Making research ethics work for global health

towards a more agile and collaborative approach

Chattopadhyay, S.; De Kok, B.

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Sreeparna Chattopadhyay,[1] Bregje de Kok[2]

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[1]Social Sciences, FLAME University, Pune, Maharashtra, India
[2]Department of Anthropology, University of Amsterdam, Amsterdam, The Netherlands

Correspondence to
Dr Sreeparna Chattopadhyay; sreeparna.c@flame.edu.in

ABSTRACT

In this reflective essay, we seek to engage in a constructive dialogue with scholars across medicine, public health and anthropology on research ethics practices. Drawing on anthropological research and ethical dilemmas that our colleagues and we encountered as medical anthropologists, we reflect on presumed and institutionalised 'best' practices such as mandatory written informed consent, and problematise how they are implemented in interdisciplinary global health research projects. We demonstrate that mandatory, individualised, written, informed consent may be unsuitable in many contexts and also identify reasons why tensions between professionals in interdisciplinary teams may arise when decisions about ethics procedures are taken. We propose alternatives to written informed consent that acknowledge research governance requirements and contextual realities and leave more room for ethnographic approaches. Beyond informed consent, we also explore the situatedness of ethical practices when working in contexts where decision-making around health is clearly a shared concern. We use vignettes based on our own and colleagues' experiences to illustrate our arguments, using the collective 'we' instead of 'I' in our vignettes to protect our research participants, partners and interlocutors. We propose a decolonial, plural and vernacular approach to informed consent specifically, and research ethics more broadly. We contend that ethics procedures and frameworks need to become more agile, decolonial, pluralised and vernacularised to enable achieving congruence between communities' ideas of social justice and institutional ethics. We argue that global health research can benefit from anthropology's engagement with situated ethics and consent that is relational, negotiated and processual; and accountability that is not only bureaucratic but also constructive. In doing so, we hope to broaden ethical praxis so that the best outcomes that are also just, fair and equitable can be achieved for all stakeholders.

SUMMARY BOX

⇒ Using ethnographic vignettes, we demonstrate that in certain situations, mandatory written informed consent may be unsuitable and may result in excessive gate-keeping in the context of global health.
⇒ We identify why decisions about ethics procedures may result in tensions between professionals in interdisciplinary teams and suggest how we might resolve these.
⇒ We propose alternatives to formalized ethics procedures that acknowledge research governance requirements and contextual realities that leave more room for ethnographic approaches.
⇒ Research ethics procedures in public health and biomedicine may not be attuned to cultural differences since these processes generally derive from Global North contexts.
⇒ In this paper, two medical anthropologists reflect on how ethical review processes, especially concerning informed consent, can become more agile, decolonial, pluralised, and vernacularised.

> 'Like Greek tragedy, the search for ethical purity is a search doomed to failure'[1]

In this reflective essay, we seek to engage in a constructive dialogue with scholars across medicine, public health and anthropology on research ethics practices. Drawing on anthropological research and ethical dilemmas that we and our colleagues encountered as medical anthropologists, we reflect on presumed and institutionalised 'best' practices, and problematise how they are implemented in interdisciplinary global health research projects.

We focus here on consent procedures, since these are meant to safeguard key ethical principles like autonomy and non-maleficence, and moreover, interdisciplinary tensions often arise regarding this aspect of research ethics. Of course, research ethics involves more than consent, and we explore more broadly how research ethics can enable research that contributes to improved global health.

Ethical principles and procedures, derived from historical malpractices and declarations like the Nuremberg Code of 1947 or the Helsinki Declaration of 1964, have evolved to provide crucial protection to human subjects. Yet, our experiences from India, Malawi, Nigeria, Ghana and the UK suggest that the nature of ethnographic research requires development of more agile and

contextualised ethics frameworks. (We include the UK to challenge reductionistic framings of global health as health in the Global South, and to recognise that health is global in that it is structured by global politics and global flows of diseases, people, goods, services, knowledge and more. We use the terms Global North and Global South and high-income countries (HICs) vs low-income and middle-income countries (LMICs) as placeholders to symbolise the power asymmetries that exists across these regions, while recognising that these terms create problematic and overly simplified dichotomies. We are cognizant of the existence of the north within the south and the south within the north but retain this nomenclature—used interchangeably with LMICs—until suitable alternatives emerge

Keeping this spirit, we aim to do the following: (1) Demonstrate that in certain situations, mandatory, written, informed consent may be unsuitable and result in excessive gate-keeping; (2) Identify why decisions about ethics procedures may result in tensions between professionals in interdisciplinary teams; (3) Propose alternatives to formalised ethics procedures that acknowledge research governance requirements and contextual realities and leave more room for ethnographic approaches. We draw on our own and colleagues' experiences to illustrate our arguments, using the collective 'we' in our vignettes instead of 'I' to protect our research participants, colleagues and interlocutors. We propose a decolonial, plural and vernacular approach to informed consent specifically, and research ethics more broadly. We argue that global health research can benefit from anthropology's engagement with forms of ethics that are situated and reflexive and consent that is relational, negotiated and processual. These, in turn, can facilitate accountability that is not only bureaucratic but also constructive.

BEYOND THE GOLD STANDARD: REVISITING MANDATORY INFORMED CONSENT

In our experience, IRBs (Instutional Review Boards) commonly demand individually signed, written informed consent along with various other measures enabling future auditing. It appears that written consent has become normative, standardised and aspirational in global health research.[2] However, standardised ethics protocols may be unsuitable in some contexts due to the historical and cultural specificity of the practices they stipulate, and their limitations. These become particularly pronounced when applied to LMICs where biomedicine, public health and anthropology are steeped in colonial history.[3] When conducting research in former colonies, we need to be particularly wary of imposing (white) foreign or Northern standards. Yet, IRB procedures across the globe tend to be heavily shaped by a Euro-American 'mould',[4] and typically draw from European or American frameworks like the Belmont Report.

While standardisation of ethics procedures has resulted from deliberative processes, standardisation also appears to reduce scope for reflection and debate on situated ethics: what ethics procedures appear just in this setting, for these participants?[2] In interdisciplinary team meetings, we have raised concerns about obtaining written consent from all professionals and all clients for conducting observations in hospital wards. Although IRB protocols may stipulate written consent, we argued that by obtaining oral consent clients with complicated conditions admitted on the ward would not be unduly burdened with reading and signing lengthy forms. Moreover, in anthropology, it is generally accepted that obtaining individual written consent is virtually impossible when conducting observations in a semipublic setting.[5] When we expressed these concerns, public health colleagues have asked us 'What is wrong with written consent?' If they participated themselves in research, they would want to be given a form to sign. They surmised that 'There is no issue here'. We responded that our divergent views on whether written consent is an 'issue' or not, in fact reflected a disciplinary difference, and that while we recognise that we should follow IRB guidelines, we also worry about client burden. The team meeting swiftly moved on to another topic, leaving the ethics procedures unchanged.

In interdisciplinary studies different, potentially conflicting notions of 'ethical' praxis converge, associated with different ideas about justice, how to avoid harm, and how to do good, and how risks and benefits should be weighed in specific situations. For instance, for ethnographers, insistence on written or even oral consent from each individual one encounters in an observation site would prevent us from doing ethnography. Obtaining explicit consent from all actors on the scene is an ideal we should pursue, if feasible. However, since these research activities could, and often have, generated valuable insights that can help improve quality and equity in care, health systems and well-being, we need to question whether the risk of not obtaining explicit consent from some participants weighs up against the loss of the benefits that could be gained. For instance, observational studies that document obstetric violence become nearly impossible especially in LMIC contexts if seeking full informed consent from each and every individual is mandatory. Obstetric violence often occurs in highly overstretched, resource-poor facilities[6] where it may be impossible to get written or even oral consent from all participants (eg, when clients enter the ward in an advanced stage of labour).

Divergent views on ethics likely lead to discomforts and tensions in research teams. Evaluating one research tradition by the standards of another is problematic, but bureaucratic procedures and interdisciplinary collaboration may push us to do so. The resulting stalemate can be overcome through meaningful dialogue on different disciplinary views on just and ethical research procedures, but disciplinary training, hierarchy and a lack of time may foreclose productive discussions.

Social groups tend to view their own internal ethical standards as universal and right; therefore, when other groups' standards differ, these are likely viewed as abnormal or wrong.[7] This is true for anthropology, biomedicine and public health alike. While anthropologists can be overly critical of public health research, they are trained in different approaches to ethics based on disciplinary and cultural locations, partly because ethnographic health studies require review by biomedically oriented IRBs. Medical and public health scholars on the other hand, rarely receive anthropological training, which is a crucial enabler for appreciation of alternative ethical logics associated with different ontologies and epistemologies.

Of course, ethics procedures have been discussed and adapted over time in global public health. For instance, community engagement is increasingly expected,[8 9] constituting a welcome corrective to the near obsession of US bioethics with individual autonomy.[10] However, 'on the ground', in the midst of a research project, busy research teams struggle to find space and time for in-depth, appreciative interdisciplinary discussions on ethics procedures, a struggle aggravated by lengthy bureaucratic ethics procedures (eg, requiring multiple visits to busy ethics bureaus to get appropriately dated, signed and stamped copies of updated information sheets and consent forms). Apart from 'there is no issue here', our questioning of formal (medical) ethics procedures has been met with retorts like '…that's just standard medical ethics, is there discussion about that in anthropology?' This well-intended question seems to implicitly query whether anthropologists are trying to 'catch up' and incorporate presumed good practices or 'standardised operating procedures' (SOPs). Such responses preclude dialogue about what might be problematic about, for instance, obtaining signatures from ill clients or labouring women, especially in contexts where signatures carry a history of extractive colonial practices,[4] and where decision-making around healthcare is not individualised, but relational, as we detail below.

We recognise that procedures such as written consent can fulfil important functions in relation to research ethics, governance and accountability. Written consent forms have both a material and symbolic dimension[11]: they are material evidence that risks, benefits and other important information about the study have been shared. They offer a paper trail should there ever be complaints about the project. At a symbolic level, they can be important signals of trustworthiness for public health projects that typically have less intense and shorter engagement with participants than ethnographic research. Furthermore, research participants may feel that the request to sign empowers them.[12] However, certain features of ethnography, the social nature of health and care seeking, and questions of accountability, problematise written consent and other presumed gold standards in global health research ethics (eg, lengthy patient information sheets).

First, the open and evolving nature of ethnography limits the extent to which subjects can be fully informed.[13 14] The precise research questions, observation foci and potential risks cannot be predefined or communicated in advance. This conflicts with a solidified form of written consent paired with lengthy patient information sheets detailing the potential risks and benefits. Such formalised procedures impose constraints (eg, serendipitous findings cannot be explored) that reduce the added value of ethnography in global health research. For instance, ethnographic research on how Coca-Cola shaped anti-obesity policies and programmes in China demonstrated the value of serendipity, full-body immersion, in-depth cultural knowledge imbibed over years of fieldwork and methodological openness.[15] Through these features, ethnography can uncover aspects that quantitative and qualitative public health methodologies likely overlook (Greenhalgh,[15] p143).

Second, ethics procedures interfere with researcher–participant relationships, that differ across disciplines. In traditional medical research, research participants are viewed as 'subjects' and may be exposed to procedures that extract data/specimen (eg, blood) from them. Ideally, anthropologists build ongoing partnerships and co-create data with 'interlocutors', not 'subjects.' Traditionally, anthropologists spend years in a single field site, even if these are periodic visits spread over decades. This requires consent to be an ongoing, negotiated and relational process rather than an act that occurs at a single point in time.[16 17] This notion of relational and processual consent remains important, even though multisited ethnographies, multidisciplinary projects and large grants underpinned by global philanthropies requiring anthropology's 'slow research'[18] to speed up and narrow its scope. These changes and new European data-protection laws (GDPR General Data Protection Regulation) have inserted very different research ethics sensibilities, demanding even more reflection on emerging ethical and epistemological concerns, including which risks and justice principles are foregrounded (eg, individual autonomy, privacy) and which are sidelined (eg, social justice) (The regulation of ethics implies regulation of knowledge-making[15]).

While the importance of dynamic and processual consent is also recognised in biomedicine and public health, the relational aspect is more central to ethnography. Formal, written procedures may obstruct development of meaningful, personal relationships and rapport, crucial for ethnography. Signing may introduce external, possibly distrusted, institutions into the researcher–interlocutor relationships and formalises these relationships in ways that may reduce authenticity of interactions.[11] Superficially read and hastily signed lengthy consent forms risks making informed consent into tokenistic procedures, a practice that we have frequently encountered in our over two decades plus of fieldwork.[19] This is contrary to the vision of informed consent espoused in 1982, by the President's Commission,[20] as inherently

dialogic, involving all stakeholders' active participation. The insistence on signatures, which has been described as a problematic Euro-American 'fetish',[11] transforms the consent process into a contractual agreement with participants possibly feeling less able to withdraw.[11] What signing means will differ per participant and situation, and is an empirical question hitherto insufficiently explored. While signatures can imbue agency,[12] it can also create discomforts.[5 21] During fieldwork, we encountered participants' confusion and misgivings due to a perceived contradiction between promised anonymity, and signing a document with one's personal signature and name. Discomfort may also result from the association between signatures (or thumb impressions if participants are unlettered) and extractive colonial and government practices, and experiences of signing as signing away, rather than attaining, rights (eg, to land).[5 21]

A third problem with individually signed, written informed consent is that it rests on an atomised notion of consent, problematic especially in resource-constrained contexts with a weak public healthcare system, where health and access to care is heavily contingent on social relationships. In maternal health for instance, not just the family, but an entire community may be mobilised to ensure access to emergency care.[22 23] Furthermore, while in HICs practitioners and scholars often refer to clients or users, in LMICs, the word patient is often employed, reiterating the limited autonomy accorded to the person in need of care. While we may disagree with this stance, in these situations, the atomised concept of written informed consent makes little sense in medical practice or facility-based health research since so many stakeholders are involved in making decisions about an individual's health. The question then arises whether, in contexts where health and health related decision-making are clearly a shared, social concern, should (white) Euro-American notions of consent prevail that deem written informed consent from the individual 'client' an essential feature of ethical research? We recognise that IRBs may allow for exceptions to obtaining written informed consent (eg, some allow for oral consent when participants cannot read or write) (We do not consider the requirement to use thumb prints an alternative to written consent; even use of witnesses that are required to sign on behalf of the illiterate participant pursue a similarly problematic form of bureaucratised, formalised and atomised consent), but written consent is still considered the ideal, and in our experience, sometimes the only permissible procedure. While we do not oppose a human-rights based framework that centres individual autonomy and rights, Northern ethics frameworks and associated epistemologies that are divorced from the practicalities and alternative worldviews of how healthcare decisions are made, impose individualised notions of consent. In doing so, they elide the relational and interdependent aspects of our existence and what allows us to survive and thrive (We do not consider the requirement to use thumb prints an alternative to written consent; even use of witnesses that are required to sign on behalf of the illiterate participant pursue a similarly problematic form of bureaucratised, formalised and atomised consent).

Fourth, written consent forms are bound up with accountability, arguably primarily towards institutions and funders and then towards participants. The rise of audit culture in academia and its associated distrust[24 25] imply that accountability concerns loom large in decisions about ethics procedures in the Global North especially, and increasingly in the Global South. IRBs appear focused predominantly on their own accountability towards their funders and their government, and pass this accountability burden on to researchers, making them responsible and answerable via time-consuming institutional processes that fetishise individually signed written consent forms. Lack of trust that researchers do the right thing leads to the tightening of procedures and focus on visual proof. What then remains of accountability towards participants and communities?

Public health colleagues have shared that signing two copies of consent forms is intended to protect participants, especially when working with research assistants with limited ethics training. The term 'protect' signals accountability towards the research participants, but also a lack of trust in research assistants and research subjects: double signing, we were told, also protects researchers, and thus their institutions, from unwarranted complaints from participants. Distrust and a desire to protect should be taken seriously given the dark history of colonial and racist research practices in biomedicine, public health and anthropology.[26 27] Signatures can be falsified and cannot guarantee protection from harm. How is it that we now trust written consent more than oral consent? Given the aforementioned problems with written consent, and its potential to disrupt ethnographic processes with implications for research quality, improved training of researchers, fostering good relationships with research participants, and demonstrating social impact may be more effective in nurturing accountability towards communities, than formalising procedures. We recognise, however, that these recommendations can be time and resource intensive.

Anthropologists, public health scholars and medical scientists are all motivated to protect 'human subjects'. However, the overemphasis on formal, bureaucratised processes prioritises limiting liability of institutions and funding bodies. Instead, accountability to participants and communities should trump accountability to processes and institutions. Such accountability goes beyond protecting individuals from harm to them as autonomous subjects. In health systems research, Freedman has called for constructive accountability, articulated as a people-centred process rooted in social justice principles, that fosters a particular 'dynamic of entitlement and obligation between people' and builds 'health systems that function for the benefit of people' Freedman,[28] Similarly, we need constructive accountability in global health research. This is a form of situated

and contextualised accountability, involving people and community-centred procedures that lead to fair and just global health research that benefits communities. The vignette below illustrates our point.

> We observed a woman, P, in her third trimester of her pregnancy come to a labour ward in a district hospital. We were conducting observations in hospitals with a focus on improving maternal health in an area with high maternal mortality. As we put down our bags on the empty beds in the ward, the labour ward was suddenly emptied of relatives, a curtain was drawn around P, and within minutes we saw that her amniotic sac was cut and P was wheeled away soon after. A few hours later when we returned to the recuperation room, we managed to speak to P. She had requested a medical termination of pregnancy because she could not afford to raise another child. She was poor, belonged to a disadvantaged community, and had not realized she was pregnant because her menstruation had not commenced since the birth of her first child who she was still breastfeeding. P lived very far from the hospital in an area with difficult terrain, and by the time she was able to attend the hospital, she was already in her third trimester. The doctor had warned her of the dangers of late termination, but she had insisted on having it.

In this study, we obtained written consent from the facility and oral consent from the participants. What we had observed was illegal, but we were unsure whether this was unethical or immoral. We had seen the doctor counselling P before surgery and knew they were a good doctor who did their best in very trying circumstances. We did not want to report the late termination to government authorities because it would be seen as medical malpractice. While some IRBs may demand that illegal activities are reported, in this instance, reporting would result in the physician losing his licence, harming the reproductive rights of women who were already underserved due to a lack of institutions, and provider shortages in this area.

This vignette highlights two issues—first, the impossibility to pre-empt the ethical conundrums we may end up with and second that it may be appropriate for our accountability and ethical moorings to be anchored in multiple sources, not just formal research governance frameworks. In this situation, the idea of constructive accountability and reflexive ethics may be useful in guiding our responses because we ought to work towards wider social justice goals, not just individual well-being. These are not only more ethical, but also makes for better science.

Reflexivity is one the primary yardsticks by which rigour is assessed in qualitative research.[29] Ethical reflexivity, common in the social sciences, 'asks the researcher to consider possible implications for the participants of the study and the larger social and political context in which the research is embedded'.[30] Reflexive ethics thus asks us to consider how our acts as researchers may affect communities and their health systems. However, this requires deep contextual knowledge obtained through prolonged ethnographic observations, unstructured conversations as well as more formal interviews. In the vignette above, without such knowledge (and anthropological training) we may have overlooked contextual nuances and may have acted differently.

We contend that the incorporation of ethnographic methods and ethical reflexivity in global health research can contribute to constructive accountability and making global health research fair, equitable and just. It has the potential to visibilise certain ethical issues, amplify concerns of vulnerable groups, and contextualise and situate ethical praxis, the need for which is discussed in more detail below. However, while reflexive ethics requires the 'deep hanging out' typical for ethnography, this does not always permit formalised consent procedures. In the vignette described and in several other cases, the participants who agreed to (informal) oral consent would likely have refused (formal) written consent, which would have meant valuable insights into everyday care practices would have been lost.

VERNACULARISE, PLURALISE AND DECOLONISE RESEARCH ETHICS

Given the tensions between written informed consent procedures and ethnographic sensibilities, when ethics boards demand mandatory, written signatures from interlocutors, they betray a biomedicine-centric approach, which is also overly universalist and Euro-American centric (Even the applicability of clinical ethics procedures to closely related fields like health systems research has been questioned. Hyder *et al*[31] (2014) eg, argue that in public health and health systems research, asking individual informed consent may become impracticable and unnecessary). Bioethicists themselves have noted 'the near obsession with autonomy in US bioethics'. Various authors have noted how IRB requirements may suppress indigenous and non-European epistemologies and concerns.[10 27 32 33]

We recommend that ethics procedures are vernacularised, by which we mean that we adapt them to contexts, participants and situations. For example, researchers may be barred from conducting research with people with dementia because they are viewed as incapable of consenting. Yet, engagement with dementia-affected adults suggests that they may find research participation worthwhile, and moreover, excluding an entire group from research stymies knowledge production and may thus be unethical in itself (Personal communication with Dr Annelieke Driessen, October, 2021). We may wish to invite 'surrogates' to consent when individuals lack capacity, but should also recognise that people with dementia may not always have the capacity to consent, but sometimes they will. This temporal view of consent, which is not static but rather seizes the moment that can best serve the needs of such a vulnerable population, is an example of situating and vernacularising consent

procedures enabling certain notions of justice and constructive accountability.

Ethics procedures could be pluralised by permitting (audio)recording of oral consent while recognising that obtaining oral consent may be equally or even more ethical than written consent if this presents an undue burden as with ill clients or labouring women, or risks doing more harm than good. For example, in her work with domestic violence survivors in an urban informal settlement in India, Chattopadhyay found that it was safer to get oral informed consent since a written document could reveal that a survivor had spoken to an outsider.[34] We do not eschew written consent and, as mentioned, recognise its material and symbolic function vis-a-vis accountability and trust. However, we recommend giving participants the option of oral or written consent, especially if insistence on formal written consents precludes an opportunity to do good in global health research by excluding (presumed) vulnerable population. Their testimonies are crucial to designing interventions for disadvantaged populations who stand to gain from such research—to exclude them to 'protect' them is contrary to the principles of social justice and constructive accountability. Moreover, participation can be beneficial for the participants themselves. While the IRB had warned Chattopadhyay about the possibilities of retraumatising the victims if made to recall instances of domestic violence, many women found the narration cathartic and helpful especially given the lack of available mental health support in this context.[34]

Other studies also find that research participants' views of research ethics may differ from IRBs, and underscore that ideas about ethical and just research are plural. In an American HIV study,[35] the IRB insisted that Haitian research participants received gifts rather than money. They were concerned about coercion and how participants might spend the money. The IRB considered this view protective and ethical. By contrast, the community perceived this to be paternalistic, condescending, racist and unjust-a perspective that appeared shaped by the history of Haitians' involvement in HIV research as well as by the specifics of this project. The authors argue that ethical research requires congruence between (IRB) procedures and the participating community's expectations. IRBs and research communities could be considered different 'cultures', and researchers may need to translate IRB concerns to communities and vice versa, to achieve a mutually satisfactory compromise. Core values of autonomy, beneficence and justice should be pursued in a manner that is culturally relevant for community members. To avoid 'empty' or 'condescending' ethics, adaptations to ethics procedures may be required especially when studies involve migrant or minority communities, or communities in the Global South away from Northern centres of power and dominance.[35] Achieving harmony between researchers' and communities' ethics is part of being accountable towards communities, and part of the decolonisation imperative.[5 32 36]As Tauri[32] p147 notes 'ethical research must begin by replacing Eurocentric prejudice with new premises that value diversity over universality'. IRBs' overemphasis on individual autonomy, reflected in the insistence on signatures, has been described as a problematic Euro-American 'fetish'.[11] IRBs should not elevate the status of individual rights and autonomy at the cost of more collective or social principles, values and risks,[26 33 37]such as a social or a communitarian ethic where a sense of duty to others is at least as important as individual rights (In many settings, concepts of personhood and therefore ideas of consent may be drawn from local idioms and notions where personhood is relational, eg, Umoja or unity in kiSwahili speaking countries in Africa continent has been used as an organising principle for community-based health programmes[33]and gender-justice programmes[38] in the HICs and LMICs).[38 39]

Decolonising research ethics and achieving congruence requires work: it demands working with, and empowering research communities,[5] and jointly exploring situated ethics, emergent ethical concerns and suitable options for addressing these concerns. In this light, the increased calls for community involvement in global health research, including exchange on perceived risks, benefits and priority setting, are exciting.[8 40 41] Community involvement and co-creation is also important for the pursuit of constructive accountability.[28] Overly standardised ethics procedures risk equity because one size does not fit all. Moreover, as mentioned, standards tend to become the unthought-of norm,[2] and may limit research teams' ongoing reflection and emergent ethical concerns.[42] The impossibility to anticipate fieldwork situations and ethical dilemmas arising from them[27 33 43] points to the limits of formal, universal and standardised procedures. What is needed is ongoing ethics reflection, and thus processual, agile and adaptive ethics procedures rather than one-off, standardised 'tick box' ethics.

THE WAY FORWARD

We suggest several practical ways to enable richer, more impactful, and truly interdisciplinary and just global health research. In the long-run, we suggest implementing empirical studies of research ethics practices around informed consent and a systematic review of such studies.

1. During projects, researchers should dedicate time to regular deliberations, reflecting on whether standardised ethics standards are indeed best practice for this specific study and these participants in this situation or context. Informed consent procedures in particular need critical reflection. After all, the mere presence of informed consent does not guarantee an ethical process.[19] As Matandika *et al*[42] p11 note: 'a willingness to consent to be part of a research project can hide a wide range of initial and ongoing concerns among study participants, which highlight the need to

further protect participants' rights and support those who consent through the life of a project.'

2. Researchers should foster participant agency rather than autonomy, by ensuring that ethical consent is based on high-quality, participatory communication which fosters mutual respect and trust, and establishes participants as coagents.[10 12] This could mean focusing discussions on participants' ability to choose, and monitoring researchers' language for formulations that leave space for participants' decision-making and participants' language for reflection of their awareness of choice.[10 19]
3. Ethics procedures and frameworks need to become more agile, decolonial, pluralised and vernacularised to achieve congruence between communities' and IRBs' ideas of social justice and ethics, and enable optimal use of ethnographic methodologies (While we do not problematise what 'communities' might mean in this context, we are aware that it is not a homogeneous concept. In global health research, there is a risk that instead of benefiting the most vulnerable individuals, these projects may end up deepening inequities by benefiting those who are the easiest to reach and may be the least precarious). This necessitates that ethics procedures are oriented to ethnography, which requires meaningful and equitable engagements between medical scientists, public health scholars, and anthropologists or other social scientists.[44]
4. Medical and public health researchers should receive basic training in ethnography and anthropological notions related to ethics. In addition, ethics training needs to incorporate informed consent communication. Education institutions must commit to developing such programmes, they need to be supported by budgets in research projects, and funders and IRBs must demand these.
5. Interdisciplinary dialogues to foster a greater understanding of different standpoints regarding ethics grounded in disciplinary backgrounds, professions and other positionalities (eg, gender, race/ethnicity, nationality). Anthropologists have written much on ethics but mainly on and for anthropological platforms[1 2 14 16]; we need to reach out more to our public health colleagues (as we do here), using accessible language.
6. Anthropologists and community members should be on IRB boards and co-shape research ethics procedures.[33] This would change the status quo that expects anthropologists or other social scientists to adapt to biomedically oriented ethics procedures, even though they normally do not collect biomedical data (eg, tissue) but social data (narratives, observations).

As a positive example, the ethics committee of the Amsterdam Institute for Social Science Research at the University of Amsterdam includes several anthropologists and has adopted a remarkably flexible and reflexive ethics procedure that is rigorous yet adapted to the specifics of projects and settings. The committee does not seek to catch researchers out but works with them to figure out together what might be the best procedures for their participants through a series of reflexive questions (see box 1). Other IRBs can adopt similar procedures.

7. Finally, academic institutions, funders and researchers need to revisit their accountability mechanisms and foci. The risk of institutional and thus professionals' individual liability needs to be taken seriously, especially when working with colleagues in less powerful positions. However, we must ensure that concerns for institutional liability do not crowd out the pursuit of other notions of justice and constructive accountability towards participants and communities that leads to research that fosters people-centred, well-functioning health systems. Details will need to be worked out, and all of this will take time, but at least we have started the conversation.

Box 1 Excerpts from AISSR, (Amsterdam Institute for Social Science Research) University of Amsterdam, ethics procedure

For full list of questions, see
https://aissr.uva.nl/binaries/content/assets/subsites/amsterdam-institute-for-social-science-research/map-1/communicatie/aissr-ethical-review-questions-2021.pdf

Informing participants
How will you inform participants about your research? If you work with different groups of people, please specify per group. And please, once again take note of the sub-questions.

How will you explain your research and its purposes to the people in your field? Will you ask people for their consent (verbal or written) to take part in the research? If so, what exactly will you ask them to consent to? If you use consent forms, please upload them as an attachment to the ethics portal. If paperwork is not convenient in the settings where you will be working, how will you explain that you are a researcher and the way you will be using what you learn?

Influence on participants
What is the potential impact of your research (both the research process as well as the output) for those participating in it and for third parties? Does this include potential negative effects? [See also the sub-questions].

What is at stake for the participants in your research and what are others likely to win or lose? First, do you intend to warn those directly involved against potential negative consequences of their participation in your research? If so, how? If not, why not? Think of situations where your informants wish to remain under the radar (such as when they are undocumented), or when governments or other organisations are at least as interested in them as you are. What kinds of risk reduction measures will you take? Do your research goals merit the risks? Second, what about other people concerned in one way or another, or other creatures involved (such as fish, if you study fisheries, and so on), what are the potential positive or negative effects for them? How do you accommodate to that?

Twitter Sreeparna Chattopadhyay @sreeparna_c_

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