சிந்தனை Sindhanai

A Practice Paper

Ethics in Participatory Research

Key Takeaways from Community-led Ethical Review Processes

சிந்தனை
(*Sindhanai*)

Durham
University
Centre for Social Justice
and Community Action

ABOUT சிந்தனை
(SINDHANAI)

In recent times, collectivisation has gained recognition as an important approach in development aid programmes. It is now seen as a strategy to ensure sustainability and to scale up social initiatives. There is growing acknowledgment that community-led efforts are central to creating systemic shifts and structural change.

With this, terms like participatory grantmaking, localisation, intersectionality, dignity, systemic shift, structural transformation, and social movement have been around for a long time and come from strong powerful roots. But today, they are often used in more sanitised, less political ways that dilute their original meaning. These are deeply political ideas, yet they often fall victim to depoliticisation in practice.

The measurement community has played a role in this depoliticisation. As more organisations and donors turn to collectives to drive social change, there is a risk that collectives are treated as a simple solution to complex problems, without understanding the power struggles and contradictions that exist within them. Often, measurement frameworks are designed separately from the collectivisation process, creating a parallel track instead of an integrated one.

There is a clear need to embed measurement within collectivisation itself. Sindhanai, a Tamil word meaning thinking and reflection, represents this idea. It is not only a journey of critical thinking within collectives but also a process of self-assessment to understand movement and change. Sindhanai draws and engages with principles of participatory action research, where learning and change happen together through collective reflection and action. As a contemplative pedagogy, சிந்தனை (Sindhanai) encourages openness and the inclusion of diverse voices through thoughtful reflection. It allows collectives to adjust their strategies and messages as needed to stay effective and responsive.

The Sindhanai initiative, launched in January 2023, recognises the need to create a collective of evaluators with lived experiences of marginalisation. Their perspectives can shape both evaluation practices and the broader norms that define the evaluation ecosystem. The initiative aims to mainstream tools, methods, and perspectives developed within collectives, especially in the Global South, to influence the politics of both evaluation and grantmaking.

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The current report is prepared by:
Pradeep, Tarini, Manjutha, Mohan, Sarulatha, Nafeesa, and Neha

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I. COMMUNITY-LED ETHICAL REVIEW PROCESS

> *"Do I obey economic laws if I extract money by offering my body for sale?... Then the political economist replies to me: You do not transgress my laws; but see what Cousin Ethics and Cousin Religion have to say about it.... It stems from the very nature of estrangement that each sphere applies to me a different and opposite yardstick — ethics one and political economy another; for each is a specific estrangement of man and focuses attention on a particular field of estranged essential activity, and each stands in an estranged relation to the other."*

In the quote above, Marx is describing a world divided into separate spheres- the economic, the ethical, the religious spheres. Each claim authority over human behaviour but each using its own, often contradictory, "yardstick." Political economy justifies exploitation by the logic of efficiency and profit; religion and ethics condemn it through moral reasoning. People stand between these spheres, alienated, forced to obey one set of rules while violating another. This fragmentation, which Marx calls estrangement, means that human life no longer forms a coherent whole.

Research ethics operates under a similar kind of estrangement. The Institutional Review Board (IRB) represents the "ethical sphere," while universities, funding agencies, and policy systems represent the "economic and political" ones. Each applies a different yardstick. The IRB asks whether participants gave consent, whether risks were minimised, whether procedures followed guidelines. The institution (universities), however, asks whether the research aligns with strategic priorities, whether it secures grants, and whether it enhances visibility or profit. Knowledge production is becoming more and more a commercial or reputational enterprise. The 'cousin ethics' is expected to keep research ethical. Do these two logics- ethics and political economy- meet? They are cousins but there is estrangement.

IRBs, operating from distant institutional centres, cannot fully account for the moral negotiations that occur in the field — who speaks, who is silenced, what harm or trust emerges in the encounter. Ethics is abstracted from life, separated from the lived relationships between researcher and community. This is the essence of estrangement in research. The yardstick of the IRB measures compliance, not conscience. Like Marx's "Cousin Ethics," it speaks in general moral terms while remaining disconnected from the material conditions of those being studied.

An ethics grounded in life, equality, and the struggle is necessary to make knowledge serve humanity rather than, merely the organisation or authority. **Community-led Ethical Review Boards (CLERBs)** was attempted to overcome this estrangement. They reunite the ethical and the social. In a CLERB, the ethical question is not only "*Did you obtain consent?*" but "*How was that consent understood, felt, and experienced?*" Ethics becomes a dialogue between equals, not an imposed checklist. It reclaims ethics as *praxis*- reflective, situated, and responsive.

Ethics in Participatory Research

Discussion on Ethics in Participatory Research begins with an explicit standpoint: communities are not subjects to be studied. They are co-researchers who contribute in knowledge creation. The true test of such ethics is simple: does the research live alongside communities, allow fairness to flow to all, stand firm against harm, and leave behind the strength for communities to carry their own legacy?

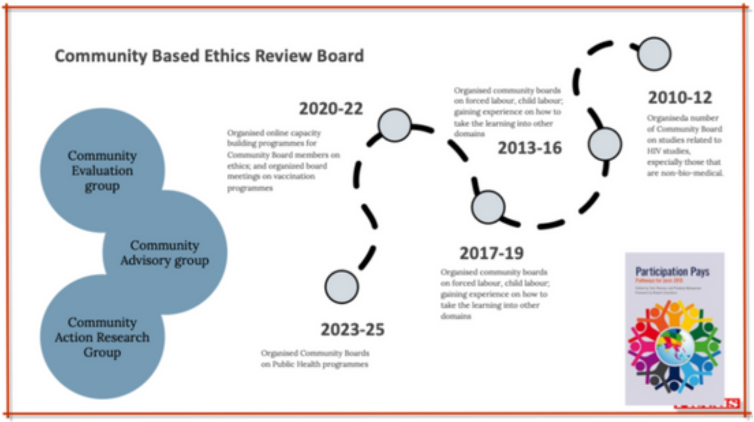
Understanding Ethics: Ethics is not abstract. It is always shaped by the work people do and the relationships that work creates. Journalists have ethics about protecting sources and serving the public. Doctors have ethics about caring for patients with dignity. Lawyers have ethics about client confidentiality. Similarly, researchers have ethics about consent, confidentiality, and avoiding harm. Activists also have their ethics. They must be accountable to movements, honest in representing struggles. Participatory researchers face yet another set of questions. Community members are co-researchers. Researchers, therefore, must think about reciprocity, shared ownership, knowledge justice, and what legacy their work leaves behind. In every case, ethics is about setting standards that protect people, ensure fairness, and build trust. But the exact form of ethics changes depending on the responsibilities and power in each field.

Understanding “Community”: Ethics is usually described as neutral, applying equally to everyone. But in practice, it cannot be blind to power. Even powerful people can be harmed through research — their privacy invaded, their identities misused, or their voices distorted. That risk must be acknowledged. Yet the mechanisms for enforcing and practising ethics must be designed with the powerless in mind. Powerless sections are far less able to protect themselves. In Participatory Research, “community” refers to this section; those with a shared deprivation of power, whose lives are shaped by inequalities of caste, class, gender, race, sexuality or migration. Researchers and institutions, by contrast, usually hold greater power, then this imbalance must frame ethical responsibility. Ethics in participatory research must therefore tilt toward protecting and strengthening those at the margins. Ethics need to hold the powerful accountable for how they use their influence.

A decade of forming Community-led Ethical Review Boards

During 2010–12, the initial Community led ethical review boards (CLERBs) were formed by Praxis Institute for Participatory Research, around HIV-related research, particularly non-biomedical studies. These early efforts challenged the dominance of biomedical ethics and brought into focus social and contextual dimensions such as stigma, access to care, and the livelihood implications of research participation. Building on this foundation, the period 2013–16 saw CLERBs expand into the domains of forced labour and child labour, extending the ethical lens beyond health to encompass questions of social justice, dignity, and exploitation. The emphasis during this phase was on how community voices could actively shape definitions of what is ethical, harmful, or just.

From 2017–19, the engagement deepened, with Praxis refining its methodologies to make ethical reflection transferable across issues, moving from a thematic, issue-based application of ethics to a more generalisable framework applicable across research domains. The 2020–22 period marked a significant shift during the pandemic, when CLERBs transitioned to online platforms, enabling wider participation and focusing on capacity building for community members who took part in ethical reviews of vaccination and public health research. This represented both a digital transformation and a new form of inclusion in decision-making.

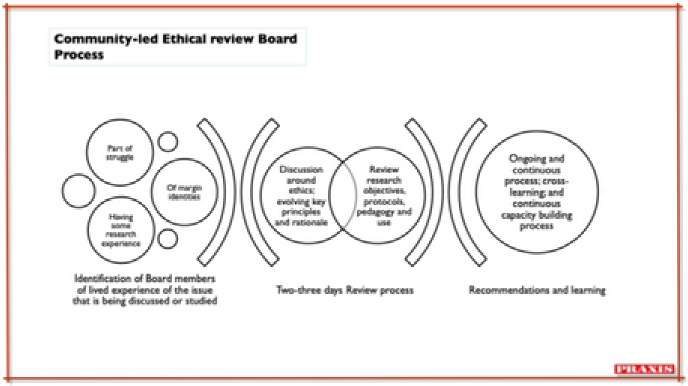


In the most recent phase, 2023–25, CLERBs have been integrated into public health programmes, signalling that community-led ethical review is no longer confined to research but is influencing how policies and implementation frameworks are assessed for fairness and accountability. Each phase has thus added a new dimension, from learning to legitimacy, from issue-based reflection to systemic application, culminating in a stage where communities themselves review and interpret ethics in public programmes through their own lived and collective lenses.

How does one build community-led ethical review process?

The formation of Community-led Ethical Review Board begins with the identification of board members who bring lived experience of the issue under discussion or study. The priority is not on academic qualifications or institutional affiliations but on situated knowledge - those who have been part of the struggle, belong to *marginalised identities*, or have some *research experience* from a community standpoint. This ensures that ethical deliberation emerges from those who understand vulnerability, power relations, and the implications of research first hand.

Once constituted, the board undertakes a two to three-days review process that unfolds through two interlinked spaces of dialogue. The first involves a discussion around ethics, where members collectively reflect on what ethical practice means in their specific context and evolve key principles and rationales relevant to the community. This step grounds ethics in shared values, respect, reciprocity, and justice, rather than rigid institutional norms. The second space involves a review of research objectives, protocols, pedagogy, and use, where members examine how research questions are framed, how participants are engaged, and how findings might be used or misused. The overlap between these two discussions, ethics and research practice, is deliberate, as it is in this intersection that meaningful ethical insight emerges.



The process does not end with recommendations alone. It is conceived as an ongoing and continuous cycle of learning, reflection, and capacity building. Board members and researchers stay engaged beyond the initial review, often revisiting ethical questions as the research progresses. This iterative model fosters cross-learning between community and research teams, gradually building a shared ethical vocabulary and collective competence. Over time, the process becomes self-strengthening, as communities develop greater confidence in questioning research intentions, and researchers learn to listen, adapt, and co-create ethical standards in partnership with those most affected.

What is the process of selection of CLERB members?

A question that often arises — "How did you select the board members?" - reveals a deep and persistent bias in how legitimacy is perceived within research ethics. When such a question is directed at community-led boards, it is almost always framed around *representativeness*: *Are these members truly reflective of the community*? *Do they speak for others*? Yet, when the same question could be asked of Institutional Review Boards (IRBs), it is never about representation - it is about competence: Are they trained, certified, or qualified researchers? This distinction is telling. In institutional contexts, ethical legitimacy is derived from professional expertise and affiliation; in community contexts, it is expected to emerge only through collective identity and representational claim. This rhetorical tension exposes the colonial residue in the architecture of global research ethics, where the power to define what counts as "ethical" has long been concentrated in institutions and among credentialed professionals, rather than with those whose lives are most affected by research.

The community-led process turns this assumption on its head. It begins with the understanding that proximity to lived experience is itself a powerful form of ethical competence. The ability to identify harm, foresee exploitation, and understand what justice or dignity means in a given context does not come from formal training alone but from living through structural inequalities and negotiating survival within them. Hence, the legitimacy of community boards does not rest solely on representativeness but also on the moral and experiential authority of their members. In this sense, the community-led approach expands what it means to be "competent" in ethics—situating it not in institutional expertise, but in embodied wisdom, collective dialogue, and social accountability. Nevertheless, a community board must still be able to justify its representativeness—or more precisely, its positionality. For community boards, clarity about who is speaking, from what standpoint, and on whose behalf is essential to their credibility. This openness about positionality, acknowledging that every ethical judgment is shaped by one's social location and relationship to power, is a mark of strength, not weakness.

Indeed, this is one of the most valuable lessons that Institutional Review Boards can learn from community-led processes. IRBs, too, must make their own positionality explicit: *Who are we in relation to this research*? *Whose risks do we prioritise*? *Whose ethics do we represent*? Recognising positionality does not undermine authority; it humanises it. For community boards, such reflection affirms legitimacy; for IRBs, it restores humility, reminding both that ethical authority is not a credential, but a practice of self-location, dialogue, and accountability.

Decision making in CLERB meetings

In a Community-led Ethical Review Board (CLERB), decisions are not about arriving at quick consensus but about engaging deeply. More they are exposed to different scenarios, more the confusion. This confusion is not a sign of failure. It reflects the reality that ethics in research-balancing benefit and harm, autonomy and justice, or short-term efficiency and long-term equity- are rarely clear-cut. The review process encourages participants to recognise that ethical reflection is not about uniformity but about plural reasoning. There is a possibility of the coexistence of diverse ethical standpoints shaped by gender, class, caste, and lived experience. In this deliberative model, members listen to one another's perspectives, weigh competing considerations, and identify patterns of concern or insight rather than trying to "vote" on right and wrong. Decisions, when made, are often in the form of recommendations or guiding reflections rather than rigid approvals or rejections. This process transforms ethics from a gatekeeping function into a shared exercise of conscience. It also cultivates accountability on both sides: board members become more reflective, as they realise that ethics involves judgement under uncertainty, and researchers become more accountable, as they are confronted with grounded, multifaceted feedback instead of abstract compliance checklists.

II. RETHINKING ETHICS IN PRACTICE: CONSENT, COMPENSATION, AND POSITIONALITY

When review boards look at research proposals, they often check if the right forms and rules are followed. But in Participatory Research, ethics cannot stop at paperwork. Three areas need deeper attention: consent, compensation, and positionality.

- Consent is not just a form; it is about how communities are asked, respected, and given space to change their mind.
- Compensation is not just a payment; it shows whose time and knowledge are valued, and whether communities are treated as equals in knowledge making.
- Positionality is not just a declaration; it is about how the researcher's identity, ideology, and power shape the entire process.

These three are not small details. They show whether research is building fairness and reciprocity, or whether it risks slipping back into extraction. Review boards need to see them not as boxes to tick, but as living practices to question and strengthen.

Consent in Participatory Research: Beyond the Consent letter

Consent is perhaps the most recognised word in research ethics, but it is also the most misused. In most conventional studies, consent is reduced to a form; a signature or an audio recording that marks the respondent's agreement. Once this is secured, researchers treat the path as clear. Yet in Participatory Research, where inquiry is dynamic and community voices are central, this narrow treatment is insufficient and even dangerous. Consent is not a one-time transaction; it is a relationship, and its meaning changes depending on who seeks it, why it is sought, and how it is enacted.

When reflecting on the ethics of consent, a first set of questions arises: **who is giving consent,** and at what level should it be understood? Is consent to be treated as an individual act, expressed through a signature or verbal agreement? Or, in contexts where knowledge and identity are held collectively, should consent be situated at the level of families, communities, or intergenerational groups? Does privileging the individual risk erasing the collective nature of belonging and knowledge? Equally important is the question of **who is receiving consent.** Do researchers and institutions, typically positioned as the sole recipients, reinforce asymmetrical power relations by reducing communities to the role of mere grantors? Should consent instead be conceptualised as a negotiated process in which communities have equal authority to shape terms and expectations?

A further set of questions concerns **what consent is for and who keeps its record**. Is consent primarily a legal safeguard for researchers and institutions, ensuring liability protection, or is it intended as a mechanism to strengthen participants' agency throughout the research process? If the former prevails, does consent risk becoming a bureaucratic ritual rather than a practice of justice? Moreover, if signed forms are held only by researchers, does this not primarily serve institutional interests rather than community rights? Would a fairer practice be for communities to also retain copies—in accessible formats such as local languages, audio, or visual records—so they may revisit or withdraw consent? And finally, in contexts of limited literacy, sharp asymmetries, or uncertain risks, how might consent be reimagined as collective, iterative, and reciprocal, rather than as a one-time procedural act? Is there a mechanism for anyone to withdraw their consent? What are the processes?

Consent can take many shapes.

At times, it operates as an institutional safeguard. Here, the research team seeks signatures mainly to protect itself in the eyes of funders, donors, or ethics boards. The form acts as legal cover, ensuring that responsibility is deflected from institutions if harm occurs. In this case, consent is less about protecting participants and more about shielding organisations.

Consent can also function as a commercial boundary. When knowledge may be tied to intellectual property rights or monetised later, researchers seek consent to avoid being accused of theft. But this can turn consent into a contract for transferring knowledge, with little room for communities to negotiate fair terms.

Sometimes, consent is framed as an advocacy tool. Researchers plan to use stories, names, or identities to influence public opinion or policy. Consent ensures that participants agree to such use. But the risk is that respondents' identities are instrumentalised for advocacy campaigns, leaving them vulnerable to backlash even when they technically “consented.”

Another motivation is consent as protection. Here, teams worry that field researchers could misuse power or expose participants to risk. Consent is a way to safeguard bodies, time, and privacy. While protective, this approach can still be top-down if protections are not co-designed with communities themselves.

There is consent as instrument to privilege individual agency over collective agency. Most consent processes emphasise individual forms. Collectives — trade unions, village assemblies, community-based organisations — are often dismissed as gatekeepers or obstacles. This sidelines collective decision-making, even though risks and impacts are frequently borne at the group level.

Finally, consent can also represent empowerment of agency. In this framing, the research team seeks consent as a sign of respect for autonomy, recognising respondents as agents with the right to say yes or no. This is the most ethically sound approach, but only if consent is treated as ongoing, revisited as research evolves, and grounded in both individual and collective contexts.

In sum, consent is not one thing. It is a shifting practice that can protect institutions, transfer intellectual property, legitimise advocacy, safeguard participants, respect autonomy, or sideline collective agency. Ethics boards must ask which of these logics is driving the process. The danger is that consent slips become legal shields for researchers rather than instruments of respect for participants. The opportunity is to reclaim consent as a political practice: iterative, dialogical, collective, and reciprocal. Over years, consent has also become a routine process, and often it is taken to ensure a smooth publication in journals, which have made ethical clearance as a mandatory requirement.

Compensation in Participatory Research: Recognition or Extraction?

For understanding ethics around compensation, it is important first to ask: **who is compensating?** Funded research often leads to monetising of Knowledge in some form. Researchers and institutions, whether in the form of for-profit consultancies, non-profit organisations, or universities, are compensated through grants, salaries, and reputational gains that later translate into further opportunities. Intellectual property rights (IPR) and publication benefits almost always flow upward. They accrue in the Global North, reinforcing existing hierarchies of knowledge and power. The ethical reflection is clear: if institutions and researchers are rewarded for knowledge production, on what grounds can communities in participatory research, who contribute to this knowledge production, be excluded?

The question, then shifts to **who is compensated**. Researchers are routinely paid for their time, labour, and intellectual contribution. Other recognised "experts" such as academics, consultants, lawyers, are also compensated, their bargaining power rooted in institutional legitimacy and intellectual property claims. Respondents, however, are inconsistently treated. Community members, workers, or marginalised groups; those without formal recognition or institutional voice are often left uncompensated. Those with power are compensated as a matter of course, while those without power are expected to offer knowledge for free.

The next question is what compensation is for. Is it for time? If so, should respondents' time be valued at the same rate as that of the researcher, or merely at the level of their "opportunity cost"—a day's wage lost? Or is it for knowledge? If so, how do we calculate the worth of knowledge? Indigenous wisdom or community practices that have shaped entire fields of research, and yet have historically been appropriated without recognition? Without clarity, however, compensation risks falling into two traps: tokenism, where a small fee trivialises deep contributions, or exploitation, where knowledge is extracted without recognition or value.

Finally, **what if organisations cannot compensate?** Grassroots movements and campaigns often lack the funds to pay respondents directly. Yet here lies a risk: introducing a "payment culture" into such spaces may distort participation, transforming relationships built on solidarity into transactional exchanges. This does not absolve us from the principle of fairness—it only challenges us to think differently about its practice. Reciprocity can take alternative forms: skills training, co-authorship, visibility for community voices, or returning results in accessible formats. Compensation can also be collective rather than individual, with contributions directed to community funds, infrastructure, or local initiatives. The form may differ, but the ethic of fairness must remain.

Framing of Compensation in Research

In research practice, Compensation may seem, or often seen, like a procedural matter. Who is compensated, and for what, reveals whose contributions are recognised as valuable. In most research, academics, consultants, and experts are paid, while communities are expected to contribute knowledge for free. This double standard reproduces hierarchies of value and power. In participatory research, where communities are co-researchers, compensation cannot be ignored. It is not only about money; it is about recognition, reciprocity, and justice.

The first framing is compensation as recognition of time. Here, communities are paid stipends or daily wages for hours spent in research activities. This acknowledges time as labour. Yet the tension lies in valuation: should compensation match lost wages (opportunity cost) or align with what researchers themselves earn for their time? Paying only at subsistence rates can reinforce inequality, while parity may be financially unfeasible for small projects. The second framing is compensation as recognition to knowledge. Communities contribute insights, stories, and cultural knowledge that shape research directions. This is intellectual labour, but it is rarely compensated as such. Does this fit legal categories of intellectual property? The challenge lies in measurement: how to fairly value knowledge that may fundamentally transform research or policy.

The third framing is bodily contribution. In some forms of research- medical trials, drug testing, or environmental health studies- participants provide their own bodies, through blood samples, health data, or exposure reporting. This is a deeper form of risk, because the body itself is used as data. Compensation here is not only about fairness, but also about dignity and safety. Without proper recognition, such practices can cross into exploitation. Fourth, compensation often reflects expert privilege. When external experts — academics, lawyers, consultants — are interviewed, they are typically paid honoraria. When community members provide equivalent knowledge, they are unpaid or paid lowly. This double standard shows that compensation is about institutional power, not fairness.

Fifth, compensation can also be understood as redistribution of risk. Communities bear risks when they share knowledge — from backlash, fatigue, or exposure. Compensation recognises these costs. Can money erase harm?

Some projects address this by emphasising benefits to collective. Instead of paying individuals, funds go into community pools, cooperatives, or shared infrastructure. This approach avoids singling out participants but one need to be mindful of risks of elite capture or uneven distribution.

Another approach is non-monetary reciprocity. Researchers provide skills training, co-authorship, recognition in reports, or translation of findings into accessible forms. These can be meaningful if substantive, but symbolic if tokenistic. A single co-author credit in a journal may not balance months of unpaid community labour.

Finally, compensation must be seen as a culture-shaper. Some activists worry that paying individuals may weaken voluntary solidarity. Others argue that refusal to compensate perpetuates exploitation.

Boards must weigh these tensions carefully, ensuring fairness without commodifying every act of solidarity. In essence, compensation is not a technical detail. It is an ethical mirror.

Positionality in Participatory Research: Ideology, Power, and the Ethics of Voice

Every researcher enters the field with positionality — shaped by identity, history, and ideology. This positionality influences every stage of research: how problems are framed, which participants are included, how findings are interpreted, and how reports are written. In PAR, where communities are meant to be co-researchers, positionality cannot be hidden or denied. The danger arises when researchers use community voices selectively to reinforce their own ideology, presenting it as "the community's voice" rather than acknowledging their own framing.

The greatest risk appears when positionality aligns with dominant ideologies. Research rooted in neoliberal, statist, patriarchal, racist, casteist, or donor-driven worldviews tends to homogenise communities, silence dissenting voices, and reinforce institutional agendas. In such cases, research becomes less a mirror of community realities and more a tool of the mainstream — knowingly or even unknowingly. Often, this happens unknowingly because not all researchers understand the diversity of ideologies that shape the world they study. Many practise one ideology while claiming allegiance to another. Some remain on the cusp, caught between shifting beliefs. Over time, as one dominant ideology takes hold, spaces for open debate among multiple worldviews begin to shrink. As Ha-Joon Chang reminds us, there was a time when the academic world encouraged discussion across ideological lines — Keynesians debated with Marxists, liberals with socialists — but that spirit has largely faded. Today, there is less dialogue across difference, and more conformity within dominant frames.

But this raises a counter-question: what about researchers with rebellious positionalities — feminist, anti-caste, anti-racist, or leftist? If they too bring their ideology into research, does it not make them equally unethical? This is where the politics of power must be acknowledged. A feminist or anti-caste researcher does not operate from a neutral platform of dominance. From the moment of designing the study to entering the field, meeting respondents, and seeking publication, such researchers are constantly negotiating, confronting, and being interrogated by the mainstream. Even communities themselves may question or resist their standpoint. The playing field is not symmetrical: dominant ideologies are reinforced by institutions, funding, and cultural hegemony, while resistant ideologies are contested at every step. *(Read annexure for Various worldviews.)*

Ethics, then, cannot be defined as if all positionalities were equal. To frame ethics as neutral, applying equally to those who dominate and those who resist domination, risks erasing the reality of unequal power. What matters is not simply that a researcher has a standpoint, but how that standpoint interacts with structures of power: does it reinforce hierarchies, or does it challenge them? Ethics in PAR must acknowledge these imbalances and judge positionality not by the fiction of neutrality, but by its relationship to power and justice.

The most ethical practice is reflexive disclosure. Researchers should acknowledge openly where they stand, how their worldview shapes their interpretation, and how they remain accountable to participants. Pretending neutrality is itself a power move.

Finally, positionality is also about **power arrangements**. Even when a researcher's ideology is progressive, project hierarchies may remain traditional: academics at the top, community researchers at the bottom. If positionality does not extend to team structures, it risks being performative.

In sum, positionality is not about choosing between neutrality and ideology. Neutrality is impossible, but ideology must not suppress plurality. Ethical positionality requires transparency about one's stance and accountability to research participants. To assume that all positionalities are equal is itself unethical. The supposed neutrality of ethics has often served as a shield for the powerful, protecting those whose worldviews already dominate institutions, markets, and states.

In Participatory Research, the question is not whether a researcher has a standpoint, but whose power that standpoint serves and whose silence it breaks. Positionality is revealed not in declarations but in everyday choices. Whether communities' time and knowledge are valued as labour or treated as free inputs, and whether consent functions as a living dialogue that safeguards participants or as a form that protects institutions? Ethics is not the absence of ideology. Ethics is the presence of reflexivity, transparency, and responsibility in how power is exercised and shared.

Key Considerations that ethical review boards should not ignore

Consent in Participatory Research

1. Who is asking for consent, and why?
2. Is consent informed — do respondents truly understand purpose, risks, and uses of knowledge?
3. Is consent iterative, revisited at multiple stages with right to withdraw?
4. Is collective consent sought where appropriate?
5. Are protections in place if knowledge or identities are made public?
6. Does the process respect agency, or simply comply with paperwork?

Compensation in Participatory Research

1. Who is compensated, and who is not? Are there double standards?
2. What is compensated — time, knowledge, or both?
3. How is value calculated — subsistence rates, opportunity cost, parity with researchers?
4. Is compensation monetary, collective, non-monetary reciprocity, or hybrid?
5. Are communities involved in deciding the form of compensation?
6. Does compensation account for risks borne by community researchers?
7. Could the approach distort solidarity or grassroots culture, and if so, how is it mitigated?

Positionality in Participatory Research

1. Has the research team disclosed its positionality and worldview?
2. Does the design allow for contradictory community voices?
3. Are inconvenient narratives preserved or filtered out?
4. Is accountability directed primarily toward participants or toward external camps?
5. Is reflexivity embedded in the process (journals, debriefs, community review)?

Returning Ethics to the Community

> “The criminal produces not only crime but also the criminal law; he produces the professor who delivers lectures on this criminal law, and even the inevitable compendium in which this same professor throws his lectures onto the general market as a ‘commodity.’”

In this quote, Karl Marx speaks about how criminal’s existence gives rise to an entire industry around crime. Laws, police, prisons, professors, and textbooks all depend on his presence. Without the criminal, there would be no criminal law, no legal scholarship, no judges, and no justification for the machinery of control. Institutions, once created, often stop serving the purpose they were built for. Instead, they begin to serve themselves. They reproduce their own authority, perpetuate their own structures, and sustain their own experts. What begins as protection against harm transforms into a system that thrives on the very harm it was meant to prevent.

If we extend Marx’s insight into the world of research ethics, the parallel is striking. The **Institutional Review Board (IRB)** exists because research carries the possibility of harm - exploitation, deception, violation of privacy, and misuse of knowledge. But over time, the IRB has evolved from a mechanism of protection into a mechanism of control. It produces its own rules, specialists, and legitimacy. It centralises the language of “risk” and “ethics”.

It is important to acknowledge that IRBs did not emerge in a vacuum. They were products of a particular historical and geopolitical context, one where knowledge flowed from the North to the South, from universities to communities,from experts to “subjects.” The language of universal ethics is itself embedded in Western moral philosophy. It often assumes existence of individual agency, legal reasoning and written contracts. Communities that operate through trust, kinship, and reciprocity are now part of signed forms paradigm. Institutional ethics, meant to protect, thus reproduces epistemic colonialism. Unlike publishing, academia or grant-making systems that control knowledge externally, IRBs seed colonial ethics directly into the researcher’s mind. They sit there even before the research begins. Proposals are written in ways that “get through ethics.” Researchers learn to speak the language of compliance. Ethics no longer lives in dialogue or reflection; it lives in fear. The IRB derives authority not from lived practice but from institutional validation.

A Community-led Ethical Review Board (CLERB) seeks to release ethics from this burden of control. It invites researchers to return ethics to the realm of relationships and lived accountability. In this space, ethics is not something to fear, but something to practice—collectively and reflexively. Participatory research, at its highest level of ethics, must return ethics to the community, grounding it not in institutional approval but in lived accountability. Yet, returning ethics to the community does not mean research automatically becomes ethical. Communities are not monoliths, and they are not inherently ethical. Power, hierarchy, and exclusion exist within them too. What changes is that ethics becomes political and contextual- situated, argued, and grounded in context. That grounding is what makes ethics real. It’s time to return ethics to the community, and thus ethics to research.

III. RETHINKING ETHICS ACROSS DOMAINS OF PARTICIPATORY RESEARCH

Ethical challenges in Participatory Research are not scattered concerns; they can be understood as belonging to four broad domains. These domains trace the full arc of research- from how communities are first approached, to how their contributions are valued, to how risks are handled, and finally to how the research concludes. Together, they offer a way to see ethics not as isolated steps but as a continuous responsibility across the entire life of a project.

(a) Entry and Engagement

This domain asks how researchers approach communities, how they are seen, how their participation is shaped, and how consent is secured.

The **first question** is about *worldview* of the researcher. How does the researcher's own perspective shape how communities are described and understood? Are external labels being imposed, such as calling groups "victims" or "backward" that reproduce colonial, racist, casteist, or patriarchal stereotypes? Or are communities given the chance to describe themselves in their own words, on their own terms? The test here is whether research begins from imposed categories or from lived realities.

The second question is how participation is understood. Is participation genuine, or is it tokenistic? Are communities invited only after decisions are already made, or reduced to the role of unpaid data collectors for academic or NGO outputs? Or are they treated as co-researchers, with real power to frame questions, choose methods, interpret findings, and decide how results will be used? The key issue is whether participation shifts power or simply legitimises it.

Finally, we must ask about consent. Is consent treated as a one-time signature or recording, or is it understood as something dynamic, ongoing, and revisited as research directions evolve? In contexts where collective life matters, is consent also sought from assemblies, unions, or worker groups, and not only from individuals? Above all, does the process of consent respect both personal autonomy and the collective context in which people live? Are there spaces for withdrawing consent at later stage?

Entry and engagement, then, is not a technical opening act but a political moment. It is about how communities are seen, how they are invited in, and how their agency is respected throughout the process.

Dimension	1. Worldview & Stereotyping	2. Participation (Genuine vs Tokenistic)	3. Consent (Dynamic, Ongoing, Collective)
Guiding Question	Does the research allow communities to define themselves, or are external labels imposed?	Is participation real, or is it tokenistic?	Is consent one-time, or is it iterative and collective when needed?
0	Research imposes stereotypes (e.g., “victims,” “backward,” “beneficiaries”).	Participation is absent or only symbolic.	Only one-time, individual consent taken.
1	Attempts to avoid labels but still frames communities from an outsider’s view.	Communities are consulted but without decision-making power.	Consent explained but not revisited.
2	Communities are consulted in shaping categories and descriptions.	Communities influence some but not all research decisions.	Consent revisited during the project but collective consent ignored.
3	Communities fully define themselves in their own terms and worldview.	Consent revisited during the project but collective consent ignored.	Consent is iterative, revisited, and collective where appropriate

(b) Fairness and Reciprocity

This domain asks how contributions are valued, how benefits are shared, and how knowledge is treated.

The first concern is knowledge justice. Whose knowledge is recognised in the research record? Are Global North journals and academic texts prioritised, while Indigenous knowledge, oral traditions, and activist writings are dismissed? Or are these acknowledged as legitimate and valuable forms of scholarship? Ethics requires that different forms of knowing be recognised.

The second issue is ownership and reciprocity. Who owns the data produced- transcripts, maps, photos, or analysis? Are these controlled only by researchers and institutions, or do communities share ownership and decision-making about their future use? Reciprocity cannot be reduced to payment alone; it must include co-authorship, capacity-building, recognition, and ensuring that findings return to communities in usable forms.

The third concern is compensation. Are community contributions treated as free, even while researchers and institutions benefit? Is time fairly valued, knowledge fairly recognised, and risks fairly compensated? Ethics requires transparency and fairness in recognising that communities are not simply contributors but co-producers of knowledge.

Fairness and reciprocity, then, is about preventing research from becoming extraction. It asks whether contributions are respected, knowledge is honoured, and benefits are shared.

Dimension	**4. Knowledge Justice**	**5. Ownership & Reciprocity**	**6. Compensation**
Guiding Question	Whose knowledge is cited and validated?	Who owns the data and benefits from its use?	Are contributions fairly compensated or acknowledged?
0	Only Global North published academic sources used.	Researcher or institution has full ownership.	No compensation or reciprocity provided.
1	Local knowledge acknowledged but not cited formally.	Data shared partially but decisions controlled by researchers.	Token compensation (e.g., travel allowance or honorarium only).
2	Local or Indigenous knowledge included alongside academic sources.	Communities share ownership but with limited influence.	Compensation partly reflects community members' time or knowledge.
3	Knowledge justice is central — oral, activist, and Indigenous knowledge recognised equally.	Communities co-own data, co-decide on storage and use, and benefit directly from outcomes.	Compensation or reciprocity is fair, transparent, and co-designed with communities.

(c) Risk and Protection

This domain focuses on anticipating risks, mitigating harm, and addressing power within the research process.

The first concern is harm during the study. Do community researchers face fatigue, conflict, or local pressures? Are participants asked to revisit trauma, exploitation, or injustice without safeguards for their well-being? Ethical practice demands that risks be anticipated, named, and mitigated.

The second issue is harm after the study. What happens when findings expose employers, elites, or state actors? Are communities at risk of backlash, reprisal, r loss of livelihood? Ethics in PAR must look beyond the present to long-term impacts.

The third concern is power inside the research team. Do academics, NGOs, and donors hold decision-making authority while local researchers do most of the labour without recognition? Are community researchers acknowledged as knowledge producers, or treated as assistants? Ethical practice requires that participation not become another form of extraction.

Risk and protection, then, is about recognising that harm can occur during, after, and even inside the research process — and ensuring safeguards rooted in community priorities.

Dimension	**7. Harm During Study**	**8. Harm After Study**	**9. Power Dynamics Inside the Team**
Guiding Question	Are risks to community researchers or participants during the study identified and addressed?	Are risks of backlash or unmet expectations after research anticipated?	How are inequalities within the research team addressed?
0	No recognition of risks.	No recognition of long-term harm.	Clear hierarchies; community researchers treated as assistants.
1	Risks acknowledged but no safeguards in place.	Long-term risks acknowledged but left unaddressed.	Community researchers acknowledged but excluded from decision-making.
2	Safeguards exist but are partial or inconsistently applied.	Some plans for continuity or mitigation, but not robust.	Some shared recognition and credit for contributions.
3	Risks are systematically mapped and mitigated in collaboration with participants.	Strong, co-created plans to prevent or respond to long-term harms and manage expectations.	Power consciously redistributed; community researchers act as co-authors or co-leaders.

(d) Continuity and Exit

This domain is about what happens after research formally ends, and how accountability and representation continue.

The first concern is confidentiality versus visibility. Is anonymity automatically imposed, or do communities have the choice to be visible and named in their struggles? Ethical practice lies in negotiating visibility, not imposing it, so that communities control how they are represented after the project ends. The second issue is accountability beyond donors. Researchers are usually accountable to funders or ethics boards, but in PAR, accountability must flow primarily to participants. Are there mechanisms for grievance redress that outlast donor cycles? Can communities question, challenge, or halt harmful practices even after the project closes? The third concern is exit. How do researchers leave? Is withdrawal abrupt, breaking trust and weakening morale? Or is exit co-created with communities to ensure continuity, sustainability, and dignity? The ethical test is whether projects leave behind relationships, skills, or structures that endure long after researchers depart.

Continuity and exit, then, is about whether research strengthens communities for the long term — through representation, accountability, and respectful closure.

Dimension	**10. Confidentiality vs Visibility**	**11. Accountability Beyond Donors**	**12. Exit Ethics**
Guiding Question	Do communities decide whether to remain anonymous or be visible?	Who are researchers accountable to after donor cycles end?	How do researchers leave? Is exit respectful and co-created?
0	Blanket anonymity imposed, without community input.	Accountability only to donors or institutional ethics boards.	Abrupt withdrawal; no exit plan or continuity measures.
1	Visibility allowed but without full assessment of risks or consequences.	Communities informed of results but no accountability mechanisms in place.	Exit communicated but not co-created with communities.
2	Options for visibility discussed but communities have limited choice.	Some grievance or feedback systems exist but are weak or external.	Some continuity or follow-up plans exist but remain weak.
3	Communities fully decide on visibility, with risks and implications openly discussed and negotiated.	Communities hold primary accountability mechanisms, with power to question, challenge, or halt harm.	Exit strategy co-created with communities, leaving behind skills, relationships, or sustaining structures.

CONCLUSION

Community-led ethical review processes strengthen ethics by rooting moral judgement in lived experience, accountability, and ongoing dialogue. They make ethics a practice rather than a permit, foregrounding reciprocity, knowledge justice, and the redistribution of power across the research lifecycle. When communities shape how problems are framed, how consent is practised, how benefits are shared, and how exits are negotiated, ethics becomes responsive to real risks and real hopes rather than a set of abstract rules. This approach is central to contemporary work on participatory ethics and has been elaborated in recent scholarship and guidance on ethics in participatory research.

Community-led boards do not replace institutional review but they do offer concrete learning for IRBs: make positionality explicit, design review as iterative dialogue, recognise multiple knowledges, and embed continuing accountability after funding ends. As Sarah Banks reminds us, ethical practice in participatory work requires ongoing reflection together: “At all stages of the research process it is important that the researchers reflect together on what they are doing and why, and what may be the ethical impact of their decisions and actions. These are practical habits that IRBs can adopt—by incorporating community voices into review, by requiring reflexive disclosure, and by supporting mechanisms that keep ethics active during and after projects.

If we want research to serve people, then the funders, universities and ethics committees must treat community-led practice as an essential partner in ethics governance. Start by piloting community review alongside IRB review, fund co-designed compensation and data-ownership arrangements, and build iterative review checkpoints into project timelines. In doing so we do not simply compare CLERBs to IRBs as benchmarks; we create a shared ecology in which institutional procedures are informed and improved by community wisdom, and ethics becomes a collective, living practice.

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ANNEXURE

VARIOUS WORLDVIEWS

Liberalism emerged in Europe's Enlightenment era, with focus on rational individuals, personal liberty, and legal equality.

From its economic foundations, **Capitalism** grew as a system based on private ownership and competitive markets, often aligning with liberal ideals of freedom and progress.

Marxism arose as a critique of this order, exposing class exploitation and advocating collective ownership of production.

In response to industrial inequalities, the **Welfare State** sought to balance markets with social protection and public welfare.

Neoliberalism reasserted market supremacy, reducing state welfare and celebrating competition and individual responsibility as universal virtues.

In contrast, **Ubuntu** — and likewise, grassroots communitarian philosophies emphasise relational existence, shared well-being, and decolonial ethics, reminding us that freedom and dignity are sustained through community, care, and mutual interdependence.

Dimension	Liberalism	Capitalism	Marxism	Welfare State	Neoliberalism	Ubuntu/ Likewise
Core Impulse	Rebellion against monarchy and divine rule — freedom through reason.	A byproduct of liberalism — dominance of property and vested interests over equality.	Rebellion against exploitation — expose the class struggle within liberalism.	Compromise born of Marxist pressure — reform without revolution.	Counter-revolution to the welfare state — market revival after political democracy.	Radical re-centering of humanity — freedom *with* others, not *from* them.
View of the Individual	Rational, self-governing citizen.	Economic actor — producer, consumer, worker, investor or owner.	Social being alienated by material relations; freedom through collective control.	Citizen with rights and entitlements; protected from market dominance.	Entrepreneurial self; responsible, competitive, individualistic.	Relational person — identity through community and care.
View of the State	Limited and constitutional; referee of liberty.	Protects property; guards capital and order.	Instrument of class domination; temporary in transition to communality.	Protector and provider; softens inequality through welfare.	Corporate player; No subsidies, retreats from welfare, enforces competition.	Moral steward; rooted in reciprocity and collective well-being.
Nation-State	Civic space for free citizens.	Expansionist empire; nationalism as tool of accumulation.	Bourgeois construct; transcended by international solidarity.	National social contract; solidarity within borders.	Market brand; competes globally for investors.	Ethical community beyond borders; humanity before nation.

Dimension	Liberalism	Capitalism	Marxism	Welfare State	Neoliberalism	Ubuntu/ Likewise
Market	Useful but morally limited tool.	Central engine of life; growth as virtue.	Structure of exploitation; must be collectivised.	Mixed economy; market regulated for fairness.	Sacred logic; market replaces ethics.	Exchange guided by mutuality, not profit.
Firms / Companies	Regulated private entities.	Instruments of accumulation and colonial reach.	Sites of surplus extraction; to be socialised.	Private partners under social control.	Model for all institutions; efficiency as faith.	Cooperative, purpose-driven creation.
Collectives, Unions, Movements	Voluntary associations protecting pluralism.	Controlled or suppressed when threatening.	Agents of class liberation and social transformation.	Institutionalised negotiation; limited participation.	Weakened, depoliticised, replaced by consultancy or CSR.	Embodied solidarity; community as foundation of self.
Colonisation	Claimed to civilise; enabled empire.	Structural to accumulation; global subjugation.	imperialism — inevitable stage of capitalism.	Post-colonial correction through aid and reform.	Neocolonial — finance, trade, and data dominance.	Decolonial-dignity restored through relational justice.
Religion	Private faith guiding civic virtue.	Moral alibi for hierarchy.	Ideological reflection of alienation.	Compassion institutionalised as policy.	Spirituality commodified and politicised.	Spiritual humanism; community as sacred.\
Intellectual Property	Temporary rights for innovation.	Enclosure of knowledge for profit.	Knowledge as collective labour alienated by capital.	Balanced protection and public access.	Total privatisation — patents on life and thought.	Knowledge as commons; shared wisdom sustaining life.
Engagement with the Planet	Nature as a resource to be managed rationally	Planet as a source of extractable value	Environmental degradation is linked to capitalist exploitation; supports collective stewardship.	Environmental regulation and sustainable policy within social welfare systems.	Promotes market-based solutions (carbon trading, green finance) but maintains growth orientation	Sees humans and nature as inseparable; promotes ecological balance, reciprocity, and respect for all life.
Moral Vision	Liberty through reason and law.	Accumulation as progress.	Emancipation through equality.	Justice through protection and redistribution.	Freedom through competition and performance.	Dignity through interdependence and harmony.

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Sindhanai