



# 'TRANSPORT TO WHERE?'

## Reflections on the problem of value and time à propos an awkward practice in medical research

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*Based upon Kenyan ethnography, this article examines the gap between the bioethics aversion to value transfers in clinical trials, and research participants' and researchers' expectations of these. This article focuses upon so-called 'transport reimbursement' (TR): monetary payments to participants that are framed as mere refund of transport expenses, but which are of considerable value to recipients. The interest in this case lies not so much in the unsurprising gap between regulatory norms and poor study subjects' lives, but in the way in which this discrepancy between bioethical discourse and materialities of survival is silenced. In spite of the general awareness that TR indeed is about the material value of research, about value calculation, and expectations of return, it is not publicly discussed as such – unless ironically, in jest, or in private. This double-blindness around 'reimbursement' has provoked discussions among ethicists and anthropologists, some of which propose that the work that generates scientific value should be recognised as labour and participants, accordingly, paid. Here, this paper argues that such a re-vision of trial participation as work rather than as a gift for the public good, risks abrogating the possibility of 'the public' that is not only a precondition of public medical science, but also its potential product. The supposedly radical solution of tearing away the veils of misrecognition that 'free' gifting ideology lays upon the realities of free labour, though analytically plausible, fails to recognise the utopian openings within clinical trial transactions that point beyond the present – towards larger forms of social association, and towards future alignments of scientific possibilities and human lives.*

KEYWORDS: clinical trials; research; value; benefits; gift; money; Kenya; Africa

### **Introduction: The Value of Clinical Research<sup>1</sup>**

#### *Transport – to Where?*

Every Monday 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'. 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 this rare occasion, the problem of TR 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, understandably because nobody present, nor the 'powers that be' can resolve it. In this paper, I do not want simply to denounce this discrepancy between rules and materialities, 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, seek direction and indeed transport towards better lives. I shall return to these questions at the end of my essay.

### *The Ethics and Politics of Bioscientific Value*

Medical research is a productive process, which involves the expenditure of effort – time, discomfort, movement, risk – and generates, like all work, value. Recently, bioscientific value, and the work in which it is generated, have 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 historical juncture, and in particular 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 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 those who propose to resolve matters by re-evaluating research participation as paid 'clinical labour'.

This paper speaks to this discussion 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 discuss them in relation to HIV research conducted in Kisumu, Kenya, in collaborations between KEMRI and its main overseas collaborator, CDC.<sup>2</sup> I draw upon interviews, conversations and observations with research participants and 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>3</sup> The trial lasted from 2003 to 2009, and involved over 500 young 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. In spite of the practical difficulties arising from this mobility, the trial lost few participants. 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).

I will show that the financial transactions called 'transport reimbursement' are generally understood not as reimbursement – that is, 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. The term 'transport reimbursement', I argue, attempts to render invisible the value of these transactions, responding to regulatory objections to payments or what bioethicists refer to as '(undue) inducement'. The discrepancy between the nature of the payments and the term by which they are referred to is so obvious to the actors that the traditional revelatory gesture of the social scientist – showing how things 'really' are – is void. Instead, speaking about the un-spoken materiality affords an opportunity to prise open the transactions of value in transnational clinical trials, both in view of finding more transparent and negotiable practical solutions, and in order to rethink the political project of public health science, beyond the alternatives of ethics and economy, gift and exchange.

I am in principle sympathetic to the motives of those who argue that understanding trial participation as labour and not as a gift – and thus of reframing reimbursements as wage payments – would open up a space for claims and contestation and thus political opportunities in the pursuit of justice. I will nevertheless argue in favour of retaining the notion of the gift, albeit not in the sense of the 'free gift' that underlies many bioethical notions of voluntariness and altruism, but in the relational and open temporal sense supported by anthropological theories of the gift, and by observations about trial participants' motivations in Kenya and other African research sites. While both the liberal notion of autonomous choice and voluntariness and the idea of free labour focus upon the individual and the here-and-now of a value transaction, a broader rendering of gift relations might alert our sensitivities to the potential collectivities and aspired-to futures – what anthropologists recently have also discussed as emergent 'citizenship(s)' (see Whyte 2009; see below) – which are referred to as well as produced by clinical trial engagements,

and thus return us to the political promise and responsibility of public health, as in producing health *and* engendering publics.

### **Transport Reimbursement – Invisible Value**

*'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. Almost all over Africa, medical research budgets contain a line on 'transport reimbursement', which is supposed to cover trial participants' fares to the clinic, for study procedures or medical care. 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 to £5 in African research sites outside South Africa.

Transport reimbursement 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. 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.

As money may easily be confused with 'payment', regulatory ethics guidelines insist that monetary transactions should be a mere prevention of cost; the sum of transport fare and reimbursement is assumed to be zero; no personal gain should be incurred. In most transnational research sites in Africa that adhere to 'Good Clinical Practice' (GCP) and international ethics guidelines,<sup>4</sup> net monetary benefits for participants – 'incentives' or even 'payments' – would 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. Similarly, IRB approval can be denied if the proposed TR, which increasingly has to be specified on the research protocol and information materials, is considered too high, constituting 'coercion' of poor participants. In accordance with these conventions and with written study documents, if TR is discussed among trial staff or with participants, mentioning of 'payment', as in 'how much do you pay your participants?' is likely to be rebuked by a 'we don't pay'. I will return to the irony that often accompanies this statement.

Reimbursement and voluntarism are flip sides of one coin: the notion of reimbursement safeguards the freedom of voluntariness, in the sense of individual choice. According to this logic, 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 less than straightforward under conditions of extreme poverty – in the words of one scientist in our study '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.

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

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 distinction made here between monetary reimbursement and soap as appreciation of time underscores the careful hedging of monetary transfers. Neither of the protocols actually specifies amounts, presumably based on the assumption that actual transport expenses simply will be refunded.<sup>5</sup>

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/- 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/- to compensate for the time they took in the clinic' (K29; email, 4 May 2010). This change of rates, motivated partly by 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.<sup>6</sup> 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'. Nevertheless it was termed – recall the opening scene of this essay – 'transport reimbursement'. 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 or reported 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 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 rather 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 global ethical norms 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. One group had resorted to transporting participants themselves, avoiding ambiguities. 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.

## **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 within a given period of time 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.

Even medical care and pharmaceuticals, probably the most important transfer of material value, was discussed by participants in monetary terms, when medical procedures such as deliveries were converted into costs: '[The study] was there to pay money: 80,000 [for a complicated delivery]! . . . [That] they paid all that money made a big difference . . . I would have been alone – all these thousands, where would I get them from in a month or two? I would be searching for donations from relatives but they would not have been enough. [. . .] Before you are booked for theatre you search the doctor's fee, 5000; it has to be there. If it is not, you have to search a relative who is working, to submit his payslip, . . . and then his salary goes to the doctors. [. . .] Then the hospital bill; until the bill is paid, [you cannot leave] . . . there is a ward where women are detained [if you fail to pay your bill], so there is no way they can't pay' (KP4).<sup>7</sup> Participants who normally could scarcely afford public health care, were referred by the trial doctors to private hospitals, and were keenly aware of their prices. '[With the study] I wasn't using money on buying medicine or discharging the baby from the hospital. Otherwise, you must buy, when you want medicine you buy, you buy syringes, and also you have to pay when leaving; if you don't pay you don't leave, you stay there, I saw a big difference [as participant]' (KP21).

Several participants remarked upon the fact that the study not only liberated them of the cost of 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 . . .' (KP14). While these conversions of care into money underline the participants' awareness of value and the inseparability of value and care, their desire to be treated with 'original' drugs also indicates that there is more than money to these considerations. The care bestowed by the study is also associated with higher levels of trust and reliability, and with wider, global medical connections, for example to multinational pharmaceutical companies, and the technical standards maintained by the ISO certified research laboratory. 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); '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 under conditions of 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). 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 one 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; or they walked, often 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; it is about remaining connected, to escape geographical and often social isolation, and to live.

The women's accounts underline their lack of reliable social networks: 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: '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: 'it is a good place, because they consider others ... these people are really willing to help me and I was happy with them' (KP1); '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, they 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).

Material transfers came with less tangible experiences of positive staff attitudes and new relations with both staff and fellow participants with whom they shared much time at the study clinic: '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. Often, the women 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).

Although this trial was rightly hailed as a success, not just in terms of its scientific outcomes but also and especially in terms of the social relations it produced, these statements should not be read as illustrations of a happy-go-lucky trial community. 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, there 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 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 and relatedness were intertwined in their experience. Economy, epistemology and morality 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 KEMRI' or 'with CDC', 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 experience or at least seek a broader sense of association beyond attaining immediate personal material fulfilment of needs. Monetary transactions and other transfers of material value are experienced as part of wider connections and collectives, larger possibilities and hopes.

### *Giving Reimbursement: 'This Can Now Help You'*

That poor participants consider reimbursements as valuable is not surprising. However, as the opening scene of this essay showed, research staff and scientists have equally few illusions about the value transfers involved in TR. Many women described how staff had encouraged them to use the money to buy food for the family – 'They were giving me four hundred, and told me that if I alight [from the bus] I can buy for the children things to eat' (KP8). They stressed how staff had carefully considered their situation and made clear that a proportion of the reimbursement was intended as a gift: 'She [said]: "I know it is hell for you, if we make you stay here up to evening, and then you come with nothing to

your house. So how much will you want us to give you, how much do I write for you?" So we calculated it [ . . . ] and she said [ . . . ] "I decided to write three sixty so that sixty shillings is for your [vegetables] when you reach your house, [ . . . ] you can buy some tomatoes and some greens you have where to start" – so that is why I was given that' (KP10). The boundary between reimbursements and gifts was further blurred by the fact that many staff members, when faced with particular situations, seem to have extended the official reimbursements with small personal gifts of money. 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. 'Being with' a study created a collective – if temporary, unstable, fragmented – out of mutual claims and responsibilities.

Staff lived in the same urban spaces as participants and although residing in more comfortable and expensive housing, they inhabited the same areas and met on the market or in the bus. They were aware of everyday needs and costs, and they knew about poverty, if not from their own experience then from close relatives whom they supported. They knew that TR assisted with needs and contributed to survival, rather than merely reimbursing costs (which they knew were often minimised by walking). They made no efforts to hide this fact from the participants. This applied also to the senior scientist in charge of the trial, the PI, who recognised the value of TR and participants' expectations – somewhat in contrast to the avoidance of payment in the protocol and official documents issued by him. He raised on various occasions the ethical challenge implied:

... in hindsight, ... the idea that people are volunteering when you are [ . . . ? ] paying them, well, 'reimbursing' them – but do they see it as reimbursement for transportation? They see it as payment, cash is cash, right? [ . . . ] I mean it has come up in the disseminations [after the end of the study] that, ... some of the participants are saying ... well, can we get paid, now that we finished the study? (C26.2)

Straddling the gap between the regulatory phobia concerning 'undue inducement' and the material realities of the studied women, the PI went on:

... in this country ... paying somebody to be in a study ... it is all semantics to some extent ... you are paying them something, but then how they perceive it ... may be very different from how we perceive it ... you know, we are using the word 'transport reimbursement', so we don't use the word ... 'paying' people, ... but the participants ... even though they are told this is for transport ... and your time ... [might still see it as payment . . .]. (C26.3)

The notion of payment appears here as misunderstanding on the side of the participants: they 'perceive' TR as payment, and erroneously experience an incentive where in the *de jure* reality of the trial protocol there is none. If the problem is phrased like this, improved information would seem to be the solution – 'we probably could have done things differently in terms of how often we went back over the consent' (C26.3) – conveying to participants the understanding that the money they carry home from a clinic visit does not actually constitute value. Semantics, indeed.

The PI is aware of the slight absurdity of these linguistic games, yet there is no easy way out, as the stipulations of 'Good Clinical Practice' (GCP) are vital for the trial's funding as well as for the future recognition and policy relevance of its important findings. Like everybody else concerned, he thus keeps mixing 'reimbursement' with compensation for time, gestures to thank participants and charitable intentions. As is the case for many of

his colleagues, he wishes to improve the conditions of those he studies. When we claimed, in a draft paper, that poverty was obscured by the structures of the research endeavour, he remarked that everything he does as public health researcher is pervaded by poverty: 'Poverty overwhelms pretty much everything . . .'. Known to staff and participants, he is the initiator of charitable events in Kisumu, and funder and fundraiser of an orphanage, and his social commitment permeates this trial. And yet, despite his ethical reflections and his openness in interviews and personal conversations, his subtle deliberations about the value of research could not make their way into official study documents and the public discourse of the research collaboration. In public he would, like any of us, have laughed it off as 'we don't pay'.

### *The Open Secret of Value – Irony, Joking and Peer Talk*

A curious aspect of the insistence upon the non-value nature of TR by trial management and staff is that, if pressed by a situation – for example, when faced with poor recruitment figures – or by an ethnographer's questions, almost everyone would acknowledge that TR indeed has a net value for participants, that it is linked to participants' willingness to join a trial, or even that it amounts to a payment. As many colleagues involved in trials in Africa privately agree, TR 'is a slippery slope' that leads one from the ethical heights of altruism and voluntarism – the gift of bodily participation – down to the level of coercion and potential exploitation, and the moral dangers of a market in bodies. The somewhat stubborn insistence that 'we don't pay' is at least partly due to awareness of the fragility of this construction.

The invisibility of value in TR is then somewhat different from, but related to, the 'erasure of obscene discrepancies', which Paul Farmer accuses bioethics of, and which he explains with the 'experience distant' professions involved in their formulation (2003, p. 204). While inequality and poverty are indeed sometimes erased from bioethics texts, or at least excluded from bioethicists' worries, they are obvious in the concrete material engagements of transnational medical research, and present in the consciousness and everyday speech of the actors involved. Hence the gap between ethics text and scientific work, which is not just about erasure, but about unknown knowns, or silences within knowledgeable practice.

This brings me back to the smile that accompanies the statement that 'we don't pay'. Irony is a crucial device in maintaining the awkward balance between knowing that TR is not a reimbursement and the terminological rigour that it is. Although the value of TR is not publically spoken about, it features in private conversations among peers, such as between the PI and the anthropologist. In these contexts, one can acknowledge that it is just 'semantics'. One can laugh – if uncomfortably – about it. What remains impossible, however, is to commit one's doubts to paper, or to discuss them publicly, involving different interest groups, such as participants, staff and scientists.

### **The Failure of the Gift?**

#### *A Misnomer*

This is then the conundrum: clinical trials transfer value, including money, to participants; this value transfer is recognised by everybody involved; and this recognition

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' – or, in Michael Taussig's terminology, a 'public secret' in the sense of a known unknown, constitutive of a particular social order (1999). The counter-factual terminological rigour concerning TR, combined with silence and irony, strategic ignorance, and implicit acknowledgement of value-exchanges, is morally and politically problematic. It can seem dishonest, and it could be said to veil the material reality of value in clinical trials. Although (or precisely because) this veil is thin and transparent, this discursive convention disallows open debate, and prevents questions of value and justice from being raised, and from becoming part of public debate about public health.

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 – be it in clinical trials or within the wider health care system, where the system of 'reimbursement' for 'volunteers' has become very widespread (see Samsky this issue, Prince forthcoming). The question that arises is then how *one ought* to 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 speech, as part of scientific practice, aims to contribute to public (just, equitable) health in a healthy public sphere.

### *Gift or Commodity?*

The centrality of value to clinical trials stands in contrast to bioethicists' insistence that considerations of value and profit – any nexus between trial participation and the fulfilment of needs – is antithetical to ethical research practice. Current bioethics centres on the notion of autonomy and, derived from it, that of voluntariness and altruism. What has to be protected is the liberty of the individual, which is threatened by implications of need and interest. Somewhat paradoxically, given the individualism of liberal economic definitions of freedom, economic rationality is here portrayed as conflicting with the absolute, immaterial freedom of disinterested self-sacrifice for the public good. Ethics appears 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 a gift should have no ties attached, not to other people, not across time, nor to one's bodily needs and desires. Motivated only by the will to contribute to scientific progress – a distant common good without a mediating 'social' – the free gift is consummated in the moment of its donation, and leaves the freedom, and the futures, of donor and recipient untouched.

These observations could lead one to conclude that the gift, as understood in contemporary bioethics debates, has simply failed. 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. Exit morality, enter the market. 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 the logical move, mentioned in the introduction, that 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. However, one could 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 the same conclusion out of broadly Marxist reasoning. By critiquing the misrepresentations that the ideology of the free gift produces, and replacing them with truthful materialist understanding, the hope is that the correct recognition of clinical labour would unleash social transformation analogous to older labour movements (see Folayan & Allman, this issue). The former 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 (see Cooper this issue). While the political intentions of both arguments are different, both seem to accept that the gift has failed, and that the market – variously understood as invisible hand, or as generative of transformative contradictions – has taken over. In the remainder of the paper I consider the possibilities and limitations of this move and conclude by considering what the gift, if reconceptualised, may still have to offer.

### **Giftng as Proposition and Evocation**

The older, purist 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.

#### *Immoral Money?*

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. Money epitomises this danger of promiscuity. It materialises the abstract, amoral, calculating quality of economic rationality that must be kept away from moral reasoning.

This understanding of money as amoral or even immoral does not seem to be as obvious to the women quoted above, who appreciated 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 as a cultural construct 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 'western' cultural formation (in the sense of deriving from Christian and enlightenment sources), 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 Parry & Bloch 1989, Maurer 2006, see also Mauss 1923). In other words, the western commonsense association of money with individuation and rational calculus might not be helpful to understand the workings of value, and values, in a clinical trial; instead, the ethnography of the trial might shed some light on the workings of such separation.

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.

### *Individual Freedom?*

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. 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 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 the central nodes around which both the free gift, and free labour are constructed.

What is absent from both 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-twentieth-century ideas about voluntary blood donation (e.g., Titmuss 1970), or as a project entailed by these transfers, a future evoked by transacting value, such as, for example, 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 replacing it with 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 assumptions about the (a)sociality and (a)temporality of clinical trial transactions reflect only one, narrow understanding of the gift which maybe symptomatic of the historical condition described by some sociologists as the 'death of the social' (Rose 1996). While it is necessary to acknowledge the vital value transacted in TR (and thus to get rid of the misnomer of 'transport reimbursement'), this need not lead to the replacement of the pure gift with a pure commodity or free labour. By way of conclusion, I want to return to the gift in a somewhat fuller sense.

*Gift and 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 that cannot be calculated and has no expectation of return or duration. Anthropologists have long argued that gifts create associations, indeed, that the idea of a 'social' may be built upon gift exchange, and that gifting plays out over time, involving memories of past actions and anticipation of futures (e.g. Mauss 1923, Malinowski 1922).<sup>8</sup> The gift is thus a pointer towards future collectives and possibilities.

The role of gifting in the creation of social collectives and futures is aptly illustrated by recent ethnography from western Kenya. Shipton (2007) argues that acts of giving and receiving permeate Luo society, creating 'attachments' which do not only form collectives of people in the present, but they also forge links between past, present and future. Such transactions – exemplified by gift-giving in the context of bride wealth and marriage – build upon previous exchanges and anticipate future ones, entangling people into each other's lives and trajectories. They cannot be understood as mere 'exchanges', even though they may be calculated, evaluated or complained about. The emphasis on gifting as engendering futures is also developed in the ethnography, from the same area, by Geissler and Prince (2010), which shows that the growth of life, reproduction and health, is premised upon acts of giving. Gifts here are always about long-term relations, creating collective associations and opening futures. Similar observations were made by other Africanist anthropologists, such as Hutchinson in southern Sudan, revealing the relational and creative role of money, intertwined with that of blood and kinship, conflating economic and moral practices (1996).

Drawing, for this argument, upon local African ethnography plays with the danger of being misread as a culturalist argument. Let me therefore be explicit: these ethnographic accounts from nearby were chosen for convenience, perhaps to facilitate a localised conversation between anthropologists and scientists. They should not imply that value transactions in clinical trials should be conceptualised as potentially creative and socially productive gifts, because of their particular 'cultural' context – as cultural relativist versions of 'African' bioethics would have it. Instead, the cultural context at hand lends itself to illustrate the universal productive force of gifting, which applies in western Kenya as much as elsewhere.

In a completely different social and historical context, the link between gifting and collective forms was thus also described by Richard Titmuss in his work on blood donation in mid-twentieth-century Britain (Titmuss 1970, cited in Oakely & 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. By contrast, if we think about practices such as blood donation – or transnational clinical trials – today, the nation-state no longer provides such

an obvious framing, and processes of societal association and collectivisation pose a pressing problem.

If I suggest here that we recognise the ability of gifting to create collectives and open futures, I do not want to evoke cultural collectives such as ‘the Luo’ (although sensitive ethnographies such as Shipton’s help us to appreciate the nature of the gift). Neither do I believe that we can ‘return’ post-neoliberal Kenya to Titmuss’ 1948 welfare Britain. Indeed, as Busby warns us, the nostalgic evocation of past collectives such as ‘the nation’ in the context of bioscience and public health may be dangerous in a situation where the nation-state has decayed or where it no longer pursues public well-being (2006). Instead, my more humble proposition is to expand 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 citizenship today, compared to Titmuss’ time, 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 it is 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 older, more comprehensive political project, that the term once entailed. The inflationary use of multiple citizenships makes it difficult to measure the shortcomings of emergent and fragile forms of association that arise, in part, in response to the collapse of nation-state citizenship; this 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. Similar observations 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 (e.g. Leach & Fairhead 2007, Molyneux et al. 2005, Geissler et al. 2007). This does not mean that a 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-twentieth-century nation state citizens. Maybe the collectives that she seeks to associate herself to do not even yet exist in a specific form. It is through her attachments that she pursues them and that they gradually take shape. As ethnographers – as well as scientists in public health, I would argue<sup>9</sup> – we should attend to this search for ‘transport’, as evoked at the beginning of this essay, 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.

## NOTES

1. I gratefully acknowledge the assistance of the people working on the Kisumu trial – scientists, research staff, clinicians, participants and their relatives. Warm thanks to all, present and past colleagues in the ‘Research communities study’, notably Philister Adhiambo Madiaga and Gemma Jones, as well as to research students Patricia Kingori and Tracey Chantler. Particular thanks, to the senior colleagues from KEMRI and CDC, who allowed us to study their work. The journal’s reviewers provided helpful advice. Fieldwork was funded by the Wellcome Trust with support from the Max Planck Institute for Social Anthropology (Research group ‘Law, Organisation, Science and Technology’).
2. 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 USD30 million, hosting approximately 1300 staff members, funded by CDC and other funders, and employed by KEMRI on temporary contracts, and hundred thousands of participants involved in surveillance and clinical trials.
3. 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 scientist and ethicist colleagues.
4. ‘Good Clinical Practice’ (GCP) is a regulatory protocol, issued by the International Conference on Harmonisation, that details practical procedures around clinical trials. It has been endorsed by the World Health Organisation and the US Federal Drug Administration, which is responsible for licensing pharmaceuticals to the world’s largest pharmaceutical market, and is therefore of crucial importance to the conduct of clinical trials all over the world (see e.g. EMEA 2002).
5. Only in 2008, prompted by a member of the Kenyan ethics review committee who had stumbled over the sentence ‘according to standard guidelines’ in a protocol submitted for ethics approval, the KEMRI/CDC field station issued such guidelines in an attempt to standardise reimbursements across a growing number of research projects. According to this document, participants in Kisumu city would be reimbursed 300 Ksh, while those

- in rural areas would receive 120 Ksh, which was explained with the higher transport costs in town.
6. As this example shows, procedures were relatively flexible and informal at the time; this has changed since then. As part of the ongoing effort at greater standardisation and regulation of material transfers in clinical trials, the precise amounts disbursed as transport reimbursement are now (2010) stated on all trial related information materials and consent forms, as well as on the approved research protocol. Any subsequent changes to reimbursement rates are now considered formal amendments of the protocol and require written approval from institutional review boards in Kenya and USA. Thus, trial participants are today fully aware of the reimbursement amounts they are entitled to. It should, however be stressed, that the practices described here did not constitute a breach of regulations at the time.
  7. Some Kenyan hospitals have, similar to other African countries, the habit of detaining patients with unpaid bills, in particular postpartum women, with the result that their bills increase further, and their health and well-being is put at risk (see <http://demokrasia-kenya.blogspot.com/2009/08/poor-kenyan-women-detained-in-hospital.html>; Kippenberg et al. 2008).
  8. Famously, Mauss quoted an Inuit proverb that 'Gifts make slaves as whips make dogs' (1923: xxiv) – a stark contrast to the tie between individual autonomy and gift-giving maintained by bioethicists' rendering of the gift.
  9. The recent proposition by the international HIV activist Marie de Cenival – a propos the widely discussed question of 'undue inducement' by trial-provided quality health care – to extend health care in transnational clinical trial sites *beyond* trial participants and *beyond* the time limits of the trial – sidestepping the concern with inducement and radically changing the aims and nature of long-term medical research endeavours – illustrates the scope of the political debate about the aims of public health research, which could result if trial participants quest for 'transport' was taken seriously (de Cenival 2008).

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