

Proposed Title

Negotiating requests for reimbursement for community engagement: challenges in developing an educational video for genomic biobanking research in South Africa

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Country context (including health features)

This study is set in South Africa where researchers are involved in genomic biobanking research including international collaborative projects such as HapMap, MalariaGEN, H3Africa, B3Africa, as well as other local collaborations.

Description of the study/research/situation in which the ethical issues arose

The Faculty of Medicine and Health Sciences (FMHS)-Tygerberg Hospital has secured a number of international research grants to develop biobanking capacity through H3Africa, B3Africa, the AIDS Cancer Specimen Resource (ACSR) and others (H3Africa, 2014; B3Africa). In view of this growing body of biobanking and related research at the FMHS, an interdisciplinary team of investigators, based at the Centre for Medical Ethics and Law, designed a multi-phase project, funded by an H3Africa Ethical, Legal and Social Implications (ELSI) grant to help develop a robust community engagement (CE) strategy. The ultimate goal of our project was to develop and implement a process for involving potential participants in biobanking research at Tygerberg Hospital to develop governance policies, and to translate that process into a generalizable model for H3Africa and other consortia involved in genomic research in Africa (Staunton et al, 2018).

Under that aspiration were a number of more specific goals, the first of which was the production of an educational video addressing evolving concepts in biobank science suitable for the understanding of the public [4]. It had a two-fold community engagement goal: first the development of the video would solicit community input into how best to script, stage, and produce a video that relates to this subject matter and second, the video would serve as a springboard for broader community participation in the governance of genomic biobanking research.

Case vignette

In 2015, we embarked on an internationally funded project to explore the ethical, legal and social issues associated with genomic biobanking. The focus of our project was the development of various

strategies to engage with the community given that the outcome of the project would be the development of a model for CE. Consequently, we sought to include the community of potential donors and their representative body – the Biobank Community Advisory Board (CAB) - from the outset. The CAB comprised both men and women who lived in a local township close to Tygerberg Hospital in northern Cape Town. They shared a similar cultural context to patients and research participants at the academic hospital. Although some members did have jobs, the vast majority of the CAB were unemployed. All members had received some formal education. Several meetings were held with the CAB and the biobanking team to discuss the co-creation of educational material on genetics, genomics and biobanking. An educational video was proposed as an important CE tool by the research team with audio-visual representation of what happens when blood and tissue specimens are donated to a biobank. Engaging with CAB members initially coincided with regular CAB meetings where each member was reimbursed by the Principal Investigator (PI) of the Biobank for expenses to the value of R75 (US \$5) per visit. This is in line with the South African Department of Health ethics guidelines that states that research participants should be reimbursed for their expenses using the Time, Inconvenience and Expenses (TIE) associated with their participation in research. The cost is calculated at the current hourly rate for unskilled labour, irrespective of whether the research participant is employed or not. For additional meetings related to our CE project, the same rate was paid and this was clearly explained within the context of our research project. This was explained to the CAB in advance of the script meetings and they were given a week to decide if they wanted to participate. It was clearly stated that they were under no pressure to take part and that it was outside of their CAB duties. The reimbursement rate was once again discussed at the first CAB meeting and the CAB members in attendance agreed to this rate.

Initial meetings were productive and guided the development of a narrative and eventually a draft script for the video. The only parameters set by the research team was that the script must discuss medical research generally and biobank research, as stated in the grant proposal. Working within these parameters, the CAB developed a 'wish-list' of topics that should be discussed. Based on this list, the research team developed a script and subsequently held a number of meetings with the CAB to discuss and refine the script. The CAB members were actively involved throughout the script development process and in between meetings, they sent the research team further suggestions and ideas from their mobile phones using the mobile application - "WhatsApp". This was completely voluntary. During this process, the CAB reinforced some of our perceptions about what the community would want to know about genomic biobanking research, but they also proposed content that we would not necessarily have perceived to be of importance. We also discovered that we tended to oversimplify some of the concepts, demonstrating the importance of including the CAB in the developmental stage.

Once the CAB and the research team were satisfied with the script, we circulated it for wider stakeholder consultation and received feedback from over 25 individuals including researchers, health care professionals, genetic counsellors, CE experts and ethicists. Based on this feedback, further changes were implemented and the script was finalised. During these meetings, the CAB decided that clinic and biobank staff would play the roles of the healthcare professionals in the video. CAB members would play the roles of potential donors and the video would include screenshots of the CAB actively engaged in a scheduled meeting.

Before rehearsals commenced, we met with the role players individually, discussed the expectations regarding rehearsals and filming, and once again explained that as the video is part of a research project, they would not be paid, but their expenses would be reimbursed to the sum of R75 (US\$5) per visit. The role players agreed with this, signed a consent form and rehearsals began in earnest.

The day before filming was due to commence, both community members withdrew from the project with the lead community member insisting that they receive payment as professional actors. Over the ensuing hours, the PI of the ethical legal and social issues (ELSI) team and the PI of the biobank met individually with the lead community member, listened to her concerns but stressed that she could not receive payment as a movie actor as the educational video was part of a research project and not a commercial venture. The community member was reminded of the discussion at the start of the process where it was clarified that expenses related to travel, time and inconvenience would be covered similarly to how research participants were reimbursed in South Africa and similarly to how CAB members were reimbursed for regular CAB meetings. In the course of rehearsals each participating CAB member had already been paid R950 (\$70) for 12 rehearsals.

The ethical dilemma facing the PI of the Biobank and the PI of this CE sub-study, at the time, emerged from a conflict between respecting the autonomy of CAB members to withdraw from the project, while ensuring that the research project was not thwarted. The CAB members were clearly empowered by the process and articulated their belief that they were adding value to the project and this required additional monetary reimbursement. However, both PIs were concerned about setting a precedent that would impact negatively on future CE and research activities in the academic institution at a broader level. While guidelines exist for reimbursement of research participants, there are no guidelines for reimbursement of CE activities. In both settings, one aims to avoid creating undue inducements via offerings of large monetary rewards as this has the potential to undermine the authenticity of the process. It also calls into question the voluntariness of the engagement. CAB members are expected to articulate the voice of the community they represent. If they are paid “salaries” as opposed to “reimbursement for expenses” communities might perceive them to be part of the research team and this may undermine the role of the CAB in the research process. It could also raise concerns that they were unduly induced into participating. One must be careful to ensure that the CAB is not exploited in a community engagement process, but concerns regarding undue inducement in research, similarly arise regarding payment in community engagement (Bentley, Thacker, 2004; Grady, 2005).

A decision was taken to cancel filming and the project was postponed for a number of weeks while we identified new individuals to play the part of biobank donors. The rehearsals recommenced with two medical students who volunteered to replace the community members. Once again we met with these students individually, discussed the research and the expectations surrounding their involvement, with significant attention given to reimbursement of research expenses. The students agreed with this process, were reimbursed at the standard rate to cover their expenses, signed the consent form and filming was completed early in 2016 (Biobanking & Beyond, 2016).

There were concerns that the relationship between the biobank and the CAB could be damaged as a result of this process. To mitigate this, in the discussions between the PI of the ELSI team and the PI of the biobank, it was decided to discuss this at the next CAB meeting, re-visit the issue on payment for research, and provide the opportunity to discuss any other issues. No change was made to CAB reimbursement or the reimbursement of the CAB for participation in research, but the importance of ongoing dialogue throughout a community engagement exercise was clear. As a result of this ‘damage control’ the biobank and the CAB’s relationship continues to grow and develop and there has been no lasting damage. In the making of future educational interventions, we would recommend the use of CAB members, subject to the issues highlighted.

Conclusions

The payment of research participants in under resourced communities remains an ongoing ethical dilemma, but our experience demonstrates that current guidelines may not be suitable to guide empirical bioethical research. There is also a need to consider the appropriateness of payment of the community in community engagement and a model that best supports the aspirations of engagement.

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How should community members be paid when they go off script?

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The role of money in health research has been debated in bioethics for many years, particularly with regard to resource-poor settings and populations. Much of the debate has focused on two key stakeholders in the research enterprise: research ethics committees and research participants. Research ethics committees, particularly in low- and middle-income countries, often do not enjoy robust support from the institutions with which they are affiliated, leaving them little option but to support themselves (at least in part) by requesting payment from researchers for ethical review. This practice has been regarded as ethically problematic for a variety of reasons, such as: the potential for conflicts of interest; threat to impartial evaluation; possible negative effects on public trust towards research ethics committees; difficulties in establishing fair review fees structure across a diversity of research projects; and contributing to 'ethics committee shopping' for the least expensive review. Payments to research participants has raised another cascade of issues, from the standard concern about 'undue inducement' violating voluntary consent to exploitation and damaging scientific validity through selection bias (Resnik, 2015). More broadly, money, research and ethics can and do meet in questionable ways at multiple levels and contexts worldwide: doctors receive money to recruit their patients as study participants (Rao & Cassia, 2002); corporations study design and (lack of) dissemination of research results (Sismondo, 2008); medical journal editors pocket money from drug and device manufacturers (Liu, 2017). The steadily entrenched commercialization of health care and biomedical research, as well as inequalities between research stakeholders, fuels such money-related ethical conflicts.

The case study presented involves money, research, ethics and community representatives. The importance of community engagement is widely recognized in terms of expressing respect for communities, enhancing study feasibility and improving the quality of research (Tindana et al, 2007). Community advisory boards (CAB) are a common engagement mechanism: constituted by members of the population or community in which the research is conducted, the CAB can provide researchers with valuable input to improve study design and procedures. Delineating the role of the CAB and its members is crucial for the analysis of the case. As the name indicates, in its classical guise, it is primarily advisory. However, community engagement can take forms other than just advisory, such as the integration of community members as recruiters within research teams (Simon & Mosavel, 2010). In the case study, the CAB members venture beyond their typical advisory role when they are invited not just to give input on the development of an educational video, but to be actors in it. Does this change of role justify their demand for higher compensation?

At first glance, the demand could be regarded as unjustified due to them having initially having consented to a lower rate. Their later demand in that case would be similar to the breaking of a promise or contract. While it is impossible to tell what ran through the CAB members' minds, one could imagine that they came to consider the rate they agreed to as unfair. Consent does not make an unfair agreement ethically justified; one can (for many reasons) agree to terms that are in fact exploitative (Wertheimer, 2010), and breaking exploitative agreements is not morally wrong (though it can be legally perilous). Perhaps the CAB members saw it that way. So what case can be made for the original agreement being unfair, and the later demand by CAB members being justified?

One possibility is that the CAB members regarded their actor role in the video as requiring some degree of special expertise. The researchers paid them the same (per visit) remuneration rate normally provided to CAB members (in their traditional role) and research participants. But if what they are asked to do goes beyond the typical advisory role, and if their expertise distinguishes them from participants, this might justify a higher rate. The idea of CAB members having expertise is not unheard of. It is often said that while community members may need help in understanding complex research topics, researchers too need insider knowledge from community members. Ignorance in this context can work both ways, and not all specialized and valuable knowledge is scientific. One could therefore argue that, in the case study, CAB members are able to tap into their insider knowledge when playing acting roles as donors of genetic material, and this is what separates them from ordinary CAB members, research participants, and the medical students who eventually replaced them. After all, hiring non-professional, untrained actors from communities for commercial and independent films is not unknown, and they are chosen on account of their local authenticity. A highly regarded Italian film, *Bicycle Thieves* (1948), cast only untrained actors, following the aesthetic dictates of neorealist cinema. An implication of this line of thinking is that the South African Department of Health ethics guidelines, which considers research participation as unskilled labor, is not appropriate as compensation for what the CAB members were supposed to be doing, even if their self-description as 'professional actors' was over the top. In any case, this argument will not justify Hollywood-level salaries: it would only justify a somewhat higher reimbursement rate within the framework of the research budget. But this could be enough to support the claim that the later demand was unjustified, though not if the sum demanded was exorbitant (The case study does not say how much they asked for.)

This also points towards a resolution of the ethical dilemma that the researchers did not pursue, namely to pay the CAB members somewhat more than research participants in recognition of their specific expertise. The researchers justify identifying alternative 'actors' instead by arguing that paying the CAB members more would (a) set a payment precedent that could undermine socially valuable research in the future and (b) the higher payment would make them workers receiving salaries rather than representatives of the community getting reimbursed for expenses. Both points are disputable. In regard to (a) a modest increase over the participant level payment might not have (or reduce the risk of) the serious consequences they fear. As far as (b) is concerned, CAB members are stepping out of their normal role of acting as the community voice, or at least channeling that voice in quite a different way. This draws them closer to the case of community members hired as recruiters. It does not seem inappropriate to reimburse such recruiters at a higher level than participants. Of course, it is not clear that the CAB members would have accepted a modest increase of reimbursement. But that is not the point: a somewhat higher amount might be ethically justified, even if they (wrongly) thought they deserved more. It is not clear whether researchers tried to negotiate a compromise level of reimbursement between 'movie actor' and research participant.

The argument I have presented has its own points of weakness. The case for higher reimbursement would be dampened if it turns out that the CAB members were motivated purely by financial gain, and not by the injustice of being underpaid for their 'community voice representative' performances. The reversal they made in the consent process may or may not reflect this kind of motivation, i.e. the more they became essential to the production, the more they sensed they could cash in, hence a desire to be released from their earlier agreement and the readiness to sabotage the project. But it is hard to

tell. The argument would also be weakened if the CAB members were terrible actors, with no claim to natural talent, though this would likely have come out to light in the rehearsals.

The real weakness, though, is the assumption that we know the monetary value, in the context of a research project, of the effort CAB members make when they go off script (pun intended) and do something like acting in an educational film. We don't, really. Maybe, when it comes right down to it, we aren't quite ready for all the ethical challenges involved in engaging communities in research, in actual practice (Horowitz et al, 2009). As community engaged research ramps further up, community members will continue to be entangled in research in a variety of ways other than sitting in CAB meetings. Should they be paid the same as those from blood is drawn, no matter how great their contribution? That does not seem right. But as the researchers suggest, we are still groping in the dark when it comes to expressing respect for the community in the form of money.

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Remuneration for Community Advisory Board (CAB) Members: A Call for Remuneration Guidelines for CAB Members in Biomedical Research

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The commentary will focus on the definition and methods of community engagement (CE), reflection on the development of the educational video as part of the CE activities of the Biobanking Community Advisory Board (CAB) members as highlighted in the case study by Staunton et al and a call for remuneration guidelines for CAB members who participate in CE activities in low and middle income countries (LMICs) such as South Africa.

Definition and methods of community engagement

Community engagement (CE) is often defined as a collaborative partnership between researchers and members of communities targeted for biomedical research and it is an important activity that can support the successful implementation of biomedical research especially in low and middle-income countries (LMICs) such as South Africa (Tindana et al, 2015). The nature of these interactions and the level of the community's involvement in the research process depend on the goals of the engagement effort itself (Tindana et al, 2007). This may range from just providing information about a research project, consulting with gatekeepers of the community, soliciting views and inputs of community members before, during and after the research, disseminating research results, to building partnerships with the community (Tindana et al, 2007). CE also plays an instrumental role by supporting the consent process and enabling the research team to provide information about research over a period of time. For example, potential research participants are able to receive information and seek clarifications before the day of recruitment as well as ensure that the research and consent processes are culturally appropriate and use appropriate terminologies and analogies understood by community members. Various methods and approaches of engaging communities in biomedical research exist in the literature and they have been used in practice. There are those that involve direct engagement with potential research participants and their communities such as community/town hall meeting and focus group discussions and indirect models that engage communities through their representatives such as CABs and Patient Advisory Groups (PAGs) (Tindana et al, 2007; Campbell et al, 2015).

Reflection on the development of the educational video by the Biobanking CAB members and remuneration for CAB members

The project on the development of an educational video for genomic bio-banking research in South Africa is one example of indirect community engagement models which involved CAB members in the development of an educational video that would be used for CE activities of the genomic bio-banking research project. It is apparent from the case study that the CAB members were involved in the genomic Biobanking project in order to assist in addressing the ethical, legal and social issues (ELSI) of the Biobanking project through the development of the educational video. Hence, the investigators of the genomic Biobanking research have to be applauded for including an ELSI project which implemented CE activities of their overall genomic Biobanking research project. However, in the course of developing the educational video, it is reported that there was a disagreement between the investigators and CAB members on the remuneration of the CAB members for their participation in the development of the educational video which was a CE activity. The disagreement arose because the CAB members wanted to be paid as "professional actors" for their role in the development of the video. Although the CAB members were informed that they would be remunerated for their participation in the production of the educational video project, they felt that the amount of R75 which was being provided to each one of them during their CE activities was too little and the disagreement led to the withdrawal of the CAB members from participation in the development of

the educational video. It is commendable that the investigators respected the CAB members' right to withdraw their participation from the video production.

While researchers, Research Ethics Committee (REC) members and research ethics regulators expect research participants to be remunerated for their participation in research and there are various remuneration guidelines/models for research participants (Mweemba et al, 2018), it is unfortunate that there are no remuneration guidelines/models for CAB members who participate in CE activities of biomedical research projects. Though it is generally considered unethical for potential research participants to be remunerated huge amounts of money nor given expensive non-monetary incentives that would unduly induce them to participate in any research project at the expense of the risks of harm involved in the research project (Mweemba et al, 2018; Ripley et al, 2010), it is generally accepted that remunerations for research participants must be reasonable enough not to become undue inducements to research participants.

Having said that, CAB members in this case study were informed that they would be remunerated for their participation in the production of the educational video project and they made their initial voluntary decisions to participate in the project based on that information. Nevertheless the CAB members had a legitimate question about the amount of remuneration they were to receive for their participation in the ELSI project. Of course, it was very unfortunate that the CAB members expected to be paid as "professional actors" given that this project was for research purposes and it was non-commercial in nature. Their demand to be paid large sums of money for participating in CE activities which were part of a research project is unacceptable since this was a research project and not a commercial project. The CAB members might have a misconception that the educational video was for commercial purposes despite the investigators' explanation that the development of the educational video was for research purposes. It is reported that the investigators reiterated that they could only remunerate the CAB members in accordance with their budget for CE activities since there are no specific remuneration guidelines for remunerating CAB members in the South African context. However, the CAB members still insisted on being paid as "professional actors" in the video. Perhaps the CAB members might have based their initial decisions to participate in the development of the video on personal benefits and not for the common good as it has been reported by Ogunrin (Ogunrin et al, 2018). Unfortunately, the National Health Research Ethics Council (NHREC) guidelines only apply to remuneration for research participants and they are very clear that research participants have to be paid for their travel, inconvenience and expenses (TIE) (NHREC, 2012) and the spirit behind the TIE model of payment is to ensure that individuals who participate in any research project that is fully funded are not exploited nor left worse off in the course of their participation in research activities. The CAB members in this ELSI project were paid according to the TIE model except that the inconvenience was not included in the amount of remuneration since the CAB members were not exposed to any invasive procedures in which case they would have been entitled to payment for inconvenience. The total amount of R75 which they received per visit covered their remuneration for time and reimbursement for out-of-pocket expenses. At the time when the video was taken, the minimum amount of remuneration for research participants was R150 for travel, inconvenience and expenses per visit which has now been increased to a minimum amount of R300 per a standard participant's visit. This minimum amount of remuneration is calculated as follows: Travel= R150 (R3 x 25 km x 2 [return]); Inconvenience = R100 (R33 x 3h [rounded up]); and Expenses = R50 (meal & refreshment). Having said that, it was wrong for the CAB members to request for large sums of money for remuneration after signing the initial consent to participate in the ELSI project. They should have discussed their expectation for remuneration with the investigators before signing the consent documents. Instead of making unnecessary demands for payment of huge sums of money, they should

have requested the investigators to remunerate them according to the NHREC remuneration guidelines for research participants at the time since the ELSI project which developed the video was a research project.

Conclusion

Investigators have a duty to respect community members or representatives that take part in CE activities for their research projects. Community representatives' decisions to participate in CE activities as CAB members and their refusal to participate as well as their right to withdraw from participation in CE activities must be respected at all times. Much as investigators are required to respect the autonomy of research participants, they must also respect the autonomy of CAB members and ensure that they are remunerated fairly for their participation in the research process. This requires consultation and discussion with potential CAB potential members prior to establishment of CABs in order to understand members' expectations for remuneration during their participation as CAB members. While research participants are remunerated accordingly for their participation in research and there are remuneration guidelines/models for research participants in the South African context, there are no standard remuneration guidelines/models for CAB members who participate in CE activities. While both research participants and CAB members participate in biomedical research activities as volunteers, both must be remunerated for their time and reimbursed for their out-of-pocket expenses so that there is no loss of income in the course of their participation in the research activities. The lack of standard guidelines for remunerating community members who participate in CE activities as CAB members in the South African context requires consideration by research ethics regulators. Though some investigators decide to remunerate CAB members according to the TIE model for research participants, it is necessary to have specific remuneration guidelines for CAB members and costs of CE activities have to be included in research budgets so that participants in CE activities are not exploited since they ensure the successful implementation of biomedical research projects. Finally, it is high time that research ethics regulators such as the NHREC developed remuneration guidelines for CAB members and all participants in CE activities.

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