Same difference? - From Northwick Park in 2006 to Rennes in 2016


As someone who has researched healthy volunteer involvement in clinical trials I was disturbed by the events in Rennes, France two weeks ago, where after taking part in a clinical trial, a healthy volunteer died and 4 others were left in a critical condition. I am left reflecting on the very human cost of involvement in clinical trials. Newspaper reports suggest that about 108 volunteers where involved in the first clinical trial for a drug to treat pain and mood disorders. They were paid €1900 each for taking part. Participants received varying dosages of the drug, with the deceased volunteer and the four others taken ill said to have taken the highest dosages of the experimental pharmaceutical drug (Agence-France 2016; WillSher 2016). It will take months before full details of what went wrong will emerge.

As is often the case in such events, the participants’ lives and reasons for taking part in drug trials have not been discussed. Partially, this is due to the anonymity around human involvement in clinical trials. While the French authorities have instituted investigations, I fear that the ensuing investigations, as was the case in the Northwick Park trial about 10 years ago, will focus on the practical procedures, working to find where the fault lies and where blame can be attributed.

In such investigations the human price paid by these volunteers quickly disappears. The focus turns to the professional technical processes while little, if not any, attention is given to why such healthy individuals take part in such trials. This thinking is informed by an assertion that they are ‘capable rational beings’ who made ‘informed decisions’ to take part in such a trial. This means-end rationality, in the context of the Western emphasis on individual rights and choice, makes it is easy to background questions about human involvement in clinical trials. This allows us also to forget about drug trial victims and their suffering.

Yet, we all part of this problem. Why? Because we all benefit from the pharmaceutical products – whether as paid volunteers, as patients or as professionals mediating the use of such products. As I ponder what happened in Rennes I am reminded of one of my own participants’ response, to the question why take part in clinical trials.

‘Look at me… 10 years ago I would have had a car, a house and a good job... but I don’t…’

‘Look at me’ is an invitation not to merely stare at someone but to see that person in context. It can be understood as an appeal to see the social, political and economic consequences of individual actions. It can lay bare the social injustices that lead some people to take certain risks to make ends meet while surrounded by such wealth.

Sometimes when disasters, such as the events in Rennes, occur, it is easy to distance ourselves or feel unconnected. Clinical trials are done by far away desperate people. We may feel that the events do not affect or happen to people like us. We feel we are not part of the conversation. However, the invitation ‘Look at me’ is a bidding to consider our shared humanity and take note of the injustices suffered by those we may otherwise see as the ‘other’.
'Look at me' invites us to consider how involvement in clinical trials should be part of a conversation that we all participate in - no matter how far away we may feel ourselves to be. Therefore, as weeks turn into months and eventually years let us not forget the human cost of human involvement in clinical trials. The ethics of clinical trials need to be considered beyond a simple utilitarian logic. We need to keep looking at others with empathy and an awareness that we are all implicated in clinical trials. As with the Northwick Park trial in 2006, the outcomes of investigation in Rennes will no doubt reveal little about why the victims in Rennes wanted to take part in a clinical trial, because society still remains unequal and divided by the same differences.