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How Participatory Are We? A Systematic Review Comparing Women'S Participation In Participatory Action Research, Community Based Participatory Research And Participatory Learning In Action

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by

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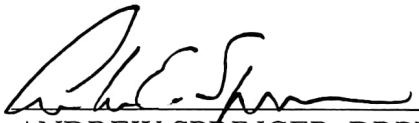
APPROVED:



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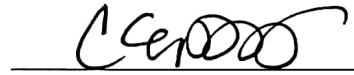

COURTNEY BYRD-WILLIAMS, PHD

DEDICATION

To Jon and Maxwell Hartman

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BS, University of Texas in Austin, 2014

Presented to the Faculty of The University of Texas

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PREFACE

In the process of engaging in grassroots educational activities with the Baha'i Community, I was pulled deeper into conversations with families, particularly about the promotion of health. I hoped to prepare myself to engage with this aspect of community by pursuing public health and studying how community members engage in learning processes of health promotion. The aim of my studies is to nurture "the involvement of a growing number of people in a collective process of learning, one which is focused on the nature and dynamics of a path that conduces to the material and spiritual progress of their villages or neighborhoods. Such a process would allow its participants to engage in the generation, application, and diffusion of knowledge, a most potent and indispensable force in the advancement of civilization."[1] The conceptual framework described by the Baha'i World Center in its document, Social Action, is a lens within which I study public health and seek to apply the insights of this field in my community.

[1] *Social Action*. *A paper prepared by the Office of Social and Economic Development at the Baha'i World Centre*. November 26, 2012.

ACKNOWLEDGEMENTS

I thank my dear family for supporting my continued studies, despite the sacrifices small and large that they bear for me to do so every day. I wish to convey my deepest appreciation for the mentorship, guidance, and friendship of Andrew Springer and Courtney Byrd-Williams throughout this program and thesis. And, I acknowledge all the friends along the way who have taught me a great deal about participation and supported my child while I worked on this.

HOW PARTICIPATORY ARE WE? A SYSTEMATIC REVIEW COMPARING WOMEN'S PARTICIPATION IN PARTICIPATORY ACTION RESEARCH, COMMUNITY BASED PARTICIPATORY RESEARCH AND PARTICIPATORY LEARNING IN ACTION

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Objective. This systematic review compares the extent of participation of women in maternal and child health and healthy living-type research projects based on three participatory research frameworks, Participatory Action Research (PAR), Community Based Participatory Research (CBPR), and Participatory Learning in Action (PLA), by examining roles, tasks, engagement, and the duration and complexity of their participation- as guided by the Community Engagement in Research Index (CERI). The review analyzed differences in underlying structure of the studies connected to their theoretical underpinnings.

Methods. Ovid Medline, PubMed, EBSCO, CINAHL, Embase, Scopus, and Academic Search Complete were searched for studies published 2009 – 2018. Eligibility was assessed by the author through predefined inclusion and exclusion criteria. Qualitative and quantitative data related to participation were extracted from each study into a coding form, then organized for analysis into tables and diagrams for each measure of participation based on categories informed by CERI.

Results. Of the 728 abstracts reviewed, 28 studies met inclusion criteria following full text review. These included 9 PAR, 16 CBPR, and 3 PLA studies. Of these,
PAR studies engaged local women primarily in data collection and analysis, often through photovoice. PAR roles involved a median of 4 research tasks and lasted 3 months. PAR studies typically had researchers worked directly with the population in small numbers. CBPR roles were more heterogeneous. They had the lowest duration (2 months) and complexity (3 research tasks), and were more active in developing institutional arrangements. PLA demonstrated the longest duration (24 months) and highest complexity (9 research tasks) of participation. PLA maintained participation through the research stages, while PAR and CBPR participation dropped at implementation and evaluation. PLA engaged the largest numbers of collaborators in projects.
Conclusion. Each framework has unique strengths to contribute to participatory research. Theoretical differences relating to objectivity of participatory evaluation, whether action should be inherent to participatory research, and how to design studies in which the recipients of an intervention are protagonists of learning processes require further exploration. Creating reporting standards for participatory research will improve the ability of future reviews to examine and synthesize insights related to participation.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF APPENDICES

BACKGROUND

1.1 Literature Review

Participation in health promotion has been described as essential for ensuring just distribution of resources, decision making power among marginalized populations, and effectively reaching indigenous populations.-The theoretical underpinnings of participatory research call for a standard beyond what many would say has been achieved. This thesis proposes to describe the extent of women's participation in participatory research aimed at nutrition and physical activity, and examine core issues of participatory research, by comparing three frameworks: Participatory Action Research (PAR), Community Based Participatory Research (CBPR), and Participatory Learning and Action (PLA).

For many, participation is a matter of moral obligation to reduce inequality while improving society, while others question the objectivity and quality of scientific endeavors that involve the objects of study as the participants or purposefully intend to act upon the reality being studied. Whyte, a PAR researcher, describes two views of science: that the scientist is to discover basic facts and relationships and others are to make use of this knowledge; or closely linking research and action is important both for the advancement of science and for the improvement of human welfare.[1] The second view assumes that science is undertaken for the explicit purpose of improving society, or what we might call "development." It is within this view that research specifically aimed at involving local communities in cycles of study, action, and reflection emerged.

Such research has aimed at creating a new paradigm of development, avoiding the traditional approaches that treated development as the transfer of technologies, goods and services, patterns

of consumption and production, models of governance and social organization, and the very way of life which had come to characterize the highly industrialized parts of the world such as the United States and Europe. Crucially, this approach gave little regard to local autonomy, history, culture, and the ability of the peoples of recipient nations to define and pursue their own course of progress, as evidenced by the phenomenon of rural development tourism.[2] A new paradigm for development took shape that emphasized local capacity for collective inquiry with the aim of developing local communities, particularly in marginalized populations. As these participatory approaches to development took shape, they paid close attention to the dynamics of power connected to who generates knowledge and who consumes it. Naturally, frameworks for research that mirrored this approach to development emerged and evolved. In 1978, the Alma-Ata Declaration listed participation in health care as a key principle in the resulting declaration, and stated that "people have the right and duty to participate individually and collectively in the planning and implementation of their health care."[3] Specifically, for maternal and child health, the conference determined that community participation should complement all facility-based components of health care provision.[3] The participation of communities and individuals in development of maternal and child health, viewed as a right and responsibility of all individuals.

Three of the more widely known approaches to community engaged research include: Participatory Action Research (PAR), Community-Based Participatory Research (CBPR), and Participatory Learning and Action (PLA). These approaches share common principles tracing their origins to two main traditions – a pragmatic approach, founded by Kurt Lewin in North America in the 1940s who described cycles of action and reflection embedded in research, and the emancipatory tradition of Paulo Freire and his contemporaries in South America who wrote

of the generation and application of knowledge as a means of overcoming oppression in the 1970s.[4]

CBPR is defined as a collaborative effort "*among community, academic, and other stakeholders who gather and use research and data to build on the strengths and priorities of the community for multilevel strategies to improve health and social equity."*[5] A first set of principles was outlined for CBPR in 1998, which has been refined several times since.[5] In 2018, Israel and colleagues stated CBPR: is participatory, considers community as a protagonist, builds on strengths and resources within the community, engages community and researchers as equal partners, involve a co-learning and community capacity building among all participants, empowers participants to have more control over their lives, achieves a balance between research and action, emphasizes dissemination of the knowledge gained to (and through) all partners, requires long term commitment and cultural humility defined as self-reflection on power imbalances and authenticity of partnerships.[5] CBPR practitioners see their work as encompassing the same approach as other terms for community engaged research.[5]

PLA seeks to empower local people to "*express and enhance their knowledge and take action.*"[6] It evolved from earlier versions of participatory research in the 1970s and 80s called Rapid Rural Appraisal (RRA) and Participatory Rural Appraisal (PRA). PLA was introduced in 1995 and is used as an umbrella term for the earlier methods as well as newly evolved ones.[6] PLA operates on cycles of reflective learning, and the interplay of three key components: facilitators' orientation, interactive methods, and sharing.[6] PLA is characterized by the trusting environments for group sharing and its dynamic techniques of assisting a group to "express their knowledge," particularly with visual activities. Unlike PAR and CBPR, which describe their

framework in terms of broad principles rather than specific methods, PLA literature, from the outset, appears technical and specific, giving much attention to carefully developed techniques, visual and tangible, developed by PLA facilitators to generate and co-analyze data while eliciting participation of marginalized and privileged populations alike.[7-9]

PAR has been described as a "*way of learning how to explain a particular social world by working with the people who live in it to construct, test, and improve theories about it so they can better control it. [With specific interest] in theories that help people learn how to better control the circumstances of their lives*."[10] Fals-Borda and Muhammad Rahman describe the process of PAR as: "*a self-conscious people, those who are currently poor and oppressed, will progressively transform their environment by their own praxis. In this process others may play a catalytic and supportive role but will not dominate.*"[11] PAR, similar to PLA and CBPR, operates on iterative reflective cycles of data collection, reflection, and action, but is specifically oriented towards the transformation of oppressive social relations as in the "emancipatory" tradition of Paulo Freire's popular education.[4] In these cycles of reflection and action, participants gain critical consciousness, leading to further action, and they come to see their work in a historical context, and that their reality is susceptible to transformation.[4] The core tenets of PAR consist of (1) collective research, (2) critical recovery of history, (3) valuing and applying folk culture, and (4) production and diffusion of new knowledge. The aim is to break the monopoly on the means of production and reproduction of knowledge ascribed to an elite class of research practitioners and intellectuals, and democratize its generation, application, and diffusion to all peoples, especially the poor and oppressed.[12] In that vein, PAR does not always fit the traditional conception of research, and is sometimes more aptly described as "people's science."[11] PAR,

while having applications to health promotion research, did not evolve in health promotion research like CBPR, but has been utilized in diverse community and even industry settings, at times without a specific intention to carry out 'research.'[1]

Underlying all community engaged research frameworks is the desire for marginalized populations to determine the course of, and contribute to, their own progress. This desire stems from a belief that with greater participation, a more accurate assessment of reality can be observed, and the action that emerges from that assessment is more effective. Whyte describes this as a special rigor of participatory action research, involving checking and cross-checking one's facts and explanations because the community is going to invest in actions based on it, while a typical researcher can offer an explanation for the data they collect and shrug off community members that argue otherwise.[1] In Whyte's experience, the more that people familiar with the context assessed, critiqued, and suggested data and its' accompanying explanations, the higher the standard of factual accuracy as a larger number of people had to agree to the final analysis.[1] In other words, higher levels of participation are essential to more accurate data and effective action to be taken. This has already been demonstrated to some degree, as participatory approaches have demonstrated success in engaging minority groups in research, and effectively reaching their intended outcomes.[5,13]

A special population of interest in participatory research has been women, who have historically been denied access to education, power in decision-making, and opportunities to contribute meaningfully to public discourse. Participation in community engaged research among groups unable to access formal education is a significant advance towards democratizing knowledge in a community. Women's participation in such research has demonstrated improved

health outcomes, and investing in their health has multiplicative benefits to their children and partners.[14] In the case of women's groups using PLA, a meta-analysis of cluster-randomized trials supports that involvement in PLA effectively improved behaviors to reduce neonatal mortality.[15] The progress of women is the progress of the whole family, making them an ideal focus of participatory research and development. However, not all participation is empowering.[10] Learning about methods and approaches that engage women fully as participants that are co-creators of each stage of the production and diffusion of knowledge is essential to increasing effectiveness of community engaged research and practice in women's health promotion. Therefore, it is essential to examine the extent of participation women are currently engaged in and describe the methods being used in public health research and practice.

1.2 Public Health Significance

Community engagement has been found to increase the effectiveness of interventions and improve retention of minority populations in health programming.[13,16]Participation has been limited to certain stages of research such as disseminating findings, participant recruitment, and delivery of the interventions more than other stages of research.[13]As described in the 1978 Alma-Ata Declaration, the community has a "right and duty" to participate in healthcare. While reviews have analyzed and supported the instrumental value of participation in systematic reviews and meta-analyses, perhaps more powerful is the intrinsic value of participation of people engaged in the generation, application, and diffusion of knowledge that develops their communities. In the arena of health, women play a significant role in the well-being of their families and community as previously mentioned. Development of capacity among women in a community to engage in systematic learning about development is significant even if outcomes

are not initially manifested. Rosato et.al. poses the question of whether the reason for not meeting Millennium Development Goals for reduction of maternal and child mortality is because of our "failure to incorporate community participation into large-scale primary health care programmes."[3] Essential to answering this is knowing what degree women's participation currently has reached in the field of public health and what methods have been used that engage women in the various stages of research and practice. This review will provide a description of women's participation, comparing three frameworks of participatory research and practice so as to inform next steps for the public health community's efforts in improving maternal and child health through achieving higher levels of participation of women in the process. A comparison of CBPR, PLA, and PAR has not yet been conducted, as far as I am aware, and I expect the differences in theoretical underpinnings will allow a fuller picture of participation to be established and outline some essential characteristics of participatory efforts.

1.3 Research Aims

The aim of this systematic review is to describe the extent of participation of adult women of child-bearing age in healthy living maternal and child research published from 2009 to 2018 that reported using CBPR, PAR, or PLA as a framework and compare the methods of participation and self-inquiry in each. I aim to address the following questions:

- How do MCH healthy living studies reporting to use CBPR, PLA, or PAR approaches compare and differ in the stages of research (assessment, planning, intervention, evaluation, dissemination) women are participating in?
- Within each research activity, what level are participants participating at? (i.e. consulted, actively engaged, or leading activities)?

- What roles do local women take on in the process of generating knowledge across CBPR, PAR, or PLA, and how much latitude do they have in these functions?
- What are the differences in the structure of CBPR, PAR, or PLA research that facilitate participation?

Comparing CBPR, PLA, and PAR, this review identifies a number of ways women are engaged in generating knowledge, the stages and tasks of research in which participation typically occurs, and future areas to learn about in participatory research.

METHODS

2.1 Search Strategy

This comparison of participatory frameworks is accomplished through a systematic review, gathering studies that involved female participants in the research process.

The search was conducted in Ovid Medline, PubMed, EBSCO, CINAHL, Embase, Scopus, and Academic Search Complete, with terms shown in Table 1. This search was used in each database, and was developed in collaboration with an experienced librarian.

Table 1. Search Strategy

1	Community-Based Participatory Research.mp or Community-Based Participatory Research/
2	(CBPR or community based participatory research or community mobilization or community participation or participatory action or participatory learning or participatory process).ti,ab,kw.
3	1 or 2
4	Female/
5	women/ or pregnant women/
6	mothers/ or single parent/
7	(female or females or mother or mothers or woman or women).ti,ab,kw.
8	4 or 5 or 6 or 7
9	3 and 8
10	limit 9 to (english language and yr="2009 – Current")
11	exercise/ or physical conditioning, human/ or running/ or jogging/ or swimming/ or walking/ or stair climbing/
12	(exercise or physical activity or running or jogging or swimming or walking).ti,ab,kw.
13	life style/ or healthy lifestyle/ or healthy diet/ or life change events/ or sedentary lifestyle/
14	(life style or lifestyle or sedentary).ti,ab,kw.
15	food/ or dietary carbohydrates/ or dietary fats/ or fast foods/ or food, fortified/ or fruit/ or meat/ or vegetables/ or diet/ or eating/
16	Food Supply/
17	(food or diet or nutrition or fast foods or vegetable* or fruit*).ti,ab,kw.
18	11 or 12 or 13 or 14 or 15 or 16 or 17
19	10 and 18

2.2 Inclusion & Exclusion Criteria

Studies that are in English, are peer-reviewed and published literature, have PAR, CBPR, or PLA in the title or abstract, related to nutrition or physical activity, include 19-49 year old women, and are published between Jan 2009 and April 2018 are included. I excluded articles that do not explicitly state that they follow a participatory framework including PAR, PLA, or CBPR, are protocols, reviews, or conceptual framework articles, or studies that engaged men as participants.

Several points were considered in designing the inclusion and exclusion criteria. The years for inclusion are 2009 to the present, because 2009 marks when CBPR became a medical subject heading (MeSH) in the Library of Medicine.[5] Excluding studies with men participating will support the comparability of approaches as the power dynamics of the learning process in which both men and women are engaged may be different from those with only women. I also limited the age range of participants to 19-49, because these are childbearing years for adult women. This stage of life for women is particularly critical to health of the whole family, because they are often the primary caregivers. Finally, the philosophical underpinnings of participation are key to comparison, so studies that do not make explicit the framework they are employing, either PAR, PLA, or CBPR, are excluded.

2.3 Data Extraction

Studies were coded for citation features (author, publication status, publication date), the study level (study location, enrollment years, participatory framework, study design, recruitment methods and setting, participant characteristics, and topic area), and participation characteristics (participant time commitment, tasks, decisions, stages of research they were involved in,

methods, criteria for the Community Engagement in Research Index (CERI).[17] New variables were added as needed. The coding form used is included in Appendix A. Information about the roles women were employed or volunteered in as well as a brief description of each was gathered in a separate excel document, along with participatory methods, and phrases in the papers that described the level of participation the women were involved at. Each paper was read in full two to three times as coding evolved to include new variables and additional information needed to be gathered. Table 2 provides the descriptive characteristics of the 28 included studies.

2.4 Data Analysis

2.41 Stages of Research

For each study, I coded which stages of research the local women were included in as collaborators. The Table also describes the duration the local collaborators were engaged in the study and what stages (Assessment, Planning, Implementation, Evaluation, and Dissemination) of the research process they were engaged in. For the purposes of this review, assessment is defined as efforts to understand the reality, such as identifying key health issues or resources. Planning is defined as the development of the intervention or action to be taken based on the identified needs and opportunities of the assessment, including the creation of materials for the program. Implementation is defined as taking action – whether programmatic, policy, or other. Evaluation includes both process and outcome evaluation, informal or formal, that assesses the actions implemented. Dissemination is defined as the sharing of insights gained from the previous steps including writing reports, presentations, hosting meetings to share knowledge, or home visits with the community.

There are nuances to defining stages. Here are a few examples demonstrating how they were categorized. A study may be implementing an assessment alone – a cross-sectional survey or focus group. In such cases, they are only categorized as assessment unless the group decides to take action upon the results. Another example is when there is a smaller research project done by groups of participants within the larger study. In this case, I use both the smaller effort and the study to categorize participation. While the group of participants may be involved in a smaller project concerning their individual gardens or hosting a short term community intervention, their learning process is also counted as participation in that stage. Another common example is when the action the collaborators decide to take is presenting the information they gained in their assessment, such as by writing to politicians or creating an exhibit of their photovoice. This kind of study is assessment, planning, and implementation. If they evaluated the success of their effort and then shared those findings, it would be included as evaluation and dissemination.

With the studies coded by stage of research, I used Excel to sum the number of studies, by research framework, in each stage of research. These totals formed the basis of the bar graph in Figure 2 to quickly see the differences in participation of research stage by research framework.

2.42 Measure of Engagement in Research Tasks

Studies were examined using an adaptation to the Community Engagement Research Index (CERI), a tool developed to quantitatively measure the extent of participation in a number of research tasks.[17] Rather than provide the number of participants and the percentage engaged at each level, as initially intended, I report the study number corresponding to Table 2 to illustrate how many research tasks the study engaged the local people in. The three levels of participation

are: consulted, actively engaged, or leadership role. By examining the descriptions of engagement reported in the studies, I began to develop definitions for these categories. "Consulted" is defined as local people providing suggestions or feedback only. For example, studies reporting that local members of their steering committee reviewed the survey or interview tool and gave comments on how to improve it would be categorized as having "consulted" people on designing interview or survey questions. "Actively engaged" is defined as when the local collaborators are doing the task as designed by others, such as when community health workers are conducting the intervention or photovoice participants are examining the themes of the data they collected. They were not decision makers in how such thematic analysis should be organized or what questions to center their discussions on, but they were nonetheless engaged fully in the activity. "Leadership role" describes when the local collaborators had full latitude to do the task in the way they planned. For example, PLA women's groups would identify challenges and opportunities, discuss possible solutions, develop an intervention, and execute it in the way that they planned. These participants would be categorized as leading the intervention. Participants that exercised agency to determine what data to collect would also be categorized as having a leadership role in data collection.

2.43 Describing Roles Collaborators Performed

One way to examine participation was describing the roles women were employed in as local research collaborators. The roles capture how women contributed to the learning process, and provided insight into the extent the research relied on local collaborators or did not. These descriptions of each role are included as Appendix 1. A second method of analyzing these roles emerged in organizational charts. While reading the studies, I began drawing simple charts of the

structure of the studies, then categorizing studies with similar structures. For each chart type, I listed the study numbers that matched, and color coded by PAR, CBPR, and PLA for ease of comparison. The charts depicting the study structure are included in the results as Figure 3, and the list is included in Appendix B. The charts were purposefully simple and broad to allow for a range of study types.

2.44 Duration and Complexity of Roles

While these qualitative descriptions more thoroughly examine each role's contribution to the research project, I felt a quantitative approach would assist with comparison. I read each description and numbered the research tasks (listed in Table 3) that the role engaged in. The number of research tasks women engaged in represents the demonstrated capacity for engaging in a systematic learning process. The second metric in Table 4, duration (months), demonstrates a capacity of the research program to sustain commitment to a long-term process of transforming the health conditions of the community. Duration, indirectly, also describes intensity across the spectrum of initiatives. Some "participatory" research projects included in this paper involved a one-time focus group, the participants of which were not engaged in research tasks beyond being consulted for information or feedback. At the other end of the spectrum, participants were engaged in weekly meetings for multiple years and sustained action related to food production and economic stability for their family, transforming their conditions.[18]

In deciding which roles to include in the analysis, shown in Figure 3, I determined not to examine committee membership. Few of the studies reported specifically what the local member's contribution to the committee was compared to the rest of the committee or if they were women that were asked to serve on these committees. Some studies also did not report

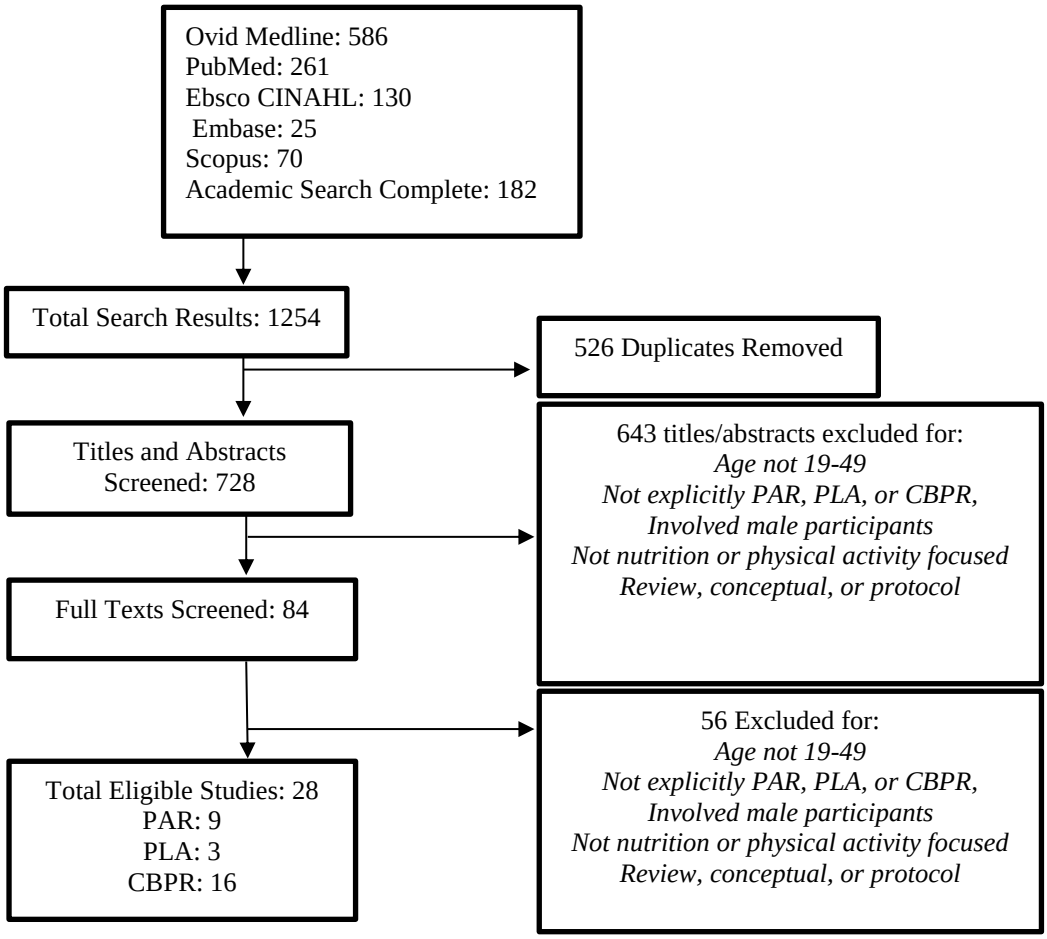
duration of the role and were also excluded. The scatterplot in Figure 3 illustrates these two metrics of participation: duration and number of research tasks, by participatory research framework (Figure 3). I also calculated the median, range, and mean of research tasks and duration of the role and report them in the findings by study type.

RESULTS

3.1 Search Results

The search yielded 1254 studies, with 526 duplicates. Among the 728 abstracts and titles screened, 84 met the criteria initially. Upon full text review, 28 studies were selected for inclusion and analysis. The results of the search strategy are detailed in Figure 1.

Figure 1. Search Results and Study Selection



3.2 Included Studies

Table 2 presents the characteristics of the 28 included papers. Among these are 9 PAR, 16 CBPR, and 3 PLA studies, with a total of 30,873 reported participants. Participants could be listed as two kinds in participatory research: (1) the recipients of an intervention or a community assessment, or (2) the local people employed or volunteering in the project carrying out research tasks. At studies with higher complexity, there may even be a third category of participants that receive some intervention that has been offered by the other "participants." More than 2,285 people were engaged from the populations in the research project as this second category. Several studies did not report the specific number of people engaged in the research work.

PAR studies included occurred in the USA, Canada, India, and Guatemala. The CBPR studies included occurred in the USA, Canada, Australia, and the Gambia. The PLA studies all occurred in South Asia - Nepal, Pakistan, and Bangladesh. Among all of the studies, the participants were in some way disadvantaged – low income, minority, indigenous, living in affordable housing, lower educational attainment, or illiteracy were reported among all studies except for one PAR study which engaged college students (Berger et. al, 2009). Data on the collaborators was less frequently reported.

Table 2. Study Characteristics, *How Participatory Are We? A Systematic Review Comparing Women's Participation In PAR, CBPR, and PLA* (n=28)

	Study	Framework	Country	Study Design	Topic Area	n	Local Research Collaborators*	Employed	Compensation	Duration of participation (collaborators)	Assessment	Planning	Implementation	Evaluation	Dissemination
1	Aldoory L, Braun B, Maring EF, Duggal M, Briones RL. (2015)	PAR	USA	Focus Group	Health messages for physical activity	43	43	-	-	2 hours		X			
2	Badry D, Felske AW. (2013)	PAR	Canada	Photovoice	Fetal Alcohol Syndrome Disorders	30	30	-	-	2 years	X				
3	Berger G, Peerson A. (2009)	PAR	UAE	Focus Group	Physical activity	20	0	-	-	1 hour	X				
4	Chilton M, Rabinowich J, Council C, Breaux J. (2009)	PAR	USA	Photovoice	Food insecurity	42	42	-	Yes	3 weeks	X	X	X		
5	Chilton MM, Rabinowich JR, Woolf NH. (2014)	PAR	USA	Photovoice	Food insecurity	44	44	-	-	3 weeks	X	X	X		
6	Chomat AM, Solomons NW, Koski KG, Wren HM, Vossenaar M, Scott ME. (2015)	PAR	Guatemala	Longitudinal Cohort Study (Experimental)	Maternal stressors on early infant growth	155	21	Yes	-	15 months	X	X	X	X	X
7	Dongre AR, Deshmukh PR, Garg BS. (2011)	PAR	India	Community Trial	Child Anemia	521	29	Yes	-	1.5 years	X	X	X	X	
8	Duffy, L. (2011)	PAR	Canada	Photovoice	Community health assessment	4	4	-	-	2 years	X	X	X		
9	Valera P, Gallin J, Schuk D, Davis N. (2009)	PAR	USA	Photovoice	Access to healthy food	9	9	-	Yes	3 months	X	X	X		
10	Hinojosa MS, Nelson D, Hinojosa R, Delgado A, Witzack B, Gonzalez M, et al. (2011)	CBPR	USA	Focus Group	Nutrition Health Literacy - developing fotonovelas	12	12	-	-	9 months		X			
11	Holloman EL, Newman MC. (2010)	CBPR	USA	Cross-sectional survey	Seafood consumption & mercury exposure	95	10	-	Yes	2 months	X				
12	Kieffer EC, Caldwell CH, Welmerink DB, Welch KB, Sinco BR, Guzmán JR. (2013)	CBPR	USA	Randomized Control Trial	Prenatal and postpartum depression among Latinas	275	-	Yes	Yes	4 months		X	X		
13	Mareno, N. (2015)	CBPR	USA	Photovoice	Parental perceptions of healthy eating and physical activity	10	10	-	-	-	X				
14	Marinescu LG, Sharify D, Krieger J, Saelens BE, Calleja J, Aden A. (2013)	CBPR	USA	Non-comparative study	Physical activity programming for women in subsidized housing	239	-	Yes	Yes	5 years	X	X	X	X	
15	Messias DKH, Parra-Medina D, Sharpe PA, Trevino L, Koskan AM, Morales-Campos D. (2013)	CBPR	USA	Randomized Control Trial	Physical activity on Mexican female immigrants	120	8	Yes	Yes	2 years	X	X	X		
16	Murray KE, Mohamed AS, Dawson DB, Syme M, Abdi S, Barnack-Taviaris J. (2015)	CBPR	USA	Photovoice	Resources and barriers for physical activity among Somali women	8	9	-	-	2 months	X				
17	Patel V, Rajpathak S, Karasz A. (2012)	CBPR	USA	Cross-sectional survey	Health Assessment of Bangladeshi women in NYC	167	6	Yes	-	3 months	X				
18	Quintanilha M, Mayan MJ, Thompson J, Bell RC. (2016)	CBPR	Canada	Focus Ethnography	Assessment of immigrant experiences in prenatal health	80	-	Yes	Yes	5 months	X				
19	Salihu HM, Adegoke KK, Das R, Wilson RE, Mazza J, Okoh JO, et al. (2016)	CBPR	USA	Individual Trial with Control Group	Nutrition intervention	49	-	-	-	8 weeks	X	X			
20	Scott A, Shreve M, Ayers B, McElfish PA. (2016)	CBPR	USA	Focus Group	Breastfeeding perceptions, beliefs, and experiences	31	4	Yes	Yes	1 day	X				
21	Simonsen SE, Ralls B, Guymon A, Garrett T, Eisenman P, Villalta J, et al. (2017)	CBPR	USA	Randomized Control Trial	Weight management and physical activity	381	-	Yes	-	1 year	X	X	X	X	X
22	Tovar A, Must A, Metayer N, Gute DM, Pirie A, Hyatt RR, et al. (2013)	CBPR	USA	Focus Group	Lifestyle changes associated with obesity	28	-	Yes	-	1 day	X	X			
23	Vanderwal L, Rautiainen R, Ramirez M, Kuye R, Peek-Asa C, Cook T, et al. (2011)	CBPR	The Gambia	Non-comparative study	Occupational safety and health intervention for vegetable farmers	48	-	Yes	Yes	2 months	X	X	X	X	
24	Wieland ML, Weis JA, Palmer T, Goodson M, Loth S, Omer F, et al. (2012)	CBPR	USA	Individual Trial	Physical activity and nutrition intervention	45	-	-	-	6 weeks		X	X		X
25	Zemits B, Maypilama L, Wild K, Mitchell A, Rumbold A. (2015)	CBPR	Australia	Non-comparative study	Cross-cultural health communication with dietary iron and screening for fetal anomalies	-	-	Yes	-	1 year		X	X		
26	Saville NM, Shrestha BP, Style S, Harris-Fry H, Beard BJ, Sen A, et al. (2018)	PLA	Nepal	Cluster Randomized Control Trial	Birth weight and child growth	25,092	1851	Yes	-	2 years	X	X	X	X	X
27	Yasmin T, Khattak R, Ngah I. (2013)	PLA	Pakistan	Individual Trial	Women's empowerment in food production	1055	175	Yes	-	1 year +	X	X	X	X	
28	Younes L, Houweling T, Azad K, Kuddus A, Shaha S, Haq B, et al. (2014)	PLA	Bangladesh	Individual Trial with Control Group	Infant feeding and child health knowledge, behavior, and outcomes	2270	9	Yes	-	22 months	X	X	X	X	X

3.3 Quality Assessment

After reviewing a few methods of assessing quality, especially GRADE, I felt it unnecessary to grade the quality of the studies for the purpose of this exploratory review, which seeks to examine the quality of participation, rather than rigor. GRADE starts with the assumption that RCTs are the highest level of quality while others are at the lowest level, then points are added or deducted given a number of factors.[19] Because outcomes are not analyzed in this study, assessing quality is beyond the scope for this review and irrelevant to the findings. These quality assessment tools were not developed with the considerations PAR is based on: that people develop their own verification systems to draw validity from the knowledge they generated.[11] PAR founders argue against external verification systems being imposed on the generation of knowledge occurring at the grassroots.[12] Without fully endorsing the position of Fals-Borda, it suggests that more effective review of participatory research might involve assessing how complex and rigorous the verification systems are that the participants put in place. This paper presents an assessment of the quality of participation being reached in participatory studies and Table 2 provides information necessary in the study design column to compare the rigor of the studies.

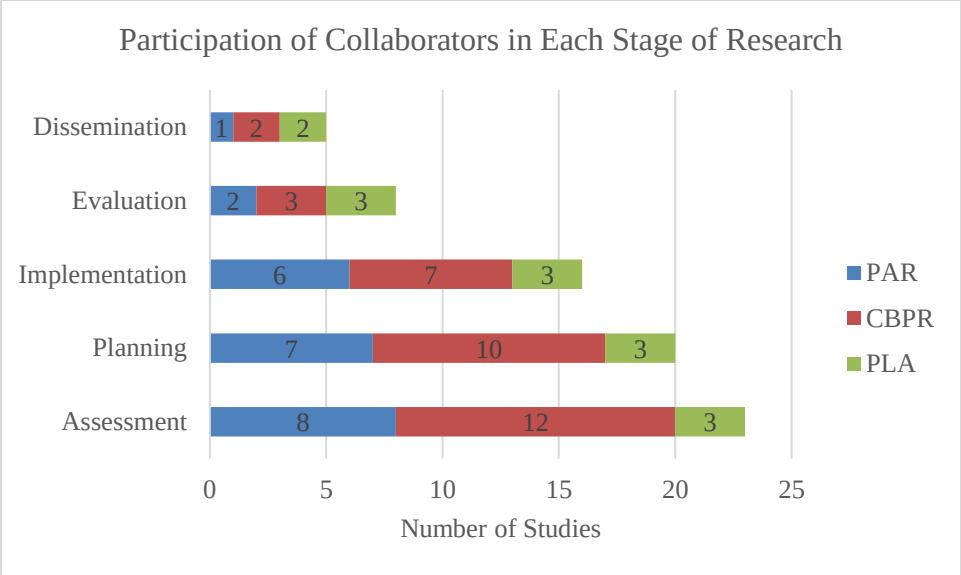
3.4 Participation Measures

3.41 Stages of Research

The participation of local collaborators in research stages is depicted in checkboxes in Table 2 and Figure 2. Across the frameworks, participation is most often seen in the assessment (n=23) and planning (n=20) phases of research. Participation in implementation was observed in 16 of the 28 studies: 6/9 PAR, 7/16 CBPR, and 3/3 PLA. While PLA studies

(n=3) had the most consistent engagement of individuals in assessment through evaluation, efforts to disseminate findings were also lower. CBPR (n=16) and PAR (n=9) had a similar trend with higher participation in earlier stages of research.

Figure 2. Participation of Collaborators in Each Stage of Research, by framework, (n=28 studies)



3.42 Research Tasks and Level of Engagement

The specific research tasks participants performed are illustrated below in Table 3 and 3a. The study numbers (from Table 2) are listed next to the research task they engaged participants in, and at what level: consulted only, actively engaged, or leadership role. As described in the methods section, this was a qualitative analysis based on how the study reported participation and only the highest level of participation was included. If a study consulted some people on a task and other people leading a task, then the study is only

marked under “leadership role.” Table 3a describes the percentage of studies by framework that involved participants in that research task.

The PAR studies ranged from collaborators engaged in 0 to 7 tasks, while CBPR saw engagement in 1 to 7 tasks, and PLA observed participation in 9 tasks for all three included studies. Certain tasks are unique to that participatory framework. PLA was unique in its engagement of collaborators to train other collaborators for research tasks, which is characteristic to PLA’s use of facilitators and groups. CBPR demonstrates greater experience in collaborators developing intervention materials, developing sampling techniques, designing interview and focus group questions, and conducting interviews or focus groups.

Referring to Table 3a, one can see that CBPR has the greatest heterogeneity among studies’ engagement of participants, as no research task has a majority of studies. The highest percentages of studies involved participants in recruiting participants for the study and collecting data. PLA studies were more homogenous in structure and multiple tasks had 100% (n=3) studies employing participants in the same functions at the same level of participation. The majority of PAR studies engaged participants in gathering data (67%) and analyzing it (56%). By numerating the tasks participants were engaged in and how much latitude they had in each, comparisons to the structure of participation can be made. The way local communities participate in PAR, CBPR, and PLA research varies, suggesting that each researchers within each framework can learn from the others.

Table 3. Participation of local collaborators in research tasks (Numbers represent studies listed in Table 2)

	PAR (Studies 1-9)			CBPR (Studies 10-25)			PLA (Studies 26-28)		
	Consulted Only	Actively engaged	Leadership Role	Consulted Only	Actively engaged	Leadership Role	Consulted Only	Actively engaged	Leadership Role
Choosing research methods			6, 7			20, 21			
Developing sampling procedures				15, 17					
Recruiting study participants		1, 7	6		12, 14, 17	15, 18, 20, 21, 24, 25			27, 28
Developing intervention materials		1, 6		24	12, 14,	10, 23, 25		28	26
Leading trainings									26, 27, 28
Implementing the intervention		7	6		18, 19, 23	14, 15			26, 27, 28
Designing interview and/or survey questions			6	11, 14, 15, 22	18				
Conduct Interviews/Focus Groups		1			18, 20, 21, 23				
Collecting primary data		1, 7	2, 4, 5, 6, 8, 9		15, 22	10, 13, 14, 16, 17, 21, 23		26, 28	27
Analyzing collected data		2, 4, 5, 7, 9	6, 8	18, 20, 22	10, 13, 16, 21	14, 23		28	26, 27
Qualitative evaluation of interventions					14				26, 27, 28
Interpreting results		4, 9	8	20	14, 21	22, 23		26	27
Writing reports and journal articles		9	8		21				
Giving presentations at meetings and conferences	5	4, 8, 9			21	25			26, 28

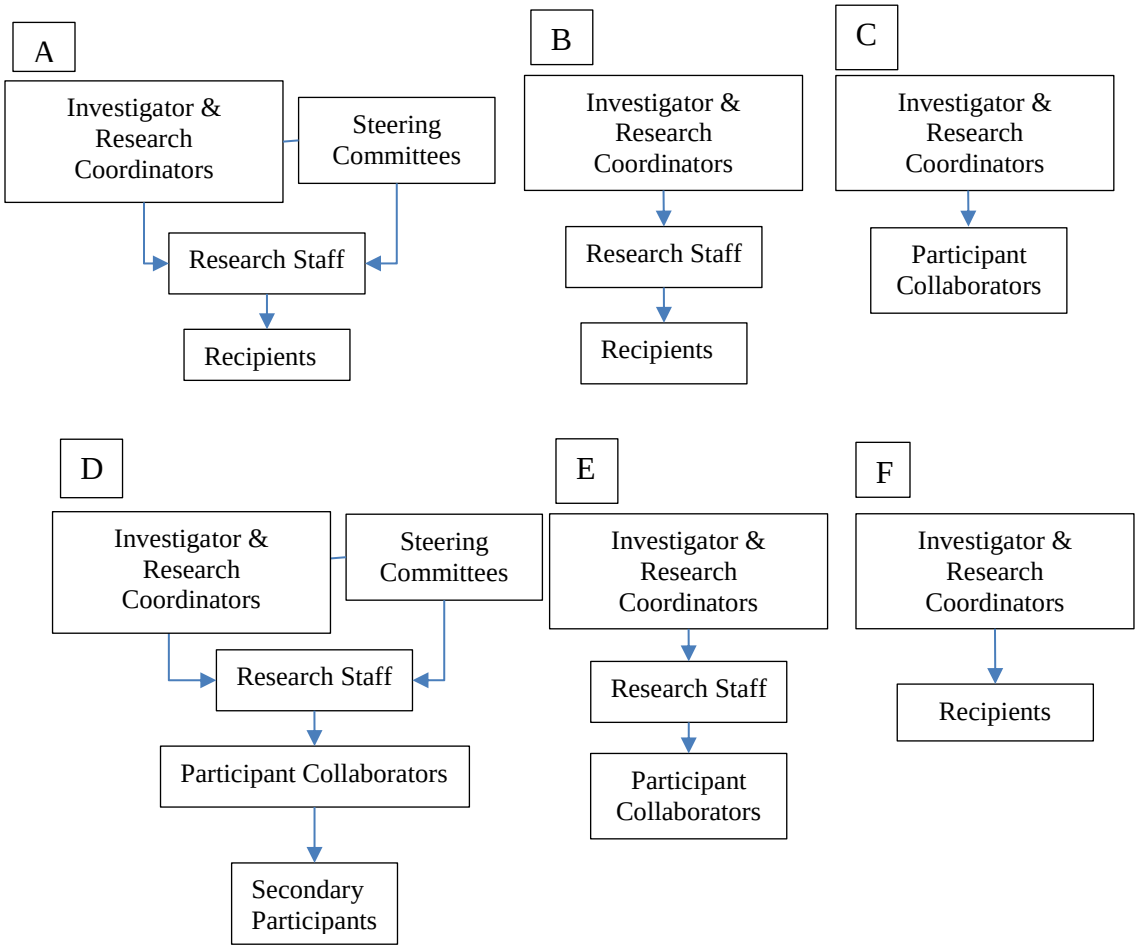
Table 3a. Participation of local collaborators in research tasks (% studies within research framework: PAR/CBPR/PLA)

	PAR (Studies 1-9)			CBPR (Studies 10-25)			PLA (Studies 26-28)		
	Consulted Only	Actively engaged	Leadership Role	Consulted Only	Actively engaged	Leadership Role	Consulted Only	Actively engaged	Leadership Role
Choosing research methods			22%			13%			
Developing sampling procedures				13%					
Recruiting study participants		22%	11%		19%	38%			67%
Developing intervention materials		22%		6%	13%	19%		33%	33%
Leading trainings									100%
Implementing the intervention		11%	11%		19%	13%			100%
Designing interview and/or survey questions			11%	25%	6%				
Conduct Interviews/Focus Groups		11%			25%				
Collecting primary data		22%	67%		13%	44%		67%	33%
Analyzing collected data		56%	22%	19%	25%	13%		33%	67%
Qualitative evaluation of interventions					6%				100%
Interpreting results		22%	11%	6%	13%	13%		33%	33%
Writing reports and journal articles		11%	11%		6%				
Giving presentations at meetings and conferences	11%	33%			6%	6%			67%

3.43 Roles Collaborators Performed

Collaborators contributed through 54 roles across the studies (Appendix A). If there was insufficient information to describe the functions of that role, it was excluded. The roles fit several categories: participants, committee membership, co-investigator/research coordinator, community health worker, focus group moderators, data collectors, group facilitators, and supervisors. A few technical roles also existed such as midwives, gardeners, interpreters, and actors.

Figure 3. Structure of the Research Studies



The simplified underlying structure of the studies is depicted in organizational charts in Figure 3 demonstrating different human resource types in the research. Among the studies, 2 co-investigators and 1 research coordinator are indigenous to the population. Collaborators performed 33 different "research staff" roles. 18 studies report local people performing research staff roles (12 CBPR, 3 PAR, 3 PLA). Three studies engaged participants to work with a secondary level of participants (all PLA). Nine studies report an investigator working directly with participants, typically in photovoice or focus group design (5 PAR, 4 CBPR). All of the 28 studies were able to be categorized within these simple charts.

Nine studies report having steering committees with local people engaged: 5 CBPR, 1 PAR, and 3 PLA. These committees designed the needs assessments and programs, edited interview and survey tools, employed local people as staff, monitored progress, determined methods of evaluation, facilitated collaborations with local organizations, and managed the flow of resources to ensure the project succeeded. The contribution of local collaborators to the functioning of committees was minimally reported on. Some were entirely organizational representatives, others included academic-community partnerships, and others had resident community members representing their community interests.

Two elements emerge from the human resource structures: steering committees and recipients vs. participant collaborators. Recipients represent those "participants" that receive a service, good, focus group or survey, without participating in the process of generating knowledge. They may provide information to researchers, but are not engaged in action or returned the knowledge generated by the study. Recipients were a feature of 13 of the

studies, 10 of which were CBPR and the remaining 3 PAR. In PLA studies, all levels of collaborators engaged in cycles of learning in action, and they did not have recipients.

3.44 Duration and Complexity of Roles

This section offers a quantitative representation of the roles that local collaborators filled in the research project with sufficient detail about their duration and the number of research tasks each role had. Studies frequently had several roles collaborators were employed in. While Table 3 reflects the number of tasks that the study engaged collaborators in overall, this breaks that down by roles collaborators had. Some collaborators did one research task in the study in one day, while others were part of majority of the research tasks for the entire duration of the study over years.

The number of research tasks described in each role are graphed in box plots in Figure 4, to compare the complexity of roles collaborators are engaged in across participatory frameworks. The duration of these roles is graphed in Figure 5. Only those roles are graphed that had sufficient details to describe the number of research tasks or duration of the role numerically. In PAR, collaborators had a median of 4 research tasks with a range of 1 to 7, and participated for a mean of 9 months (median 3 months). PAR research demonstrated the greatest variety in complexity and duration of roles. The CBPR studies tended to be of shorter duration and engage collaborators in fewer tasks with a median duration of 2 months (Range 0 to 24) and median number of tasks at 3 (range 1 to 6). However, there were some outliers with higher duration and complexity. The PLA studies observed a median duration of

24 months and 5 research tasks (range 1 to 9). The PLA studies had the opposite trend of CBPR studies, with longer study durations and high numbers of tasks per role.

Figure 4. Complexity of Roles for Collaborators, *How Participatory Are We? A Systematic Review Comparing Women's Participation In PAR, CBPR, and PLA*, 2009-18, (n=22 studies, 43 roles)

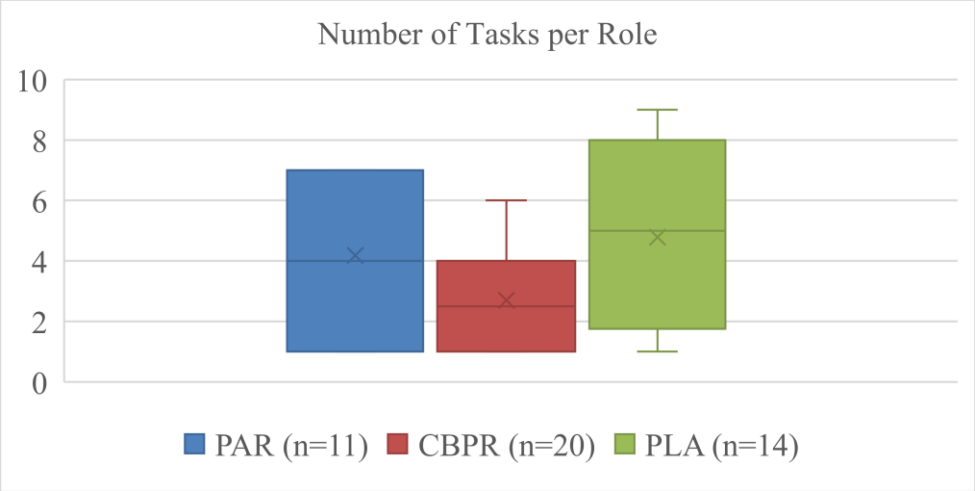
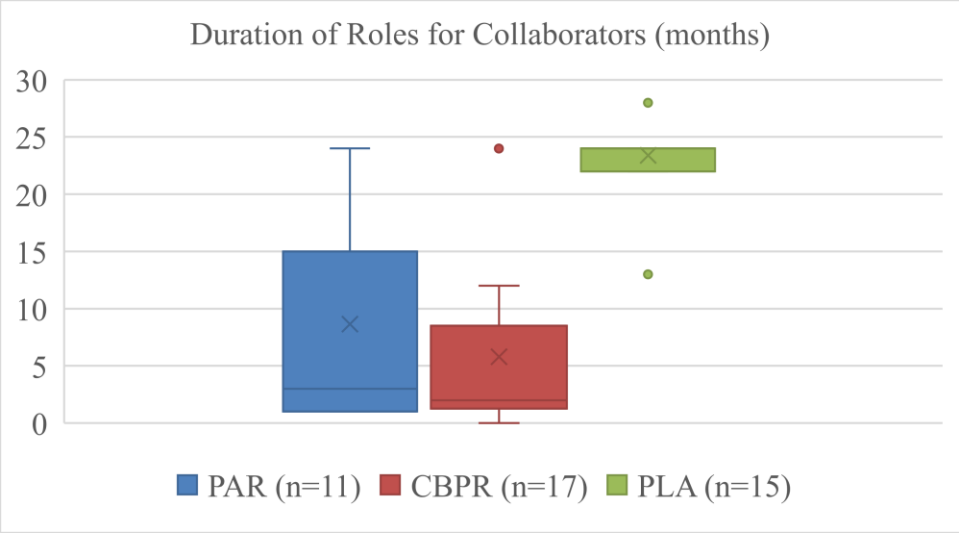


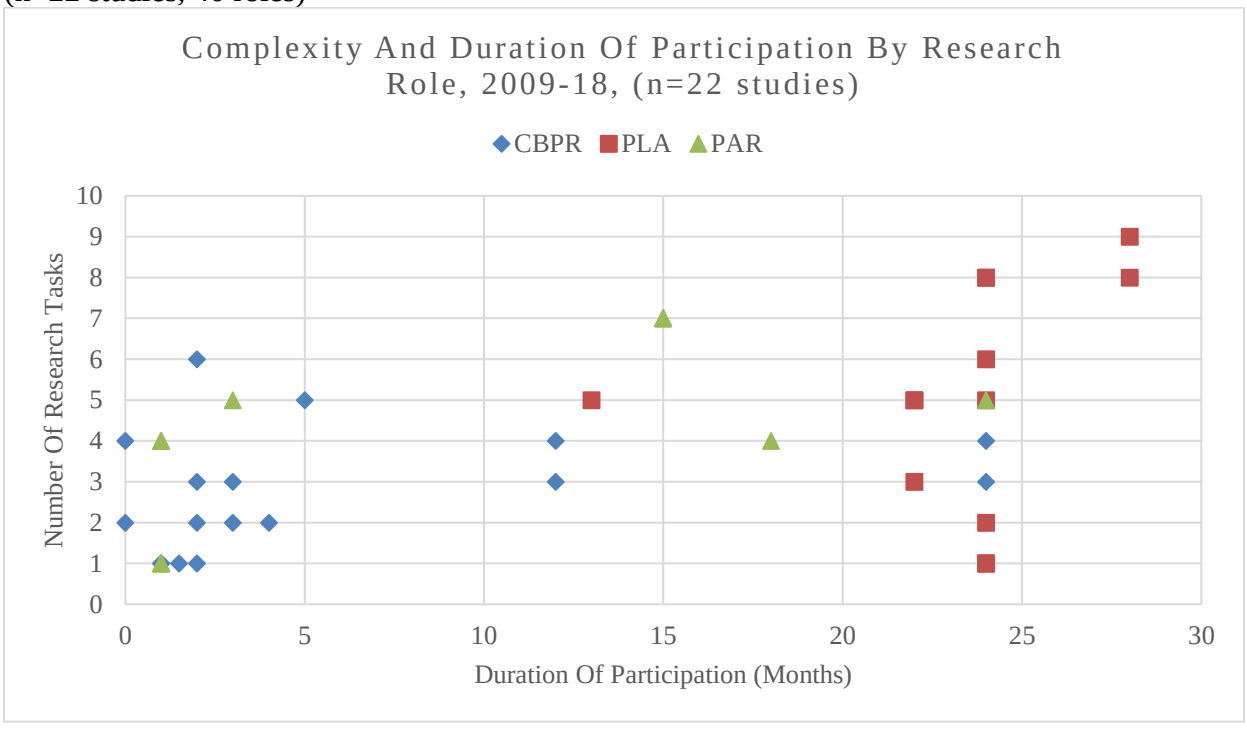
Figure 5. Duration of Roles for Collaborators, *How Participatory Are We? A Systematic Review Comparing Women's Participation In PAR, CBPR, and PLA*,2009-18, (n=22 studies, 45 roles)



The data in Figure 6 represents 40 roles in 22 studies which had data on both complexity and duration: 10 roles across 6 PAR studies, 17 roles across 13 CBPR studies, and 14 roles in

3 PLA studies. Some studies had several roles, while others had one. Within the research project, certain roles had different durations. Figure 6 illustrates the number of research tasks each role had and the duration of each. For example, photovoice participants were often coded as being engaged in 1-4 tasks. In one photovoice study, women gathered data (photos), analyzed them with a researcher (in interviews or focus groups), had a follow-up meeting to discuss action steps they could take with their findings, and presented the knowledge they gathered to politicians in a meeting. [20] Their participation was coded as 4 tasks in Tables 3 and 3a. Because their duration of participation was about 1 month, they appear in the graph below at the coordinate (1,4). It's important to note that some roles have the same metrics for complexity and duration and are not visible.

Figure 6. Complexity and Duration of Collaborators, *How Participatory Are We? A Systematic Review Comparing Women's Participation In PAR, CBPR, and PLA*, 2009-18, (n=22 studies, 40 roles)



DISCUSSION

This systematic review describes the extent of participation of adult women in research published from 2009 to 2018 that reported using CBPR, PAR, or PLA and compares the structures that facilitate that participation in each. I examined the stages of research participation was observed in, the level of engagement in research tasks, described the roles women were employed in, the complexity and duration of these roles, and examined differences in the underlying structure of the research studies comparing PAR, CBPR, and PLA – all with the overarching aim of examining the extent to which women are engaged in generating, applying, and diffusing knowledge in health promotion.

Among the stages of research, participation was observed most often in assessment and planning, then implementation, with a marked drop in evaluation and dissemination across all frameworks. The level of engagement women had in PLA studies was most homogenous, with community members consistently taking leadership roles in the research tasks. In CBPR studies, there was great heterogeneity, with no pattern emerging that defined most of the studies. In PAR studies, engagement was observed primarily in data collection and analysis, and at the level of active participation and leadership. We observed CBPR studies had the lowest complexity and duration on average with three tasks per role lasting only two months, on average. PLA studies consistently engaged local collaborators for two years, in 5 research tasks on average. Figure 6 shows the clusters of CBPR studies at the lower end of duration and PLA studies at the higher end, while PAR studies spread across the spectrum of duration. The difference in duration could likely be regional differences in government structures and funding availability. The PLA studies all occurred in South Asia

and two relied upon existing efforts supported by the government which they bolstered capacity in and built upon. Lower availability of funding for CBPR studies may translate into shorter studies. Participatory research programs will need to secure stable funding to advance.

Participation in Stages of Research

When comparing the engagement in the stages of research among the frameworks, the differences in theoretical underpinnings in PAR, CBPR, and PLA become evident. We observe that the PAR and PLA studies had a higher percentage of engagement of participants in implementation. PAR and PLA frameworks stresses that when the individual takes action, they "re-form power and create justice, their reality is transformed. In doing so, they are also transformed"[21] This is the first distinction between CBPR and the PAR/PLA studies. CBPR does not appear to have the explicit interest of social transformation. As described by Nina Wallerstein and Bonnie Durham, there is a continuum between the problem-solving utilitarian approach and the emancipatory approaches. [4] PAR and PLA approaches are more associated with emancipation and Lewinian models (CBPR) with pragmatism.[4] This theoretical underpinning regarding the purpose of the research being to transform, is evident in the participation of people in the implementation stage of the research.

Across the three frameworks, participation in dissemination and evaluation was the lowest. PAR literature emphasizes the importance of these stages: "There is an obligation to return this knowledge systematically to the communities and workers' organizations because they continue to be its owners."[12] The evaluation stage differed significantly by research framework. In PAR, one aim is "to return to the people the legitimacy of the knowledge they

are capable of producing through their own verification systems, as fully scientific, and their right to use this knowledge… as a guide in their own action."[11] This perspective of evaluation is not universally shared across participatory frameworks. In CBPR, this view of participation varies by two traditions. CBPR discourse has a growing body of knowledge on participatory evaluation, though it is divided by 2 streams: 1) practical participatory evaluation (P-PE) which focuses on producing valid findings to be used for improvement and is of the northern tradition, and transformative participatory evaluation (T-PE) which focuses on challenging unequal power structures by including the people and comes from the same tradition as PAR.[22] PAR discourse describes the "scientific character or objectivity of knowledge rests on its social verifiability, and this depends on consensus as to the methods of verification… the people can choose or devise their own verification system to generate scientific knowledge in their own right."[11] We cannot separate this strain of evaluation from PAR, because CBPR is explicit that the source of T-PE is PAR.[22] Within the discourse of CBPR research, the question of whether detached observation from outsiders is more valid than involved observation will require resolution for a greater percentage of CBPR studies to engage populations in evaluation. While three CBPR studies engaged participants in evaluation, others were intentional in not involving people in the evaluation: "Because the promotoras subsequently delivered the intervention, other researcher staff conducted the follow-up survey interviews."[23] The participation of populations in implementation, evaluation, and dissemination remain as objects of further learning for participatory researchers across all frameworks.

Comparing Participatory Research Structures

Among the included papers, PLA demonstrated the most potent examples of both scientific rigor (all were RCTs) and participation. Certain features make PLA distinct. PLA inherently relies on its participants working in cycles of action and reflection. One could describe these PLA studies as having a research project within a research project. At one level, the research team, its staff and facilitators are carrying out an intervention on the participants, which is the PLA groups. These PLA groups themselves are also engaging in research. They are examining their community health issues, learning relevant scientific and local knowledge about the problems, developing strategies to address these issues, and evaluating their efforts. These strategies engage a larger pool of participants in their community. The facilitators are supporting these participants to engage in these research cycles, usually involving monthly or weekly meetings for 1-2 years. Another noteworthy achievement of these PLA researchers is their capacity to engage illiterate women in systematic learning to develop their communities through methods of pictorial charts, role-playing, groups discussion, and coordinating participants to visit and learn from each other's projects. This framework and its structure of groups with facilitators seems to have transcended the concept of participants being recipients of goods and services, and has achieved a dynamic in which every level – from the women in groups, the facilitators and committees managing their implementation, and the research team – engages in generating, applying, and diffusing knowledge.

The PAR studies typically (5/9 studies) employed photovoice and had much smaller sizes and simpler structure. A researcher worked directly with a group of women or a number

of individual women to gather data and interpret it. In some, these women determined strategies to act upon the knowledge gained. This typically took the form of presentations, exhibits, or visits to government officials to raise awareness about the area of knowledge they generated. The more complex PAR studies engaged local people in roles as research staff designing, implementing, and evaluating the intervention.[24,25,25] However, the participants of the intervention were recipients, not also engaged in the learning process. While these more complex studies engaged people in a broader range of research tasks, the actual relationship between the research team and the population was not noticeably different from that of traditional approaches except in purposes of trust and effectiveness of the tools. The research process is more able to be tailored to the community because of the involvement of indigenous people as the research staff. However, the study did not engage the 'participants' to transform their reality as PAR proposes.[12] Despite the smaller scale and lower level of evidence provided in the photovoice studies, perhaps these studies such as Valera et. al 2009 which engaged homeless women in examining their access to fruits and vegetables and led to them advocating for changes to improve their access achieved the kind of participation described in PAR literature.[26] The authors in each paper noted examples of individual transformation the participants themselves experienced as a result of participating in the project. It seems that within PAR, the next stage is to learn about larger scale research programs that treat all levels of participants as protagonists of the learning process.

Capacity for Collective Learning with Large Numbers

Another characteristic for consideration is capacity for collective learning and action. CBPR and PAR seem to have learned about the participation of the individual women in

research tasks. They have engaged handfuls of community health workers, committee members, data collectors, and other functions, but not large numbers of collaborators. Included CBPR studies report 12 women at most engaged as collaborators, while PAR studies reached 44. The dynamics of engaging whole cohorts of a population, as demonstrated in the PLA studies with consistent participation levels above a thousand, remains to be discovered within these frameworks.

In the PAR study that reported the highest number of collaborators (n=44), the individuals were engaged largely through interviews and then a portion of those participated in a focus group.[27] The whole did not engage in collective analysis of their findings and action beyond the focus group. The CBPR study with the largest nucleus of collaborators (n=12) engaged them for 9 months in a process of collective fotonovela development.[28] As previously described above, a collective dimension to learning in action is characteristic of PLA groups. In rural Pakistan, collaborating women, though working on their individual gardens or farms, met weekly to learn more, share progress and challenges, and discuss solutions.[18] They assisted each other through such informational support, but also had field visits to each other's gardens to share insights. In the other PLA studies, the groups designed interventions that the group carried out and then reflected on.[29,30,30] The collective dimension of these women's groups was their openness to others to engage with them, and their further commitment to ensuring the rest of the community participated in the development of their efforts: "Women could enter the women's groups at any time during the study period and all members of the community, including men, were welcome to attend meetings in a more passive role. Community meetings were held at the end of phase 2 to engage the wider

community in the development and implementation of the women groups' strategies."[30] In that study, 15,272 community members, including 32% men, attended community meetings hosted by the 2,270 participants. While the included studies fall across a continuum of demonstrated capacity for collective learning, it is a shared characteristic.

Participation of Three Protagonists: Individuals, Communities, and Institutions

A related observation is that a number of studies relied primarily on steering committees (of various names) as the method of participation. In these, a few residents of the community are identified to participate in decision making about the project's direction for their community or to serve as focus group moderators or health educators or community health workers. While this is a meaningful step towards participation, engaging representatives is not equivalent to engaging populations. None of the studies reported the number or characteristics of those that served on committees from the local population, so further analysis is not possible.

One way to consider such committees in the larger process is that there are three protagonists: the institution, the individual, and the community. Each of the three participatory frameworks seems concerned with building capacity in each of these protagonists. Formed committees or councils are new institutions being developed in the community with the authority to manage the flow of resources and final decisions, then there are individuals asked to carry out certain tasks with a specified degree of agency such as facilitators, community health workers, or other research staff from the population. Lastly, is the protagonist of the community, where a pronounced collective dimension to consultation and action could be felt. An example of this protagonist being consciously developed in a

research project is the PLA groups and their community meetings. By comparing these frameworks through the lens of three protagonists, we see that the 9 PAR studies included were largely centered on developing capacity in individuals. The CBPR studies, in large part, developed institutions and utilized collaborations between institutions to enable the research project. These institutions in CBPR studies often identified individuals (community health workers, brokers, interpreters, moderators, etc.) to train and participate in the research. The PLA studies similarly developed village councils or strengthened existing institutional structures and collaborations to enable the research to advance, and trained facilitators who focused on the whole community. In Yasmin et. al., the master facilitators were then assisted to form a nongovernment organization to increase the sustainability of their work following the research program.[18] As previously described, there was large focus in the PLA studies on community engagement in designing the strategies of the women's group and supporting the project. Overall, participatory research that builds capacity all three of the protagonists seems more adept at facilitating greater numbers to engage in the generation of knowledge.

Limitations

The most significant limitation of this review is that it only captured data that was reported in peer-reviewed papers. Contacting researchers for this information was out of scope for this project. Relying solely on the reported data illustrated the need for greater transparency and reporting. As this work advances, researchers should be explicit about the framework they are operating within and report greater detail about the nature of the participation being attained in their study: the description and number of research tasks performed, duration of engagement, the level of engagement reached, the number of

collaborators that participated, and their demographics. There was limited quantitative or detailed qualitative information reported about the collaborators involved in the research. There are no reporting guidelines standard for participatory research or even specific frameworks of participatory research. Such guidelines would significantly improve the quality of systematic reviews. A significant limitation is publication bias, as the search included English only studies. This likely inhibited a larger body of PAR and PLA studies from South America and South Asia from inclusion, as they are more common in other regions of the world. Subjectivity would have been reduced with additional coders or by verifying the findings with the authors of the studies included in the review.

CONCLUSION

Participatory research demonstrates its capacity to enable women to contribute to the improvement of themselves and their community. CBPR demonstrates the greatest heterogeneity of research structures and levels of engagement, but lower duration and complexity of the roles local women engaged in. They had a special emphasis on institutional collaboration and citizen participation in committees. PLA particularly has developed an effective structure for engaging large numbers of women in research processes to promote health and sustains complex participation for the long periods of time compared to the other frameworks. PAR was between PLA and CBPR for both duration and complexity, but uniquely observes principal researchers engaging directly with the population at the grassroots, learning to walk with them through every task of the research project. The differences of these frameworks are apparent, and strengths and challenges were highlighted at length in the discussion.

Future research will continue to push the frontiers of participation. This paper highlights that systematic effort in learning to engage populations in evaluation and dissemination of knowledge remains a key area of weakness for all participatory research frameworks. Another object of learning is how populations are engaged in a collective learning process, in addition to populating the traditional roles with local people. Insights from PLA studies can assist CBPR and PAR researchers in learning the dynamics of cohorts of people generating knowledge together. While insights from CBPR about raising institutional structures within a community could benefit PAR researchers as the projects grow in complexity from small numbers at the grassroots to larger numbers working on

various lines of action. Each framework has generated unique experience, though certain principles of participation, action, and objectivity differ among them and are yet to be resolved.

APPENDICES

Appendix A: Description of Research Roles

Study	Roles	Description	# Research Tasks	Duration
1	Extension Educators	Educators did outreach, recruitment, screening interviews for participants.	1	1
1	Moderators	Conducted focus groups, transcribed recordings, and reflected with participants on the experience	1	1
1	Focus Group Participants	Focus group participants co-created health messages on physical activity	1	1
2	Photovoice Participants	Women were trained in digital photography and provided cameras to take photos describing what health and healing looks like in the community. They met back together to review their photos and examine the themes.	2	-
4	Photovoice Participants	Participants took photos and discussed them in interviews or focus groups. Some interviews were video recorded. 9 of the participants visited politicians to share their knowledge about food access.	4	1
5	Photovoice Participants	Participants took photos and discussed them in interviews and focus groups. The focus group identified representative themes and selected photographs for an exhibit and webiste.	4	1
6	Research Coordinator	They participated in design, pretesting, semantic validation of study	15	7
6	Traditional Midwives	instruments, participant recruitment, administering questionnaires, collecting	15	7
6	Community Health Workers	biological samples, house visits, and follow-up, and disseminating	15	7
7	*doots* (female community-based health workers)	Made home visits to provided education about iron supplementation and a weekly iron supplement. They participated actively in "force-field analysis," a technique to uncover and analyze the pertinent positive and negative forces operating at the field level and thus affecting program implementation.	18	4
7	Village Coordination Committee members	The Village Coordination Committees were endorsed by the village gram-panchayat (local governing bodies) for implementation and monitoring of the healthcare services at the village level. They held monthly village-level meetings, and selected community based female health workers (doots), and supervised their work. They identified barriers to implementation and advocated higher level governing bodies for adequate support. They continued the intervention program.	-	-
8	Photovoice Participants	Participants met once a month for 5 months taking photographs and reflecting on them. They then met more frequently to analyze and prepare public presentations and posters to disseminate their insights.	5	24
9	Photovoice Participants	Participants took photos on food access, reviewed the data and identified themes, which led to discussion of possible solutions. They then implemented their action plans by writing to local government and presenting at a conference.	5	3
11	Community Health Advisory Council Participants	Local collaborators were consulted on the design of the study survey.	-	-

14	Steering Committee	Provided feedback on interview guide content, structure, and wording, then designed and pilot tested a community driven intervention. They decided the main process and impact evaluation activities to assess the effectiveness of interventions and to provide formative feedback.	-	-
14	Community Health Workers	They were involved in door to door recruitment of participants.	-	1
14	Bicultural/Bilingual Facilitators	They conducted focus groups in the native languages using an interview guide developed by the research committee.	-	1
15	Promotoras	Promotoras were responsible for planning and implementing the organizational logistics for the focus groups held in their neighborhood. They were consulted on various parts of the research, recruited participants, conducted the intervention, and gave feedback on the survey/focus group questions used.	24	4
17	Community Health Promoters	They identified geographic area for target population, pre-tested the survey, and conducted door to door household surveys with informed consent.	3	3
18	Health Brokers	Health brokers directed researchers on the most appropriate data generation strategies, questions to pose to participating women within their communities, and data interpretation. They delivered an intervention of weekly meetings on various health topics, explained the research project, and recruited participants. They also moderated and translated in the focus group discussions, then participated in the analysis afterward.	5	5
19	Certified Community Educators	Led classes 2 hours per week for 8 weeks for perinatal women.	2	1
20	Community Health Workers (CHW)	CHWs recruited participants, led focus groups, provided feedback on the interpretation of thematic codes, contributed to discussion section of journal article.	0	4
20	Community Co-investigators	3 CHWs served as co-investigators, one conceived of the research idea. Does not describe what they did as co-investigators.	-	5
21	Coalition Members	Included leaders from 5 urban/ethnic community organizations; Conducted a needs assessment and adapted an intervention; Identified CHWs; Consulted on study design; Disseminated findings of program;	-	-
21	Community Health Workers (CHW)	CHWs enrolled participants, conducted interviews, collected data (including clinical information), used motivational interviewing to help participants set personal goals, and conducted the intervention for 12 months. The intervention involved leading monthly coaching and group activities.	12	4
22	Trained Bilingual Moderators	Moderators facilitated the hour long focus groups and convened with note-takers to debrief and discuss initial reactions and thoughts.	0	2
23	Local Project Assistants	Consisting of students of a local college course in occupational health, these assistants collected physiological data, facilitated focus groups, conducted interviews, translated Madinka into English and transcribed recordings. They observed gardeners and worked alongside them for extended time to gain first-hand understanding of all the gardening tasks and build credibility with subjects; discussed coding of interviews and subject observations; reviewed findings and identified farm tasks that could be addressed in the remainder of the study through locally available/reproducible tools.	2	6
23	Focus Group Facilitator	Conducted focus groups with farmers and interpreted data, and reviewed notes taken of the focus group for accuracy.	2	2
23	Gardeners & Lead Gardeners	As participants, they gave feedback in focus groups about their difficulties then tested the new tools provided by the research team for 1 week and reported their observations back in another focus group. While not considered the research team, they were generating knowledge about the functionality of the tools.	2	3
24	Rochester Healthy Community Partnership Members	The Partnership recruited women from community to intervention, and one member provided childcare for older children to enable women to participate.	-	-
24	Focus Group Moderators	Moderators facilitated half day retreat for community members to participate in planning the intervention	2	1
25	Indigenous Co-investigator	She engaged in all aspects of the research project. Because of her local knowledge, she recruited participants, developed the concept and script of the film, acted in the film with other local women, and enabled testing and feedback of the film in the community.	12	3
25	Actors	Actors developed the story of the film with elders and indigenous co-investigator, incorporated local knowledge of the health issues discussed, and were filmed.	1	1
25	Interpreters	They added english subtitles to the footage	1	1

26	Data collectors	Gathered anthropometric measures for children and mothers repeatedly over the course of the study.	24	1
26	Data collector supervisors	Supervisors oversaw work of data collectors, and provided additional training and support to poorly performing data collectors.	24	1
26	Volunteer Enumerators	They maintained menstrual monitoring registers to track missed menses, pregnancies, births, women's vital status, and migration. They informed interviewers via text of pregnancies and births.	24	1
26	Intervention Implementers	Managing the flow of resources for the different clusters, including cash and food transfers to participants of specific arms.	24	
26	Supervisors	Supervisors oversaw volunteer mobilisers and Female Community Health volunteers in their facilitation of PLA women's groups, monitored the distribution of food and cash transfers and home visits, and used observation checklists when attending women's group meetings, community planning meetings, strategy implementation, and participatory evaluation.	24	6
26	Volunteer Mobilisers	Nutrition mobilisers were enlisted to assist with PLA group facilitation, transfer of food/cash distribution, and record-keeping.	24	8
26	Female Community Health Volunteers (FCHV)	FCHVs facilitated 539 PLA women's groups through over 20 monthly meetings using pictorial manuals about low birth weight and malnutrition in pregnancy, formuating strategies to overcome barriers to improve health and nutrition, implementing strategies, and evaluation. They also assisted their participants to implement their chosen strategies in addressing LBW/malnutrition and evaluate their efforts.	24	8
26	Women in PLA Groups	The PLA groups carried out their chosen strategies to address LBW and malnutrition. These included: to conduct home visits, hold community meetings, host separate meetings with mothers, in law, adolescent girls, or male family members, held rallies on maternal nutrition, and screening pregnancy-related videos	24	5
26	Village Development Committee Interviewers	VDC interviewers as completed an interview and questionnaires with women after confirmation of pregnancy 4 times during the pregnancy and post-neonatal period, and with women and children at follow-up.	24	2
27	Master Facilitators	Each master facilitator trained 20-30 facilitators from their geographic area in Farmer Field School (FFS) /Women's Open School (WOS) through the Women's Facilitator Training and monitored the progress of the WOS groups conducted by those facilitators. These facilitators underwent a process of facilitation and adult education/non-formal education and learned organizational and management skills to organize themselves in a local nongovernmental organization, Women Agricultural Development Organization (WADO), which could serve as a lead group in capacity building of their community and could play an effective role in decision making processes.	28	9
27	Facilitators	Conducted FFS/WOS courses on a weekly basis for 2-3 hours, wrote reflections on the session including awareness, self-confidence, knowledge improvement, skill development, kitchen gardening success, home and self-management, and social interactions of attendees. Conducted field visits with participants, and supported their women's group to share successes and challenges to facilitate the dissemination of learning across the group. The curriculum was imparted in the form of activities involving group work, brainstorming, and transforming the information into pictorial descriptions, role playing, and so on as majority of the women in their groups were illiterate and 25% had primary-level education.	28	8
27	WOS participants	Composed of housewives and farm workers, they regularly visited their vegetable gardens or fields and compiled agronomic, plant protection, and general ecology data on a given format which was shared and discussed in each session. The worked in small groups observing and measuring field conditions, creating an ecosystem drawing as a visual analytical tool, and presenting and defending their results and management decision to conduct agroecosystem analysis (AESA) of plants. They also were encouraged to design their own experiments. Some conducted cost-benefit analysis of their home gardens and maintained records. They met weekly for 2-3 hours with facilitators.	13	5
28	Supervisors of PLA facilitators	They supported facilitators in preparing for meetings and liaising with community leaders and government and non-governmental healthcare providers.	22	3
28	PLA Facilitator	The role of the facilitator was to activate and strengthen groups, support them in identifying and prioritising under-5 health problems (phase 1), help identify possible strategies (phase 2), and support the planning, implementation (phase 3) and monitoring of the strategies led by the women's group members. They met with their groups monthly for 22 months, using a women's groups' community facilitation manual and pictorial flip charts to communicate key health messages.	22	5
28	Women in PLA Groups	The participants in the PLA group studied health problems of children under 5, identified strategies, planned and implemented those strategies, then reflected on their effect.	22	5

Appendix B: Study Structures

A – Study #s: 7, 11, 12, 14, 21, 22 Total 6

B – Study #s: 6, 15, 17, 18, 19, 24, Total 6

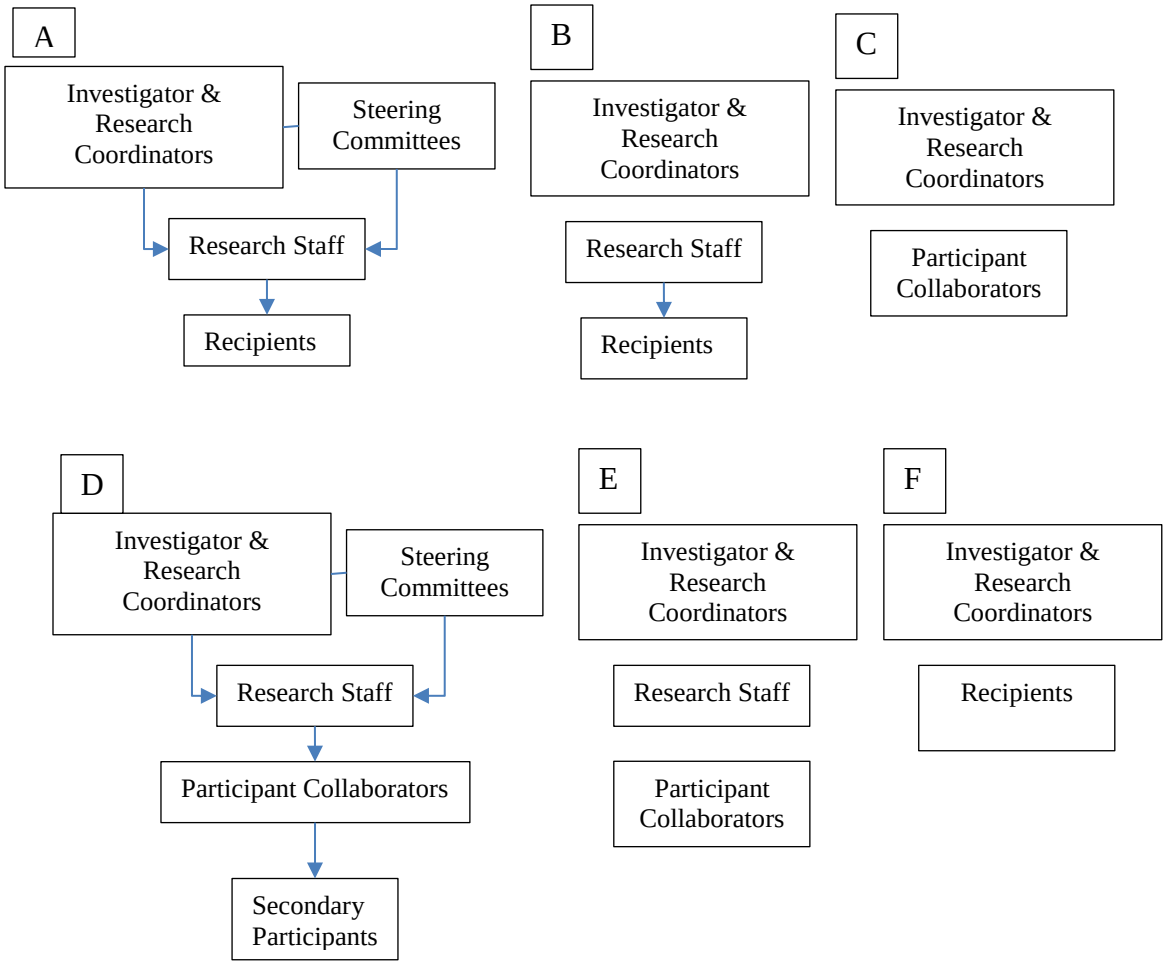
C – Study #s: 2, 4, 5, 8, 13, 16, 20, 25 Total 8

D – Study #s: 26, 27, 28 Total 3

E – Study #s: 1, 10, 23 Total 3

F – Study #s: 3 Total 1

PAR, CBPR, PLA



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