Developing Community-led Ethical Review Processes in India: Issues and Challenges

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Blog post based on talk given at a webinar on 18th November 2020 on 'Rethinking ethics in Participatory Research', hosted by the Centre for Social Justice and Community Action, Durham University, UK

Introduction For Participatory practitioners, mere extraction of information from communities is *unethical* even if done in a participatory way. Participatory research thus has its own ethics. In a participatory action research programme, a researcher cannot blame the research design for not deliberating on information, issue or theme emanating from the participants. Participatory approaches oscillate between being a 'Science' (adhering strictly to design) and being 'Art' (exercising creative discretion based on information and analyses from participants and contexts). In this context, what has happened is that 'Ethics' has become significant; and assumes itself to be 'neutral' for the cause of curbing the potentially unbridled freedom of the artist and conceivably insensitive application of techniques of 'science'. Organisations have created Institutional Ethical review boards (IRB). They are most often projected as independent bodies, and they have become the de facto guardian of 'Ethics'.

Control over Knowledge Now, over the years, it was not difficult to realise that Research, however participatory it is at the time of data collection, when organised under the control of the North, cannot be termed participatory. Three ways through which the North controls the Knowledge is through aid (funding), certification (control over publishing) and Ethics. Interestingly, while aid and certification is headquartered in the North; the Ethical review system is not. However, it may not be untrue that the IRB would define its "ethics" keeping in mind the concerns of the donors and the publishers. Now, when we say, North, it is not a geographical, but a political category. It is a metaphor that represents Brahmin. There is a capitalist, able bodied, heterosexual, masculine, Brahmin in most terrain. Would it be a wrong assumption that this category, although minuscule, controls funds, knowledge and ethics in those terrains?

Community Ethics Review Process: Now, a lot of the struggle for equity in research has always focused on the aid industry, less on the publishing industry and the least on Ethics. Keeping this domination in mind, Praxis embarked into institutionalizing community-led ethical review processes. Primarily recognizing that communities should have a role in defining ethics of the research, Praxis has been organising the same for the last six years, primarily to understand community perspective of ethics and thus inform its own projects. Praxis organized three ethical review processes; one comprising communities considered vulnerable to HIV, that is, sex worker, MSM, transgender persons and IDUs; a second comprising bonded labour; and a third comprising child labourers.

There has been some significant learning for us from these processes as well as a reflection of their functioning. Two significant learning are these: -

(a) Do these community committees give any information newer than institutional review boards? No. In fact, an honest comprehensive research proposal generally lists a lot of ethical risks; and these are based on the cumulative knowledge of various researchers. So, it is not that community boards discover any new issues, but the

discussion in the review meetings were based on examples that were real and lived, so were the understanding of risks for them. When they explore solutions to address those risks, they are more real, but yet are varied and probably instinctive.

(b)   Have community committees contested what the IRB recommends? Yes. Firstly, community committees seem to be more inclined to study difficult aspects related to the community. They are not averse to taking *risks, when compared to* the IRBs, especially when they are related to systemic constraints. For example, owing to stringent legislation that makes it mandatory to report any child sex abuse cases to legal authorities in India, IRBs often worry about sanctioning research reaching out to potential victims for the fear of probable violation of laws. Community committees, however, encourage researchers to organize such studies and reach out to difficult to reach groups; and in fact elude that the restraining is considered as unethical.

Secondly and interestingly, there have been quantitative surveys where respondents are paid monetary compensation. Community committees often ask what the compensation is for: time spent by respondents or for the information; how honorarium rates are fixed, are they at par with researchers; and how the compensation to respondents affects other studies often done by grassroots organisations. Is it not true, that by compensating for respondent time, the researcher gets priceless information for free? Their fear is that often the compensation is to compensate for the guilt that is present in researchers owing to unfair profit that they earn in the form of funds or career growth or fame from the publications. Many are not monetisable.

Lastly, the institution of the consent letter is the biggest scam of the research industry. The consent letter was meant to be an instrument of acknowledgement of having conveyed all risks and potential harm that respondents might face if they become part of the process. However, it has emerged into a consent system, through which researchers absolve themselves of any responsibility if the respondent faces any future harm. The community ethics groups while recognizing and understanding this, have often wanted the research teams to explore whether researchers could provide a consent letter to the respondents about how researchers would use or not use this information? Is it not surprising that the 'consent letter' meant to protect community is pocketed by researchers, and there is no copy with the respondent? How will communities make researchers accountable for breaking the promises in the consent letter, when they do not have a copy of the consent letter? Is it not that IRBs' proceedings are primarily to protect the institution from getting any 'bad name' if the communities are not protected during the research? The real question for any ethical review board is whom they are meant to protect: the community, the research or the organisation? Do these three necessarily align? And when they contest, how do "ethics" get defined? Are there any 'ethics' of defining ethics?

Standing Community Review Committees: With these questions, since March 2020, Praxis embarked into the formation of standing community-led ethical review boards, to review any kind of research proposals, participatory or non-participatory. While pursuing that, the following three additional considerations were made.

First, generally, we have only a daylong training of community board on ethics. This time, we have prepared a 4-month intensive capacity building programme for member.

Second, we also focussed on knowledge on community identity politics. We attempted to provide space for communities to understand the stigmatization associated with identities that they may not belong to, as well. This became relevant because of the way intersecting identities, such as caste and gender, operate.

Third, there was focus on knowledge on how programmes and research function, for it was felt important that members are able to connect, appropriately, the ethics with the practices followed in research and programmes. The community boards are going to be more informed boards on research, the programme, community identities and their politics.

Three community ethical review boards are being established to correspond with certain ongoing programmes of Praxis. The idea was to ensure that the capacity building programme does not remain as a one-off isolated process. We identified three groups, each of 4 members: one, belonging to a denotified and nomadic community that, as a community, is traditionally into sex work; second, transgender community, who have been engaging with HIV projects; third, dalit community, who are part of a project as beneficiaries or agents of change. These categories were chosen primarily to resonate with our programmes and to gain insights into identities such as caste, gender, sexual orientation, sexuality, criminalization and stigmatisation.

Further, Denotified community members have been those who have already done research after being helped with capacity building on research per se by Praxis. These members know each other. The group is expected to become the Community Ethical Review Board of the National Alliance Group for DNT communities; a coalition of CSOs in India.

Integrating Committees with Live Projects: In the case of the MSM and Transgender member participants, they were identified through partner organisations with whom we had worked earlier. The group will initiate a project that would provide "ethical clearance" from the community lens to all research on these communities in Tamil Nadu, including one of the Praxis initiatives.

The Dalit women participants were part of a project organised by a partner organization; and they would become Project Ethics Advisory Board. The selection was made among persons with whom Praxis has engaged: a mix of peer volunteers, researchers and community members residing in the project area. Owing to the pandemic situation, one consideration was added, that is, they need to have access to smartphones. However, we were able to provide honorariums, smartphones and data costs to participants based on their needs with support from a fellowship grant.

We organised an intensive capacity development programme, which was largely discussion based, around a number of case studies. We got Fellowship support from Durham University for these programmes. The four areas that were covered were: one, understanding the role of ethics in everyday practices and how they influence decision making process; two, understanding different processes within research and various kinds of decisions that are made in research; three, understanding and contrasting ethical research and non-ethical research; four, understanding and deliberating around the meaning of a strong ethical review group. These groups are now going to review a live research or project proposal in the next couple of months from an ethical lens, and make recommendations.

Key Preliminary Learning: There was tremendous learning, but it exposed a number of complexities involved in the way any ethical review group could make their recommendations. One complexity that stood out, in the discussion, is explained below.

All three groups independently worked on a case study, which is taken from a different community development context where the programme team faced an ethical

dilemma. We used this case study to engage community in discussion about the complexities of ethical issues involved.The case study is as follows:

There is a village with 90 garment workers, residing in three caste homogenous hamlets. Caste system categorises people into hierarchy and there also results what is called as untouchability. In India untouchability is banned, but not the caste system. Hamlet A is a dominant caste hamlet having 80 families with 27 Garment workers, whereas Hamlets B of middle caste and C of dalit caste have 100 families, 35 garment workers and 95 families and 18 garment workers respectively. A programme opens a tuition centre to build trust with community and also to reach out to garment workers. In which hamlet should the centre be started? With the rationale that Hamlet B has the largest number of garment workers and families, the Community Support group that consisted of the programme team and representatives from three hamlets decided to start the centre there. The centre is functional and the programme is running successfully. But Hamlet C is a dalit hamlet; and the children from the hamlet, when enter other hamlets have to remove their slippers; and the Tuition centre is in B. The dalit children are subjected to the practice of discrimination, although it appears to have been 'normalized' in the village.

Individual members in each of the 3 groups had a number of opinions in the first instance. These opinions could be categorised as the following:
1. Conservative: Project should work within the 'accepted' cultural setting of the communities, so hamlet B is fine.
2. Rational: Project objectives are getting fulfilled, so Hamlet B is fine.
3. Moderate: The decision promotes casteism, but for achieving project objectives, Hamlet B, be the starting point and over the period sensitise the community.
4. Liberal: The decision promotes casteism, so the project needs to have one more centre in Hamlet C. Avoid contestation but ensure 'equity'.
5. Radical: Project needs to confront casteism, so start in Hamlet C only. At the end, it is unethical for a project to not confront casteism once it realises the presence of the same.
6. Participation: Project needs to go by the community's decision, so Hamlet B is fine. The programme cannot impose its ideology on the community.
7. Transformative Participation: Project needs to confront and re-engage with Community. In this case, it is important to understand that the community in the first instance will throw a decision that is in consonance with patriarchy or the caste system; and only if confronted, it would be able to change its stance, for many silent voices will emerge in the discussion.

Similar to these, a number of other case studies were thoroughly discussed, and when members went beyond political correctness, various nuances emerged. The crucial challenge that was seen in the discussion was how to arrive at a consensual decision. In the first round, there was a lot of disagreement. When we revisited the same case study after a couple of months, many changed their opinion; and more members were among the radical or transformative participation categories, but still not a singular opinion.

Based on the above, while we continue with evolving a community-based ethical review process, some preliminary inferences are the following:

Firstly, a number of decisions are often taken at the research and programme level, which appear very rational from the lens of the research objective, but there is a possibility of intrinsic presence of patriarchy and casteism. Unless one proactively dissects the decisions from that lens, it may not be visible, especially in the scenario

of socially conditioned existence. In this context, what is ethical: Ignoring these intrinsic factors or proactively looking for these factors? In the case of the latter, one is asked, whether is it ethical, when one *imposes* a particular lens on a decision that appears to be comfortably embedded in a programme?

Secondly, there are multiple opinions within a group; and each of these bounce from an ideological viewpoint. In the above case study, there are three dimensions: one, whether the decision promotes the caste system or not; two, whether the decision is an imposition on the community or not; and three, whether the decision is going to affect the project outcomes negatively, thereby harming the existing beneficiaries or not. These dimensions also intersect, for there would be contradictions. The challenge here is that decision would align with a particular ideology; and contradictions are about conflicting ideologies. The key question is whether these conflicting ideologies play any role in defining the ethics that would govern your decision-making? If yes, is that right?

Ethics as Commodity of the Mainstream Ideology: Thus, the real challenge is in arriving at a decision. It may not be wrong to assume that even an Institutional Review Board would have been required to confront these kinds of situations, and one wonders how they would arrive at a decision based on consensus. What would have mattered? The high volume of the chairperson or the ideology of the organization that the committee is of, or the considerations of funders? For example, in this case, for the organisation, that is, Praxis, the dimension of social equity is important. Hence, at no point of time, would Praxis like any of its practices, to support caste-based discrimination. Does this mean the organisation's ideology would be the governing ideology for an ethical review group to base its recommendations on? If yes, is this process ethical? What if for the organisation those are patriarchal or those ignore patriarchy or caste system? In that case, the ethical review process would avoid addressing issues related to patriarchy? And if organisational ethics is the basis, then isn't the entire mechanism of institutional review process a sham? Hasn't the review process then become the basis to introduce organisation ideology and even the ideology of donors from the backdoor? These are some of the questions, which need to be studied in depth. Often, we end up trying to reform the institutional review mechanism, but the real challenge is in unearthing the purpose why it exists in the first place? Whose interest does it serve? Whose reality counts for them!

A quote from Marx[1], here, will be self- explanatory:

"A philosopher produces ideas, a poet poems, a clergyman sermons, a professor compendia and so on. A criminal produces crimes. If we look a little closer at the connection between this latter branch of production and society as a whole, we shall rid ourselves of many prejudices. The criminal produces not only crimes but also criminal law, and with this also the professor who gives lectures on criminal law and in addition to this the inevitable compendium in which this same professor throws his lectures onto the general market as 'commodities'......The criminal moreover produces the whole of the police and of criminal justice, constables, judges, hangmen, juries, etc."

Just imagine, if it were true that the ideology that governs the development aid industry after having secured the publishing industry thought that it has seized the research agenda as well as the certification agenda, but has no control over the academic freedom enjoyed by the academics. It needed an institution created by academics to control themselves, for otherwise they will scream about their freedom being taken away. So, the solution of creation of an Institutional Review Board emerged. And then they thought about how to ensure they do not have an independent ideology. And they

just called that an *ethical* review committee! Just a lighthearted comment! But, if true, there is a need to decommoditise ethics!

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[1]https://www.marxists.org/archive/marx/works/1863/theories-surplus-value/add1.htm