

# Ethical Practices in participatory health research: A systemic review of studies in Latin America and the Caribbean

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## Introduction

Community-based health models postulate that it is through community participation that disease/ health processes affecting communities can be revealed. The same principle allows communities to reach higher levels of well-being since the community itself is recognized as having authority. Simply stated, the community can define its own problems & priorities (including their significance) to identify problems and priorities.

Participation itself fosters meetings where a critical review of health/disease processes is possible. Participatory health research is predominantly framed within the structure of Participatory Research & Action (IAP), within in which not just the generation of new scientific knowledge, but also the ability to generate scientific knowledge while seeking the transformation of the communities lived reality.

However, many community health inventions involve a research component to measure health outcomes. The theoretical bases of IAP outline duties which are primarily ethical in nature. These duties typically do not explain the “research” component of the study. The result is

that communities are now down-graded and become disempowered “subjects” who don’t understand the aims of the intervention, nor the use to which the results will be put.

The theory of IAP outlines ethical duties which are principally focused on the definition of “the other,” who will be included in the production of knowledge and who will be respected.

The goal is to establish a horizontal relationship based in equality and respect. The participants are not seen as an “object to be studied.” Instead they are seen as subjects who aware of their reality, have their own voice, and their own capacity to manage their own decisions.

As the asymmetrical “subject/object” relationships – where there is a subject who decides - and an object who obeys - disappear, the door is opened for true participation.<sup>2</sup>

With respect of knowledge production that recognizes the value popular knowledge, there are basically two schools: The first school seeks to “translate” popular knowledge into scientific knowledge. The other school seeks a dialogue between these two schools within which new knowledges will emerge from this dialogue.<sup>3</sup>

IAP recognizes that community members can be producers of new knowledge; knowledge is not the result of the work of isolated individuals; rather scientific understanding emerges from both scientific and popular knowledge. Communities develop knowledge from their daily activities. This means their participation in the leadership of the study and its results.<sup>1</sup>

There are also international regulations that provide a framework for protection against possible risks for participants in health interventions and research, such as the Universal Declaration on Bioethics and Human Rights<sup>5</sup>

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This is particularly relevant when working with vulnerable populations, a group which includes people who belong to groups in society who may be at greater risk of harm by participating in an academic study. This, for example, would include people who have less access to their medical care or education; those who can be stigmatized by their behavior, for example: sex workers; women, children, adolescents, older adults, ethnicities and native peoples. Among the possible damages, we are concerned about stigmatization, loss of status, genetic determinism or transgression of cultural norms, among others.<sup>7</sup>

One of the ways to protect and respect the rights of participants is through measures taken to protect the privacy and confidentiality of their information. In this respect, it is essential to anonymize the identity of people, groups and institutions.

This series of reflections on ethics in research and interventions in community health led us to question the quality of research produced in participatory research in community health in Latin America and the Caribbean. We also wanted to understand which aspects of research are the most difficult in practice.

## **Methodology**

We undertook a systematic review of participatory community health research carried out in Latin America and the Caribbean published between 2006 and 2015. In addition, surveys were conducted on the authors to complete the information

## **Criterios de inclusión**

All studies describing and/or evaluating a participatory intervention in community health were considered relevant for this systematic review, understanding community participation as:

“An organized, collective, free, inclusive process, in which there are a variety of actors, activities and degrees of commitment, which is guided by shared values and objectives, in whose achievement community and individual transformations occur” (Montero, 2004: 109).<sup>1</sup>

In addition, the studies had to meet the following requirements: a) the article describing the intervention in Spanish, English or Portuguese; b) the intervention was carried out in some country of Latin America or the Caribbean; c) The focus of the intervention was on collective health; d) Articles published between 2006 and 2015. This requirement is due to the fact that in October 2005 the Universal Declaration on Bioethics and Human Rights<sup>5</sup> was approved, which can be taken as the basis for ethical aspects related to health interventions.

## **Choosing the Studies**

The search was carried out through the search engine LILACS (Latin American and Caribbean Literature in Health Sciences).

The search strategy consisted of combining the terms: “Systematic Review” y “Sistematic Revision” in the title as the interest of the authors was to examine articles that evaluated interventions.

## **Study Selection**

La Figure 1 describe el proceso of selecting the articles. This involved three stages: The first was determined by the titles of the articles and turning down those articles which did not conform to the inclusion criteria. The second stage took place after the abstracts were evaluated to see if the article was appropriate. In some cases the decision to include the article was a decision based on the title and abstract only.

## **Data Analysis**

A narrative synthesis was carried out describing the interventions, their characteristics, the theme of the intervention, the context in which it was carried out, the activities, the participants, the facilitators, as well as the evaluation design, The techniques and that shows.

To assess ethical aspects, including individual or community informed consent, the ethics committee, participation of vulnerable community, confidentiality and privacy and co-authorship of articles, the Universal Declaration on Bioethics and Human Rights<sup>5</sup> and relevant authors were taken as reference on IAP issues.

**Tabl 1**  
**Characteristics of the Interventions**

Article	Country	Health issue	Context	Activities	Participants	Facilitators
8	Brazil	HIV	Support House for Children	Health care, housing, emotional support and restoration of family ties	Orphaned children with HIV	Coordinators, volunteers, health professionals
16	Mexico	Diarrhea	Municipality	Health committees, health promoters, song, interpersonal discussions, community meetings, socio-drama, radio, comics	5 municipalities, local authorities, community leaders, health workers, teachers	Community leaders, health workers, teachers, with the support of researchers
9	Brazil	Sexuality	school	Discussion about problem situations, anonymous questions, social networks	1st and 2nd year students of a high school	9 first-year medical students, 6 community health agents, university professor
23	Venezuela	Intestinal parasites	school	Copro-parasitological study, educational talks, consultation sessions, participatory techniques, group, recreational and work activities	Children from 0 to 14 years of an educational unit, parents, formal and informal leaders, community in general, different sectors related to health, well-being and education	Doctor, community staff after training in a workshop
10	Brazil	Mental health	Health Unit	Life history, group dynamics, manual work	Older women attending the Mental Health Program of a Health Unit	Technical team
11	Brazil	Mental health	Health Unit	Community therapy	Women who have suffered some loss and participate in community therapy meetings	Community therapy group coordinators
21	Argentina	Respiratory infections, diarrhea and parasitosis	Community dining room	Health promotion workshops	Mothers of families who attend community canteens	Pediatrician
24	Nicaragua	Pneumonia, diarrhea and dysentery	Municipality	Case management in the community	Low-income children in remote communities	Brigadistas (community health volunteers)
18	Chile	Disability	Commune	Community based rehabilitation	People with disabilities, families and community	Ministry of Health, National Disabled System
25	Dominican rep	HIV and STDs	Sexual establishment	Workshops, meetings, posters, stickers, condom disposal, monthly STD checks, messages per speaker, informational stands, educational materials, interactive theater presentations, politics and regional regulation that requires the use of condoms between sex workers and clients	68 sexual establishments in two cities (34 per city)	NGOs, sex workers as interpar educators, Ministry of Health

26	Colombia	Healthy school	school	Health promotion and disease prevention in schools	15 primary school educational institutions	Meta Governorate, the Department of Departmental Health and the Family Welfare Institute
19	Cuba	Special Educational Needs (NEE)	Medical Center	Attention to children with special educational needs	Family members of children with SEN and neighbors	Technical team
17	Mexico	Waste management	Municipality	Identification of solid waste sites	76 local residents and 3 environmental health experts	Center for Health Systems Research, Cardiovascular Foundation of Colombia, Center for Population Health Research
12	Brazil	User Human Rights	Psychosocial Care Center (CAP)	Psychosocial care	Phase 1: references of each of the 5 CAPS. Phase 2: Users, family and professionals of each CAPS	Referents of universities
27	Peru	HIV, cancer and tuberculosis.	Social organization	HIV, cancer and tuberculosis programs	Government references, representatives of civil society organizations (CSOs) and leaders of organizations of people affected by HIV, cancer and tuberculosis	Government references that implement public policies and OSC leaders.
13	Brazil	Health control by the population in the family health strategy	Basic Health Unit	Community approach, problematization of health system logics, walks and informal conversations, interviews	Users of the health system, organized social movements, health service workers. Total user population 3400	Health service workers and users.
20	Cuba	Community participation and empowerment	Popular tips	Workshops, participant observation, in-depth interviews with key informants	129 leaders, 16 of them represented the health sector, 40 intersectoral and 53 the community.	Health area workshops
14	Brazil	Facilitators and barriers in social projects Community-School	school	Sport activities	Children and teenagers	Teachers and referents of the municipality in charge of the program.
22	Argentina	Chagas disease	Primary Health Care Centers, school	Recovery of knowledge, design of actions with each community, sampling and intervention with infected	Women with Chagas, health teams, community referents, teachers, students and parents	University teachers - research and extension experiences.
15	Chile	Inhalation of carbon monoxide	Commune	Training, obtaining a building authorization stamp	519 municipalities and 771 people trained building managers.	Expert professionals - trainers
28	Brazil	Social control in family health strategy	Municipality	Participation and social control activities	Users and coordinators of the health service.	Health service coordinators.

Source: self made.

**Table 2**  
**Study design, technical issues, and sample**

Article	Design	Techniques	Shows
8	Qualitative	Oral history, documentary analysis	Key informants: president of the institution, 2 coordinators, 1 member of the board of the financing company, 1 volunteer social worker; 1 NGO member, 1 doctor and a psychologist.
16	Mixed	Questionnaires, institutional survey of schools and health centers, discussion groups with community members, training for local interviewers	3,000 homes in 5 municipalities.
9	Quantitative	Questionnaires	118 students
23	Quantitative	Copro-parasitological study, questionnaire	172 children between 0 and 14 years of educational unit and their parents
10	Qualitative	Bibliographic and documentary review, observation	Older women attending the Mental Health Program of a Health Unit
11	Qualitative	Interviews	13 women participating in community therapy meetings
21	Quantitative	Poll	145 mothers of families attending 7 community canteens
24	Qualitative	Discussion groups, interviews, documentary review	National, departmental and municipal staff of the Ministry of Health, technical organization staff that finances the intervention, volunteers who carry out the intervention, mothers of children participating in their communities
18	Qualitative	Focus groups, observation, interviews, field diary, document review	Professionals, technicians and staff of the centers that had community-based rehabilitation programs, community actors, organizational actors, people with disabilities and their families
25	Quantitative, pre and post intervention evaluation	Questionnaires, STD testing, observation	200 sex workers
26	Quantitative	Action plan, instrument for evaluation of the process, questionnaire on evaluation of results, registration form of the healthy school and observation guide	100% of managers and teachers (215), parents who voluntarily wanted to participate (300) and 1,710 students from the 15 educational institutions
19	General dialectical-materialist method, historical-logical, systemic theoretical methods, participatory and ethnographic action research.	Interview, participant observation, survey; discussion group, semantic differential and family environment inventory.	4 families of children with SEN, neighbors of the communities where families live together
17	Quantitative	Identification of areas on maps and Procusto analysis.	76 lay informants, 3 expert informants.
12	Mixed	Census of resources of the CAPS. Interviews with referents and direct observation.	5 CAPS references, 25 users (5 for each CAP), 25 family members (5 for each CAP) and 25 professionals (5 for each CAP)
27	Qualitative	Document analysis, semi-structured interviews.	20 individuals (10 by the government and 10 by civil society), 17 people involved in general health policy and national responses to HIV, tuberculosis and cancer, 8 government officials, and 9 NGO leaders and organizations of the community that work with the selected themes
13	Qualitative. Investigation action.	Participant observation, walks and informal conversations,	3,400 users of the health service. 59 interviews were conducted, 5 interviews of professionals and 5 of users were

		field diary, interviews, discussion groups / conversation rounds.	selected.
20	Qualitative, participatory action research applying the CPPE (Comprehensive Participatory Planning and Evaluation) methodology	Participant observation, questionnaires (to leaders), in-depth interviews, standardized reports of the case studies of the methodology (REECM)	129 leaders, (16 represented the health sector, 40 the intersectoral and 53 the community)
14	Qualitative - grounded theory	Systematic observations and interviews (individual and collective in the case of children)	1 program coordinator, 5 regional coordinators, 4 teachers, 5 student interns, 3 volunteers, 45 children and adolescents from different schools
22	Mixed	Meetings with referents, screenen	Women with Chagas, health teams, community referents
15	Quantitative	Attendance and approval records, satisfaction and opinion surveys	519 municipalities. 717 people trained
28	Qualitative	Semi-structured interviews, systematic observation and document analysis.	20 workers that make up the ESF teams, 5 registered users on those teams

Source: self made.

**Table 3**  
**Ethical Committee & informed consent**

Information obtained from	Ethics Committee		Use of informed consent				
	Yes	They do not inform	Yes	They do not inform	Type		
					Individual	Community	Both of them
Item only	7 (33%)	14 (67%)	6 (28%)	15 (72%)	6 (100%)	0 (0%)	0 (0%)
Article and survey	10 (48%)	11 (52%)	11 (52%)	10 (48%)	7 (72%)	1 (9%)	3 (27%)
	21 (100%)		21 (100%)		10 (100%)		

Source: self made.

### Authors survey

In order to complete and / or corroborate the information obtained from the articles, closed surveys were conducted in Spanish, English and Portuguese. They were sent by email to the contact address that appeared in case it was no longer available, emails were sent to the other authors, following the order in which they appeared. After fifteen days a reminder was sent to those who had not responded. Twenty of the twenty-one authors were contacted, of which eight responded

### Results

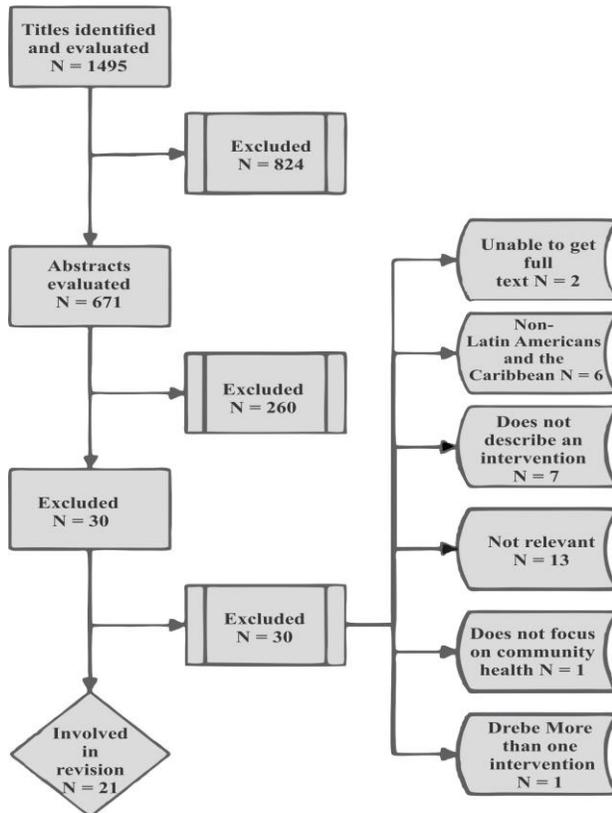
Twenty-one interventions were identified. Table 1 summarizes its main characteristics:

country, health issue, context, activities, participants and facilitators. Table 2 describes the research design, techniques and sample used to evaluate the interventions.

### *Comité de ética y consentimiento informado*

As can be seen in Table 3, of the interventions highlighted in this systematic review, ten detail that the research protocol was evaluated by an ethics committee.<sup>8,11-14,16,18,22,25,28</sup>, eleven mention the use of informed consent.<sup>11,14,18,19,22,23,25,27,28</sup> In the cases in which informed consent was used, eight were individual consents<sup>13,15,19,22,23, 25,27,28</sup>, one was community<sup>11</sup> and three included consents of both types.<sup>12,18,22.</sup>

**Figure 1**  
**Article selection process.**



Source: self made **Ethical Aspects**

### Vulnerable Populations

Table 4 shows the research in which vulnerable populations participated, including the low socioeconomic status;<sup>14,16,19,21</sup> minors;<sup>9,23,26</sup> women;<sup>10,11,21,25</sup>; students<sup>9,23,26</sup> sex workers<sup>25</sup> and people with disabilities<sup>19</sup>. In most cases there was more than one vulnerability condition.

**Table 4**  
**Vulnerable population**

Article	Vulnerable population
16	Population of low socioeconomic status
9	Minors, students
23	Minors, students
10	Women, older adults
11	Women
21	Women, population of low socioeconomic status
18	People with disabilities
25	Women, sex workers
26	Minors, students
19	Minors, disability, population of low socioeconomic status
14	Minors, population of low socioeconomic status

Source: self made.

### Privacy and confidentiality

Of the articles analyzed, five describe the procedures used to guarantee privacy and confidentiality<sup>13,14,25-27</sup>. Table 5 details what they were, grouping mainly in: anonymity or fictitious name assigned to the participants or given by privacy at the time of the interview or documentation of the information.

**Table 5**  
**Confidentiality and way of guaranteeing**

Article	Way to guarantee it
27	Conduct the interview in a private room.
25	The interventions were anonymous and developed exclusively within sexual establishments.
26	After the interactions, research was documented in private rooms also within the establishments.
13	The name of the people was not mentioned
14	In the presentation of results, people are assigned names of fruits to ensure anonymity.

Source: self made.

### Community co-author

Of the twenty-one articles, none included the co-authorship of the community that participated in the intervention and only one co-authored the facilitators of the intervention<sup>11]</sup>

### Other ethical considerations

Table 6 shows other ethical considerations mentioned in the articles.

**Table 6**  
**Other ethical considerations**

Article	Ethical considerations
8	Written permission to use the name of the institution
16	Free medical consultations for the duration of the study
23	A first version of the intervention strategy was submitted to the criteria of experts in the areas of general medicine, community intervention and epidemiology. Authorization of government, health and educational authorities. Necessary experience of the researcher to carry out the study. No international authorizations were required, since invasive methods that jeopardized the integrity of people were not used.
21	The pediatrician who coordinated the workshops is independent of the food delivery program, to avoid that the answers to the questionnaire are assumed by the participants as a consideration for food delivery.

24	Verbal Consent Return to the community.
25	Potential participants were given detailed information on the objectives, procedures, risks and benefits of the study. In cases where STDs were detected, compensation was immediately paid for participation. The local organization of sex workers was asked for approval on the use of participatory observation. The investigation was based on the International Ethical Guidelines for Research and Experimentation Bioethics in Human Beings and bioethicists were consulted.
26	The ethical principles of privacy, confidentiality, self-determination and the provisions of local regulations were taken into account
19	They consider the ethical principles of respect for self-determination and are based on the informed consent of the parents of the children. The authorization is indicated by the management of the institution to which they belong to carry out this investigation. Do not make differences by economic or sociocultural class.
27	Consent is requested to record interviews.

Source: self made.

## Discussion

The present investigation answers the question about the ethical considerations that are taken into account in participatory research in community health in Latin America and the Caribbean and about those aspects that need to be reinforced.

The interventions and research identified in this systematic review are very heterogeneous in relation to the participants, activities and research methods. Vulnerable population participates in most cases, which is expected, as collective health interventions try to support those who have been most affected by different social and economic policies. However, fundamental ethical aspects are not described, for example, it works with minor students and it is not detailed if parental consent was used.

Half of the articles communicate the use of informed consent and approval by an Ethics Committee, only a quarter describe the procedures to guarantee privacy and confidentiality.

As mentioned earlier, the theoretical body, both of health interventions in communities, and of the IAP, outlines ethical duties related to the role of the researcher, the definition of the other, their inclusion in the production of knowledge and respect for that other. However, as Montero (2004) points out, ethical aspects are sometimes present in the action but are not usually considered as an integral part of a way of producing knowledge, of doing science. This can be seen in the null or brief communication about ethical aspects that appear in published articles and that we believe are a challenge to think about participatory research publications. However, by consulting them through the survey, some of the researchers expressed the importance that ethical aspects have in their practices, which goes beyond mere compliance with the regulations that regulate them.

Other ethical aspects, such as co-authorship and ownership of knowledge produced by the community, present greater challenges. On the one hand, it is necessary to think about the framework of the practices, whether it is from translation or from the dialogue of knowledge and, on the other hand, to consider around which themes and with what participatory social scenarios this would be possible.

From these reflections it follows that it is necessary both with the communities and in the scientific field, to generate more visibility of the ethical aspects in health research, especially with regard to the real participation of the communities in the research steps. reflection-action. On the other hand, the contribution and knowledge of community members is recognized within the process of knowledge construction. Likewise, the tools for the protection of the rights of the community should not be left aside as participants in an investigation, such as informed consent and ethics committees.

Finally, another aspect that has not been part of the present investigation, but that both the studies of Castillo and Winkler,<sup>29</sup> and those of Keatinge<sup>30</sup> point out, are those referring to the degree and mode of involvement of the researcher in the IAP processes. This will clearly impact ethical dilemmas that need to be analyzed in health research with communities through the use of IAP.

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