Why do healthy people get into ‘guinea-pigging’?

by Shadreck Mwale Apr 25, 2014

Image: Guinea-Pigs Nogeyama Zoo from Toshihiro Gamo's Flickr Photostream

Human involvement in clinical or medical research is not new, however today levels of human involvement in clinical trials have increased, ironically following the high profile Northwick Park incident in 2006 in which 6 healthy subjects suffered life changing unexpected side effects. Clinical trials are a process used to test the safety and efficacy of the drug before it is made available for us the general public. However, before the clinical trial stages, drugs are subject to nonclinical animal testing in which toxicity levels are tested to ensure the drug is safe for human use.

The clinical trials process involves four phases that sometimes involve both healthy individuals as well as patients. Phase I involves testing the drug on a few select individuals’ usually healthy subjects, Phase II usually includes larger numbers mostly people suffering from the condition the drug is aimed to treat includes further testing of safety and efficacy. If a drug passes Phase II then it proceeds to Phases III and IV were further tests are done on intended patient population samples and comparisons with existing drugs respectively.

Of interest here is why people who have no health benefits to gain from the drug being tested volunteer to be ‘guinea pigs’. Commonly held assumptions are that such people are mostly
poor and uneducated people whose primary motivation is to make quick and easy money, however proponents of ‘guinea pig’ trials focus on altruism as the motivating factor.

I have been researching healthy volunteering in first in-human clinical trials in the UK, with registered volunteers of a Contract Research Organisation (CRO), an organisation contracted to carry out research on behalf of pharmaceutical companies. Most of the healthy volunteers are university graduates, some with postgraduate qualifications. In addition, most of the healthy volunteers were employed in permanent jobs and in well-paid jobs, usually well above the level of the minimum wage.

This is the conundrum. Often, they had taken part in several clinical trials and were actively looking to take part in more clinical trials. As such, it appears there is far more complexity than simple financial necessity or altruism in people’s decisions to engage in guinea pigging. It also suggests that having a job does not necessarily mean being financially secure and that healthy volunteers come from a variety of backgrounds.

Whilst participants acknowledged that monetary rewards were their primary motivation for taking part in clinical trials, most participants talked of starting to take part in clinical trials in order to sort out very immediate financial crises that they were facing at a specific point in time;

I was in some debt that really needed to be paid off, otherwise I was going to be in some shit if I didn’t, you know.

The participants were either unemployed at the time or if employed they felt that pay from their jobs would not resolve the financial problem quick enough;

At the time I had a job, the pay was good and everything and I had some debt that I had to urgently pay off. I would never have managed to pay off the debt if I had relied on the job so the only way was taking part in a trial

Most participants talked of trying other means to resolve their financial problems before taking part in clinical trials such as looking for jobs or borrowing money, but ended up doing clinical trials because payment for clinical trials offered the best means of resolving the problem;

I tried looking for a normal job, worked in a bar but it was not really helping, I worked hard but by the time I paid my rent … I had nothing left , my debt was still there untouched, so I had to do something else

Entry into the clinical trial world then seems to be predicated on the need for immediate access to cash to avert a financial crisis. However, this explanation does little to address ongoing involvement, after the point of financial crisis has passed. Most of them (though they have now found jobs or have paid off their debts) continue to take part in clinical trials as it provides a source of additional income.

At the time the pay [reward in clinical trial] was good enough for me to cover for that. I did not intend to do a trial after that, though … It was intended to be a one-off thing, pay the debt and move on to normal life.
These observations might lead one to question the assumption that healthy volunteering is regarded as primarily appealing drawing from a poor, unemployed or uneducated population. While monetary rewards are the primary motivation for people taking part in clinical trials, the relationship between money and engaging with risk in clinical trials is much more complex.

About the Author: Shadreck Mwale is a PhD Sociology candidate at the University of Sussex and is also a lecturer in Applied Social Science at University of Brighton. His research interest are in global healthy and pharmaceuticals, clinical trials, inequalities and health and public engagement with medical technological innovations and regulation.