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Paul Wenzel Geissler, Richard Rottenburg, Julia Zenker (eds.)  
Rethinking Biomedicine and Governance in Africa

## Editorial

Since the late 1970s, *empirical science studies* have developed into a key field of research at the intersection of science, technology and society. This field merges a repertoire of theories and methods stemming primarily from cultural anthropology, sociology, linguistics and history. Its main characteristic is the detailed analysis of scientific practices and epistemic cultures and how these become entangled with public discourses and everyday life. This focus tries to reveal specific, local configurations and their epistemological as well as social consequences. Beyond a mere deconstruction, science studies are constantly looking to engage with the fields in which they do their work. The goal of this book series is to offer to scholars a German and English speaking Forum that

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- supports young scientists through opening up a new field of work which runs across existing disciplinary structures;
- encourages the formation of *tandems* through co-authorship. In particular, it supports, evaluates and comments on collaborative projects with colleagues from the natural and engineering sciences.

The series is directed towards scholars and students from both the empirical science/social studies and the natural sciences and medicine.

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PAUL WENZEL GEISSLER, RICHARD ROTTENBURG, JULIA ZENKER (EDS.)

**Rethinking Biomedicine  
and Governance in Africa**

**Contributions from Anthropology**

**[transcript]**

This volume emerged from the work of the research group »Law, Organization, Science and Technology« directed by Richard Rottenburg, financed by the Max Planck Society and located at the Max Planck Institute for Social Anthropology, Halle, Germany.

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# **“We are not paid—they just give us”: Liberalisation and the longing for biopolitical discipline around an African HIV prevention trial**

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P. WENZEL GEISSLER<sup>1</sup>

## **INTRODUCTION**

### **The end of the monolithic biopolitical collective**

From the vantage point of the mid-20th century, it seemed as if an almost inevitable connection existed between ideas and practices shaping the well-being of people’s bodies, and the larger body of the national collective, represented by its government. The somatic existence of citizens and the larger form of the nation-state jointly demarcated biopolitical space, our later understandings of which were shaped, among others, by Michel Foucault’s early writings on scientific knowledge and the clinic. The nature and operation of the nexus between medicine and nation was then open for discussion—ranging from the critical scrutiny by Foucault (but also e.g. Illich 1976), to the positive appreciation of national health as a collective political programme, epitomised in the works of Richard Titmuss (1970). Yet, that such a nexus existed, and that our thinking about the biological as well as the political had to take place within the remit of the national collective, was not put in serious doubt before the end of the 20th

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**1** | I gratefully acknowledge the assistance of the scientists, research staff, clinicians and participants of the Kisumu HIV trials. Warm thanks to all present and past colleagues in the ‘Research communities study’, notably Philister Adhiambo Madiega and Gemma Jones, as well as to research students Patricia Kingori and Tracey Chantler. Ruth Prince and Ann Kelly offered invaluable advice on earlier versions. Particular thanks, to the senior colleagues from KEMRI and CDC, who allowed us to study their work. Fieldwork was funded by the Wellcome Trust with support from the Max Planck Institute for Social Anthropology (Research group ‘Law, Organisation, Science and Technology’).



century. One of the premises of this volume is that this has changed, that the once taken for granted bond between individual and collective body, citizen and nation, has been ruptured, or at least that it no longer is the dominant frame of biopolitics.

The dissolution of the unified collective, the nation, as frame of biopolitical intervention is hard to overlook in Africa. Outside South Africa, national academic institutions have ceased to produce recognised medical science and have passed on this task to “para-statal” institutions that adhere to neoliberal regimes of ownership, property and global standards, and operate largely dependent upon funding, expertise and organizational structures in Europe or North America. Biomedical health care provision is no longer procured, nor indeed often expected, from the state, but provided on a fragmented, partial, emergency-focused basis—as ‘projects’ and ‘interventions’—by non-governmental and transnational agencies and programmes. For the inhabitants of mutating African nation-states, the demise of the national biopolitical collective implies a progressive ‘baring of life’; no longer anchored in the entitlements and duties of citizenship in its older nation-state sense, they have to orient themselves within less coherent geographies of rights and responsibilities.

Crucial for those living under these conditions is the search for association, not only to others who in similar conditions pursue aligned interests, or to those in more privileged positions through whom resources or power can be accessed, but to larger wholes that, while never replacing the comprehensive imagined community of the nation, partially substitute it or patch some of the holes in its strained texture. Ethnographic observations of this quest for association have over recent years produced a plethora of (always partial, often ‘biological’, somatically grounded) ‘citizenshipS’, with the plural referencing a qualitative shift away from the older totalizing notion of citizenship rooted in enlightenment readings of classic *civitas*. This inflationary use risks abrogating the claim for citizenship as comprehensive emancipatory reference to (just) society; but notwithstanding whether one calls any quest for collectivization a citizenship or not, this searching movement for larger associational forms is very important for contemporary African lives. It may be expressed in shifting religious groupings that have been observed in cities across Africa for several decades, through attachment to development projects or NGOs, to single-disease vertical treatment programmes or, as I will suggest further on in this essay, through participation in medical experiments.

### **Transnational clinical trials and post-nation-state biopolitics**

Social scientists have observed, over the past decades, a proliferation of transnational medical research—especially clinical trials conducted with funding and expertise residing in institutions in Europe and North America,

upon bodies, and in collaboration with medical institutions, in post-socialist and postcolonial nations (e.g. Petryna 2002; Rajan 2006; Cooper 2008; Reubi 2010; see also Turnbull 2003, Leach/Fairhead 2007). These trials differ (to some extent) from clinical trials conducted in the same countries where pharmaceutical industry and leading scientific institutions reside, because they stretch across vast inequalities in health and resources.<sup>2</sup> And they are different from clinical trials conducted within the framework of national health services in that they involve non-nation actors and thereby create different bioscientific territorialities. The most prominent publications about this new regime of clinical research concern south-east Asia and the territories of the former Soviet Union: these areas differ from Africa in terms of their relatively well-organised health and scientific infrastructure and their highly trained, but comparatively cheap, scientific work force, as well as in their disease patterns (resembling those of major Euro-American drug markets), which has made them a main target for pharmaceutical companies' drug trials.

In Africa outside South Africa, this type of for-profit transnational research is still relatively rare although it is likely to grow, for example in relation to anti-cancer treatment (see Livingstone 2012). The dominant transnational formation of bioscientific production in 21<sup>st</sup> century Africa is not the corporate pharmaceutical drug trial, but the publicly funded collaborative field station or research centre, often with an associated demographic surveillance system, sizable areas, often with several hundred thousand inhabitants, where demographic events as well as morbidity are closely surveyed, in view of providing a sampling frame for controlled clinical trials of health interventions and vaccines (see e.g. Adazu et al. 2005). Such field stations—involving large 'Northern' scientific organisations such as the USA's Centres for Disease Control, the British Wellcome Trust and Medical Research Council, and some of wealthy American universities, in conjunction with African para-statal organisations or health facilities—have over the past three decades emerged all over Africa. Disposing over highly trained and motivated scientific leaders, state of the art laboratories, large and highly trained, flexible workforces, and the mentioned highly capital intensive demographic surveillance systems, these field stations have become the primary sites of bioscientific production on the African continent, and have largely replaced African academic institutions as well as national ministries of health, with whom they sometimes collaborate, as centres of scientific productivity and excellence.

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**2** | While this dimension of inequality is absent in the remaining strong nation and welfare states (e.g. Scandinavia), where most trial participants are recruited from the general population, clinical trials in less egalitarian western societies such as the USA do of course share many of the ethical and political challenges of transnational clinical trials (see e.g. Abadie 2010).

These new large-scale units are exemplary of the biopolitical forms of the post-neoliberal age in Africa. Their relationship to the nation-state is weakened, even though the African partner organisations are often ‘para-statal’ organisations combining state endorsement with corporate traits, and although they continue to rely on state regulation and state health facilities for subject recruitment and above all for post-trial referral. Usually they are situated close to participant recruitment areas—hence the term *field station*—and distant from centres of national government or higher education, as well as from the global ‘centres of excellence’ to which they are attached. Due to the high capital input in a context of generalised poverty, these installations tend to be segregated from the surrounding territories—creating enclaves of perfect bioscientific possibility within the wastelands of post-nation-state health care and academia. Biomedical science, rather than progressively extending its reach over a national territory, contracts here into islands; the possibilities and aspirations of the modern rendered as an archipelago. Connections to the national loci of public health governance are sometimes challenging, while worldwide communications, material flows and data exchanges among such enclaves of global bioscience, and between them and the mother institutions in the North are immediate—‘hopping’ as it were in real time across the globe.<sup>3</sup> As such, the geography of contemporary African clinical trial sites reflects the novel territoriality that anthropologists have described for neoliberalised African resource extraction industries—e.g. multinational mining corporations’ and oil industries’ ‘capital hopping’ and ‘enclaving’ (see Ferguson 2006). They do thus have a distinctly ‘neoliberal’ flavour to them, without, however, the direct economic causalities, which shape pharmaceutical companies’ drug trials.

A second characteristic trait of these installations, intertwined with their spatiality, is their experimental temporality. Their activities are, unlike those of state education or national health care, never explicitly long-term, although, incidentally, many of these sites look back at 20 or 30 years of existence. Instead, they are framed by time-limited funding cycles and temporary contracts, and

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**3** | Characteristic of these real-time global data networks are disease specific consortia, such as the HIV Prevention Trials Network ([www.hptn.org](http://www.hptn.org)) or the Malaria Vaccine Initiative ([www.malariavaccine.org](http://www.malariavaccine.org)), which produce ‘multi-site’ trials, which are centered in some global centre of academic excellence, and recruit participants (often competitively, racing against time) in sites accross the globe, continuously pooling data from study subjects in different parts of the world; many of the most infkuntial and important medical research endeavours of our time are organised in this way. Another example of a global network of scientific spots is the International Network for the Demographic Evaluation of Populations and Their Health in Developing Countries (INDEPTH) ([www.indepth-network.org](http://www.indepth-network.org)), which links health and demographic surveillance areas from around the globe.

by the limited horizons of experimentation, which extend towards previously defined endpoints in time—'outcomes'. With this experimental mode of engagement between research institutions and their congregation comes a particular relationship between knowledge and action, in which interventions (treatment, disease prevention) are conducted as experiments, without certainty about the outcomes; although such 'experimentality' could be said to have existed in earlier, colonial, scientific regimes (e.g. Lachenal, this volume), it becomes a dominant trait of present scientific work in Africa, partly because of the retreat of long-term state interventions based on consolidated evidence (see Rottenburg 2009). Again, these temporal and epistemological conditions are not limited to the production of scientific knowledge, but resemble the politics of 'exception' that anthropologists have described as foundational to contemporary formations of global capitalism (e.g. Ong 2006), without, however implying the same economic determination.

As far as the economics of contemporary African trial sites are concerned, much funding still originates from national governments—albeit not the governments of the nation's where these stations are situated, but that of Northern nations government budgets—and not from private corporations. There is a significant and growing proportion of 'public private partnerships' in which private funding, including that of pharmaceutical industry contributes, and shapes, public scientific enquiry (see Gerrets this volume), but the dominant source of funding remain national government institutions like the US NIH, or the UK MRC, and public charities like the Wellcome Trust. Despite the overall public nature of these institutions, by contrast with the commercial clinical trial settings described for Eastern Europe and south-east Asia, the way these installations are managed and audited, the flexible short-term contracts under which the (predominantly) local workforce is employed, and the structures of transnational management and funding flows, is not entirely dissimilar to transnational corporations. Control over the scientific production process resides with Northern institutions, data is often transferred to and analysed by these, and published by British and American academic journals; processes are managed and supervised by these institutions and their staff, and the existence and continuity of the institutional arrangement depends upon them.

Similar debates about the production and distribution of value created by scientific labour that apply to multinational corporations' outsourced production sites in post-colonial territories, arise then from today's African field stations, although the value produced and transacted around these sites is less directly identifiable as a form of capital. Economic questions about exploitation, accumulation and justice are here often negotiated through the idiom of research 'ethics', which—if sometimes by implicit evasion or explicit exclusion from its purview—engages economic contradictions in the idiom of justice, freedom and social good. It is the active exclusion of value from view that such ethical

reflections and regulations often encourage, that provide my starting point for the discussion about experimental value and collective below.

### **The ethics and politics of bioscientific value**

Bioscientific value has recently received attention from anthropologists and bioethicists who—from different institutional and political viewpoints—emphasise the political, economic and practical challenge that this value poses, at this particular juncture, and in economically deprived regions (for ethicists see e.g. Dickert/Grady 1999; Lemmens/Elliott 1999; Anderson/Weijer 2002; for anthropologists see Petryna 2005; Rajan 2006; Hayden 2007; Cooper 2008). The discussion includes very different viewpoints: traditional bioethicists who insist on the ‘social value’ of scientific knowledge and reject consideration of individual interests and profit, those who propose value-distribution through ‘benefit sharing’, others who denounce the privatised value of pharmaceutical research and uphold the virtues of the nation-state, and finally those who propose to resolve matters by re-evaluating research participation as paid ‘clinical labour’.

What is at stake in all these approaches to the problem of value arising from scientific production under conditions of economic inequality, is the relation between value and collectives (or processes of collectivisation); who creates the value; who is the rightful owner of this value—society, mankind, nation, individuals, or other, intermediate collectives; and how, by whom, and to whom should value be transferred? Value is produced, and disbursed, within and among collectives; but what these collectives are has become much less clear today, compared to when medical science was produced by state institutions through the scientific and bodily labour of national citizens (see Hayden 2007).

This chapter contributes to this discussion about value and collectives, and to the wider problem of post-governmental biopolitics in Africa, by examining the practice of ‘transport reimbursement’—small financial payments to trial participants on the occasion of their participation in clinical or data collection procedures. These are part of most medical research settings; I will here discuss them in relation to HIV research conducted in Kisumu, Kenya, in collaborations between KEMRI and its main overseas collaborator, CDC.<sup>4</sup> I draw upon interviews, conversations and observations with research participants and

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**4** | KEMRI was founded by government act in 1979, as one of several ‘para-statal’, usually collaboratively funded, scientific institutions. The US government CDC is a main collaborator, conducting research on malaria, HIV and emergent diseases. KEMRI and CDC have since 1979 focused on western Kenya and have jointly built the KEMRI/CDC field research station, which is part of the KEMRI ‘Centre for Global Health’ which has expanded continuously during the 1990s and is today one of the leading medical research sites in Africa, with world-class laboratories and an annual budget in excess of

staff during long-term ethnographic fieldwork among the 'trial community' (Geissler/Molyneux 2010) of a scientific study evaluating an innovative regime of maternal triple anti-retroviral prophylaxis from late pregnancy through six months of breastfeeding for the prevention of mother-to-child transmission of HIV (PMTCT).<sup>5</sup> The study showed that the relatively inexpensive experimental regime could reduce mother-to-child HIV transmission to less than one fifth of the rate that one would have expected under standard medical procedures in the area; indeed, the rate of transmission at birth was only little higher than what would be the case in developed country medical settings (Thomas et al. 2008). The trial lasted from 2003 to 2009, and involved over 500 women, who were recruited from antenatal care centres upon their diagnosis as HIV positive. The women and their babies were followed for up to two years after delivery. Most of them lived at the beginning of the study in the city of Kisumu, but many moved during the follow-up between city and rural areas, reflecting the instability of many young women's lives in Western Kenya today (see e.g. Geissler/Prince 2010). In spite of the practical difficulties arising from this mobility, the trial lost few participants, because the women, for various reasons, liked to be part of it—which, as I will discuss below, is very important for our understanding of the value of scientific work, and the collectives it engenders.

In this essay, I will show, first, that the financial transactions called 'transport reimbursement' are generally understood not as reimbursement—i.e. zero-sum transactions—but as net value transfers, and that all members of the 'trial community'—study participants and the people they live among, research staff, and scientists—are aware of this discrepancy between the nature of the payments and the term by which they are referred to. The term 'transport reimbursement' attempts to render invisible the value of these transactions, responding to regulatory objections to payments or what bioethicists refer to as 'undue inducement', and as a result, it removes the problem of value from the sphere of legitimate discourse. Speaking about this un-spoken materiality affords us then an opportunity to prise open the transactions of value in transnational clinical trials in order to rethink the political project of public health science, beyond the alternatives of ethics and market, gift and exchange, that shape much of the on-going bioethics debate, especially in Kenya. This will lead us to reflect about the potential collectives and aspired-to futures—emergent 'citizenship(s)' (see Whyte 2009) or the 'publics' in public health—which are referred to as well as

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USD30 million, hosting approximately 1,500 staff members, funded by CDC and other funders, and employed by KEMRI, and hundred thousands of participants.

**5** | Fieldwork was conducted from 2006 to 2010 with the approval of KEMRI, CDC and other collaborators involved in HIV research. I am grateful for the support and trust we received from our colleagues. This article presents the author's reflections and aims to contribute to an open discussion with scientists and ethicists.

produced by clinical trial engagements. Thus the discussion returns us to the political promise and responsibility of public health, as in producing health *and* engendering a collective.

## TRANSPORT REIMBURSEMENT

### “So what shall I call this?”

Every Friday morning the coordinator of one of the HIV trials conducted in Kisumu, Kenya, meets his staff, including clinicians, laboratory technicians, counsellors and interviewers, employed by the Kenyan Medical Research Institute (KEMRI) in collaboration with the Centres for Disease Control and Prevention (CDC). On this day, about 20 staff members are gathered in the conference room of the custom-built clinical research centre. The principal investigator (PI), who usually attends staff meetings, is absent. One purpose of the meeting is to discuss encounters with specific trial participants. A clinician reports about a pregnant participant who asked for transport to the clinic because she felt unwell and could not walk. After she was taken to the clinic by taxi, she asked for ‘transport reimbursement’, which she regarded as an entitlement. When the clinician told her that she could only have the taxi fare *or* reimbursement, she responded that she would then come on foot anyway. The case provokes lively discussion, in which the majority of staff members advocate to pay both for the taxi *and* for transport reimbursement.

When the clinician concludes: “She was not really sick. She could walk ...”, a female field staff objects: “You can’t do this. She is pregnant, she maybe cannot walk! Do you still want her to walk all the way in order to get the reimbursement?” Another male clinician interjects: “We have to look at the ethics. We should not be seen as coercive, and we must not set a precedent.” The female colleague retorts: “Now who will see this?” Patiently, the second clinician continues: “Transport reimbursement is supposed to take care of her transport. Now if you give her taxi [fare] and then you still pay her transport reimbursement, this is transport to where? If I still pay her, what shall I then call this?” “*Transport reimbursement!!*” retorts the female staff, supported by laughter and nodding from other staff members. The clinician pauses and resigns, proposing to take the matter up with “the powers that be”, the PI. Everybody including the clinicians laughs. No further action is taken on the matter.

On this rare occasion, the problem of ‘transport reimbursement’ was made explicit, for a moment, before being covered again by terminological rigour combined with mirth and irony. For a moment the gap between names and things was opened, but it was quickly closed again, quite rightly so, because nobody present, nor the “powers that be” can resolve it. I do not want simply

to denounce this discrepancy between rules and realities, but take it as a point of departure to reflect about transactions of value in clinical research in HIV trials in Africa. The rhetorical question posed in this exchange: "transport to where?" orientates my enquiry, as I will suggest that one important function of value transfers like transport reimbursement, pharmaceutical treatment, blood specimens or clinical data, intertwined with the more immediate fulfilment of vital needs, is to propose emergent collectives, to evoke futures, engender movement and seek direction—indeed *transport* towards better lives.

### **"We don't pay..."**

Practices and discussions as well as silences around 'transport reimbursement' (TR) concretise the problem of value, faced by transnational research in the current historical and political-economic moment.<sup>6</sup> TR is one of many transfers of material value to individual study participants, which, in the Kenyan context, may include medical treatment and pharmaceuticals, food, bars of soap, bed nets and water containers and other health enhancing commodities.<sup>7</sup> TR is distinguished from these by being monetary, which makes it particularly problematic to bioethicists sharing a broadly 'western' understanding of money as abstract, calculative and individuating (see e.g. Maurer 2006). A bar of soap, a cinema ticket or a project party can here more easily be construed as a gift because none of them is vitally necessary, and the first has additional legitimacy because of its health impact. Such gifts are often referred to in the trial context as 'a thank you', rather than as an 'incentive'. By contrast (general purpose) money is, in this tradition, not suitable as a gift or 'thank you' because it is convertible and invites calculation and notions of economic exchange.

The aversion to money changing hands within a public health context extends—at least in the eyes of many older public health experts—to the wider health care services. Only after considerable national and international scholarly debates could so-called "user fees" for government health services be introduced within the broader framework of neoliberal "structural adjustment"; today, Kenyans have to pay contributions to almost all medical services provided by government facilities; and although these fees are relatively low, they do set

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**6** | Since in most economically deprived settings, receipts for transport are hard to get (or all too easy to obtain), TR is often based on fixed rates specific to a site or a particular trial. Rates vary between collaborative sites and sometimes between research groups and projects in one site, usually ranging from 2-5£ (higher amounts being paid in trials based at referral hospitals covering large areas, and for participants who for various reasons travel long distance).

**7** | Even cinema tickets, underlining the attempts to retain the notion of the gift and the effort to keep transactions separate from any actual needs and survival.



limits to the care available to poorer people, they opened, some argue, the door to unofficial payments and corruption in health facilities, and they did away with the idea of health care as a service that the nation bestowed upon its citizens (see e.g. Mwabu et al. 1995). It is this liberalised world of illness and health, which provides the context for local understandings of value transactions in clinical research.

As money may easily be confused with ‘payment’, regulatory ethics guidelines applied in Kenya insist that monetary transactions should be a mere prevention of cost;<sup>8</sup> the sum of transport fare and reimbursement is assumed to be zero; no personal gain should be incurred.

Like in most transnational research sites in Africa that adhere to ‘Good Clinical Practice’ (GCP) and international ethics guidelines, net monetary benefits for participants—‘incentives’ or even ‘payments’—would here be considered ‘undue inducement’ contrary to the spirit of voluntariness, and they would not be given approval by the Institutional Review Boards (IRB) that assess project ethics. Likewise, IRB approval can be denied if the proposed TR, which increasingly has to be specified on the research protocol and information materials and consent forms, is considered too high, constituting ‘coercion’ of poor participants. Official documents emphasise therefore the link between reimbursement and travel, relating reimbursement rates either to transport fares or to distance, but not usually to other equivalents such as time spent, effort undertaken, leave alone risk incurred. In accordance with these conventions and with written study documents, if TR is discussed among trial staff and especially with participants, any mentioning of ‘payment’, as in ‘how much do you pay your participants?’ is likely to be rebuked by a ‘we don’t pay’.

Reimbursement and voluntarism are flip sides of one coin: the notion of reimbursement safeguards the freedom of voluntariness, in the sense of individual choice. The significance of using ‘reimbursement’ instead of ‘payment’ is underlined in the terminology applied to another kind of bodily research participation in entomological research conducted by KEMRI around Kisumu: young men recruited to catch mosquitoes off their bodies (human landing catch), and those who sleep in tent-traps to catch mosquitoes, can only be recruited as ‘volunteers’ and be given ‘reimbursement’ for that time as well as the risk of malaria infection (reduced by chemoprophylaxis); their remuneration must not be referred to as ‘payment’, and rather than employment contracts, they sign consent forms. By contrast, young men recruited from the same village communities to set mosquito traps or empty them are employed as casual

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**8** | In other regularly contexts (e.g. USA) payments are acceptable, even to pull participants, as long as they do not induce unreasonable risk taking (undue inducement), but even where such payments are formally allowed, they often draw public moral debate, such as around the 2006 British Paraxel incident (e.g. Wadman 2006).

workers and paid exactly the same amount as volunteers for a specified number of hours. The terminological rigour is important here, so as not to create the ethically problematic situation in which one pays for bodily risk. Lending one's body to science remains here linked to voluntarism and citizenship, to avoid the potential accusation of exploitation, which does not seem to arise from ordinary labour relations. Apart from terms, however, the two kinds of research work and pay are identical.

To maintain the moral value of autonomy, and to protect participants from the force of resource-rich research institutions, transfers of material value, notably money, to them are avoided or kept minimal. While this is the argument behind ethics rejections of 'inducement', one could argue that the notion of 'voluntariness', understood as autonomous choice without material entanglements, is anyway less than straightforward under conditions of extreme poverty—in the words of one scientist 'a bit of a middle/upper class luxury'—and that one should instead explore concepts such as 'responsibility' or, in medical terms 'care', as a frame for ethical scientific engagement. I will return to this.

### **Reimbursement in western Kenya**

TR is a relatively recent development. When I conducted epidemiological research in Western Kenya in the early 90s, study participants in rural areas did not expect monetary transactions around their research participation. Indeed, the government scientists and technologists with whom I worked at the time were strongly opposed to the idea, both on the grounds that they regarded people's participation in research as a citizen's duty (reciprocated by their own efforts at government disease control), and because they feared that independent research by Kenyan government agencies without external funding would be made impossible if Kenyan citizens would expect individual payments for blood, stool or urine specimen delivery. In other words, at the time the collective nation-state frame of medical research and public health intervention was still taken for granted; from this followed not only that participants were not paid, but also that their consent, as citizens, was taken largely for granted by the government researchers, and no individual written consent was sought.<sup>9</sup>

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**9** | The organisation that I worked with at the time, and which had dominated medical field research in Kenya for many decades, was probably relatively more conservative in its civic values and 'developmentalist' nation-state imaginary than others who began operating in the area at the time, and who eventually took over at the helm of medical research. The anachronism of some of their procedures in a changed scientific world, in which good science was no longer nation-state public health, but 'Good Clinical Practice', became very clear when a large collaborative project of the former (government) organisation was closed down in 2000 after an external review by North

Since that time, new agencies have become leading in Kenyan medical research, and the social contract that the older generation then still envisioned as basis of public health science has been eroded; instead, along with standard consent procedures, TR has become an obligatory part of medical research and potential research participants are keenly aware that research participation entails some monetary transactions.

Among the reasons for transport reimbursement becoming ubiquitous in Western Kenya are changes in the conduct of transnational medical research, its relation to the national health system, and the wider political economy, from epidemiological field research to the model of clinical trials run according to global regulatory frameworks—and the attendant transnational transfer of procedures and models, as well as growing prominence of Euro-American institutions in research collaborations. While up to the early 1990s collaborative medical research projects in Kenya had minimal expatriate staff and operated usually within facilities provided by the Ministry of Health, using government transport and permanently employed civil servant staff, today's medical research programmes in Western Kenya are widely known by the name of their overseas collaborative partners, and recognised by their custom built research centres and laboratories (often erected within or next to public facilities but recognisably different from them) and their highly visible modern transport fleet. Staff—on temporary short term contracts funded by the external collaborator—and research participants today tend to identify with the overseas collaborator (as in 'I'm with ...') rather than with national government and citizenship.

While medical research in the past used to be integrated more tightly with government health care provision and often directly linked to public health campaigns, the social benefit of today's transnational clinical trials is often less immediate and visible to participants—mediated through a long loop via academic centres of excellence in the USA, and international policy bodies such as WHO, making short-term benefits a more salient and contested issue. Moreover, the exponential growth of medical research and aid activities in Western Kenya—one of Africa's key HIV intervention zones—has during the last decade led to a very different local economy, marked by new income opportunities and raised expectations of monetary gain among the general populations (see also Prince, this volume). In areas like this, models and relationships derived from medical research have extended across society, and transport reimbursement—tied to the notion of 'voluntary' action—has gained currency far beyond the limited purview of medical research. Thus, in HIV care and treatment, which in this area are again spearheaded by KEMRI and CDC,

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American reviewers, who found the ethics procedures lacking. This was, then, the definite endpoint, in Kenya, of medical research premised on and legitimesed by the taken for granted social contract between citizen and nation.

large numbers of ‘volunteers’ assist donor funded patient support centres with recruiting, counselling and testing, and tracing patients who defaulted, as peer educators and by transporting blood samples and managing patient records. Volunteers may in such facilities well outnumber regular employees, and the status of the volunteer—often envisaged as a step between HIV self-help or ‘peer’ assistance, and more formal employment in the HIV-NGO sector—has become emblematic of especially younger people’s lives in Western Kenya. As volunteers, they are not paid for their labour, but given ‘reimbursement’ or ‘tokens’. This economy of voluntarism and reimbursement opens up new possibilities of engagement, learning and civic identity to young people, but it also creates possibilities of exploitation and abuse by institutions and by formally employed actors.

### **Do we have a Standard Operating Procedure?**

The fact that transport reimbursement still is a relatively new phenomenon is reflected in the flexibility of the practices around it. Thus, in the HIV prevention trial we followed, the project protocol from 2003 contains no details about TR. The fact sheet for prospective participants states under “benefits” that: “Neither you nor your baby will be paid for being in this study. But you will receive money to pay for your transport,” and, under the heading of “costs”, that: “there is no cost to you or your baby for the study drugs, study clinic visits, physical exams, transport to study clinic visits, lab tests for the study, or for your delivery at the hospital.” An attached sub-study protocol specifies: “Participants will be reimbursed transport according to standard ... guidelines already described in the main study protocol. For their time, sub-study participants, like all KEMRI/CDC participants will receive a bar of soap.” The main protocol does not specify amounts, presumably based on the assumption that actual transport expenses will be refunded. The distinction made here between monetary reimbursement and soap as appreciation of time underscores the careful hedging of monetary transfers as presumed zero sum transactions, separate from gifts and not to be confused with exchanges.

When the PI, after the end of the study, tried to find us some documentation of reimbursement rules and asked his staff for the ‘standard operating procedure’ (SOP), no such document existed, although trial practices had been regulated in great detail by specific SOP’s. The staff member who had been in charge of reimbursements explained retrospectively: “We did not have an SOP for transport reimbursement. The initial figure of 100 KSh was arrived at from [a preceding] study [in the same site]. After a while due to the amount of time mothers spent in the clinic it was agreed that we increase the figure by 200 KSh to compensate for the time they took in the clinic” (K29; e-mail, May 4th 2010). This change of rates, motivated partly be the realisation that

some women travelled longer distances, and partly by the long time the study procedures took, was recorded in staff meeting minutes, which were the only official written document concerning TR rates for this study: “scheduled visits participants will receive Ksh.300 [up] from Ksh.100” and, “participants will start receiving Ksh.300 on enrolment” (Minutes K, August 2006). These decisions were taken by research staff and the PI based on practical experience and personal judgement, joint deliberation and improvisation in a setting where even the most mundane research procedures were fixed in written SOPs. Part of the motivation behind the threefold increase of the rate was to provide some payment over and above the actual transport fare (which at the time was about 50 KSh for most distances within Kisumu), as underlined by the provision, in the same minutes, that for “those who come from far Ksh.200 will be added on the rates they receive.” Moreover, the additional 200 shillings were only to be paid for visits to the clinic relevant to the study, whereas “unscheduled visits” due to sickness were only compensated by the old rate of 100 shillings, based on the assumption that those who attend the clinic for health reasons already receive a benefit and do not need further incentive. As the PI recalled: “There was quite a bit of abuse going on with sick visits... we figured we were already providing care for the sick visit, so perhaps we could compensate a little bit less for transport” (C26.3).

Between 2003 and 2009, transport reimbursements were regularly paid to over 500 participants. The amount paid was based on the considerations discussed by the study team, which were not recorded as they arose in everyday practice. The PI recalled the discussions with study staff:

“Well, ...it is fair to say for someone who walked, it covered more than their transport, literally their transport reimbursement. [...], there was another rationale there ... we were setting it perhaps at the minimum wage? Which was about 250, so we were slightly above minimum wage. I think just to compensate...they may be there for a long time, so ...they might have been, could have been, working, ... to compensate. And we did, for women who came a long way and brought a receipt, we compensated even over and above [the actual rate].” (C26.3).

This PI was particularly thoughtful and open about his considerations, and the potential ethical issues involved—“I mean its a fine balance, you know, to sort of compensate people for their time, sitting in a matatu [minibus]... without being coercive.” (C26.3)—and he repeatedly encouraged us to study TR, which he, like other colleagues, found a slightly awkward concept. Similar themes emerged in conversation with other PI’s and study coordinators, who were struggling with the task of setting an adequate rate, aware of ethical norms of non-payment as well as participants’ needs and the requirements of trial management. Some said they had used an assumed minimum wage as a standard, others

had added a token onto documented transport fees, others again had copied other research groups. Underneath the seeming obviousness of the concept of ‘reimbursement’ many other considerations were at play and informally negotiated. These included questions of justice and ethics, and personal commitment to provide some help for poor study subjects, but also budgetary constraints, competition with other groups for participants, and concerns with recruitment rates and participant retention. The resulting negotiations between researchers and research staff were somewhat improvised, and with little input from participants.

## Stabilisation

At the time when our study came to an end, transport reimbursement became stabilised in an official document. This was provoked by an oversight: a research student moving from the urban research zone to a rural area had used the common TR rate in the city (300 Kenyan shillings) on her ethics application for a new project in the rural area (reflecting growing awareness of the issue, by 2008 the KEMRI ethics committee required the stipulation of transport reimbursement rates in every protocol). Upon arrival on the new research site she realised that the rural rate was lower (120 Kenyan shillings), and other researchers on site understandably urged her to adjust her rate in order to avoid competition. When this change was submitted, with reference to ‘standard guidelines’, as an amendment to the ethics committee, the committee comprehensibly wished to see those guidelines. In collaboration with senior colleagues, the research student produced official ‘reimbursement guidelines’ which formally stated the different rates for, respectively, the urban and the rural research site. It also ended ambiguities concerning the meaning of transport reimbursement—such as the reference to the time spent in the clinic, noted above—by stating: “Reimbursement is understood as meeting travel costs participants incur to attend study visits”, and specifying further that based on a “mapping exercise of rural districts” it had been determined “how much a participant would spend to travel to a facility” arriving at the lower rural rate, and that “travel costs are higher in peri-urban and urban Kisumu and participants usually travel longer distances to reach the research facilities” within the city, justifying the urban rate of 300 shillings.<sup>10</sup>

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**10** | Interestingly, the rural rate of 120 Kenyan shillings that had been determined through careful deliberations by the rural research teams prior to the formalisation of reimbursement rates, had, according to one rural study coordinator, been derived from comparison with approximate daily labour rates in agricultural production. While, as we saw above, the urban rates had been produced by adding 200 shillings—to appreciate time and effort—onto an earlier rate inherited from a previous project, the rural rates

## VALUE APPRECIATED, ACKNOWLEDGED AND HIDDEN AGAIN

### Receiving reimbursements: ‘But I am paid’

Much as the notion of payment, and of monetary value, is avoided in official trial documents, study participants perceive these transfers not as mere reimbursements. That they value the additional cash is unsurprising in a place where, for most people, a day’s manual labour would earn 100-200 KSh—an amount that could pay for one substantial family meal—in a situation of generalised unemployment, rising food prices and unstable food production, where opportunities to earn even such modest amounts are scarce.

Participants expect, at least after some time in a project, reimbursement attached to every trial activity, usually even if they had no actual transport expenses or when a research team had come to visit them to collect data or conduct an interview. All participants expected some amount over and above their actual expenses—“they don’t give you the exact transport, you are just given, so it really helps.” (KP8)—and many were aware of the 200 shillings excess that had emerged from the deliberations above. The amount of cash that the participants took home varied slightly, depending upon the number of clinic visits and the actual transport expenses; but all mothers appreciated the money, and praised CDC’s ‘generosity’ (lit. ‘wide hand’, *bade lach* (KP18)), embodied by the PI, whom they referred to as the ‘owner/father of the clinic’ (*wuon* clinic) or the leader of the study (*jatend* [study]), and the attentive and generous KEMRI staff. The idiom of generosity and the emphasis on the paternal figure inserts trial participation into a wider frame of patronage as local idiom of entitlement and responsibility. I will return to his relational and collectivising effects of the payments below.

Even medical care and pharmaceuticals, probably the most important transfer of material value around trials and definitely more significant than TR, was discussed by participants in monetary terms, when the prices of medical procedures such as deliveries, in public and private hospitals, were converted into costs. Several participants remarked upon the fact that the study not only liberated them of the cost of consultations and drugs—“Even if I’m a little sick, they give me good medicine which can cost a lot of money if I go to buy it and this relieves (lit. ‘frees’) me (*giketa thuolo*)” (KP8)—but even used “original drugs [brand packaged], not just drugs that are being sold ...” (KP 14). While these conversions of care into money underline the participants’ awareness of

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had been directly derived from comparison with labour rates. The result of the mapping exercise stabilised the more complex, contextualised considerations of research teams in city and rural area, and translated earlier deliberations about compensation for time and effort into reimbursement for transport fees.

value and the inseparability of value and care, their desire to be treated with 'original' drugs also indicates, again, that there is more than money to these considerations. The care bestowed by the study is also associated with higher reliability, and with wider, more robust, global medical connections, for example to leading multinational pharmaceutical companies or the technical standards of ISO certified research laboratories: if one's HIV test is done by the world's largest and most influential public health agency, by staff trained by a world leading old school of tropical medicine, or if one's drugs are produced by a known multinational pharma-company and licensed by the FDA, one's bodily state and well-being is, if ephemerally, connected to much larger wholes, which—despite the fears and concerns that power always also provokes in the powerless—engender expectations and trust that the nation-state health system can no longer instil in its citizens. Thus, while value calculations permeate social engagements of the trial, this does not prevent them from being linked to wider notions of belonging and care. I will come back to that.

### **Covering vital needs**

The cash obtained through trial participation is quickly converted into life sustaining food—"something to swallow because, you know, we were breastfeeding, [...] so this money helped us a lot; we could have at least something to eat" (KP10). Invariably, the women describe how they would use the 'reimbursement' for food, to eat, to obtain particularly "good food [such as fruit] to boost up your blood/foetus" (KP4), or, more commonly to feed their children and to share with others: "the money that we were given, these 200, was helping us all. When I leave Kisumu I carry something. Doesn't it help everybody? You can buy something for the baby, and you can cook something in your house, and people share; so people are happy" (KP15). While daily food needs were the priority, some participants increased the value of their reimbursement by investing it, as they travelled between home and clinic: "the remaining fare [TR] made me join business; when I come to them I can go back with three or two pairs of shoes. I sell them higher than I bought them. The ones from this side have a bit of profit" (KP15).

The small amounts of reimbursement money contributed to the women's, and their children's, lives in an economy of survival, where the means to satisfy one's vital needs have to be found anew, day after day. Many of them described not having access to cash and often not knowing in the morning how to buy supper. Many lived in rented accommodation (single rooms) which cost around 5-700 Kenyan shillings a month, and described a family meal as consisting of vegetables for 20 shillings cooked with tomatoes for 10 shillings, accompanied by maize porridge (in 2009, maize flour cost 120 shillings for 2 kgs) which gives an indication of their regular cash flows, that transport reimbursements added



to. The scarcity of money in these women's lives, often controlled by husbands and relatives, was underlined by their quest for health care: "when the child becomes sick, or when I am sick, I am in problems. I don't have money, I will not be treated. But then [with the study] I was just treated even if I don't have money" (KP9). "Sometimes the baby is sick, you carry the baby for treatment; in the hospital you are prescribed expensive drugs but you cannot afford them at that time, so you leave the baby until the sickness becomes worse, and only then you get money to go and buy" (KP18).

Those who had moved out of the city since the beginning of the study to live with relatives experienced particular difficulties in obtaining even the money (at times less than hundred shillings) needed to take a child to hospital in town. They had to borrow from neighbours and relatives, promising them to repay upon their return—which, incidentally, was comparatively easy for those who were known to 'be with KEMRI/CDC', since the association made them more creditworthy; often they walked, even for hours. For poor HIV positive mothers, the possibility of reaching the city or a hospital is about survival: "If a child is sick or if I am sick, even when I am far, I can call them to come for me or I just go and they will pay the transport" (KP12). "[When I was told the study was over] I said 'what am I going to do?' I had got used to Kisumu: when I'm sick I just looked for fare to go to Kisumu, and they treated me, or my child" (KP15). To have an institution pay for your transport when the need arises—"If you really need to go, it is always easy to borrow from a neighbour, because in the evening, he knows, you can repay [because he knows you are with CDC]" (KP10)—means here more than just a bus ticket; here again, trial participation is about remaining connected, to escape geographical and often social isolation, and to live.

### **Being cared for**

Striking in the women's accounts was the lack of social networks and help that they could rely upon in times of need: vain attempts to secure funding for medical bills from husbands or relatives, and narratives of sick husbands unable to contribute—"it was at night and my husband refused to give out money so that I go to hospital so what could I do, I just gave birth" (KP9)—and not least stories about lack of trust between the women and husbands, relatives and neighbours, whom they hid their HIV status from. While some participants lived in supportive marriage and kin relationships, many others gave a picture of a lonely struggle for their own, and their children's, survival, where study participation provided vital associations: "if I had not joined [the study], the way I later became sick, nobody would have treated me. I would have stayed in the house until I was yellow and there was nobody there to take me to the hospital" (KP8).

Under conditions of isolation (economically, and in kinship and gender terms, compounded by HIV status and stigma) it is not surprising that the women described their participation in an HIV research project in extremely positive terms: "they really care about the children. These [study] children of theirs, they really liked them" (KP4); "they were happy people, they loved people, they loved us so much" (KP21); "They were taking good care of us. [...] transportation, [...] food, tea when you are hungry, there were nice to us" (KP6). Money, conviviality and attachment were intertwined: "like, sometimes I left my house before taking breakfast, so when they gave [breakfast] I say it is a good place because they consider others. Sometimes I could use my transport to come from home, and they gave it back to me; I said it is a good place, these people are really there to help me and I was happy with them" (KP1).

The experience of caring personal relations was also underlined by the prevailing idiom of kin- and friendship ('our baby', 'my sister' etc.); and the boundary between reimbursements and gifts was further blurred by the fact that staff members regularly extended the official reimbursements with small personal gifts of money or in kind. Thus, most follow-up staff who visited participants in their homes reported that they occasionally had given mothers small sums of money to buy food for their children, or brought them used clothes or flour. 'Being with' a study created a collective—if temporary, unstable, fragmented—out of mutual claims and responsibilities, as well as affect.

Material transfers came along with less tangible experiences of positive staff attitudes and new relations: "they gave me ... encouragement, they are talking to you ...they don't just talk to you like that" (KP15); "I was getting different teachings [...that] make your heart strong: my husband had left me then, but I said that we are many, I am not alone." (KP17). In particular, many mothers praised the knowledge they had gained—"knowledge on how I will continue living in good health, what I can do when I have a baby, the health of the child..." (KP9)—"a way of reasoning how one can live, with HIV" (KP12); "exposure", as some of them called it, to new ways of thinking and living, enforced by a sense of encouragement and of being cared for, being included into a larger collective. All women wished for greater continuity in the relations with the research project, and expressed regret that 'their' trial had ended, and said that they would be happy to join another research project. They summarised these experiences in terms of relief, if only temporarily, from the burden of everyday survival: "I saw a lot of lightness [due to the fact that I am cared for]" (KP18); "They really set me free" (KP8).<sup>11</sup>

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**11** | When, during a dissemination meeting that fed back trial results to the women, our own anthropological study was mentioned, almost all women were keen to join this new 'project', even though it fell short of some expectations.

This does not mean that everything was perfect. While most mothers appreciated the good healthcare, some were unhappy with how they were treated. Among the many who were proud that they had prevented their children from being HIV positive were others who had lost their children or had to cope with HIV positive babies. Some disagreed with particular staff members, and about 50 women out of 500 left the trial because of misgivings, or because they did not see the point. Twelve women had died of AIDS during the trial either because they had been recruited in an advanced stage, or because they could not adhere to treatment. Almost all remained desperately poor after the trial and continued to struggle for their daily needs and for health care from insufficient public institutions. What these quotes do suggest, however, is that material transfers, knowledge, conviviality, relatedness and belonging were intertwined in their experience. Economy and epistemology on the one hand, and morality and sociality on the other, were here not separate, even antagonistic domains, but mutually dependent and reinforcing each other. ‘Being with’ the study and the institution conducting it—‘being with CDC or KEMRI’, as people in Kisumu often say about trial participants as well as staff—implies a broad sense of attachment. Even if this sort of belonging may not always be achieved or lasting, it appears that people who participate in trials seek a broader sense of association, beyond attaining immediate personal material fulfilment of needs. Material value, everyday needs, the desire for knowledge, trust and care, are mixed in trial participation in ways that make the liberal idea of individual autonomy and voluntariness questionable. Instead, monetary transactions and other transfers of material value are experienced as part of wider connections and collectives, larger possibilities and hopes.

## **THE FAILURE OF THE GIFT?**

### **A misnomer**

Trials transfer value, including money, to participants; this value transfer is appreciated by recipients, and recognised by everybody involved; and yet it is excluded from the public space of the trial. It is, in the words of more than one of the researchers and staff we spoke to, an ‘open secret’. This is morally and politically problematic. It can seem dishonest on a personal level, and may inhibit open debate, preventing questions of value and justice from being raised, and from becoming part of public debate about public health.<sup>12</sup> As it stands,

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**12** | One space in which such negotiations could have occurred were the ‘community advisory boards’ (CAB) that were set up by the HIV research group with distinguished ‘community representatives’, and which served to facilitate ‘community engagements’,

TR looks like a compensation for trial participants' value-creating efforts, which is set more or less arbitrarily by the trial management—analogueous to a wage determined by the owner of the production process at will.

Given the fact that everybody involved seems to have accepted that value is transferred in TR it would seem appropriate to abandon this performance of valuelessness. There isn't much point to calling payments 'transport reimbursement' any more. But then, how ought one instead understand the transfers of value in clinical trials, epitomised by 'transport reimbursement', instead of concealing them. This 'ought' is not only a matter of representation—how does one correctly *represent* the reality of value transfers—but at least as much a problem of deontology—how *should* one speak about the value of public health research, if one takes seriously the women's biopolitical longing to be part of the trial, and aims to contribute to public (just, equitable) health in a healthy public sphere?<sup>13</sup>

### **Gift or commodity?**

The centrality of value in clinical trials stands in contrast to earlier bioethicists' insistence that considerations of value and profit—any nexus between trial participation and the fulfilment of needs—is antithetical to ethical research

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participant recruitment, and the negotiations of potential problems. However, during the years of this fieldwork the only occasions when transport reimbursement was discussed by the advisory board was in relation to the board members' own transport reimbursement, which eventually was set at a higher rate than that of research participants, presumably somehow related to the higher income of these employed or professional advisers. These different transport reimbursement rates again underline that something other than reimbursement is at play, in this case the different value of people, while the absence of other negotiations of reimbursement from community advisory board deliberations demonstrate the non-public nature of the reimbursement problem (and might raise the question whether the advisory board represents the interests of participants or of the research organisation).

**13** | In a recent, methodologically very different, economic study carried out among Zambian HIV volunteers, experiments showed similarly, that money was at best part of social engagements and not the prime driver of voluntary health work (Ashraf et al. 2011). Monetary incentives were here less efficient to provide motivation than 'social' rewards and recognition. While the authors explained this—limited by their rational actor paradigm—as pointing to 'intrinsic motivation' and 'social comparison' (rather than mere financial rewards) as prime drivers of action, they also note in an aside that the 'reputable organization' for whom the volunteers worked, might have influenced their willingness to contribute. From our perspective, this dimension of belonging to a larger whole would deserve greater weight.

practice (see e.g. Titmuss 1970). This dissociation of ethical medicine from its political-economic context has been debated among progressive academic bioethicists for a while, most notably in reflections on ‘benefit sharing’ around medical research (see e.g. Hayden 2007). Yet, in the Kenyan context, ethics review boards as well as scientists and institutions take as yet little notice of these ongoing discussions (see discussion in Lairumbi et al. 2011); and in practice they remain focused on protecting individual autonomy and voluntariness, which they see threatened by implications of need and interest. Ethics appears here as antithetical to economics. To remain ethical, material transfers attendant on bodily participation in research must conform to a specific idea of the gift—what anthropologists have referred to as the hypothetical concept of the ‘free gift’, a ‘gift for nothing’, valueless, non-calculating, pure, and without expectation of return. Such gift should have no ties attached, not to other people, not across time, nor to one’s bodily needs and desires.

From the observations about TR, above, one could then be led to conclude that this gift has simply failed as foundation for ethical medical science. Indeed, it seems futile to deny the omnipresence of value and calculation throughout human subject engagements with trials. If the gift has failed, its supposed opposite, the commodity rears its head. If people don’t deal with research in terms of gifts, well, then transactions are probably commoditised—that is they should be recognised as exchanges of value in different currencies, including bodily substance, risk, time and money. This is a logical move, which some ethicists propose in an effort to realign medical ethics and a particular economic notion of freedom. The crudest conclusion from this shift would be to consider research participants’ bodily materials as commodities—selling blood samples, organs etc.—but this conflicts with the near universal idea of the inalienability of the body.

Instead, one could move to consider participation in trials as free ‘labour’ (which can be bought and sold), and transactions of value, such as ‘reimbursement’, as payments or wages. In recent literature this idea of ‘clinical labour’ (Cooper 2008) comes in two different versions. One, proposed by some bioethicists, is economically liberal, aligning clinical labour with other unskilled labour in economically poor, low-wage settings, at a fixed low rate—talking about the ‘price of a research subject’ (Dickert/Grady 1999)—accepting the commercialisation of research and the place of unskilled labour in late capitalism as givens. Trial participants are here, like labourers, free to choose selling their time and bodily substance. The second one, developed by anthropologists and sociologists of medical research, comes to a similar conclusion out of broadly Marxist reasoning. By critiquing the misrepresentations that the concept of the free gift produces, and replacing them with a materialist understanding, the hope is that the correct recognition of ‘clinical labour’ would unleash social transformation analogous to older labour movements. The former

proposition wants to adjust norms to the economic status quo, while the latter proposes, within a progressive deontology, to find origins of political-economic transformation in the given material reality. While the political intentions of both arguments are somewhat different, both seem to accept that the gift has failed, and the market—variously understood as invisible hand, or as generative of transformative contradictions—has taken over.

If matters are discussed, and resolved, within this frame, the linkage between bodily participation in public health research and similar medical practices and the older biopolitical collective exemplified by the developmental nation-state fades from view; the market appears as the only possibility in a post-governmental age. In the remainder of the chapter I consider the possibilities and limitations of this move in view of the evidence, above as well as in the literature on 'trial communities', that clinical trials in Africa (and similar settings) continue to engender associations and visions of collectives, against the backdrop of the relative weakness of the older nation-state forms of collectivity. I will conclude by considering what the gift, which according to anthropologists never was free, may still have to offer to our rendering of medical research and public health.

### **Emergent labour markets?**

The notion of 'clinical labour', noted above, does open some political possibilities. In some situations, participants' bargaining power could allow for negotiations about the fair remuneration for their efforts. One of these situations is in the middle of long term trials, when each participant carries the value of the previous investment into examinations, treatments and other procedures; at this stage, participants are, as trial staff are the first to acknowledge, 'too valuable to lose', and trial managers and researchers invest considerable additional funds into maintaining participants or finding them and bringing them to the clinic (yet, participants seem to rarely notice the relative power they hold at this point, partly because they have started worrying about the end-of-the-trial). Another situation of potential bargaining power is when a research organisation has established a long term research site with high investment of capital, infrastructure and training; in such trial sites, which are increasingly common all over Africa, negotiations with (potential) participants are increasingly high on the agenda—often under the heading of 'community engagement' and 'public engagement' (see Molyneux et al. 2005). Finally, participants hold bargaining power where different research groups or projects operate in the same area and compete for participants. Here we see some form of incipient struggle, in which we can discern the shapes of an emergent clinical labour market.

If, within one area, different research groups offer different TR rates to the same potential trial population, this is quickly picked up by potential participants and discussed in terms of payment. Competition becomes

particularly sharp when different trials are looking for participants with specific, rarer conditions or particular risks, in the same population. This situation is less uncommon than one would think, partly because transnational clinical trials are increasingly concentrated in large-scale, long-term research sites with favourable epidemiological conditions and global standard laboratories and facilities, and partly because scientific and policy developments, as well as drug market trends, can lead to waves of certain kinds of studies at a given time. If, for example, in HIV research and intervention, male circumcision is en vogue, young men have an edge; if HIV resistance genomics are hot, prostitutes in cities with state of the art laboratories are needed; and if drugs for pre-exposure prophylaxis (PREP) are to be tested, HIV negative members of 'high risk groups' such as prostitutes, youths or widows are needed; for such studies, HIV discordant couples, in which one partner is positive and one not, and in which both infective and uninfected partner can be enrolled in the same trial (giving either the positive or the negative part antiretroviral treatment to prevent transmission between them) are in particularly high demand.

The market analogy of these situations is recognised by trial managers who may express concern with the differences between different research collaborations' TR payments and the competitive effects on recruitment and trial success. As managers, they are constrained both by institutional agreements and study protocols, and by budgets, and find themselves thus squeezed between the need of recruiting numbers within a limited time, and the need to cap production costs—like any manager in moments of labour scarcity. In such situations, participants might enter into actions that bear analogy to incipient labour struggles. One of the more rudimentary forms of contestation is 'double enrolment' in more than one trial at the same time. This poses a scientific problem as it may affect a trial's validity, and a grave medical and ethical concern, as it might affect the health of the participant, especially where pharmaceuticals and invasive procedures are involved. Another form of contestation can be found in rumours about the 'exploitation' of research subjects and the alleged profits of the researchers—the so called 'guinea pig' rumours, which can express discontent and make claims for better remuneration (Geissler/Pool 2006; Leach/Fairhead 2007; Graboyes 2010; see White 2000). Thus, in 2004, a main national broadsheet carried large articles in which inhabitants of Kemri/CDC's demographic surveillance system accused the institution of major abuses; CDC responded, exposing the cited witnesses as disgruntled ex-employees, and by setting up a dedicated and well-funded "community engagement" section, with the "responsibility ... to generate community support and acceptance for KEMRI/CDC activities and to mobilize the community for informed participation". If local resistance and claims were put forward in more organised forms, demands for compensation, or just higher TR, might be pushed forward by local groups like 'community based organisations', which often play an important role in

trial recruitment itself, or even by local administrators and chiefs, on behalf of their constituency. Such situations may offer opportunities to mobilise critical research subject advocacy in Africa, which so far have often failed because they did not account for African participants' fundamental desire to be part, through trials, of larger regimes of reliability and care.

In spite of these incipient political possibilities, so far research institutions and groups respond effectively—though mostly unwittingly—to preclude the possibility of such challenges. One important strategy is, not unlike missionary societies of the past, to stake out territorial claims, which are more or less informally negotiated with and acknowledged by different groups. Thus, in western Kenya, one large zone covering several districts is the principal area of KEMRI/CDC research (as well as, until recently, KEMRI/CDC managed, GAP funded HGIV care and treatment), a neighbouring district is covered, in terms of research and HIV care, by the US Department of Defence, beside this area is (with a slight, not unproblematic overlap) a zone 'run' by AMPATH, the 'Academic Model Providing Access to Healthcare', a Kenyan bridgehead of major US Medical Schools combining research and care provision, and parts of Kisumu city by FACES, 'Family AIDS Care and Education Services', a similar outfit initiated by another main US medical school running numerous collaborative trials etc. This territorial organisation ensures relatively uncomplicated recruitment in one's given study area—although for rare participant types like discordant couples, these might have to travel some distance to attend a particular trial—and avoids competitive participant claims. Also, the massive investments made during the past decade by the leading transnational research groups, universities and funders in local infrastructure, allow groups to lay claim to areas and their populations and preclude competition. If a territorial agreement cannot be reached, the very different resources and power of research groups or organisations can lead to effective struggles over territories, and weaker groups tend to withdraw from areas worked on by stronger ones.

An important mechanism in this context is demographic surveillance data collection, i.e. establishing longitudinal databases of the population in particular areas as well as their morbidity, which constitutes the backbone of randomised controlled trials in many parts of Africa. Such demographic surveillance systems, which come at very high cost and greatly enhance the value of a study population, constitute a novel form of governance over a specific territory (usually in the range of 100-300,000 inhabitants, in some cases much more) which is much more long-term than the usual clinical trial; as such they tend to prevent incursions by non-collaborating research groups, and thus competition for participants. While demographic surveillance areas indubitably stake a claim in an area, they also provide a form of governance and attendant forms of citizenship, which can be utilised both for improved health care provision, as is the case in many surveillance areas, and as a framework for wider negotiations



about clinical trials, their benefits, and other health care related matters. They are thus both a potential mechanism of control and of representation, of discipline and democracy.

If competition cannot be avoided and different groups work on similar issues in one area, double enrolment can be prevented using Photo ID cards and fingerprint readers, and sharing the attendant person-codes and data between different projects and research organisations. This strategy is increasingly used by clinical trials management in areas without reliable person registration and documents, and high concentration of research. And finally, if different clinical trials by several groups have to share the same population, the inevitable competitive instincts between groups and their scientific leaders must be overcome and agreement reached over TR rates and the level of other participant benefits.<sup>14</sup>

## **Freedom?**

As these examples show, the political promise of reframing research participation as labour is still limited given the unequal distribution of power, and the unlimited pool of (bare-)life labour. More important doubts also arise on a more analytical level. The older bioethicists who insist on participation being a free gift, and those who advocate the liberation of 'clinical labour' could be opposed (and pose at times) as 'idealist' and 'materialist'. However they share certain premises regarding the nature of money and monetary exchange.

First, they seem to agree that moral and economic considerations belong to separate spheres and should not be conflated, each of them giving, respectively, priority to morality or political economy. Promiscuity between the two is a threat, much as in Marx' understanding as acid that dissolves the social. Money materialises the abstract, amoral, calculating quality of economic rationality that must be kept away from moral reasoning, lest sociality will suffer. This understanding of money as amoral, even immoral, and anti-social, does not seem to be as obvious to the women quoted above, who appreciated precisely the moral value of monetary support as much as the material manifestations of care. The distinction between money and morality has for long been analysed

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**14** | In this case, if groups actually negotiate to cap reimbursements and benefits at one level in order to curb competition, TR is treated almost openly like labour-wage within a labour market, running very much against the formal denial of TR being a payment. This paradox is possible, because the two processes happen on the different, disjointed levels of the protocol and its GCP commitments, and of trial managers and local implementers; and because the two operations are separated, in the everyday of trial planning and operations, by the veil of discursive rigour, denial and ironic detachment.

as a crude simplification by social anthropologists who showed that monetary exchanges and moral action are commonly intertwined, and that the neat separation between morality and economy may indeed be part of a particularly cultural formation, or even of an ideology of capitalism, while people all over the world, including those in core capitalist institutions, tend to mix and connect economic and moral domains (see e.g. Shipton 1989; Parry/Bloch 1989; Maurer 2006; see also Mauss 1923). In other words, the common-sense association of money with individuation and rational calculus, which continues to underlie much medical ethical discourse, might not be helpful to understand the workings of value, and values, in a clinical trial.<sup>15</sup>

The notion of money as abstract and individuating is linked to another premise shared by advocates of purist bioethics and of clinical labour alike: the idea of freedom and autonomy as basis of good science. For both, the gift is free, that is an (individual) gesture without calculus, value and expectation of direct return, performed by free, individual actors out of individual moral (or spiritual) motivation. This idea of gifting is in their vision opposed to an alternative vision of individual action as commodity exchange, premised upon self-interest, calculation and the maximisation of pleasure or utility. Liberty and autonomy are here the central nodes around which both the free gift, and free labour are constructed.

What is absent from both these renderings of value transactions is the notion of a collective—a 'social'—be it as an existing reality that facilitates and underwrites value transfers, in the way in which the nation-state did in mid-20th century ideas about voluntary blood donation (e.g. Titmuss 1970), or as project entailed by these transfers, a future evoked by transacting value, such as in the communities engendered by 'benefit sharing' in relation to bioprospecting and intellectual property (see Hayden 2007). The possibility of value transactions, not as individual acts but as *produced by and productive of* collective forms does not occur either in the imaginary of free gifting, or in the alternative proposition of free labour. It is assumed that the act of giving and receiving material value is a momentary engagement between individuals, existing in the present. These

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**15** | In the scientific context examined here, a related common assumption about money deserves mention. By engendering an interest in personal profit, money might endanger not only moral reasoning, but also the (supposedly amoral) validity of scientific knowledge which, in theory, arises from impartial investigation premised upon universal social values. Economy and epistemology are here opposites, just like morality and economy. While this argument deserves consideration where funding for medical research and the commodification of its results are concerned, this opposition does not seem to hold for the women above, for whom 'being with' the trial produced simultaneously knowledge of medical facts as well as health care possibilities, and opportunities for modest material gain.

assumptions about the (a)sociality and (a)temporality of clinical trial transactions reflect only one, narrow understanding of the gift, which may be symptomatic of the current historical, political-economic condition, which some sociologists also described as the ‘death of the social’ (Rose 1996).

While it may be practically advisable to acknowledge the vital value transacted in TR (and thus to get rid of the misnomer of ‘transport reimbursement’), this does not lead to the replacement of the pure gift with a pure commodity or free labour. By way of conclusion, I want to argue in favour of retaining, somewhat doggedly, the notion of the gift to science.

## **END: GIFT AS COLLECTIVE**

When I propose that we hold on to the notion of the gift to designate trial value transfers, it is not in the sense of a pure, free gift, but as a gift in a classic anthropological sense (supported by the trial participants’ experiences detailed above). Gifts imply, firstly, social relationships, attachments, and the collectives that arise from such associations; and secondly, they are deployed over time involving memories of past actions as much as anticipations of futures. The gift understood as such is thus a pointer towards futures collectives and possibilities, as early anthropologists had argued and as has been reiterated with different emphasis for more than a century of anthropological writing (e.g. Malinowski 1922; Mauss 1923; see e.g. Strathern 1988).

In a completely different social and historical context from that of classic ethnographic accounts, but somewhat closer to our clinical trial site, the link between gifting and collective forms was explored by Richard Titmuss in his work on blood donation in mid-twentieth century Britain (Titmuss 1971, in Oakely and Barker 2004)). In Titmuss’ version, the collective in question is the nation-state, and, he argues, it is because this collective is already in place that people are able to give ‘gifts to strangers’ (1970). What Titmuss’ analysis is less interested in, is that gift-value transfers also contribute to bringing collectives into being. The post-war British National Health Service, Titmuss’ prime subject of analysis, was not only premised upon the nation but also contributed to the creation of the specific mid-twentieth-century British nationhood. For Titmuss, the nation-state in its post second world war welfare version was a quasi-natural frame of reference and the question of how collectives such as this come into being was of less interest than what they can make one do.<sup>16</sup> By contrast, if we think about practices such as blood donation—or transnational clinical trials—

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**16** | While the foundation of the NHS was premised upon a nation state that had just emerged solidified from the collective effort of the World War, the question of how, in turn, health services can help making the nation was a more obvious issue in Titmuss

today, the nation-state no longer provides such an obvious framing. Indeed, as Cecilia Busby has warned us, the nostalgic evocation of past collectives such as 'the nation' can be problematic and indeed dangerous in a situation where the nation-state has decayed or where it no longer pursues public wellbeing (2006). Such, we might argue, is the case in some contemporary African nations.<sup>17</sup>

If I suggest here that we recognise the ability of gifting to create collectives and open futures, I do not want to evoke 'traditional' cultural collectives of the Levy-Bruhl'ian kind (*pace* certain African bioethicists 'Ubuntu'-inclinations); neither do I believe that we can 'return' post-neoliberal Kenya to Titmuss' (and Keynes') 1948 welfare Britain. But at the very least we should expand—maybe inspired by these older imaginaries—our ethnographic sensitivities to the possible collectives and aspirations that are implied and evoked when trial participants choose to give their time and bodily substance, and to accept material transfers of value, including money.

### Citizenship as experiment

Partly in response to the less stable and obvious nature of government and national collective today, compared to Titmuss' times, the past decade has seen an abundance of fruitful anthropological explorations of increasingly manifold, fluid and fragmented 'citizenship(s)', including, importantly 'biological citizenship' (Rose/Novas 2005). The latter concept, and its more comprehensive predecessor 'biosociality' (Rabinow 1996), would seem particularly relevant here (see especially Biehl 2004; Nguyen 2004). The social ties described above could, derived from this literature, be described as 'experimental citizenship'. Such terms would reflect some of the participating women's claims and desires: the material transfers provided by the trial substitute in part for the welfare and health care they would be entitled to as national citizens, and in turn most of them struggle to be 'good citizens' of the trial and of KEMRI/CDC. 'Experimental citizenship' would also reflect the peculiar nature of this kind of association: it is citizenship on time, on trial, more a search for citizenship, than a comprehensive and lasting attachment as national citizenship would claim to be.

On the other hand, describing the tentative associations produced within the trial as (yet) another form of 'citizenship' risks devaluing the larger promise held out by the older, more comprehensive political project, conceived in enlightenment readings of an even older civitas. The inflationary use of multiple citizenships makes it difficult to measure the shortcomings of emergent and

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efforts to help shaping the health services of the newly independent nation Tanzania (see Titmuss 1964).

**17** | Busby reminds us that the relationship between imaginaries of association and political economic realities needs to be continually assessed (2006).

fragile forms of association that arise, in part, in response to the collapse of nation-state citizenship; the latter seems now just like one of many of its kind, rather than a universal standard and aspiration. Thus, although trial participation might entail a search for a lost citizenship, and although it indeed is an experimental social formation, the multiplication of citizenships is marred by the same problem as the anthropological proliferation of ‘modernities’ in the 1990s: that of discounting people’s aspirations for a more encompassing, universalist and enduring form of societal association (see Ferguson 2006).

The women quoted in this essay evoke the ‘hospitality’ and conviviality of trial relations, they describe trust and care, and they make reference to the larger institutions of scientific knowledge of health care and of government that they imagine behind their clinical trial. These allusions to ‘being with’ something larger than individual and local do not map onto one another, nor add up to one coherent whole. Some are limited to the trial in question and its caring staff; others refer to the Kenyan and US government institutions behind it; others again evoke the certified standards of drugs and diagnostics sourced from Europe or the US; and all of them are aware of the ephemeral temporality of any of these associations, and yet, they yearn for a stability (that in turn is referenced in memories and remains of past national projects). These associations cannot match the high-modern ‘imagined community’ of the nation-state. But although these imagined and experienced collectives are limited and temporary, they reveal the Kenyan trial participants’ longing for biopolitical inclusion. In the absence of effective care or control, leave alone biomedical discipline, even fragments of larger wholes are objects of desire: the chip card for trial participants, the GIS based surveillance, the finger print scan, even the regular blood specimen collection, become not threatening targets of potential anti-biopolitical resistance, but signify towards imaginary—sometimes remembered—modes of inclusion and citizenship.

Similar observations to those above were made by other ethnographers who attended to the experience of African participants in transnational public health research and found that they pursued long-term relations and new kinds of belonging in their engagements with clinical trials, rather than seeking mere material benefits or means of survival under conditions of deprivation (and far from resisting the threat of biopolitical domination) (see especially Leach/Fairhead 2007; Molyneux et al. 2005; Geissler et al. 2007). This does not mean that a Kenyan woman gifting bodily specimens and accepting reimbursements necessarily has a clear picture of the collectives and affiliations she aims to attach herself to, and in this regard her situation may be different from mid-20<sup>th</sup> century nation-state citizens. Maybe the collectives that she seeks to associate herself to do not yet exist in a specific form. It is through her attachments that she pursues them and that they gradually, and partially, take shape. As ethnographers—as well as scientists in public health, I would argue—we should attend to this

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search for 'transport', mentioned earlier in this chapter, for movement and transformation—of knowledge and of the world that is made known—beyond the existing conditions of life and of economic, political and social deprivation.

In Africa after the demise of the monolithic biopolitical nation-state, our primary challenge then may not be to discern and critique (or delineate resistance to) the classic biopolitical regimes of surveillance and discipline—which have become almost extinct species, confined to the reservations of demographic surveillance systems and HIV treatment programmes—but to attend to the longing and nostalgia that these older, once threatening orders evoke today. The shadow, not of the dark, imposing underside of modernity as in 1970s antimodernism, but the rather more faint shadow of a distant modern constellation, which from the vantage point of contemporary African ex-citizens of biopolitical nationhood, appears again as an utopia.<sup>18</sup>

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**18** | In terms of concrete responses to this situation, then, the proposition by de Cernival to extend health care in clinical trials to everybody, within and outside the trial, points towards a political debate about the collectivising aims of public health research (de Cernival 2008). Although theoretically closely linked to the liberal 'clinical labour' proposition, above, this seems to me a politically more promising route.