents that 'research will one day leave us' are finally going to be realised. Although perhaps not.

Okbichaloni.

In Kisumu City the feeling of the HIV research clinic is now more like a contract research organisation. This arm of the centre has survived the recent challenges by marketing itself as an expert point on a network of sites available for global multi-sited clinical trials. It is always ready for action. Staff are highly technically skilled, and the team constantly bids to join multiple multi-sited global trials. It feels like Kenyan city based NCRO/CHA staff who managed to hang on to their employment travel overseas more now for conferences and for further education courses and longer- term placements. Even some members of the NCRO/CHA community advisory board have had the chance to travel to international conferences. Some of the dedicated community interviewers let go from their employment in various rounds of research contraction have not managed to find any new salaried work at all and are hustling. Several clinically trained staff, especially those without Medical Degrees or PhDs have returned to Ministry of Health employment. Yet, despite all these difficult setbacks, it seems as if many of the former and current researchers are still managing to find multiple ways of 'developing themselves'. In the clinic itself, following the dramatic terrorist attack on Westgate shopping mall in Nairobi in 2013, security has been ramped up. It is no longer possible to forget your badge and enter with a smile.

JaKenya

JaKenya no longer sleeps every night in his cosmopolitan-traditional mud thatch hut amidst his trees, bees, and flowers. The forest is flourishing, and the bees are thriving. Two more babies have been born. JaKenya's Granny celebrated her 90th birthday. Both occasions were joyfully marked with tastes of honey, brown *ugali* flour, and the shady protection of trees.

Figure 51: Celebrating the birth of Dana Yuna Joy. Source: Okoth.

But JaKenya has been promoted and now oversees an HDSS in another rural site in Luoland. Much to his disquiet he has been forced into renting a small house in a marketplace again. He escapes to his Akinda idyll at the weekends and continues to propagate his cash through seedlings and saplings nurtured in several pieces of otherwise unused land that he has access to. His salary has tripled. He is currently considering taking a loan to purchase land with good irrigation potential along the Akinda lakeside. He is concerned about the future of his employment with NCRO/CHA and thinks perhaps business will be the only stable future. He sees potential for selling good food to the Akinda youth who are turning away from subsistence farming in favour of cash earned through *boda boda* (motorcycle taxis). But they still need to eat.

JaKenya told me he felt a sense of pride and accomplishment when looking through the pictures I selected for our paper in Etnofoor (Chapter 5), seeing the contrast between his forest when we first met ten years ago and now. To my initial surprise (*okbichaloni!*) he told me that Chacha, a young Luo man I interviewed who came to Akinda from Nairobi City where he grew up to intern on a development project at the same time as me, had stayed in Akinda all this time. Chacha, like JaKenya, developed a love for rural living and is now working on a forest of his own. In JaKenya's words, spoken to me through WhatsApp, the most analogue and digital of the series of multiplatform mobile communication applications that have caught hold across the continent in the last decade: "he planted and planted. Another [person we know] also planted and planted. They have really tried."

Exposure

The transformations for Min Favour, the tiny research participant who 'carried her umbrella' and her small baby to ask the American Principal Investigator of the prevention of mother-to-child HIV transmission study for a job, have been particularly striking. Her 'exposure', his open-door ethos, and her determination have taken her far. After her peer educator work, discussed in the paper in Chapter 6, she got the chance to work for another

transnational medical organisation. This time as a community interviewer on a male circumcision study employed on merit, rather than due to her biological status and research participation. She later returned to work with NCRO/CHA, applying directly, as would any other applicant. She got a job as a provider-initiated HIV counsellor and tester, then moved into a more senior position as a programme facilitator.

A few years later she became a research assistant for a different transnational medical research organisation in Kisumu, and next a social science interviewer. She was then, essentially, doing the same work I had been doing when we first met – conducting qualitative interviews and focus groups with women on their experiences of living with HIV. Along the way, she used her new monetary capital acquired through formal employment to obtain a degree in social work. When I showed her the paper to check she was happy with her portrayal she told me two things. Firstly, on reading my version of her story that: 'It's amazing. I really never thought that I was a source of encouragement to many. I mean it is just totally amazing.' Secondly, that it was only now, being a social scientist herself, that she properly understood what I was doing 'back then' when I sat together with her in her house and audio-recorded several interviews about her life — a timely reminder for me that the fullness of the meaning of 'consent' is always contingent, and not adequately pin-downable in signed written informed consent documents.

Yet, a few months later, this now highly experienced and competent researcher whose life finally seemed secure contacted me to see if I knew of any global-north researchers offering piece-meal transcribing work in Luoland. The research project she was working on was coming to an end and she had not yet managed to line up another. I was reminded of the limits of exposure as a strategy for keeping going under the economically uncertain conditions of life in the HIV driven economy of Kisumu City.

 Okbichaloni.

Ka' Mama Unita

In Akinda, my host Mama Unita is still there, still walking around her villages talking to everyone and liaising between researchers and researched. The arthritis in Mama Unita's hip is causing her much pain and she is not sure how much longer she can continue the work. She had a stroke but made a full recovery. One of her two remaining adult sons, whose land and home borders hers and who once told me he did not expect to live beyond 40 years, also had a stroke. He was less lucky than Mama Unita and is now confined to a wheelchair, unable to work or move his legs.

But perhaps the biggest change around Ka' Mama Unita can be seen in her widowed daughter-in-law Min Thea's home. When I first visited in 2009, Min Thea and her three children were in a time of despair, living in a tiny two room crumbling mud-thatched home and struggling to find school fees. Now, in her words, Mama Thea is in a 'go-getter' stage of her life. She has managed to slowly build herself an impressive large brick home, mobilising all her networks, resources, and energies, and without much support from her relatives-by-marriage as relations have finally broken completely, perhaps irrevocably. She still volunteers as a Community Health Worker. The promised formalisation of the position and monetary incentives never came. But she makes some money from reselling second-hand clothes, and other entrepreneurial revenues. Her daughters are grown and are all doing well in their own ways. Thea who I spent the most time with and who helped look after my child during piloting of case study materials in 2014, is living in Nairobi. She rents her own small, beautifully kept bedsit, and works in a supermarket wholesalers. The eldest, who was staying with one of Mama Thea's sisters in Nairobi for schooling during most of my time in Akinda, is living at home with her toddler and Mama Thea, an immensely proud grandmother. Most joyfully of all, Mama Thea's youngest daughter, Queenie, got a chance to go to a church-run secondary boarding school for children with hearing impairments. She has just sat for her final exams, hopes to go to a specialist university and can both sign and translate Kenyan sign-language

into Dholuo, English and Kiswahili. Seeing and listening to her teach me and my children how to greet and sign our names via WhatsApp video from Akinda, was a moment of pure happiness.

Okbichaloni

The hustlers

The fortunes of many of the young-ish men whose life stories were encapsulated in Chapter 7 have continued to be changeable. The Star-Kuzz gang, of which the late Atomic was once a part, are a case in point. One worked for a Kenya bank with outlets across East Africa. On the creation of the new nation of the Republic of South Sudan (bordering Kenya), in July 2011 he was seconded to the Juba branch. Living in the capital of South Sudan gave him a lot of *exposure* to both business opportunities and to risk from political violence, especially from December 2013 onwards when South Sudan was embroiled in a civil war with periodic violence across the capital. But living out of high security hotels with all his expenses paid for had some advantages and he saved enough to buy some prime real estate land in Kisumu City and construct an aspirational multi-storied house there, as well as in his rural home. Recently, however, he has been seriously ill and his friends fear he may not recover.

Another, who won the green card lottery and emigrated to the USA before I started fieldwork (we have only ever met on Skype), is now a medic with the US Army. He is trying to get himself posted to the Nairobi barracks. Another is back in the village. He, and his wife, became desperately ill with TB. His difficulty with taking his medication was compounded by alcoholism. Fearing another avoidable death like Atomic's, he was taken by his friend Omondi to live in his empty *simba* (bachelor hut). Omondi's mother keeps an eye on him and he is, it seems, recovering.

Omondi is also back in the village. He has found a new, very 2019 hustle: programming to build climate change resilience. He is currently vice-chair of

a county Climate Change Coalition. He spends a lot of time at conferences and meetings, working out how to improve his village and leverage value from the networks of government departments and international donors interested in this new concern.

Okbichaloni.

They are just trying.

Know that for sure.

Figure 52: JoNam (people of the lake) catching dreams. Kisumu City Homes Expo poster
©JOmondi 2010

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