# Ethical Considerations of Community-based Participatory Research: Contextual Underpinnings for Developing Countries

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**Brief Communication**

## ABSTRACT

**Background:** The nature of community-based participatory research (CBPR) poses distinctive ethical challenges. In the absence of organized guidelines, a remarkable amount of researchers' time and energy will be spent tackling these ethical challenges. The study aimed to explore ethical issues and principles potentially arising when conducting CBPR.

**Methods:** This qualitative study conducted in CBPR Center of Tehran University of Medical Sciences. Required data were gathered through systematic literature review and semi-structured interviews. Representatives of community, academia, and nongovernmental organizations (NGOs) participated in our study. Ten interviews with representatives of partner organizations, four group interviews with academic staff, and four with representatives of community were conducted. Repeated thematic analysis was used to elicit ethics-related overarching themes from transcribed interviews. As recommendations, these themes were then organized into a set of CBPR-related ethical issues and principles.

**Results:** Four CBPR ethical guidelines (including 173 articles) were selected from a systematic review. Overarching themes relating to ethical principles which emerged from interviews were as follows: Trust, transparency and accountability, equity and inclusion, power imbalance, tolerance and conflict management, and attention to cultural sensitivity. Practical principles that emerged included: Consensus rather than informed consent, ownership of data and research achievements, and sustainability and maintenance of relationships. According to findings and in comparison to international guidelines, the present study put more emphasis on cultural sensitivity and sustainability as CBPR ethical tangles.

**Conclusions:** Community-based participatory research ethical challenges are of the same kind in most parts of the world. However, some discrepancies exist that calls for local scrutiny. Future use and critic of current explored ethical issues and principles are highly encouraged.

**Keywords:** Community-based participatory research, ethics, ethical guideline

## INTRODUCTION

Community-based participatory research (CBPR) is one of the most promising fields of inquiry in health research.[1-7] Some scientists emphasize that CBPR is a reliable way to bring about consistent changes respecting health inequalities.[8-13] As a result, the number of studies about CBPR have been constantly soaring during recent years.[11,14-18] CBPR is a participatory perspective to research that tries to equitably involve community members, organizational representatives, and researchers in all phases of the research process.[19]

As a result and due to the collaborative nature of CBPR and complexity of related issues, some ethical challenges in conduct of this kind of research emerge.[20-27] So, many of CBPR researchers spend a lot of energies to address these ethical challenges and predicaments.[20,23] One of the matters that is worthwhile to scrutinize is to explore issues that represent ethical concerns of all parties taking part in CBPR.[28] To put another way, some scientists believe that CBPR ethical issues should be explored and apprehended, contextually with cultural relevance.[20,23,29-31]

Hence, considering increasing popularity of CBPR and, concurrently, dearth of ethical sets of principles on CBPR, especially in developing countries, this study aimed to explore and propound ethical issues and principles for CBPR according to themes emerged from experiences of Iran's CBPR case studies partners. The ethical principles can be used in future participatory research pursuits in the countries with similar situations.

## METHODS

A qualitative study was used to explore and propound a CBPR-related ethical issues and principles. Institutional Review Board (IRB) of Tehran University of Medical Sciences approved the study. Required data was gathered through systematic review of the literature and semi-structured interviews. To develop the guideline, four following stages were taken: (1) To build a team to work on the set of ethical issues, et,(2) to review existing ethical guidelines, and related articles, (3) to conduct interviews, and (4) to revise, and approve the ethical set of issues and principles.

Indeed, a thematic analysis was conducted to explore, unravel, and use emerging themes.

The team that participated in the exploration of the ethical issues and principles consisted of a technical steering committee. The committee included people who were working and cooperating as research partners at CBPR Center of Tehran University of Medical Sciences, coming from academia, nongovernmental organizations (NGOs), and community. They had at least more than 3 years of experience in CBPR and were interested to participate. In the second phase of the project, during a meeting with the team, it was agreed upon to propose a set of ethical principles that can be used in two ways: First, as a tool for adjustment of CBPR projects in IRBs of academic and nonacademic institutes with those principles, and second, as a guide for the conduct of CBPR projects by community researchers in the field. In the third phase of research, a systematic review of the literature was conducted to find the existing relevant ethical guidelines and articles. Databases of MEDLINE, Cochrane Collaboration, CINHAL, Google scholar, and sites of Community Campus Partnerships for Health, National Institute for Health and Care Excellence, and the universities and research centers that have collaborative research departments/courses were reviewed. Keywords used were as follows: "Ethical guideline," "ethics," "CBPR," "community-based research," "participatory action research," "ethic board," "institutional review board," "ethic principle," "ethical challenge." All obtained materials were subsequently translated into Farsi. They were then assessed by steering committee according to their comprehensiveness and feasibility. Ethical principles, ethical issues and the solutions to these issues were subsequently used as interview guides. Then, in the fourth phase, ten interviews with representatives of partner organizations, four group interviews with academic staff, and four group interviews with representatives of communities involved in CBPR projects were conducted. Team members, especially civil society members, were trained to conduct the interviews in a consistent way. To include all possible partners of CBPR in the interviews, maximum variation sampling was used. There were as many as 6–8 persons in each interview group. Interviews continued until no new information came through. Having informed

consent of the interviewees, the interviews were recorded and transcribed immediately after they were done. Participants were assured that their anonymity to participate will be preserved throughout the study. In the fifth phase of research, repeated thematic analysis of transcribed interviews was done, and overarching themes were extracted. Peer debriefing and member checking was used to confirm the credibility of extracted themes. To ensure the external audit of the study, a researcher not involved in the research process examined both the process and product of the research. Finally, the steering committee revised, and approved the ethical set of issues and principles.

## RESULTS

Based on a systematic review conducted by the technical committee, four guidelines (including 173 articles) on ethical issues in CBPR were selected.[28,32-34] A summary of ethical principles of these guidelines is shown in Table 1. These principles were used to develop the questions to be used in interviews. Overarching themes emerged from repetitive thematic analysis of interviews are shown in Table 2.

Concisely speaking, ethical principles are as follows: Trust, transparency and accountability, equity and inclusion, balance distribution of power among partners of the study, believe in collaborative and participatory research, humility and co-learning, respect for diversity, tolerance and conflict resolution, attention to cultural sensitivity, and commitment to personal and professional responsibilities.

Implementation principles of the guideline are as follows: Consensus on expectations, preparing cooperative agreements, consensus rather than informed consent, courtesy of personal information, privacy, anonymity, ownership of data and research achievements, share of knowledge and knowledge translation, sustainability, and maintenance of developed relationships.

### Some of emerged themes are more discussed in the following

#### *Little belief in collaborative and participatory research*

Researchers from academia told "policymakers and managers at our universities do not believe in participatory research," or, "among academia

researchers there is an ambiguity in the role, ability, and capability of community members to take part in a research project." Representatives from NGOs stated "to have a monopolistic approach in a participatory research can be problematic, and some NGOs do not consider this."

#### *Power imbalance*

Community members declared "there are hierarchical and class-related differences between participants" or "community members" opinions are not as important and weighty as other participants… they are not equally involved in decision-making." In this respect, academicians mentioned "participation of community members is mostly of tokenism" or "participation of some authoritative organizations lead to projects that are mainly of interest of those in power." Representatives from NGOs put "there is a tendency among NGOs to impose their ideas on other stakeholders."

#### *Sustainability of community-based participatory research projects*

Academicians put "as time passes, communities usually trust the research and participate and even become hopeful of its future effects. But when the research project meets its ends, researchers leave the community while community members hope for expansion of the research. There is an ethical issue here, that is, we researchers cannot leave the community while the process of empowerment is not completed."

#### *Transparency and accountability*

Community members told "secrecy is a commonplace problem, starting from those on top hierarchical levels down to low levels," or "regarding our problems, people do not know who to talk with and which person to refer to." Academicians pointed "community members expect researchers spend all the allocated financial resources to community issues, while it rarely happens. This leads to financial transparency of researchers to community members." NGOs representatives put that "transparency is of the ethical values and being accountable to stakeholders is an unbreakable tenet and information should be extended to them, but this does not happen sometimes."

#### *Insufficient cultural sensitivity of community-based participatory research*

A community member told "having young girls and boys, or even men and women, working together has some cultural sensitivity," another one stated "due to cultural constraints

**Table 1:** Summary of ethical and practice principles of existing guidelines on CBPR based on a systematic review

| | Guideline 1 (28) | Guideline 2 (32) | Guideline 3 (33) | Guideline 4 (34) |
|---|---|---|---|---|
| Ethical and Practice Principles | Mutual respect, Equality and Inclusion, Democratic Participation, Active learning, Making a difference, Collective action, Personal integrity. Preparing and planning: Why work together? Who should be involved? What are the aims and objectives of the research? Doing the research How will the participants work together as research partners? (working agreement) How will researchers handle information and treat people? How to get Informed consent? How to handle personal information? How confidentiality of participants is assured? How anonymity of participants is secured? Who owns the research project? Who controls and uses the research data and findings? Sharing and learning from the Research How to analyze and interpret research data and findings? How to share the research? How to make an impact? | Autonomy, Nonmaleficence, Beneficence, Justice, Compassion, Honesty, Humility, Practical reasoning | Respect the rights and dignity of the community and the people involved in the research, Respect the academic researchers and the professional responsibilities of the academic researchers, Respect the Indigenous methodologies, Incorporate the strengths, knowledge, experiences, and culture of the community, Acknowledge the community as an equal partner in all aspects of the research, Continuous consultation and collaboration, Relevancy of research to community needs and priorities and being beneficial to the community, Provide opportunities for the involvement of community researchers and utilize community resources. Active, free and informed consent, Present and discuss research analyses, interpretations by all partners, returning reports and summaries in a language and format that is comprehensible to the community, Present research results to the community before disseminated in the public domain, Involve all partners in making decisions about the publication and dissemination of the research and interpretation of the research results, Commitments and obligations of academic researchers, community researchers and partners, Collective rights of the community to know the objectives, methods and potential results of the research Data Collection and management issues and access to them, Ethical approval for secondary data analysis, Dissemination and publication of research results, Knowledge translation, Authorship | Definition of community of interest, Participants involvement in definition of research question, Facilitate learning among community participants about individual and collective resources for self-determination, Apply the knowledge of community participants in all phase of research Empower the community to address determinants of health as the purpose of study, Involve community participants in analytic issues: interpretation, synthesis and the verification of conclusion, Secure benefit of community participants from the research outcomes Reach an agreement between researchers and community participants with respect to ownership of the research data |

CBPR=Community-based participatory research

**Table 2:** Overarching themes (set of ethical issues and principles) emerged from interviews

| Domains | Academicians | Representatives of Community | Representatives of Organizations |
|---|---|---|---|
| Ethical Issues | Insufficient believe in participatory research, Detract from voluntary nature of CBPR due to payment Different expectations among academics and other stakeholders, Power imbalance among the participants, Limited role for community in development of research proposals Financial non-transparency due to uncertainty of payment Inadequate mutual relationship, Limited sustainability and continuity of cooperation, Insufficient mutual trust, Difference between formal informed consent and CBPR-driven appropriate ethical framework, Lack of knowledge translation to community members in all stages of research process, Lack of collaborative research ethics guidelines, Absence of ownership regulations in publication of results, Low commitment to copy right and authorship rights, Limited of scientific humility and respect for implicit knowledge of community members, Inequality in treating with different communities and lack of equal access to opportunities, Inadequate skills in integrating qualitative and quantitative data obtained from different sources, Existence of conflict of interests among participants | Low self-esteem to participate and contribute, Existence of conflicts among different stakeholders based on their expectations and benefits, Discrimination in choose of communities for CBPR, Power imbalance among participants, Insufficient Trust and mutual communication between community members, and between community members and researchers, Lack of sense of security and protection to participate in CBPR, Inadequate transparency and accountability among community and organizations representatives, Insufficient attention to cultural issues and sensitivities, Lack of sustainability and continuity of collaboration in CBPR projects, Bias in selection of priorities due to other partners possibilities | Power imbalance Insufficient mutual relationship between participants Lack of access to adequate funding sources Inadequate ability to accept differences and conflicts, Teamwork challenges among different cultures (existence of cultural sensitivities), Inappropriateness of current informed consents for CBPR (consensus is a better alternative), Lower involvement of community members because of low skills and knowledge, Bias in selection of priorities due to partners' interests and limited resources. Low commitment to ownership regulations regarding data and publication |
| Ethical Principles | Flexibility, Equity, Empowerment, Transparency and accountability, Believe in participation , Balance of power, Collective benefit, Confidentiality, Effective communication | Work ethics, Confidence, Commitment to promises, Transparency and accountability (Feedback in all phases of process) Cultural appropriateness Active listening and effective communication | Believe in collaborative work and coordination, Transparency and accountability, Capacity building and empowerment, Balance of power, Collective benefit, Conflict resolution |

CBPR=Community-based participatory research

and possibility of social activities, women's participation is problematic and limited to some extent." Representatives of NGOs put that "when working with human communities and different cultures we cannot expect to exactly meet whatever is committed to in university contract. In some cultures like western provinces of Iran, it is harder to conduct CBPR projects

than others. For example, due to cross-cultural tolerance and immigration, southern provinces in Iran are stamping ground for many people and strangers, so it is easy to conduct community work there."

## DISCUSSION

Community-based participatory research is often seen to be inherently more "ethical" than so-called traditional research in which there is allegedly a clear distinction between researchers and researched.[20,35] CBPR keeps the track of issues of power, rights and responsibilities, and the roles of all stakeholders, and, due to respect for and partnership with community partners, is more egalitarian and democratic.[20,35-40] CBPR demands complex liaisons of power and accountability, and entails difficulties in preserving anonymity and fuzzy boundaries between researchers and researched, therefore, poses unique ethical challenges for the partnership.[20,35]

The present study aimed to explore and come up with a set of ethical principles and issues for CBPR via a participatory approach. Trust, transparency, and accountability were of the common themes that three interview groups mentioned as core ethical aspects of CBPR. To the authors' mind, there are some reasons for such emerged concerns, mainly: Inappropriate feedback of research results to participants throughout and after completion of projects; history of not keeping up with project promises and changes in research processes due to cut to project financial credits; and policy makers preferences in the selection of CBPR pilot areas (while some other people from other areas participate in research and expect to have the project conducted in their corresponding areas). This calls for measures of trust building as well as knowledge, information, and feedback exchange to all partners. Based on similar concerns, Schaffer's virtue ethics guide acknowledges that the participatory work is in need of professional commitment, integrity, and honesty.[32]

Another touchy ethical issue strongly raised and emphasized by participants of the present study, especially community members were those of equity and inclusion. This emphasis can be an indication of previous experience of gruesome marginalization of nonacademic partners in classical practice of science in which ethical issues of participatory work are not of major concern. Such a concern is also mentioned in other CBPR guidelines and related articles, namely Durham and Kahnawake Schools Diabetes Prevention Project ethical guideline.[28,33] However, insufficient self-efficacy emanating from previous experience of tokenism can impact on people's participation in CBPR.[41] This may lead to dependence on direct governmental support for social change, and reluctance to bottom-up approaches in decision-making, and not to believe in the ability to change.[42] Increasing the level of involvement and participation, and observational learning from successful stories can be of resolutions to germinate and foster positive attitude towards participatory research.

Power-related issues were also of main ethical challenges of CBPR in views of present study participants. Disproportionate distribution of power among the partners of research is mentioned in the Mercer *et al.* guide[34] and many other related resources on collaborative research ethics.[43,44] Power imbalance prevents collective decision-making and empowerment of participants and community involvement in all stages of the research process. Shared power is a democratic style through which all partners of CBPR, especially community partners, have access to sources of legitimacy, and authority. Recognition can be an effective approach to tackle the thorny problem of power lopsidedness.[20] Of sources of legitimacy, authority, and recognition to which all partners should have access in the process of research are ownership of research materials and funds, data, logistics, governmental relations etc., all which should be agreed upon collaboratively.

As per accentuation on the power imbalance, tolerance and conflict resolution was also emphasized namely by representatives of organizations. Due to the nature of participatory research, various stakeholders with different views and perspectives attend in the process of research.[45] Therefore, openness to differences and achieving a shared vision and adjusting the expectations is an essential part of every ethical approach to CBPR, as it can be seen in Durham ethical guideline.[28] It is advisable to develop a process in which all CBPR partners, or at least their representatives, take part

in courses focusing on skills of conflict resolution including negotiation, mediation, diplomacy, and creative peace-building.

Cultural barriers were also among the main issues for conducting an ethics-informed CBPR project. Participants especially were mentally occupied with cultural sensitivities of women's, especially young ones, participation in CBPR. It was told that any CBPR pursuit that forgets to consider norms and attitudes of participation of young girls may encounter challenges. Other studies have also focused on the importance of cultural sensitivities in CBPR projects.[29,46-48]

Sustainability and continuity of the partnership was also signified. Community members were especially concerned with discontinuity of projects that demolish all cooperation and relation bridges built during the process. They felt that they fade into oblivion by researchers or representatives of organizations when research project is completed. Empowerment and improving self-sufficiency of all CBPR partners, maintenance of ongoing academia relations with community members, respect of leaders and local representatives after leaving the community by academicians, and keeping connection of community leaders or representatives to policy makers are some of the measures that can bring about and boost a continued and sustained partnership in CBPR.[49,50]

Generally speaking, however, findings 0f the present study corroborate the principles of reviewed CBPR-related ethical guideline.[28,32-34] This matter comes as no surprise because we used those guidelines issues and principles to develop our questions. Nevertheless, some differences exist between our set of ethical issues and those reviewed guidelines of which cultural sensitivity to women's participation and concern with sustainability of CBPR can be counted.[48,51] It is, indeed, due to the nature of participatory research that firmly takes cultural contexts into account.[31,50] These differences are of local and global importance. It locally shows that why it is somehow tougher to conduct CBPR projects in Iran and other similar developing countries, particularly Muslim ones.[52,53] Those who imagine setting foot into the realm of CBPR in these countries must keep these cultural sensitivities in mind. Globally, the nuances of our

set of ethical issues can add items to repertoire of CBPR-related developed so far, to be considered in future intentions to develop guidelines.

However, the authors never go so far to claim that this explored and propounded ethical set is complete and needless of modifications. We are open to all queries that can enrich the set no matter who raises them.

## CONCLUSIONS

This study demonstrates that CBPR partners in Iran are experientially aware of CBPR ethical challenges, but a lack of an organized set of ethical principles and issues, especially a participative one, prevents their actions to be based on an ethically approved framework. Using the proposed principles by IRBs of ethics and the parties involved in CBPR projects is highly recommended.

## ACKNOWLEDGMENTS

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