



# Unfair Benefits: When Research Hosts Can't Say No

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## Abstract

Research situated in developing countries disproportionately benefits wealthy Western companies, opening up the potential for exploitation. Fair Benefits aims to solve this by making host communities the moral adjudicators of agreements, but when facing structural power imbalances, they may have to accept deals which are grossly unfair. I argue that the approach is correct to consider the will of host countries, but countries often have no choice but to agree to unequal contracts. In such a position, the agreement of the host need not be morally transformative, so the approach leaves open the possibility that numerous contracts are exploitative.

**Keywords:** Consent; Exploitation; Medicine; Research

## 1. Introduction

When medical companies from wealthy countries situate research in poorer countries, there is the potential for exploitation, because the research tends to greatly benefit the interests of the wealthy while helping host communities very little. Fair Benefits is one proposed solution to this problem which puts the impetus on communities to lead negotiations, choose the benefits they most need, and judge the quality of deals they reach with companies. It says that fairness comes down to a judgement by the host community, and thus so long as a community accepts a research deal, it is not exploitative. However, when power and resources are stacked against them, host communities may be forced to call deals 'fair' even when they are extremely inequitable and undesirable. In this essay, I set out the Fair Benefits approach and its answer to a central objection about power imbalances. I then pose a series of thought experiments which aim to isolate whether, and when, agreeing to a deal prevents that deal being exploitative. Finally, I assess this in the context of medical research, arguing that the Fair Benefits approach is correct to listen to communities, but when hosts have only poor options to choose from, we cannot infer from their agreement that they consider a deal fair.

## 2. Fair Benefits and the Right to Evaluate a Transaction

The Fair Benefits (FB) approach sees exploitation as ‘unfairness in the distribution of benefits and burdens between parties’ to a deal. It focuses on the informed interaction between parties and the outcomes of that interaction (Wenner 2018). Exploitation is thus avoided when benefits are ‘fair’ – they are proportional to the social surplus of a transaction and the burdens and risks taken on by each party to the transaction (Millum 2012). In the context of medical research, these benefits are often ‘direct’, a direct consequence of the research, such as community access to the drugs being tested. But they can also be ‘indirect’, such as training local doctors or providing research participants with high quality care (London 2008). A process of open deliberation and negotiation between parties, called ‘collaborative partnership’, determines the size of these benefits for each side, and in order to guarantee the benefits are responsive to local needs, the host community is the ultimate arbiter of whether a deal is fair (El-Setouhy 2002; London 2005). There are specific requirements the benefits should follow: they should, for example, increase with the burdens and risks communities take on (London and Zollman 2010). By empowering host communities to negotiate directly with companies, the approach argues, host communities can choose appropriate benefits and exploitation is avoided.

A central objection to FB is that it does not lead to outcomes which are by its own metric desirable. Large power asymmetries make it likely that communities will have to accept poor deals often. For example, researchers usually have lots of choice about where to situate their experiment, forcing potential sites to compete with each other by lowering their demands for benefits; and, unlike profit-driven companies, poor communities desperate for medicine cannot afford to drag out negotiations (London 2005; London and Zollman 2010). Communities must then choose between nothing and a deal which violates FB’s self-imposed burdens.

In response, FB says it is not our right to adjudicate whether a deal meets standards of ‘fairness’, but the right of the host community. By making the host community the moral arbiter, insight as to whether a community considers a deal fair or not – and thus exploitative or not – is determined by whether the host community accepts it (London 2005; Wandler 2017). A host community is in a much better position to understand its needs than research companies or academics, and so it is that community’s prerogative to choose the benefits it deems appropriate (London and Zollman 2010). We are thus faced with two competing metrics for fairness. Should the deal meet the burdens FB imposes on itself, intended to ensure proportionate distribution of surplus, or need it merely be agreed to by the host community? The two compete when, for example, communities accept very inequitable deals. I aim to resolve this dilemma, and the question of whether Fair Benefits really prevents exploitation, below.

### **3. The Morally Transformative Power of Consent**

Consider the following thought experiments below, entitled ‘Dividing Sweets’:

Dividing Sweets 1. Two siblings are discussing how to share two sweets between them. Your sister offers to split the sweets equally; however, you, the younger brother, are so determined to get both sweets that you threaten to throw away all of your sister’s toys unless she forfeits hers. Faced with this threat, she reluctantly agrees to give you both sweets.

Dividing Sweets 2. Now consider a similar scenario. Sibling relations have improved, you are forgiven and this time, you suggest splitting the sweets one each. In fact, your sister, who is in a good mood after coming top of her class in a maths exam, lets you have both because

she knows it will make you happy. She is under no pressure to do so and does it without expectation of future reward.

If exploitation is avoided only by proportionately distributing surplus, both situations are exploitative. It is possible and reasonable to divide the sweets equally, but instead the younger brother unfairly receives all the benefits in both cases. But intuitively, one case is exploitative and the other is not. Case (1) is exploitative because the brother uses a power asymmetry – his willingness to destroy his sister's beloved toys – to gain disproportionate benefit. Case (2) is not, because the inequitable outcome was voluntarily agreed to by the disadvantaged party. If (2) was exploitation, so would any gift or kind act. Agreeing to an outcome can therefore be 'morally transformative': making an unfair transaction non-exploitative.

Under what circumstances is consent meaningfully given? To understand this, we first need a clear conception of what real consent to a transaction looks like. For the purposes of this essay, I take consent as a particular kind of agreement or acceptance which has the moral power described above. Consent, unlike other forms of agreement, transforms the existing obligation of parties to distribute surplus to a transaction fairly. I suggest that a necessary condition for consent to a transaction is that agreeing parties judge a deal to be acceptable, believing that it rewards them fairly. In (2), consent was present because the sister judged freely that even though the outcome was materially unfair it was acceptable for other reasons, namely because she valued her brother's happiness. This made the transaction non-exploitative. By contrast, (1) illustrates agreement without consent. Although she agreed to the deal, the sister did so under coercion, and her accession was not accompanied by a judgement that the deal was fair. In absence of her consent, her mere agreement does not prevent the transaction from being exploitative. Thus, what matters for consent is not what participants to a transaction ultimately agree to, but whether those participants sincerely believe a transaction to be fair, and case (1) shows that these two need not align.

Having established a framework for consent, I now consider under what circumstances we can infer that consent was given. I posit that when someone is presented only with options they find unacceptable, the choosing of one option does not imply consent. Consider a third thought experiment:

Dividing Sweets 3. Suppose now that there are not two, but a whole bag of sweets to share, which were originally entrusted to you. Your parents are busy with long video meetings so you can be quite confident there will be no harmful repercussions on you if the sweets end up being distributed unequally. You offer your sister just a couple of sweets in exchange for her not bothering you, leaving you with the vast majority. Lacking better options, she accepts.

Our intuitions indicate that the sister is still being exploited by her manipulative brother. As a result, and like case (1), her agreement to the deal cannot have been morally transformative. Why is this the case? Unlike case (1), she is not being violently coerced, but instead chose freely between two undesirable outcomes. Maybe she even did so enthusiastically, perhaps surprised to be offered the few sweets she did get. And she might also, for a whole host of reasons like in case (2), have chosen that deal even if offered a fairer one. But we cannot infer from her agreement that she did so because she found the deal acceptable, rather than because there was no feasible alternative. It is possible, if not likely, that she resented the imbalanced outcome even as she accepted the deal. Therefore, even ostensibly noncoercive agreement does not necessarily imply consent.

#### 4. The Free Choice of Host Communities Is Not Enough

The above argument has two powerful implications for the Fair Benefits approach. Firstly, the theory is correct to place at least some weight on the judgement of the host community. A theory which evaluated transactions only by their outcome would not distinguish between case (1) and (2), even when one is clearly exploitative and the other not. The cases are separated by the judgement of the sister in (2) that the outcome is acceptable. Comparably, if a community was genuinely happy to accept a smaller cut from situating scientific research – perhaps it normatively valued scientific advancement or wanted to build a good relationship with the research company – that would be sufficient to make an unfair deal non-exploitative.

Secondly, giving host communities the ability to choose their own benefits does not guarantee that exploitation is avoided. Like the sister in (3) offered only a measly portion of treats, a host community faced with only bad offers from companies or suffering in absence of a deal would necessarily have to choose something that it did not find acceptable. And a terrible deal, seen as terrible by the community, is not made acceptable just by the necessity of choosing some outcome. This does not imply that a community will always find materially disproportionate deals unfair, but it seems likely it will in at least in some cases. Therefore, we cannot infer as Fair Benefits does that the acceptance of a deal implies a judgement on its fairness. Without that sincere judgement, consent is not given and exploitation is not prevented.

But moreover, I take on the higher burden of showing such exploitation is not only theoretically possible, but quite common. It should be clear from the analysis above that research companies frequently offer deals on terrible terms. Moreover, they do so only because they know ‘impoverished, undereducated, local prospective trial participants will accept the deals anyway (Schüklenk 2010). This is because the alternative choice, no deal, is even worse when many developing countries ‘lack a widespread and robust’ public health system (London and Zollman 2010). To take one statistic of many, only 17% of mothers and infants in the bottom wealth quintile globally receive six of seven basic medical interventions, compared to 74% in the richest quintile (WHO 2017). Even a disproportionate deal might at least allow communities to train a few more doctors or acquire a little more medicine. If this community does not accept, another community will, so the deals stay unfair and local communities continue to be exploited.

The Fair Benefits approach wants to empower communities by giving them the power to negotiate and choose the benefits they find important. But while the consent of communities to hosting research is of fundamental moral importance, we cannot be confident that it is sincerely given. This essay has set out the view that under power imbalances and situations of desperate need, communities may be unable to negotiate a deal they judge to be fair. And where the only choices are unacceptable, agreement does not imply consent. Thus, Fair Benefits cannot be confident its model prevents exploitation, and evidence suggests it could be rife. As such, any approach to the fair distribution of benefits from research must reconcile the wishes of the local community with a realistic assessment of what they should proportionately receive. It is right and important to listen to communities, but before we ask if they say yes, we must consider if they can say no.

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