Involuntary experiments in former colonies: the case for a moratorium


This version is available from Sussex Research Online: http://sro.sussex.ac.uk/id/eprint/89443/

This document is made available in accordance with publisher policies and may differ from the published version or from the version of record. If you wish to cite this item you are advised to consult the publisher’s version. Please see the URL above for details on accessing the published version.

Copyright and reuse:
Sussex Research Online is a digital repository of the research output of the University.

Copyright and all moral rights to the version of the paper presented here belong to the individual author(s) and/or other copyright owners. To the extent reasonable and practicable, the material made available in SRO has been checked for eligibility before being made available.

Copies of full text items generally can be reproduced, displayed or performed and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.
Involuntary experiments in former colonies: the case for a moratorium
Nimi Hoffmann


There is a rich literature on the use of medical trials as a model for designing and evaluating the outcomes of social policy interventions in former colonies. Yet social experimentalists have not engaged in a correspondingly vibrant discussion of medical ethics. A systematic review of social experiments shows that few studies explicitly discuss informed consent, or the serious constraints on securing informed consent from impoverished or child participants, particularly in the context of cluster randomization. The silence on informed consent, and in some cases active denial thereof, suggests that it is often considered less important than other elements of experimental design. This matters since involuntary experimentation on vulnerable people violates their personhood, increases the risk of unintended harm, and establishes continuities with colonial experimentation. There is a need to develop more effective mechanisms for regulating social experiments in former colonies. In the interim, scholars in the South have a responsibility to call for a moratorium on experiments.

Racialised and impoverished people have long borne the brunt of involuntary experimentation (Washington 2006). During the Nuremberg Trials, the principle of informed consent became a matter of international concern when Nazi scientists were prosecuted for subjecting people to involuntary and often fatal experiments. This principle was subsequently incorporated into the International Covenant on Civil and Political Rights as one of the “inalienable rights of all members of the human family . . . derive[d] from the inherent dignity of the human person.” (United Nations 1966, quoted in Schuman 2012) This framing conceptualises the absence of informed consent as a violation of personhood in and of itself, outside of any negative consequences it enables.

Yet rights are always contextual, always struggled over. One of the ironies of this period is that while the United States prosecuted Nazi scientists for conducting involuntary experiments, its Public Health Service had been conducting the Tuskegee Study of Untreated Syphilis on unconsenting black men from 1932 to 1972 (Washington 2006). And involuntary medical experimentation on impoverished people in former colonies persists to this day (Schuman 2012).

I preface my remarks with this brief medical history since there is a rich literature on the use of medical trials as a model for designing and evaluating the outcomes of social policy interventions in former
colonies. Yet social experimentalists have not engaged in a correspondingly vibrant discussion of medical ethics. In particular, they have largely been silent on informed consent.

To make this claim, I draw on a systematic review of all randomized controlled trials published between 2009 and 2014 in ‘top economics journals’ conducted by Peters et al. (2016). I use their review because it indicates the standards of journals considered to be the most rigorous in the discipline. It is plausibly an ‘upper bound’ on the ethics of experimentation. Since the original review only extracted general information on participant awareness as a threat to external validity, I add information on informed consent, country focus and author location.

Peters et al (2016) find that 46% of the studies discuss whether participants were aware that a study was being conducted (even if participants did not consent). I then disaggregate by region: participant awareness is discussed in 65% of experiments conducted in Europe and the United States, compared with 34% of experiments conducted in Africa, Asia and Latin America – all former colonies. This suggests a troubling difference in ethical standards.

<table>
<thead>
<tr>
<th>Table 1: Articles discuss whether participants were aware of the study</th>
<th>% no</th>
<th>% yes</th>
<th>Total</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Western Europe and United States</td>
<td>35</td>
<td>65</td>
<td>100</td>
<td>34</td>
</tr>
<tr>
<td>Africa, Asia and Latin America</td>
<td>66</td>
<td>34</td>
<td>100</td>
<td>58</td>
</tr>
<tr>
<td>Other regions</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>54</td>
<td>46</td>
<td>100</td>
<td>92</td>
</tr>
</tbody>
</table>

I now focus on studies conducted in former colonies, which constitute the majority under review. How many explicitly secured informed consent? For this, I use one criterion: participants knew they were in some sort of study before agreeing to participate. By this criterion, 78% of authors do not discuss informed consent, 12% state that participants were intentionally left ignorant, and 10% indicate informed consent for some sort of study. No study indicated whether participants were explicitly aware they were being experimented upon. This silence on informed consent, and in some cases explicit denial thereof, suggests that it is considered less important than other elements of the experimental design.

<table>
<thead>
<tr>
<th>Table 2: Features of experiments in former colonies related to informed consent</th>
<th>% not stated</th>
<th>% no</th>
<th>% yes</th>
<th>total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants consented to participate in some sort of study</td>
<td>78</td>
<td>12</td>
<td>10</td>
<td>100</td>
</tr>
<tr>
<td>Participants aware that they were in an experiment</td>
<td>100</td>
<td>0</td>
<td>0</td>
<td>100</td>
</tr>
<tr>
<td>Cluster randomization</td>
<td>0</td>
<td>36</td>
<td>64</td>
<td>100</td>
</tr>
<tr>
<td>Impoverished subjects</td>
<td>0</td>
<td>3</td>
<td>97</td>
<td>100</td>
</tr>
</tbody>
</table>
Moreover, the experimental design of these studies raises serious concerns about whether participants were able to consent. 61% randomly allocated treatments to clusters, such as schools or clinics. Yet no study discussed whether participants could not opt out because it was costly to leave the cluster, and how this was addressed. Furthermore, 16% used children directly as participants, yet only one study explicitly gained the consent of parents. Finally, nearly all the studies used impoverished participants, but no study discussed whether penury compelled people to participate. These substantial constraints to informed consent suggest that it may have been difficult or infeasible to secure informed consent in the majority of these studies.

The suspension of informed consent is consequential. First, it “raises the subtle but important distinction between treating human beings as willful agents who have a right to participate or not as they so choose, versus treating them as subjects to be manipulated for research purposes.” (Barrett and Carter 2010, 520). It violates the personhood of some of the world’s most vulnerable people – impoverished black and brown people, many of whom are women.

Second, it increases the risk of unintentional harm. If participants are aware of the true nature of the intervention, its risks and trade-offs, they may be able to alert experimentalists to unintended negative consequences. This is important for experiments that allocate critical resources, such as income or healthcare, to impoverished people. Withholding or providing resources to particular groups may harm vulnerable groups or catalyse contestations that are socially destabilising (Acemoglu 2010).

Third, it increases the risk of establishing historical continuities with colonial experimentation. While many colonial experimentalists hoped to help the lives of the poor and contribute to science, their experimentation was often involuntary and harmful, and had the effect of positioning entire regions as though they were “living laboratories” in which scientific curiosity and the urge for beneficence could be satisfied (Tilley 2011). Stark regional asymmetries in authorship heighten this risk. Of the experiments conducted in former colonies, 84% of lead authors were at institutions in the United States or Western Europe. No first authors were located in Africa or Latin America and 5% were in Asia.

<table>
<thead>
<tr>
<th>Child subjects</th>
<th>0</th>
<th>84</th>
<th>16</th>
<th>100</th>
</tr>
</thead>
<tbody>
<tr>
<td>Addresses design constraints on ability to opt out</td>
<td>100</td>
<td>0</td>
<td>0</td>
<td>100</td>
</tr>
<tr>
<td>Approved by university ethical review board</td>
<td>91</td>
<td>0</td>
<td>9</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 3: First author location of experiments conducted in former colonies

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Africa</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asia</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Europe</td>
<td>10</td>
<td>17</td>
</tr>
</tbody>
</table>
The suspension of informed consent in social experiments is typically a response to the problem of external validity (Barrett and Carter 2010). If participants know that they are in an experiment then they may behave differently than they would under non-experimental conditions, so that the outcomes of an intervention might not scale up to a population. Yet the standard solution in medical research – assigning a placebo – is not possible in most social experiments. Thus, there is a prima facie ‘greater good’ argument for violating informed consent – it helps ensure the external validity of experiments in order to contribute evidence for more beneficial policies.

With or without informed consent, however, social experiments face serious problems of external validity (Heckman 1992; Deaton 2010; Muller 2015). And even if experimental results could generalise to different people or times, this assumes that experiments lead to more beneficial policies than alternative forms of research. This is a counterfactual claim for which no experimental evidence has yet been forthcoming (Chelwa and Muller 2019). Indeed, the role of medical experiments in harmful outcomes, such as the opioid crisis, cautions against strong claims about policy benefits (Deaton forthcoming).

Adopting a less ambitious, more cautious approach may help investigators attend more closely to ethical requirements, but more is needed. As with medical experimentation, social experimentation requires regulatory oversight. Reflecting on his own role in conducting experiments, Sarin (2019) examines harmful and potentially illegal experiments that were approved by university review boards. In light of this, he urges the 2019 Nobel laureates to call for halting all experiments on vulnerable people until effective ethical safeguards are established.

This is an important intervention, but it fails to account for the responsibilities of southern scholars to our societies, and elides the role that southern scholars have played in enabling unethical experimentation. It is our responsibility to insist that experiments in our societies follow rigorous ethical protocols, and we should be at the forefront of ensuring this is enforced.

As with medical experimentation, however, existing mechanisms for regulating social experimentation are likely ineffective. Social experimentation has rapidly become a multinational enterprise, one with significant financial and political interests (Jatteau 2016). J-PAL, which propelled the rise of this
industry, has a model of policy influence that focuses on driving demand by “co-creating” experiments with governments, NGOs and funders (Gyamfi and Park 2019). Thus, key institutions, which might have held experimentalists accountable, are no longer at arm’s length from the research and their will to enforce ethics may be undermined by a conflict of interests (Hoffmann 2018).

Securing informed consent is crucial to upholding the dignity of vulnerable people, reducing the risk of harm, and mitigating continuities with colonial experimentation. To this end, it will likely require new models for regulating this multinational industry, which involve southern scholars and governments working collaboratively. Yet as ongoing involuntary medical experimentation shows, the precise details of this require careful thought. In the interim, scholars in the South have a clear responsibility to call for a moratorium on experimentation. Racialised and impoverished people deserve the same protections and dignity that are afforded to wealthy and white people.

References:


---


2 This data was gleaned from the online appendix, which contains a list of all the papers reviewed. I extracted information on informed consent and country focus from each article. I identified the institutional location of first authors from the author notes in the article, or if this was missing, by conducting a Google search. I then coded each institution by country and region.