Community organisation-researcher partnerships: What concerns arise for community organisations and how can they be mitigated?

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Abstract: Universities and research funders' growing emphasis on community partnerships, engagement, and outreach has seen a rise in collaborations between university researchers and staff of community organisations (COs) on research projects. What ethical issues and concerns are experienced as part of these collaborations has largely not been described, *particularly from the perspective of COs*. As part of a recent, broader qualitative study, several concerns arising during health research collaborations between COs and university researchers were captured during thematic analysis. The concerns were described in semi-structured interviews by four staff of three COs that work with marginalised groups (i.e. migrants and refugees, women who experience domestic violence, Indigenous populations) in a high-income country. In this paper, the three concerns are taken as the starting point for ethical analysis. Interview data is first used to illustrate the three concerns: being restricted to a recruitment role in studies, reinforcement of stereotypes of marginalised groups, and weakening CO-community relationships. The paper then explores why the concerns are morally troubling and demonstrates how each concern generates feelings of disrespect, creates harm(s), and/or reflects or reinforces unfairness or injustice. It concludes by proposing three ethical criteria for CO-researcher partnerships: fair division of labour, balancing CO advocacy goals with research goals, and balancing CO service goals with research goals. Where researchers and COs discuss how to meet these criteria at the start and during research collaborations, it can potentially help mitigate or prevent the occurrence of the concerns described in this paper.

Key Words: community organisation, partnership, collaboration, ethics, health research

INTRODUCTION

Universities and research funders' growing emphasis on community partnerships, engagement, and outreach has seen a rise in collaborations between university researchers and staff of community organisations (COs) on research projects. CO's primary objective is to improve a given community's health, overall standard of living, social connection and wellbeing. They provide health and other services to particular communities, which may be defined geographically, through shared experience of marginalisation, or through shared interests or circumstances. They may also conduct advocacy work aimed at furthering the interests of that community. [1] COs are typically physically located in the communities they serve and have extensive networks with their members.

Over the past 10-15 years, there has been growth in the theory and practice of engagement as a key feature of higher education.[1] Universities are under increasing pressure to help solve the complex challenges facing their local communities. Many universities now have engagement strategies that (amongst other things) call for undertaking research in partnership[2] with COs. Such partnerships are seen as a key way to ensure that research

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[1] Charitable organisations' primary aim is philanthropy and social well-being. They don't have to focus on the community level but some can. In cases where charitable organisations focus on communities and provide services, the distinction between them and community organisations is small, but charitable organisations typically do not take up advocacy as one of their main aims.

[2] In this paper, the terms research partnership and research collaboration are used interchangeably. CO-researcher partnerships are defined as researchers and COs working together as a team to complete a health research project.

projects ask the “right” questions—those that are responsive to pressing community-identified needs—and create “better” knowledge that draws on and reflects a diversity of knowledge systems and is more widely shared—beyond peer-reviewed journals and academic conferences.[2] Also driving the rise in research collaborations between university researchers and COs are research funders. In the United States and Canada, for example, a growing trend is to require such partnerships as a condition for research grants.[3,4] These changes have brought new opportunities for joint research endeavours between university researchers and COs.

What ethical issues and concerns do arise has largely not been investigated, *particularly from the perspective of COs*. Literature on the ethics of collaborative research has typically focused on collaborations between research institutions and between researchers, particularly high-income country and low and middle-income country (LMIC) partnerships.[8-10] Very little attention has been paid to the ethics of researcher-CO partnerships,[11] though some work has been done.[7,11] Scholarship on the ethics of community-based participatory research has also included discussion of ethical issues and concerns inherent in such collaborations.[12,13] Yet much more ethics research is needed to document the issues and concerns CO’s face and to develop guidance on how they might be addressed.

As part of a recent qualitative study on sharing power with marginalised communities in health research priority-setting, interview data captured several concerns that were described by COs as arising during collaborations with university researchers. These concerns were not limited to the agenda-setting phase of research projects. They were raised by staff of three COs that work with marginalised groups (i.e. migrants and refugees, women who experience domestic violence, Indigenous populations) and identify aspects of public health research collaborations they have found troubling.

In this paper, the three concerns are taken as a starting point for ethical analysis. Interview data from the qualitative study is drawn upon to illustrate the concerns: being restricted to a recruitment role in studies, reinforcement of stereotypes of marginalised groups, and weakening CO-community relationships. Each concern is introduced using an illustrative quote from a CO staff member. More information about the staff member’s concern and its context is then provided and linked to relevant literature or data from the same respondent. This is followed by an exploration of why the concern is ethically worrisome. The paper demonstrates how each concern generates feelings of disrespect, creates harm(s), and/or reflects or reinforces unfairness or injustice. This is intended to unpack how the voiced concerns can be seen as ethically problematic. While the concerns were voiced in relation to projects undertaken with university researchers, it is quite possible that such concerns could arise in partnerships between COs and researchers outside the university sector. The paper concludes by proposing three ethical criteria for CO-researcher partnerships: fair division of labour, balancing CO advocacy goals with research goals, and balancing CO service goals with research goals. Where researchers and COs discuss how to meet these criteria at the start and during research collaborations, it can potentially help mitigate or prevent the occurrence of the concerns described in this paper. How the proposed criteria operationalise existing ethical principles of research and can be incorporated into existing toolkits for research practice is discussed.

A key contribution of this paper is that it reports CO voices on a topic they are not always included in discussing. It is important from an epistemic justice perspective and also builds an understanding of CO-researcher partnerships from the CO viewpoint. Robust ethical guidance for equitable CO-researcher partnerships cannot be developed unless it is informed by the issues and concerns experienced by *both* researcher and CO partners. By proposing ethical criteria corresponding to the reported concerns, this paper contributes to the development of such guidance.

THE QUALITATIVE STUDY

A qualitative study investigating how power and decision-making can be shared with communities in health research priority-setting was recently carried out. It sought to answer the following research question: what is necessary to share power with marginalised communities when selecting research topics and questions for global health research projects? As part of that study, staff at COs (along with researchers, ethicists, and community engagement practitioners) were amongst 29 individuals who participated in semi-structured interviews. Given the study's research question, COs with experience working with marginalised communities were specifically sought to participate. Global health research was defined as research addressing health problems worldwide, including those of the most disadvantaged, who live primarily (but not exclusively) in LMICs. It thus encompasses research with marginalised groups in high-income countries. COs were identified through snowball sampling. Researchers who were interviewed as part of the study suggested particular COs and their staff to interview. Ethical approval for the study was obtained from the [removed for blinded review]. Written informed consent was obtained from all study participants.

In total, four staff members at three high-income country COs that worked with migrants and refugees, women who experience domestic violence, and/or Indigenous populations agreed to be interviewed. These staff members had partnered with university researchers to conduct public health research projects and included three women and one man. Two were senior staff and two were junior staff. Following the technique of thick description, interview questions were open-ended [14]. They included questions such as: In your experience, what's important to balancing power between researchers and community partners in decision-making about a health research project's topic and questions? In your experience, what's important to ensuring community partners have an equal opportunity to speak and be heard in decision-making about a health research project's topic and questions? Thematic analysis was undertaken by two coders in the following five phases: initial coding framework creation, coding, inter-coder reliability and agreement assessment, coding framework modification, and final coding of entire dataset.[15,16] The categories and sub-categories in the initial coding framework were derived inductively. The initial coding framework was developed by L.B.[changed for blinded review purposes] and N.E. each co-coding three transcripts independently and jointly coming up with a list of codes. Using the initial coding framework, L.B. and N.E. next undertook an iterative process of coding a transcript, assessing inter-coder reliability and agreement, and modifying the coding framework.[15] Once a high level of inter-coder agreement was reached and the coding framework was finalized, L.B. applied it to re-code all 30 transcripts using NVivo Version 10.[16]

Thematic analysis of the interview data identified ‘ethical issues and concerns’ as a theme. Within this theme, various ethical issues and concerns related to sharing power in health research priority-setting and decision-making were described by researchers, ethicists, community engagement practitioners, and CO staff. In particular, CO staff identified three matters arising during collaborations with university researchers that they considered to be troubling. These concerns were not necessarily related to the priority-setting phase of research projects and they were not described by other interviewees. The next section introduces the three concerns voiced by CO staff and undertakes ethical analysis to elucidate what is morally troubling about each of them. How do they generate disrespect, harm, and/or unfairness and for whom? Where interview data drew out why a concern is morally troubling, it was incorporated in the ethical analysis. (That primarily applies in the section on weakening CO-community relationships.)

CONCERNS IDENTIFIED BY COMMUNITY ORGANISATIONS

CO’s role is restricted to recruitment

“*I think sometimes academics when they seek to partner with community based organisations there’s a bit of a sense that the research bit sits with the university and the community stuff sits with the community organisation, so they might see a role – so when you’re developing a project you carve out a role for the community based organisation and that often involves linking, helping you link with the community, getting research subjects you know that kind of role, and then the, the research itself kind of goes on without you*.” (CO staff member)

The CO partner’s role was limited to recruitment and other aspects of project implementation whose achievement required a robust relationship with the research project’s community of focus. These aspects would vary by project but might include liaising with recruited participants to set interview times/dates, organising their transport to interview, and disseminating project findings to participants. The division of labour between university researchers and COs was uneven because the CO partner was only involved in certain aspects of project implementation, rather than co-designing the project, leading its implementation, and/or being involved in all phases of implementation. This example is consistent with a recent quantitative study that identified a serious lack of equity and decision-making power as a key problem for CO-university research partnerships. Just over 60% of CO respondents had rarely or never jointly submitted a research proposal when working in collaborative research partnerships. Less than 15% of CO-university research partnerships identified in the study had originated in the community. They were overwhelmingly initiated and controlled by the university partners, in addition to outside sources such as government or industry.[17]

In the example provided by the interviewee, being allocated a recruitment role directly followed from the CO’s role as a service provider and the assets it brought to the research collaboration in terms of its community networks. However, where CO assets are utilised but CO staff are excluded from decision-making, it generates feelings of being involved as ‘partners’ largely to make project recruitment processes (and other aspects of project implementation) run smoothly. COs feel used by researchers for their connections rather than feeling respected as research partners. They feel disrespected when researchers treat them as a means to advance their [the researchers'] own interests.

Where the CO partner is restricted to a recruitment role, it also creates an unfair division of labour within the research enterprise. COs are relegated to the role of "task executers" and largely excluded from making many basic decisions about research projects. These are not features of a just workplace. A hierarchy of labour distinguishing between privileged "task definers" and less valued and compensated "task executers" enacts domination and oppression in the form of exploitation and powerlessness.[18]

Finally, when limited to a recruitment role, CO staff are not asked to provide their knowledge, opinions, thoughts, or judgements about what research topics and questions should be investigated or about how research projects should be designed or conducted. This reinforces epistemic injustices and hierarchies of knowledge, which are particularly dominant in the health sciences, that privilege the knowledge of "expert" researchers over other systems of knowledge.[4] CO partners are not given proper respect as knowers and sources of information. They are susceptible to unjust credibility deficits, often based on their assumed lack of research training and experience relative to researchers, which prevents their views from being solicited. Yet, CO staff commonly have significant research experience through both formal and informal training. Learning by doing is a well-recognised research capacity development strategy.[19] CO staff often have accumulated a wealth of research knowledge after partnering on several research projects. Their lived experience and close links with the communities they serve also give them insights into the problems those communities face and which of those problems are priorities.

Stereotypes of marginalised groups are reinforced

"*And that [being restricted to a recruitment role] for us created, so I guess it was from experience, created some issues because we then had no control over the way that the academic represented the issues for the group we focus on and sometimes they would be kind of not complimenting the kind of messages we wanted to get out there… and it feeds into the types of stereotypes that we as an organisation are trying to challenge.*" (CO staff member)

In this example, research findings were reported in a manner that reinforced stereotypes of the marginalised group on whose behalf the CO partner advocates. Women who experience domestic violence were represented in a unidimensional way that wasn't positive; they were represented as "super-oppressed" which does not speak to their agency, inner-strength, or other characteristics that the CO wanted to highlight. This outcome in part was due to the CO's lack of control over data interpretation, which again speaks to an unfair division of labour. It further reflects a tension between the goals of researchers (i.e. to report research findings and get published) and the advocacy goals of COs (i.e. to advance interests of particular marginalised groups or communities). COs often place a different value on research relative to researchers due to these goals. For COs, research is inherently political and should be used in a strategic way:

> *"Choosing a topic even from the very beginning, I guess that in itself is a political act… when we make a choice about whether this is something that we should be bringing out*

> *in research, so amplifying those voices through research… we're also thinking about well what kind of research is gonna make a difference in this space, what do people need to know in order to understand this issue better and how is this research gonna be translated then into an advocacy kind of platform to be able to make a change at that federal level."* (CO staff member)

To some extent, concerns about reinforcing stereotypes may potentially arise more commonly when researchers partner with COs that work with marginalised groups and communities. Underlying tensions between research and advocacy goals would, however, arise generally in CO-researcher partnerships, where CO partners have advocacy missions.

Where research findings are reported in a way that depicts certain groups as having stereotypical characteristics, it puts the weight of *scientific evidence* behind that representation. This is harmful to the well-being of these groups' members. Giving people a stronger reason to think a stereotype is accurate can make them more likely to act as if the stereotype is true. When individuals are the objects of negative stereotypes, they are perceived as having less value and negative traits on account of their group membership, and treated accordingly. Being treated as though, for example, one lacks agency and inner-strength can then make individuals feel that they are of lesser worth and have less control over their lives. Being disrespected by others can undermine individuals' self-respect, which is a core dimension of well-being.[20] Where reinforcing stereotypes means members of a marginalised group fall below a sufficient level of respect, it comprises an injustice.[20][3]

Reporting research findings in ways that reinforce negative stereotypes can also harm COs and their staff. Where research findings depict groups or communities as having stereotypical characteristics, they obstruct or counter COs' advocacy goals. CO staff may feel psychological distress at being involved in research projects whose findings counter their organisations' mission. They may feel complicit by being part of any project that has a detrimental and harmful impact on the groups or communities that they are trying to help, especially where they have close relationships with particular group or community members. This can generate feelings like guilt, shame, and/or anxiety and negatively affect their mental health.

Finally, where research findings whose reporting reinforces negative stereotypes are disseminated and published, researchers effectively put their interests ahead of CO and community interests. Where research goals are taken forward at the expense of CO advocacy goals, this reflects an unequal power dynamic between university researchers and CO partners and signals a lack of respect for CO partners and communities. Hierarchies within research and academic knowledge production, where experts' interests dominate, are upheld.

Weakening CO-community relationships

"*You know obviously being a randomised control trial they had a set magic number that we had to reach and it got to the point that you know our teams had relationships with these organisations and then you know we were really getting – well I shouldn't say getting pushed but it was you know imperative from the university's perspective that we go in and get these*

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[3] Theories of social justice demand securing a sufficient level of all dimensions of well-being for everyone, especially for those who are marginalised by social norms and institutions.[26]

numbers whereas for us it was a long-term relationships that were most important and we got so desperate to a point they had us standing out the front with T-shirts and clipboards trying to get people to sign up and it was, you know, a lot of people didn't feel comfortable with that because then you know next time we come in as a CBO [community-based organisation] person working with these organisations they're gonna go oh it's that person trying to sell us something or push something on us and that's not the way that we would have liked to do things." (CO staff member)

In this example, pressure to stick to research timelines and meet recruitment targets were negatively affecting the CO partner's relationship with the community to whom it provides services. Rather than seeing the CO as an organisation that assists them and puts their needs first, community members were starting to feel that the CO has its own agenda that may not align with their interests. This can undermine community members' trust in the CO and its staff. The example further reflects a tension between the research goals of university researchers (i.e. timely recruitment of participants to achieve robust study design and finish in the grant period) and the service goals of CO partners (i.e. build long-term, trusting relationships with their communities; attend to community members' hierarchy of needs).

Putting pressure on CO partners to achieve recruitment targets can result in research participants' hierarchies of need being ignored. According to a CO staff member, university researchers

> *"want the numbers and we'd organise these community sessions and you know these are vulnerable newly arrived families that things, you know hierarchy of needs and life stuff comes up and you know trying to kind of push them or get them to come when you know what's going on for them*." (CO staff member)

Convincing individuals to participate in research activities when you know it may be at the expense of ensuring their own or their families' basic needs are met is disrespectful to participants because individuals are treated as a means to an end (i.e. successfully performing a research project). It may also be unfairly burdensome to ask such individuals to participate in research projects. The opportunity costs they experience by participating may be too high to balance the benefits of participating for them or society.[4,5]

Pressuring COs to achieve recruitment targets comprises a harm because it creates psychological distress for CO staff who experience a dual role conflict:

> *"I remember our workers that were responsible for sort of doing that engagement were really stressed because – or the message that they were just getting is we need the numbers, we need the numbers but you know their role is to support the people and if coming to that session that weekend isn't the best thing for that person or that group then you kind of you know could be conflicted sometimes*." (CO staff member)

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[4] Here, it is assumed that research participation is not a way for individuals to meet their basic needs, e.g. to access health care, because they can meet such needs through other avenues designed for that purpose, e.g. a well-functioning health system. The interviewee is discussing a high-income country setting.

[5] It is important to respect people's hierarchy of needs. It is also important to do research with populations that are considered disadvantaged and marginalised in order to ensure their priorities and concerns are reflected in the research questions asked and the interventions that get designed. Ideally, this research is with participants for whom the opportunity costs of participation are not too high. Tension arises between these two imperatives when there are not a sufficient number of prospective participants for whom the opportunity costs of participation are low.

As highlighted by the interviewee, CO staff members' role as researchers comes into tension with their role as service providers who put the needs of community members first. This can generate feelings of anxiety, uncertainty, and letting others down (either research team members or community members), which can negatively affect their mental health.

Weakening CO's relationship with their communities is disrespectful to COs because it means that the impact of research decisions on COs are not adequately taken into account. According to a CO staff member, although they had a "great working relationship" with university researchers, "it was all very much around how things were tracking [for them], you know, it wasn't very much about how's this working for our organisation." Again, researchers effectively put their interests ahead of CO and community interests. In the example above, research project goals relating to recruitment are taken forward at the expense of CO *service* goals, and CO staff didn't feel comfortable pushing back and asserting themselves. This speaks to a broader unequal power relationship with university researchers, where how project-related decisions affect the CO is not adequately voiced or considered during the collaboration. Where this lack of consideration negatively affects a CO's relationship with its community, its capacity to achieve its service-related mission may be stymied. If community members' diminished trust in the CO leads them to seek care and services less frequently, there will be a detrimental effect on community health and well-being.

A WAY FORWARD

The concerns identified by CO staff members arise due to differences in power and missions between university researchers and COs. Current hierarchies of knowledge within the research sector place much higher value on the knowledge and expertise of researchers relative to that of communities and COs.[18] In addition, COs and their staff generally have different missions—related to service delivery and advocacy—and cultures compared to researchers, universities, and research institutions. They have different work and communication styles and timelines.[19,20] Differences in power and resources are a feature of partnerships between high-income country institutions and LMIC institutions and similar concerns arise where LMIC partners are restricted to an implementer role.[8] Concerns arising due to varied organisational missions, however, may be more common to partnerships between researchers and COs, industry, NGOs, and/or government.

Drawing attention to CO concerns and their sources and exploring why they are morally troubling, however, is only half the job. The next step is to think about what ethical criteria or considerations can address the concerns. To help prevent or mitigate the occurrence of the concerns, three ethical criteria for CO-researcher partnerships are proposed: *fair division of labour*, *balancing CO service goals with research goals*, and *balancing CO advocacy goals with research goals*. After introducing and defining each criterion, initial suggestions for how to incorporate them into research practice are offered. The criteria's content is informed by both the concerns voiced by CO staff and the analysis performed to explain why they are morally troubling.

A fair division of labour means jointly determining the roles different partners will take in a research project, while ensuring that their assignment doesn't reinforce unfair hierarchies between task definers and task implementers. It also means ensuring that all partners are included in making basic decisions about the research project such as what its agenda is (research topic and questions), how its budget is allocated, how the project is designed, how data is interpreted, how project outputs will be disseminated, etc. Partners will need to decide how communication structures (e.g. monthly meetings) can be set up to achieve shared decision-making. When doing so, it may be helpful to look to literature on deliberative democratic approaches that are adapted to attend to the way power enters deliberative spaces.[21-25]

The function of the two latter criteria is to help COs and researchers acknowledge their different interests and come to agreement on how to balance them. Balancing advocacy goals with research goals entails discussing partners' goals for the research and how both researchers' goals and COs' political aims can be furthered by what research topics and questions are selected. It also means discussing how to design projects to avoid generating data that reinforces negative stereotypes and how to avoid presenting research findings in ways that reinforce them. This is intended to promote the conduct of research projects that give greater weight to CO advocacy goals, recognising that they often receive little consideration in CO-researcher partnerships. The consideration is not calling for researchers to adopt the advocacy goals of the CO, or vice versa. Balancing service goals with research goals entails discussing how a research project's design and implementation will affect CO-community relationships. It could further mean considering whether the social value of research projects justifies any identified harms to CO-community relationships. In cases where the social value justifies the harms, the criterion nonetheless requires modifying studies' design to minimise identified harms to those relationships and/or participants' hierarchies of needs. Again, this consideration is intended to promote the conduct of research projects that give a more balanced weighting to research and service goals relative to one another. The consideration is not calling for researchers to adopt the service goals of the CO, or vice versa.

All three criteria seek to shift the balance of power between COs and researchers to a more even footing. In each of the concerns described, unequal power was a fundamental underpinning issue. The criteria are thus intended to help promote the development of more equal relationships.

Existing guidance on equitable and fair research partnerships identifies various principles to steer such partnerships, particularly those between high-income country researchers and low and middle-income country researchers.[8,10,26,27] Collaborative partnership is itself also identified as a principle of ethical research.[28,29] At present, much of the existing guidance on fair research partnerships does not give clear instruction about how principles to steer them can be achieved in practice, how those principles should be balanced against each other, or how principles for fair research partnerships should be balanced against other principles for ethical research.[27] The proposed criteria could be seen as a way to help operationalise certain principles for fair research partnerships in the CO-researcher partnership context. For instance, two principles in the Swiss Commission for Research Partnerships with Developing Countries' *A Guide for Transboundary Research Partnerships* are: "set agenda together" and "clarify responsibilities".[26] The former could entail balancing research goals with service and advocacy goals and the latter could entail fairly dividing roles and responsibilities. Similarly, Kingori and Parker identify “respect for the needs, interests and agendas of all partners” and “active involvement in cutting-edge, interesting science” as criteria for “good” global health research collaborations.[8] These criteria could be applied to CO-researcher partnerships and explicitly defined to include the proposed criteria. Additionally, the fair division of labour criterion could help operationalise the ethical principle of collaborative partnership and the latter two proposed criteria could help operationalise the ethical principle of favourable risk-benefit ratios[6] in the context of CO-researcher collaborations. Thus, the proposed ethical criteria could be seen to operationalise principles for fair research partnerships and/or for ethical research (i.e. collaborative partnership and favourable risk-benefit ratios).

Having an open discussion at the start of collaborations about the proposed ethical criteria (amongst other things) and how they can be met during projects can potentially help mitigate or prevent the occurrence of the concerns described in this paper. Open discussion would ideally exemplify norms associated with fair deliberative processes such as transparency, equal voice, deliberation amongst participants, and inclusion.[23, 30, 31] Its facilitation would seek to mitigate power disparities between participants. Existing tools can be drawn upon to guide these discussions. The Canadian Coalition for Global Health Research’s Partnership Assessment Tool is a practical tool to help research partners openly discuss the ethics of their partnership and put in place structures that create ethical accountability.[27] The proposed criteria could be discussed in each of the Partnership Assessment Tool’s phases: inception, implementation, dissemination, and good endings and new beginnings. Another toolkit that could be adapted to incorporate the criteria and used at the start of CO-researcher partnerships is: Are We Ready? A Toolkit for Academic-Community Partnerships in preparation for Community-Based Participatory Research.[32]

Once agreements have been reached about how to fairly divide roles and responsibilities and to balance interests, developing memorandums of understandings (MOUs) for partnerships that speak to these decisions can then formalise the outcomes of those discussions. The Partnership Assessment Tool guides research partners through the development of MOUs.[34] The Council on Health Research for Development’s (COHRED) *Guidance for fairer contract negotiation in collaborative research partnerships* is also instructive here.[33] In that guidance document, MOU clauses are identified that address particular ethical issues— intellectual property, capacity building, ownership of data and samples, compensation for indirect costs and research contracts— experienced by LMIC research institutions partnering with high-income country research institutions. Although the key ethical concerns do not encompass those discussed in this paper, the concept of developing MOU clauses to address specific ethical concerns can still usefully be applied as part of CO-researcher collaborations. MOU clauses can be created that speak to fairly dividing research roles and balancing research goals with CO service delivery and advocacy goals.

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[6] In Emanuel et al.’s framework for ethical research, this principle is defined as assessing “the risk-benefit ratio by comparing the net risks of the research project with the potential benefits derived from collaborative partnership, social value, and respect for study populations.”[36, p. 931] Net risks could also derive from collaborative partnerships as well and be understood to include harms to CO advocacy goals and weakening their relationships with their communities.

Thus, one approach COs and researchers could take is to start with an open discussion that encompasses the proposed ethical criteria and is guided by the use of a toolkit. Then MOUs can be developed (also with the assistance of toolkits) that formalise the outcomes of those discussions. For this sort of strategy to be effective, however, certain foundations need to be in place. For instance, COs need to feel confident and empowered to initiate discussions and/or raise the topics covered by the three ethical criteria with researchers. They also need to be confident and comfortable asking for and developing MOUs. Where COs do not have significant experience collaborating on research projects, they may not have the skill set and knowledge to raise such topics or write MOUs that speak to those topics. In such instances, where the requisite foundations aren't in place, researchers have a clear ethical responsibility not to take advantage of CO's vulnerability and inexperience to structure collaborations that primarily serve their needs. They should raise the aforementioned topics at the start of collaborations and work with COs to develop fair MOUs. Researchers also have an ethical responsibility to help empower CO partners and build their capacity in relevant areas (ethics knowledge, MOUs) so that they are less vulnerable in subsequent partnerships.

CONCLUSION

The ethical issues and concerns experienced as part of CO-researcher collaborations have largely not been investigated, *particularly from the perspective of COs*. This paper draws on data from a recent qualitative study to illustrate three matters of concern that CO staff encountered during public health research collaborations that are morally troubling: being restricted to a recruitment role in studies, reinforcement of stereotypes of marginalised groups, and weakening CO-community relationships. By doing so, it reported CO perspectives on a topic that they are not always included in discussing but that is essential to get their views on. Robust ethical guidance for equitable CO-researcher collaborations cannot be developed without information on the issues and challenges *both* COs and researchers face in such partnerships.

In light of the concerns raised by CO staff, three ethical criteria were proposed to help guide CO-researcher collaborations: *fair division of labour*, *balancing CO service goals with research goals*, and *balancing CO advocacy goals with research goals*. It is recommended that researchers and COs have an open discussion about each of the criteria as part of entering partnerships. Once agreements have been reached about how to fairly divide roles and responsibilities and to balance interests, MOUs can then be created to formalise them. Existing toolkits can support both these discussions and the development of MOUs.

The documentation of concerns experienced by COs in partnerships with university researchers and the proposed ethical criteria are, of course, initial work in an underexplored area. Future work could usefully identify additional ethical issues and concerns experienced by COs during research collaborations; COs undoubtedly experience many concerns that this paper does not capture. A key limitation of the qualitative study was that the sample was limited in numbers and to COs in a high-income country. It also did not involve specifically asking interviewees to describe the ethical concerns they faced, as this was not the broader qualitative study's main focus. In future studies, it will be important to consider whether and to what extent the ethical issues and concerns COs identify are unique or nuanced relative those encountered in HIC-LMIC research collaborations, whether existing principles for fair research collaborations are sufficient to address them and, if so, how they can be operationalised to do so. Existing principles for fair research partnerships have been developed for collaborations where power disparities exist between partners but have not been designed with CO-researcher collaborations specifically in mind. Future research can also further define what is necessary to discuss as part of the ethical criteria proposed in this paper. There are likely more ways the division of labour between university researchers and CO partners can be unfair and other ways CO service and advocacy goals can be in tension with research goals. As a result, additional guidance is likely required about what the criteria entail beyond what is discussed in this paper. Future work might develop example clauses for MOUs linked to the identified ethical concerns as well.

Ultimately, there are many avenues to explore in relation to the ethics of CO-researcher partnerships. This paper will hopefully stimulate greater discussion and collaboration amongst bioethicists, researchers, and COs on these matters.

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