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Roberto Abadie

University of Nebraska-Lincoln, rabadie2@unl.edu

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Guinea Pigging in Philadelphia

Roberto Abadie

On June 16, 2001, the national press first reported the death of Ellen Roche, a healthy 24-year-old who volunteered for an asthma study at Johns Hopkins University. The story revealed that a few days into the trial she felt very sick, was discharged, and sent home. Within some hours she checked into the emergency room at a local hospital and fell into a coma. Ellen remained in this state until her death a month later. She had received \$375 for participating in seven to nine sessions as an outpatient in the clinical drug study that resulted in her death.

This tragedy exposed real gaps in our understanding of human subjects in medical research. Although bioethicists have focused on the ethics of paying subjects to test drug safety, less attention has been paid to who the healthy paid subjects are, what motivates them, how they make decisions about joining a trial, or the effects money has in the way they perceive and deal with risk. The pharmaceutical industry is one of the most globalized and profitable businesses in the United States. Anthropologists have been exploring—particularly in this last decade—different aspects of the industry, from the influence of drug reps on medical prescription practices, to the globalization of clinical trials. Yet the participation of healthy paid subjects selling their bodies in the first phase of drug development has remained all but invisible.

In 1998, anthropologist Michaela di Leonardo invited scholars to focus on what she called “exotics at home.” Her intention was to re-center anthropological inquiry, shifting the discipline’s emphasis on “the other,” often living in remote cultures, to groups living among us. Di Leonardo argued for the need to look at domestic sources of power, wealth, and inequality in an attempt to understand how they affect the everyday lives of numerous groups and institutions that had remained, until then, hidden or invisible. My ethnographic research on human subjects in pharmaceutical trials is an attempt to respond to Di Leonardo’s call for

anthropologists to refocus our selection of research topics and respondents. In *The Professional Guinea Pig: Big Pharma and the Risky World of Human Subjects* (2010), I present findings from ethnographic research with “healthy paid subjects” earning a living by testing drug safety in Phase I Clinical Trials. This research took place in 2003 and 2004 in Philadelphia— a center for clinical trials conducted by such giant pharmaceutical corporations as Merck, AstraZeneca, Pfizer, and Bristol-Meyers Squibb.

I lived with a group of healthy paid subjects in an area of West Philadelphia. This group, mainly white men, had a visible “guinea pig” culture, with its own professional zine entitled *Guinea Pig Zero*, a magazine describing their participation in the drug trials from the perspective and interests of the professional research subjects. Some professional “guinea pigs,” also identify as anarchists, holding a very strong view of the pharmaceutical industry and governmental regulation.

This tight-knit community of young, radical political activists is located just a few blocks from the University of Pennsylvania campus. Guinea pigging, as the practice of selling one’s body to pharma is informally known, provides a flexible schedule and a steady income to support a lifestyle that includes living in communal housing, usually in squat homes, and free time to devote to creative and political interests. Most members of this community have at one point or another taken part in this trial economy.

I was aware that this would be an unusual subpopulation of professional guinea pigs, who overall tend to be less affluent, less educated, and overwhelmingly from minority groups. Still, I felt confident that their experiences as professional subjects would provide a window into the roles that the social organization of clinical trials and financial compensation play in recruiting, retaining, and controlling trial subjects. I spent 18 months from mid-2003 to the end of 2004 among them, following them to the trials, screenings, and follow-up appointments and witnessing their trial preparations and subsequent tribulations.



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I wanted to understand how much guinea pigs knew about the risks they would face and the degree to which they were concerned with the risk factor of medical trials. Financial compensation can reach up to \$400 a day for an in-patient trial, which usually lasts between two to four weeks. Some subjects have volunteered in more than 100 trials in the course of a few years. A full-time professional subject can enroll in seven or eight trials a year, deriving an income close to \$20,000. Although at the beginning of the trial, healthy subjects sign an Informed Consent Form that delineates the trial's design, goals, and potential risks, I wondered how much the promise or prospect of financial gain shapes the subjects' understanding and willingness to take risks.

I was also concerned that the pharmaceutical industry would use the large sums of money to coerce professional guinea pigs both to join the trial and to remain in it.

The Emergence of the "Professional Guinea Pig"

After drugs are tested on animals, they are tested on a small group of humans to make sure they will be safe for human consumption. This is called a Phase I Trial. If a drug is proven to be safe for a small group of human beings, then it is further tested in much larger groups of humans, partly for safety, but mainly for efficacy. These are the Phase II and III Trials. Until 1970, drug safety was tested on prisoners, but concerns about their capacity to give ethical, uncoerced consent brought the practice to a halt. The pharmaceutical industry stood to lose billions if drugs coming down their research pipelines could not be tested. Pharma started offering payments to potential recruits, and initially, unemployed and unemployable people, students, artists, part-time workers, and others showed up. Some could not withstand the boredom, the discomfort, and the dehumanizing treatment, and never showed up again. But some stayed and were lured with phone calls, mailed ads, and other recruiting tactics. These subjects became accustomed to the role of trial subjects, and the industry in turn became dependent on professional, dependable, and compliant research subjects. A new profession emerged: the professional research subject.

Some guinea pigs I met in Philadelphia had other low-paying jobs on the side as cooks, house painters, construction workers, or bike messengers, but for most, trials were their only occupation. As one professional guinea pig told me, "You become addicted to the trials, to the easy money." They saw themselves not as "paid volunteers," as the

industry refers to them, but as workers performing a strange type of work. In fact, that they have been paid to test drug safety has become an integral part of the clinical drug trial enterprise in the United States. Pharmaceutical companies depend upon paid subjects to test an ever-increasing number of drugs coming out of their "pipelines." Many subjects, like Spam, a seasoned guinea pig volunteer and janitor organizer, consider bodily pain, boredom, and compliance as the "mild torture economy" of trial participation.

I don't know, another thing kind of funny too is that the manufacturing has been taken off, outside the country, so you are not allowed to do things anymore. They call it the new economy, the informational economy. And the other side of this informational economy is the mild torture economy—you are not asked to produce or to do something anymore, you are being asked to endure something. So, if you are a guinea pig you are enduring something, people are doing things to you and you are just enduring it, you are not actually producing something. I feel that I am a worker, but it is not work, it's like a security guard that does not produce nothing, just watches stuff. A security guard just gets paid to be bored, it's about how much can you deal with being bored, that's the real hard part of it, the time and discomfort of being there. But it's different when you are in a cleaning job, I am doing something, but being a guinea pig is just being paid to endure something that happens to me, which is weird. It's a different type of activity, I still feel that there is some work in it but the nature of work has changed. And I am letting people pay me in exchange for the control they have over me.

A Risky Business

Professional guinea pigs perceive most trials as being of moderate risk. Adverse drug reactions are extremely rare and most subjects have not experienced any serious effects even after years of participation, and besides, they reason, the trial is designed as a controlled experiment and supervision is constant. They feel that the pharmaceutical industry is doing the right thing, not because the industry cares about the subjects,

but because the industry fears lawsuits if something goes wrong. Their preferred trials are those that test drugs such as pain killers or gastritis drugs that have already been on the market for some time and thus have been tested by millions of people, thus presenting only a moderate risk. The drugs they perceive as riskier are those that are tested for the first time on humans after being tested before only in animals. In the case of a new, experimental psychiatric drug, professional guinea pigs would see it as presenting the highest risk, something to be avoided if possible because "it messes up your mind."

Robert Helms elaborates why these trials are perceived as high risk and something to be avoided at all cost.

Psychiatric trials are for a couple of reasons very different from trials of nonpsychotropic drugs because they involve your mind. You are renting your mind and your body at the same time instead of just your body. It is a completely different economic deal. Secondly, in the psychotropic drug trials, people are writing diseases into existence. You cannot fake fast heartbeat into existence; you cannot make people believe that the heart is beating faster. I put a stethoscope onto your chest and check your fucking heartbeat, that's simple. They cannot invent your blood pressure but they can invent your depression; they can invent your mood. And they can change the interpretation of what you say according to what the drug market wants. The marketing department writes the label of the drug, not the fucking doctors, the scientists. It is the marketing department. And they also write the disclaimers, fight the lawsuits. Blame the disease, not the drug. Like, he is getting into middle age, a lot of time on his hands and is getting a little raunchy, goes into the psychiatrist for a little talk, gets put on Prozac and two weeks later he slaughters the whole family with a rifle and blows his own brain out. Tell me it is not the fucking Prozac! That is what I think, "Fuck you, fuck you." And it happens over and over again, and the lawsuits get buried by companies that put [out] a lot of money to quiet people down.

Still, mindful of these obstacles, the pharmaceutical industry offers the highest payment for these types of trials in an attempt to recruit

reluctant trial subjects. Almost everybody I encountered during my fieldwork admitted that, despite their concerns, they had done at least one trial they thought was too risky, enticed by the \$5,000 to \$10,000 financial reward. Subjects considered these trials as presenting high risk but were tempted to join them because as they put it "the financial gain was too good to refuse."

The industry has outsourced the daily operation to Contract Research Organizations (CROs) which recruit the volunteers, carry out the trial and then hand the data to the industry. Since Phase I trials involve a small number of volunteers, between 20 and 100, if only one or two drop out in the middle of the trial, it compromises the validity of the whole trial. To avoid this, the CROs use professional subjects who know what to expect from the trial when possible and they also use money to make sure subjects stay in the trial until the end. If a subject drops out in the middle of the trial they get a prorated amount. But the bulk of the payment is scheduled at the end, usually followed by a bonus for completion to encourage participants to complete the study, no matter what.

Some, including me, might argue that this practice is unethical and challenges current standard guidelines governing human subjects research ethics. The promise of financial gain can unduly coerce vulnerable research subjects, leading them to participate in trials they might not join otherwise. My main concern is that the market recruitment of trial subjects might place "guinea pigs" in danger, not only because of the risks they face in particular trials, but also because they ingest a high dose of chemicals during their years of trial participation. These chemicals might interact many years later with each other, with drugs taken by the patient as part of a treatment, or with toxic environmental pollutants. I suggest the creation of a centralized registry of Phase I participants to discourage them from participating in more than one trial at a time or neglecting to wait the mandatory 30-day wash-out period after a trial ends. This recommendation is not a silver bullet; it will not automatically solve all the problems brought by the increasing reliance on paid subjects involved in clinical trials research. For example, its implementation couldn't have avoided the death of Ellen Roche, who died after volunteering for only a clinical trial. And while this registry would increase the protection for paid research subjects, its implementation would also diminish their financial gain. For this reason, the professional guinea pigs I have encountered seem reluctant about this recommendation. Besides, because the pharmaceutical industry does not want to jeopardize its ability to recruit paid healthy subjects quickly and efficiently, until this date, it has opposed the creation of such a registry in the United States.

In Europe Big Pharma adopted and supported the creation of such a registry after the Parexel incident in 2008, in which research subjects testing an experimental drug were badly injured. This incident revealed that research subjects were volunteering in multiple trials at the same time, disregarding the wash-out period, and traveling from country to country in search of trial opportunities.

After finishing my research, I realized that this recommendation could in fact be extended to all phases of clinical trials research in the United States, not just the first phase of drug development. A source who manages a CRO recruiting for Clinical Trials Phases II and III informed me about something that is cause for great concern. According to this informant, HIV patients often enroll in two trials at the same time, seeking to maximize financial gain. These trials involve hundreds or thousands of participants and last many years. They do not pay the large amounts Phase I trials command. These trials might pay only a few dollars every month, sometimes \$20 to \$30 or so, to encourage participation. Still, for poor patients this meager reward seems lucrative. Their trial, designed not to treat them but to answer a scientific question about a drug or drug regime, may instead be making these patients sicker. As in the case of professional guinea pigs doing Phase I Trials, there is no centralized registry of their participation that could help track the future health of participants.

In fact, the lack of a centralized registry or the ineffective FDA oversight of the participation of human subjects in pharmaceutical research signals a deeper problem. Research subjects lie regarding their simultaneous participation in different clinical trials to avoid the mandatory wash-out period, and they lie about other things that might exclude them from the trials. In turn, Big Pharma pretends that their trial subjects are carefully recruited and monitored and that the trials' outcomes are valid and unbiased. As such, consumers cannot be sure that the data a particular trial produces have not been obfuscated by the surreptitious participation of some subjects in another trial, or by the subjects' neglect of the mandatory 30-day wash-out period. Thus the professionalization of research subjects in the first phase of trials research can endanger not only participants but can also challenge the validity of the trial results. The process is so fraught with manipulation and deceit that as a result we cannot be sure which drugs work and which ones do not. As some professional guinea pigs reminded me, they are willing guinea pigs, but the consumers might end up as unwilling guinea pigs, forced to consume drugs that have not been sufficiently or adequately tested. The lack of control and oversight of Phase I Trials and in subsequent phases of

drug development might not only endanger professional research subjects and trial participants, but might also compromise the public health and well-being of us all.

Suggestions for Further Reading

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Roberto Abadie is currently [2011] a research associate in the Biomedical Ethics Unit at McGill University. He is interested in researching and advocating for human subjects in clinical-trials research and has conducted fieldwork among healthy paid human subjects in phase I trials and among HIV and cancer patients participating in the later phases of clinical trials research. The photo in this article is courtesy of Roberto Abadie.