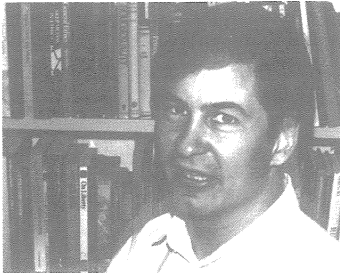


The Ethics of Payment for Research Participants

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Health research ethics committee practices and guidelines treat participant pay with suspicion. I shall argue, against this orthodoxy, that for any health research which is otherwise ethically permissible, it is also ethically permissible for researchers to pay participants for their out-of-pocket expenses, participation, inconvenience, and risk-taking. An initial case for this view is easily made. First, pay for participation as a researcher is ethically permissible, so unless there is a relevant disanalogy, pay for participation as a subject is permissible too. Second, liberty is better than its absence; in this case liberty to pay, not to pay, to receive pay, and to be unpaid. Third, participation in health research often involves substantial time, inconvenience, or risk. One is generally permitted to pay others for these things, so why not here too? Fourth, payment is one standard way to acknowledge valuable activities, and research participation is valuable. Fifth, payment is a good signal of inconvenience or risk. Sixth, pay benefits participants.

Objections

Scientific integrity

Participant pay might sometimes introduce bias into participant selection. Researchers should watch this. If scientifically flawed studies are also ethically flawed studies, ethics committees should do so too. Still, failure to pay participants might also bias participant selection. This shows that there is no intrinsic connection between payment and selection bias. The matter consequently has to be looked at case by case, and there is no persuasive across-the-board objection here to participant pay.

Community Standards

It might be argued that opposition to participant pay is widespread in the community, whose standards ethics committees should reflect. I have two responses. First, I know of no evidence that this community standard exists. Furthermore, there are many activities, such as coal mining and police work, for which community standards deem it appropriate, even obligatory, to pay for risk-taking. Second, even if a relativist or communitarian can establish a general obligation on ethics committees to reflect community standards, and even if there is such a standard opposing participant pay, that is no reason to give it priority over the other community standards outlined above, which favour treating like cases in like manner, increasing liberty, benefiting people, acknowledging valuable activities through pay, remunerating burdensome or risky tasks, and signalling burdens and risks through pay.

Inducement

I shall understand inducement in this context to refer to any action on the part of researchers which increases the probability that people choose to participate in their research, regardless of whether or not this is what the researchers intend.

Inducement to participate is present in every health study. Sound processes for participant decision-making and the provision of readable, friendly, and instructive information sheets induce participation. So do appeals to gratitude for treatment previously received, and to participant altruism. This shows that general objections to inducement to participate are implausible. Is financial inducement peculiarly objectionable? Surely not. The promise of any payment, even for out-of-pocket expenses, is a financial inducement, since it sometimes secures participation. Yet payment of that sort is uncontroversial, and rightly so.

Some ethics committee guidelines reject payments which induce risk-taking. If the risks of participation are unacceptably high, however, the ethics committee should simply not allow the study to proceed at all. Issues of financial inducement do not then arise. If the committee regards the risks of participation as acceptably low, on the other hand, it thereby allows people to choose between non-participation and participation-for-free. It would then be very odd to claim that a choice between non-participation and participation-with-pay is unacceptable, since the only difference between the two choice situations is that participation-with-

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pay is better for participants. What of inducement to take acceptable risks we wouldn't otherwise take? This is utterly commonplace. When airlines or rafting companies cut their fares, many of us decide to travel with them. Some workers with risky jobs leave unless they are paid "danger money" And so on. Why ban so mundane a thing from research? There cannot be a special problem about health risk, since we all face this constantly, and trade it off against numerous other considerations, including financial ones. Furthermore, financial inducement to take risk is already widespread in health research. Any promise to pay participants' out-of-pocket expenses is a financial inducement to participate, and participation almost always carries extra risk. So promises to pay out-of-pocket expenses are nearly always financial inducements to take risk. I conclude that there is no convincing general objection here to financial inducement to take risk by participating in health research.

Might pay induce the participation of those who are financially hard-pressed, but who are ineligible to participate under a study's exclusion criteria? Consider, for example, a poor person with a heart condition which excludes her from a

pharmaceutical study, but who is tempted to deny its existence so she can get the \$100 participation fee and thereby feed her children. Other things being equal, it is plausible that payment in such a case makes excluded participation more likely, and given a sufficiently large number of participants, the result is an increased number of excluded participants. Serious injury or even death to one or more of these participants, and serious damage to the science of the study, might result.

I concede that the argument of the last paragraph gives ethics committees some reason to disallow participant pay, but not much reason. First, it is a peculiar response to the risk of excluded participation. Suppose that paedophilic mood disorder is an exclusion criterion for being an early childhood educator, and that Parkinson's disease is an exclusion criterion for being a surgeon. It would be bizarre to respond to the risk of excluded participation in these activities by making sure that no-one could be paid to perform them. The analogous move in health research is equally bizarre. Second, the ethics committee which stops participant payments thereby tells the woman with the heart condition that no matter how clearly the researcher and the study information sheet set out the risks of excluded participation, as soon as money is offered to her, she is incompetent

to make her own decision on the matter. This ethics committee also

denies the person with hungry children and no heart condition, who is eligible to participate in the study, a clear opportunity to alleviate her or his situation. Third, banning participant pay misses the central issue here. Elimination of all health research which has exclusion criteria is the only guarantee against excluded participation. Short of this extreme, ethics committees should halt the standard practice of a "checklist" which simply invites a "yes"/"no" answer to a series of "Have you got condition x?" questions. This approach is wide open to excluded participation from those who are ignorant of their excluded conditions, who for whatever reason

misunderstand or do not read the questions, or who suppose that the researcher always wants the answer "no". None of these big risks of excluded participation is addressed by disallowing participant pay, and nor are the risks generated by good researcher manner, participant gratitude, altruism, or the desire to please men in lab coats. All these risks are addressed, however, by an ethics committee which requires that researchers properly test intending participants whenever excluded participation would be seriously risky.

Those who wish to pay participants could reasonably be directed to scrutinise them against

study exclusion criteria even more vigilantly than the norm. There is, however, no persuasive case here for disallowing participant pay.

Exploitation

Does participant pay exploit vulnerable people? Allegations of exploitation usually rely on the claim that people are not paid enough, but here the complaint is that participants are paid, rather than not at all. Consider the various groups involved. Those who would not participate, with or without pay, are not exploited by payments. Those who would participate if not paid but would not

participate if paid are put off, not exploited, by participant payments. It is also hard to see how payments could exploit people who would participate, with or without pay. This leaves only those who would participate if and only if paid. Exploitation usually harms people, and yet it is plausible to regard payment as a benefit to these people. Some objectors might persist that even if participants are not made worse-off by pay-with-participation, researchers do use their vulnerable situation, and do thereby exploit them. It might be added that some people who are induced to participate in health research are only vulnerable in the first place because of previous injustice or exploitation. The ethics committee which allows researchers to induce them to participate could itself be

accused of participating in their exploitation.

This is a weak argument. Note first that money might induce the participation of some well-off individuals, who simply have pecuniary motives. It is implausible that pay-with-participation exploits them, so as far as the exploitation objection is concerned, only participant pay to the poor and vulnerable is unacceptable. This is an unattractive implication. I do agree that many participants are in

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vulnerable situations, perhaps resulting from previous exploitation, and that

were it not so, they might not participate in research, no matter what the pay. But I cannot see any support here for a ban on participant pay. That would rule out an opportunity for these people to ameliorate their situation, and it would ensure that they were left in exactly the vulnerable and exploited condition they were found in. This despite the available alternative of allowing them an opportunity to improve their situation. An ethics committee which does this cannot plausibly claim that its hands are clean of participation in the exploitation of these people. Still less can it credibly point the finger of accusation at any ethics committee which allows participant pay.

Slippery Slopes

It might be argued that participant pay drives out altruistic motivation, the "gift relationship" in research, the valuable social practice of unpaid participation, or the option of giving something which cannot be sold. There are many problems with this sort of argument. First, it is formally symmetrical, so one could equally argue that the gift relationship and the rest drive out valuable financial motivations, the purchase relationship, the option of selling something which cannot be given, and so on. The perfectionist response that gifts and altruism are intrinsically valuable, and purchases and financial motives are not, might well be true, but a lot of argument in political philosophy is needed if it is to justify an ethics committee stand against participant payments. This claim is incompatible, for example, with the

core liberal idea that the state and its agents (including New Zealand ethics committees) must as far as possible not adopt any view about which particular activities and ways of life are valuable and which are not. Second, as before, one needs to ask here whether pay for researchers also pitches us down this slippery slope. Third, most individuals and societies sustain a mix of high-minded and pecuniary motives in a great many activities, so why not also in research participation? Fourth, the diversity of health research carves many large

footholds into this allegedly slippery slope to the death of a volunteer ethos. Participation is sometimes on the invitation of multi-national corporates maximising the profitability of their pharmaceutical products; but other participations involve some students in the thesis projects of others, or people previously given life-saving treatment now invited by their clinician-researcher to assist future similarly placed patients, or individuals opting into inquiries they are simply curious about, or groups of people on research registers who

develop a substantial social life together over many years of participation. And so on. It is rather implausible that if we let the smell of money in amongst these diverse, powerful, and generally non-financial motivations to participate, we will make philistines of health research participants.

Since there are good reasons to allow participant pay, and no good reasons to disallow it, ethics committees have some bad habits to change.

At the Centre

By the time readers get this issue of the Report the Centre's Summer Seminar will have been and gone. We are planning to produce Proceedings of the Summer Seminar, so any readers that could not make it here for the Seminar will be able to be up to date. For more information about the Seminar see Barbara Nicholas' Report in this issue.

Over the Summer the Centre was fortunate to have two exceptional summer studentships completed. One was completed by fourth year medical student Marie Van Wyk who researched for the Health Research Council information about the make up of ethics committees. Sarah Gordon spent the summer working on workshop materials for community education about Euthanasia. All those interested in these workshop materials see the notice in this issue.

Professor Campbell was at the East Asian Bioethics Conference in China during late October (for some of his observations

see the interview with him in this issue). One result of the networks that he created while there was contact with the people producing the Chinese Bioethics Newsletter. As readers will be aware Bioethics is relatively new in China, so the developments that are reported are important and interesting. Those interested in medical ethics in China, or making donations to this developing organisation can contact its chief editor Dr Ip Po-Keung at the

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During 1995 the Centre initiated discussion across departments in the university about teaching and research in environmental ethics and informal networking is continuing. Two students are beginning Bioethics doctoral study in this area. One

candidate is Alex Lautensach. Alex has completed his time with the Bioethics Research Centre as a Teaching Fellow. He is now working for the Otago Polytechnic, but also beginning his doctorate in education in environmental ethics. The Centre also welcomes new doctoral candidate Kent Palmer. Kent is researching issues in environmental ethics.

While a Master of Medical Sciences student at the Bioethics Research Centre Dr Scott Hollingsworth submitted an essay to the UK Forum Essay Competition. We are pleased to announce that Scott's essay won second prize in that competition.

BITC 401, theories of biomedical ethics is being distance taught at Christchurch School of Medicine this year. Christchurch participants will travel to Dunedin for a combined block course with Dunedin participants during the first week of the semester.

Events to watch for

The new Code for Health and Disability services

The implementation of the new immunisation and vaccination policy

Changes in the patient Advocacy services?

Visitors to the Centre

Professor Robert Veatch, Director of the Kennedy Institute of Ethics at Georgetown University visited the Centre from early January until February 8. While here Professor Veatch researched Otago Medical School records for the oaths that have been taken by medical students here and for the influences on the design of the medical curriculum. We will be publishing some of Professor Veatch's findings in the next issue of the Report.