

Fair Go: Pay Research Participants Properly, Or Not At All

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We thank the authors of the 5 commentaries for their careful and highly constructive consideration of our paper [1] which has enabled us to develop our proposal.

General Points

Participation in research has traditionally been viewed as altruistic. Over time, payments for inconvenience and lost wages have been allowed, as have small incentives, usually in kind. The problem, particularly with Controlled Human Infection Model (CHIM) research or “challenge studies”, is that they are unpleasant and time consuming. Researchers want to offer carrots to incentivise participation (as Fernandez Lynch and Largent suggest [2]).

We are proposing that research participation be viewed as a *job* with the full suite of financial entitlements of fairly remunerated work, including payment for risk and labour law protections. This would be a significant shift from current practice and standards.

Ambuehl, Ockenfel and Roth have grasped this basic point and have beautifully elaborated how a fair price could be arrived at using economic theory. They build on our proposal helpfully and suggest:

“(1) salary for time involvement that is adjusted to account for the amount of discomfort experienced during participation, (2) insurance against ex post adverse outcomes and (3) ex ante compensation for risks that cannot be compensated ex post (such as death).” [3]

This effectively addresses Lynch and Largent's [2] concern (echoed by Jamrozik and Selgelid [4]) that compensation for risk is inappropriate for harms which do not eventuate. However, because death cannot be compensated for, there must be payment for risk of death, as Ambuehl, Ockenfel and Roth convincingly argue [3].

Indeed, the three part model suggested by Ambuehl, Ockenfel and Roth make us realise that Job Model would be a better title for our model than a Payment for Risk Model.

The alternative to a properly remunerated Job Model is the original Altruistic Model. But this requires that participants be paid *nothing*, otherwise it risks exploiting them. It is one thing to give your life for your country, it is another to be insufficiently paid to give your life. The current situation is an unstable intermediate between a fully Altruistic Model and the Job Model. An Altruistic Model does avoid the risk of exploitation, but may not secure recruitment of enough participants.

Thus, the key message of our paper is: *Pay them properly, or not at all.*

If we stick with middle-ground solutions, we will likely end up exploiting participants who do not have enough altruistic motivation to enrol for free, but who would enrol for very small payments. “Incentivisation” which pays less than a fair labour price is exploitation, whether or not it increases recruitment. Payment practices involving insufficient payments have been exploitative.

At present, challenge studies for COVID-19 are being proposed [5]. There are over 37 000 volunteers who have themselves proposed and advocated for challenge studies as a part of the self-formed organisation 1DaySooner¹. There is no need to incentivise participation and no need for a Job Model in this specific case. These participants should not be paid (the over 2000 pounds which is being proposed) because they are volunteering out of altruism. But *if* they are paid, they should be paid according to the 3-part procedure outlined by Ambuehl, Ockenfel and Roth, which would be considerably more than what is proposed.

We agree with several authors (eg Fernandez Lynch and Largent [2] and Gelinas [6]) that it can be exploitative not to have compensation schemes in place, but this only applies when participants are engaging in a job. If participation is purely altruistic, it is necessary to make it absolutely clear what the risks are and that there is no compensation. After this, it is up to individual’s autonomous choice whether to take the risk, including of no compensation. People should be able to die for their country, or for research, or any moral cause of their choice, as long as they are informed of the risk and can make autonomous decisions.

True, there are many cognitive biases that can affect judgement, both in the case of altruistic and paid participation. Ambuehl, Ockenfel and Roth [3] give a succinct summary of some of these and show that underpayment may also adversely affect risk perception. It is important that CHIMs and all research design ensure that these are addressed and their

¹ See <https://1daysooner.org/>

effect on individual decisions minimized. But withholding payment or caps does not address these and may even exacerbate their effect, as Ambuehl, Ockenfel and Roth rightly point out [3].

Several authors note payment for risk may be small (Payne [7], Lynch and Largent [2], Jamrozik and Selgelid [4]). Jamrozik and Selgelid also claim that payment may cause over-volunteering, loss of trust and other negative effects [4]. These observations might be true, but are irrelevant to the central claim that if you pay participants, they should be paid fairly. How large the payment should be will depend on proper economic costings. We note that we did not attempt a full and formal economic costing and urge authors like Ambuehl, Ockenfel and Roth to do this. Whether in certain cases there are other reasons whereby it would be overall better to actually exploit people (by lower payments), or move to an Altruistic Model, depends on the strength of those reasons. But there is a strong *prima facie* reason to pay people fairly. The default position should be to pay people for their work fairly.

We note that there would be nothing necessarily wrong with paying people above a fair minimum price to incentivise participation, just as there would be nothing wrong with paying a construction worker more than is required by a fair price model, as one of us has argued before [8]. Whether such large payment would cloud their judgement will depend on the way in which the offer is made, as Ambuehl, Ockenfel and Roth rightly notice [3]. And we agree with Gelinas [6] that undue influence can operate when offers are in a person's interests. It is essential that any participation in research be fully autonomous, regardless of whether participation is in the participant's best interest.

Specific Points

Two of the commentaries argue that payment in CHIM research should not be treated any differently from payment in other research involving human participants [2][7]. We agree with this position. If payment for risk is ethically permissible in CHIM research, then it ought to be ethically permissible in all human research which poses an acceptable level of risk to participants.

In fact, CHIM provide a valuable lens through which to explore the permissibility of payment for risk in research more generally. Payment in CHIM has attracted an abundance of public attention and concern, much more so than other areas of research, with concerns about overpayment. But as we and Ambuehl, Ockenfel and Roth highlight [3], it is really underpayment that should be the concern. A Job Model would apply to any payment in research which is not fully altruistic (and unpaid).

In their commentary, Jamrozik and Selgelid identify three main concerns, aside from undue inducement [4]. The first relates to the increased risk of "over volunteering" and

participants omitting relevant information that may preclude them from participation. We agree this is a legitimate concern, but we are not convinced that it should warrant a blanket ban on risk payment as both these concerns can be minimised. As they mention, this is only one reason against fair payment, and better regulation of studies including a database of CHIM participants, can minimise the risks of over volunteering. Furthermore, not disclosing the exclusion criteria to potential participants and using physiological testing may not eradicate participants lying, but is likely to minimise this risk.

Jamrozik and Selgelid's second concern is that higher levels of payment may not be culturally acceptable in some countries in which CHIMs may be performed. We believe this warrants more empirical research to further understand how widespread these beliefs are and to identify their rationale. Of particular importance is determining whether these beliefs are based on a poor understanding of what CHIM research entails and of the risks involved. But again, the fact that a culture does not want fair payment of its workers is not an ethical reason to exploit them, unless you are an ethical relativist. Perhaps, an Altruistic Model would be preferable in such cultures.

Their last concern is that large payments may result in detrimental changes to the relationship between CHIM researchers and participants. It is not clear to us how large payments would do this. CHIM participants should be well aware that their relationship with researchers is distinct from the therapeutic relationship that exists between patients and doctors. Actually, payment can help make this distinction clearer. As Ambuehl, Ockenfel and Roth point out [3], CHIM participants are providing a service, for which they deserve payment. We would not say our employers respect us less just because they pay us fairly. In fact, we might say that our employers respect us more by paying us above the minimum which is fair. In that sense, CHIM researchers could indicate a higher level of respect and recognition for the burdens and risk CHIM participants endure by paying them more.

In their commentary Fernandez Lynch and Largent [2] argue that risk compensation for CHIM participation is ethically permissible but should by no means be obligatory. They argue this on the grounds that uncompensated risk which does not eventuate to harm does not leave participants any worse off than their baseline. As stated previously, Ambuehl, Ockenfel and Roth point out ex ante risk compensation is necessary because death cannot be compensated for [3]. In addition, the uncertainty that comes with risk taking is itself a distinct kind of harm as it is known to contribute to anxiety [9]. Accepting risk and living in a state of anticipation of physical harm is likely to have some negative psychological effects on participants. This may be bundled into actual burdens of participation or as a part of payment for risk – we leave this issue to the economists. We agree with Lynch and Largent that risk payments can additionally be utilised as an incentive and can critically aid in accelerating recruitment. However, these incentives should be over and above the fair price for the job. Paying for risk is simply fair compensation for participants. Compensation for

risk is considered standard protocol in other risky jobs and we don't see why this should change when it comes to CHIM participation. Once again, we echo the sentiments of many of the commentaries in recognising that insurance for any actual harm that eventuates from participation should be guaranteed over and above securing risk payment.

Ambuehl, Ockenfel and Roth also provide an invaluable economic perspectives on payment in challenge studies in their commentary [3]. They highlight a practical limitation of providing risk compensation via an hourly "risk bonus" as some risky activities take very little time to perform. They are completely correct and this illustrates the importance of integrating economic perspectives into practical ethics.

Gelinas [6] and Payne [7] both identify some limitations of our empirical study. Gelinas points out that our survey should have assessed participants' agreement with providing risk payment *without* any compensation for actual harm [7]. In fact, we did assess this in our public survey and found that, as expected, the public had the strongest level of disagreement with this statement (mean level of agreement (SD) = 1.54 (1.73), with levels of agreement ranging from 0 – strongly disagree to 6 – strongly agree) compared to the other two options involving paying or not paying for risk with compensation for actual harm. Unfortunately, due to time constraints we cut this option from our expert survey and did not report this data in our final report, as we prioritised data which could be compared between our two respondent groups. This finding shows that the public supports our and the commentators' stance that payment for risk should always be accompanied by compensation for actual harms. We agree with Payne that one of the limitations of using Prolific Academic (PA) to recruit UK survey responders could be that it introduces a bias in support of payment for research [7]. However, our survey primarily assessed attitudes towards *payment for risk* in research and not just payment in research generally. As survey research does not tend to involve any risks, it is not clear that PA responders would carry a bias in support for the payment for risk in research as compared to other members of the general public. Furthermore, we are currently collecting data from broader public audiences across multiple continents (visitors to public museum exhibitions) and early analysis of this data shows it replicating the trends of our PA data.

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Competing interests None