

## COMMENTARY

## Ethics in processing research participants' payments: navigating institutes' finance and administrative mandate

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**Abstract**

*Processing payments (reimbursements or honoraria) to study participants by researchers working in institutional setups can raise ethical concerns, as the institute's administration and finance departments control the procedural mandate of this issue. This commentary discusses this critical and often ignored aspect and provides suggestions that could help minimise the risk of violating research participants' anonymity.*

**Keywords:** research ethics, confidentiality, participant protections, payments, ethics review

Research ethics guidelines recommend appropriate monetary payment, approved by Ethics Committees, to research participants [1, 2]. These payments are seen as compensation for the time put in by the participant and allied costs of participation. They can take the form of: (i) reimbursement for costs incurred by the participant eg, travelling to the study site (direct costs), (ii) compensation for participants' time, loss of wages (opportunity costs or indirect costs) or any inconvenience caused due to their participation, (iii) coverage of costs of medical treatment in case of research-related injury, or compensation to next of kin in cases of death, and (iv) incentives which are meant to encourage participation in research especially in clinical trials. Monetary payment to research participants extends to all forms of health research, whether interventional or not and whether funded by a pharmaceutical company or not. The moral basis for such payments is the principle of fairness, as there may be no direct benefit to the participants otherwise, and there may be harm due to loss of time and wages [3], and also the principle of social beneficence, which pertains to maximisation of the common good [4].

The research ethics discourse on payment is extensive and discusses multiple aspects: whether to pay, frameworks to determine how much to pay [3], the risks of undue inducement, payments to a person who is incapable of giving consent, payments when the person withdraws from the research study, what constitutes an "unacceptable compensation" (too high or too low payment), the role of institutional review boards (IRBs) in assessing payments, the different forms of payments (monetary and non-monetary) and their acceptability depending on the study population and the nature of the study [1, 5], including differential payments within the same study [6]. However, there is relatively less discussion on how such payments to participants should be made and what could be some risks

and mitigation approaches involved while processing these payments. This commentary discusses one such risk and the potential ways to mitigate it. The issue is identified by authors based on their own experience of working on research projects in the development sector and academic settings. Taking cognisance of this issue will strengthen ethical rigour in processing participants' payments.

**The mandate of institutional departments in processing research participants' payment**

Investigators and researchers are often associated with or affiliated to an institute or an organisation. The organisation would typically have its own finance and administrative (F&A) department, which oversees the finance and administrative activities across the institute. Processing all kinds of bills and payments, be it staff salary, purchase of equipment or software, payments to vendor, are handled by this department. Processing the payments of research participants also falls in the scope of this department's mandate or procedural control.

Organisations have their own bylaws and standard operating procedures which guide the processing of any financial transfer. Before the advent of the internet, computers, and mobile phones, these payments would involve direct provision of cash to the participants followed by obtaining their signature on vouchers. However, payment systems are now increasingly digitised, and a typical payment approach may require requesting certain specific information from every research participant. This could include the participant's names, contact details, and bank details — which are all personally identifiable information — as well as copies of documents such as passbooks, Aadhaar numbers and PAN cards, which contain information such as their permanent address. These details may be needed to document the entire process of financial transfer. While such digitisation is presumed to improve financial transparency and minimise the prospects of corruption [10], they bring their own risks. An institute's F&A may demand to know what documents are being signed by the research participant, tallying the names and other details of the participants with the bank details received separately to process payments. The only document the participant may sign is the consent document and the F&A departments may view it as a "contract" like any other service delivery contract. There are, in fact, instances in other parts of the world where research participants are expected to sign an actual contract

with the institution and share their personal information to receive financial compensation [7].

As payments are processed this way everybody in the F&A department could potentially have access to the identifiable information of the research participants. This could include — depending on the size of the institutions — finance and administrative assistants, auditors, chartered accountants, finance officers and directors.

### **The problem — loss of anonymity and the lack of transparency**

Participants when agreeing to participate in research are assured of confidentiality and anonymity as part of the study protocols. There may be times when participants agree to participate only when they are convinced of this assurance [7] but processing payments through institutional procedures could lead to a loss of anonymity. What if the participant is a closeted gay person, and is participating in a study focused on the health needs of gay people in the city where the institution is located? The person will be 'outed' to all those who can access their identifiable information as it might be well known that all participants in the study are gay. The same is true for research projects that focus on subjects such as sexuality, substance abuse, and mental illness. They also carry a risk of social harm, given how several of these identities are stigmatised in the larger society.

Typically, the researcher who is in direct contact with the participant may request information to process the payment, and in most cases the participant is not aware that their personally identifiable information can be accessed by so many people. This level of transparency as to research participants is often missing when it comes to processing payments. Though the principle of transparency is an important ethical principle, the rarity of transparency in payment procedures is noteworthy [8]. Besides not knowing who can access the personal information, the participant may also not know for how long their personal information is kept in the records of the F&A department. Ideally, participants should be able to exert a certain level of control over this shared information.

Besides ethics principles, the processing of payments in this way could be against the law. In the year 2017, the Indian Supreme court upheld the right to privacy as a fundamental right under the Right to Life which is enshrined in the Article 21 of the Indian Constitution. The Digital Personal Data Protection Act, 2023 in India is clear that processing any data (which includes its collection, storage or sharing) would require *specific consent* and that this comes with the right to withdraw the consent accompanied by erasure of any data collected [9]. Are these factors taken into consideration as one requests participant information to process payment?

### **The solution — the role of different stakeholders**

It's important to understand that the obligations of research

ethics extend to activities like processing payment which may be done after data collection. Caution and sensitivity are required at this stage as well. For instance, a participant information sheet often mentions that only the research team will have access to the identifiable information of the participants. One may think that through and be transparent about whether this includes the F&A personnel of the institution. Transparency should also be observed around how much time the processing of the honorarium may take. In institutions where there is a shortage of human resources and other systemic challenges, this process may be longer. Some participants may prefer receiving an update on the completion of all processing formalities, whereas others may not. Being transparent from the beginning helps avoid untoward situations at a later point. Some or all the members of the F&A team could be treated as a part of the research team if admin and finance-related work are a core part of the research project. Researchers can choose to have selected members of the F&A team involved in processing participants' payments, and only those members can have access to identifiable information of the participants. Any communication to the participant, say through informed consent documents or orally, must be clear on this. Besides mentioning the name of the research team (inclusive of administrative and finance personnel), the documents can specify what information will be collected to process any payment, so that participants are not surprised when details such as bank information are requested. This is important since there may be participants who have reservations about sharing their bank details with anyone other than the researcher(s) who directly contact them. This is no different from a patient wanting to share relevant personal details only with the doctor and not with the hospital administration. From the authors' experience, situations where participants are anticipating getting money sooner or preferring to get the honorarium directly from the researcher rather than through the research host institution are not uncommon.

Another aspect is training and capacity building. As we expect every researcher to be trained and aware of the principles of research ethics, including those pertaining to the privacy and confidentiality of research participants, this can be extended to administrative and finance personnel as well. At times, the finance and admin team might be working across different research projects and might be involved in processing payment of different components within the research project, like staff payments or vendor payments. The ethics obligations relevant to payments to research participants are different from these other categories of payments and thus an orientation in this issue is paramount. A form of research ethics training can benefit the F&A personnel in other aspects of their work, like coordinating with and supporting the Institutional Ethics Committee (IEC). Besides structured capacity building, researchers having a conversation and reinforcing this messaging with the F&A personnel to orient them about the

sensitivity of research could also be a helpful step in this regard. This can contribute to team building and help raise the overall standard of ethics in the institution.

Beyond the researchers and the F&A team, two important stakeholders on this issue are the institution and the IEC. The IEC's review should not skip the "how" of payment and compensation and should take note of what information may be collected for this purpose and who has access to it. Where possible, some guidelines can be developed for researchers and for the F&A team by the IEC. Institutes, on the other hand, could develop standard operating procedures (SOPs) on this issue, which can be followed by the F&A team. These SOPs should consider how the confidentiality of all research participants would be upheld, ways to minimise the risks of potential breaches, and specification of the period for which any data or identifiable information pertaining to research participants' payments will be stored.

Processing of payments of research participants is done in all institutes where research involving human participants takes place. Hospitals, universities, and non-profit organisations are all on this list. And payments are increasingly getting digitised. Though digital payments carry their own risks such as malware, technological error or incorrect payment details, these are still becoming the preferred mode of payment, especially in light of laws such as the Foreign Contribution Regulation Act [11]. Yet, the interplay between researchers, administration finance team and institutional policies, which together drive these payments, is seldom discussed. Research ethics guidelines also do not directly address this issue or guide researchers on the best policies in this regard. As a result, the current research practices around participant payments are not fully compatible with participant protection. One need not wait for a bad event to come to light to better one's ways; the need to address this gap in research institutions is real, and the arguments and suggestions provided in this article could be helpful in this regard.

**Note:** <sup>1</sup>Refers to someone's sexuality or gender identity being revealed to others without their consent

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