

Co-creating ethical frameworks for community-led approaches to GBV prevention

Critical bioethics in practice

Geordan Shannon,
Nicole Minckas &
Jenevieve Mannell

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Extreme settings (Campbell & Mannell, 2016)

Government services limited or absent – or too complex /costly to navigate

Secondary or tertiary violence prevention = too little, too late

Mainstream prevention strategies not appropriate



This requires a shift in mindset:

→ Towards primary prevention

→ From resource shortages to uncovering and mobilizing local resources

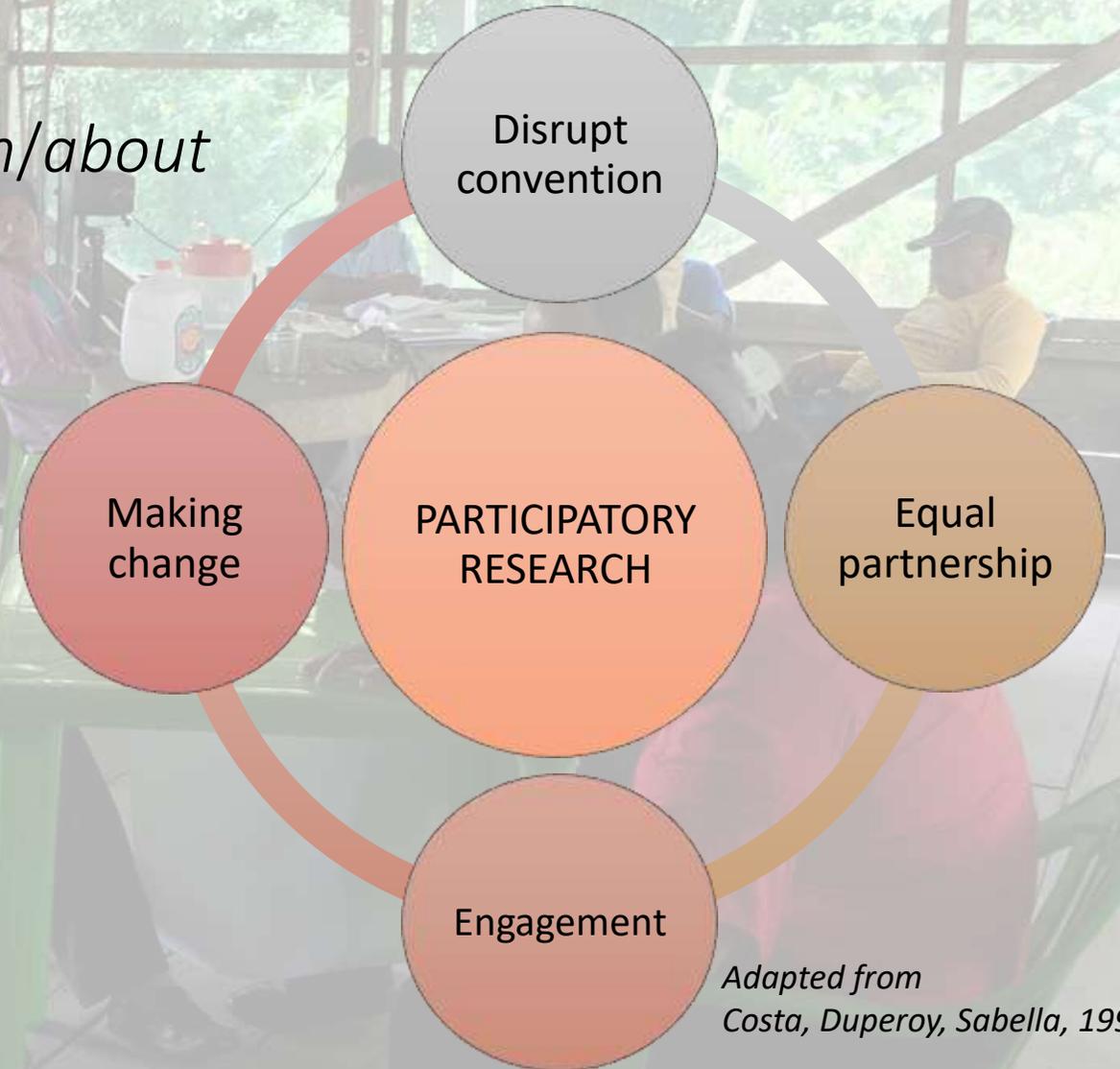
→ Developing systems of effective community-led responses

The Gender violence in the Amazon of Peru (GAP) Project



Participatory Action Research

- Researching *with*, not researching *on/about*
- Location of power: equity & justice
- *Process* rather than *outcome*
- Pragmatism
- Co-learning, mutual benefit
- Long-term commitment
- Action oriented:
 - *Knowledge for action* versus *knowledge for understanding*
- Transformation of social reality



Adapted from
Costa, Duperoy, Sabella, 1990

Participatory Action Research

- Four stages:

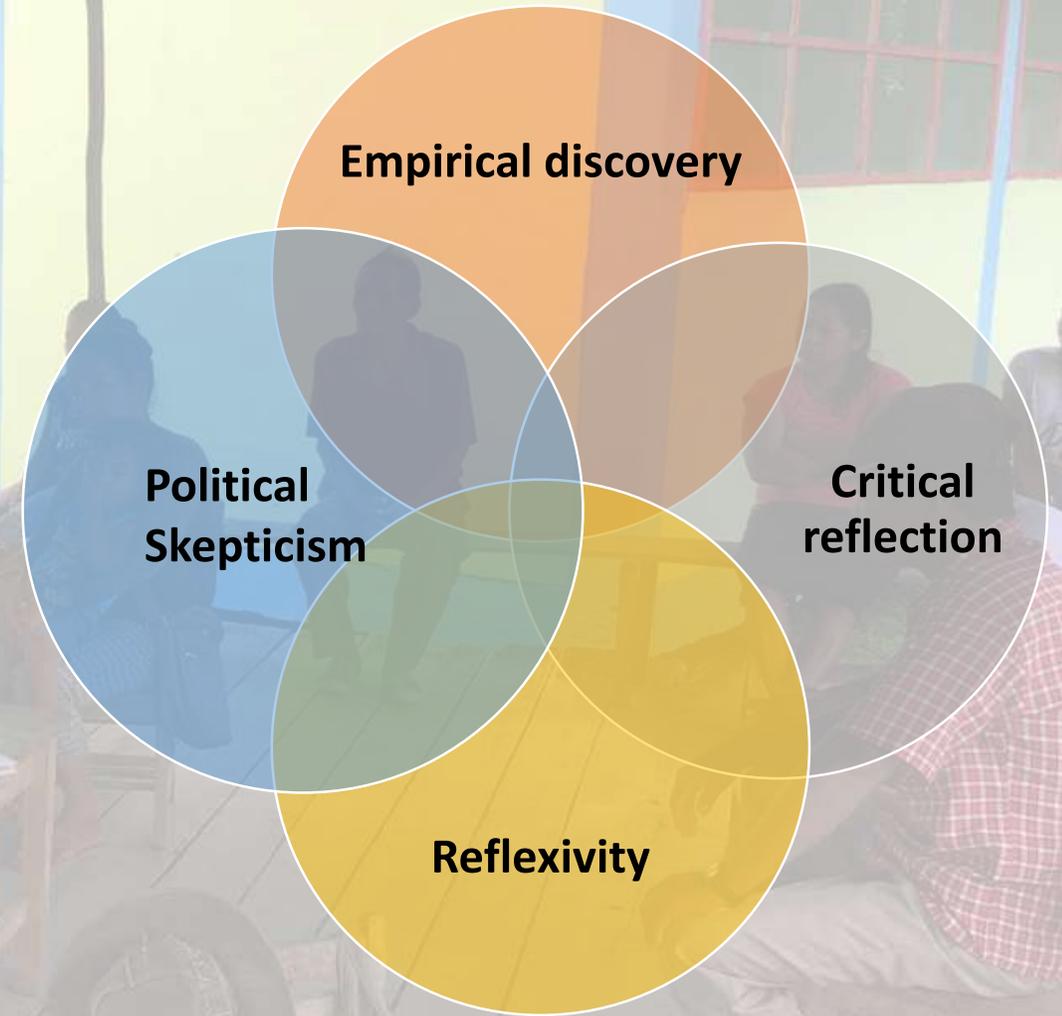
1. Reflecting
2. Planning
3. Acting
4. Observing

- The GAP Project:

- Engagement and ethics
- Reflection
- Planning
- Action
- Observation

Critical Bioethics

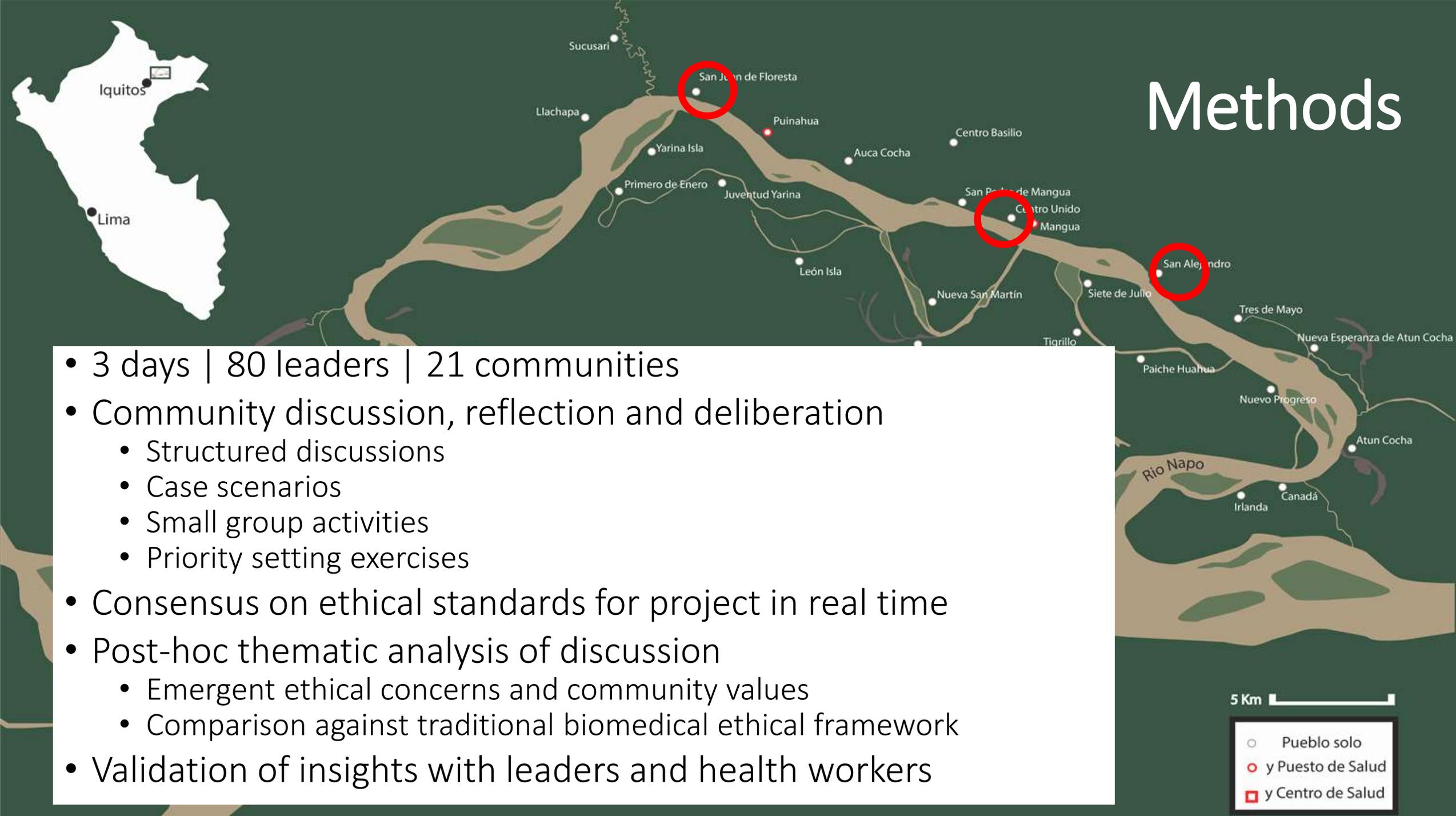
- **Positions** study of emergent ethical challenges in local contexts
- **Critically** examines socio-cultural, socio-political and socioeconomic dimensions of ethical issues (Murray & Holmes, 2009)
- **Values** social and cultural context and lived moral experience over idealised, rational thought dominant in traditional philosophical bioethics (Hedgecoe 2004)



Adapted from Hedgecoe, 2004

Methods

- 3 days | 80 leaders | 21 communities
- Community discussion, reflection and deliberation
 - Structured discussions
 - Case scenarios
 - Small group activities
 - Priority setting exercises
- Consensus on ethical standards for project in real time
- Post-hoc thematic analysis of discussion
 - Emergent ethical concerns and community values
 - Comparison against traditional biomedical ethical framework
- Validation of insights with leaders and health workers



Results

confidentiality	love of service	punctuality
justice	volunteering	solidarity
respect	setting an example	tolerance
valuing the individual	compromise	honour
honesty	sincerity	responsibility
privacy	friendship	security for women
valuing health	love	sensitivity
dialogue	fidelity	coordination
valuing life	family security	collaboration
confidence in the family	care / affection	education

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	care / affection	education
		love of service

confidentiality
justice
respect
valuing the individual
honesty
privacy
valuing health
dialogue
valuing life

Women sometimes do not report violence or do not have that confidence to talk to their leaders, because that leader tells his neighbour, like this. There are many things in which you have to have a lot of privacy, then there are things that you have to keep as professionals... there are many reasons and that is why the leader must be more cautious with that kind of thing. (Teacher, SA)

*The main value is **respect**, it is the most important of the values. The second, **privacy**, the third that I have put, **security** ... security there must be a lot, very important is to find and another, to have trust between people and be supportive of the latter, to be in solidarity with those, be it with adults or with children, good or bad, we always have to help participation, value what they say... (Leader, CU)*

confidence in the family
volunteering
setting an example
compromise
sincerity
friendship
love
fidelity
family security
care / affection

*First of all for me it is the [value of] **affection**, because having affection before all people, with your friends, with your children mostly, in our house... having that love, **love** for your children, giving them more confidence so that they lose that fear, be affectionate, hug them, kiss them, talk to them. That is my grasp [of ethics], thank you very much. (Promotora, AC)*

*I believe in a whole family conversation, because without **dialogue** there are sometimes no values [established in] in the house. As parents we must know how to value what our children are, with whom we live and we must know how to value that. (Leader, SS)*

punctuality
solidarity
tolerance
honour
responsibility
security for women
sensitivity
coordination
collaboration
education
love of service

***Love** in the home and in the **community**: the love of neighbors, their friends, so that no one disrespects each other... More than anything, to gain the **trust** and **respect** of the people, because imagine that you have to know how to reach that person, arrive with love.
(Promotor, SJF)*



Ethical Foundation → GAP Project

1. Broader community engagement
2. Knowledge and dialogue
3. Facilitation of project activities by leaders who had invested in the ethics sessions
4. Guiding principles for participatory planning and action stages of the project
5. Shaping community support pathways for victims

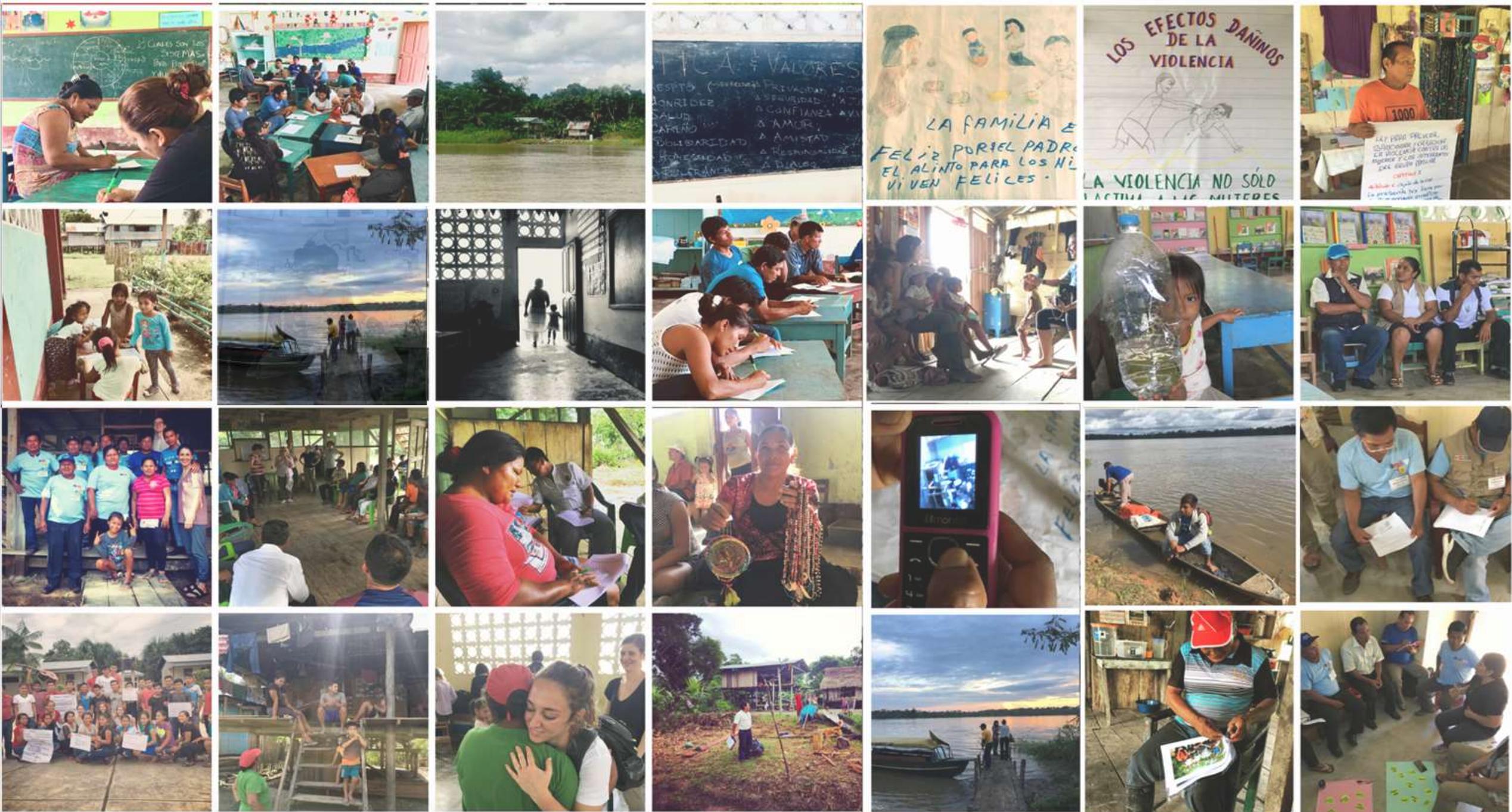


**Thank you!
¡Gracias!**

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Shannon G, Tuanama I, Pérez J, Inuma H, Lavy C, Diaz J, Tello J, Bowie D, Peña R, Minckas N, Mannell J.



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Topic		Comments	
Informed Consent	The theoretical literature emphasized on the importance of obtaining an informed consent from the participants before enrolling them in any study. Researchers should make their the obligation to ensure that the participants can make an informed decision regarding taking part in the project. Researchers should design information sheets in different languages/ formats to ensure that all participants understand the project they are taking part in. It is worth to note a consistency procedure for conducting a ethical research. The consistency procedure did not state that the community members are aware of the importance of obtaining an informed consent before taking part in the study.		
Privacy/No Harm	Security (the existing harm)	The theoretical literature emphasized that no harm should be caused by the researcher. This includes all kind of physical, emotional, economic harm. Researchers should take all the possible actions to minimize the risk of any possible harm.	Q: When do you think about security? M1: The one you are being harmed. I think of the security in that it is protected through our activities, to avoid many illnesses, an inability to access community, to access health, we can be a victim of an assault and to feel we must be protected from this, with a security of our activities, that's what I understand, a little bit more. E: Oh. M2: Because the presence of us, do we have security, we have nothing, without security, without justice there is no security, then, my way of thinking is that, there are 90% of the most interesting forms.
	Protection	Community members demonstrate good understanding that research should not cause harm for the participants. This was illustrated by using the word "consent" and looking at looking in the importance of protecting the participants from any physical or emotional harm. The supporting data evidence provided for how the community member illustrated their principles in their discussion.	Q: For example, have you seen how as most important, respect is the most important value, in project (00:15) the second priority, the third that I have put, security what I am not finding, security must be very, very important to feel and another to have trust between people and the fact is, actually, by supporting with them, either with adults or with the children, good or bad, we always have 100% participation what they say, a value, that.
Privacy, Confidentiality and Anonymity	Privacy	The theoretical literature emphasized that participants data should always be private and confidential. No identifiable data that can help identify the participants should be accessible for the public.	Q: In each case of evidence, the question is, in each case of evidence, how do you take it as a private item or does the community feel included everything? It's not private? Is it private unless someone find out? Do you know what is private? That? M1: Yes. M2: Sure. I think the authority in the police private sector. M3: I want to be confidential.
	Confidentiality	Community members also emphasize that all the data that the participants may share with the researcher must be private and confidential and researchers should not share this data in the community. Community members talked the importance of sharing the data confidential with the safety and security of the participants.	W: Because I believe that, as someone of health, they, I do not know if it will be the correct word, as in the obligation to keep it when things occur. And I'm going to take what the doctor told only in extreme cases when they come out of that, of confidentiality. E: Researcher come to us it is because they have confidence in us and I as a health promoter try to find a solution and if I don't can not solve the problem, I go to another entity. And what better than you, you are the center of the project or you are doing, thank God, the project here is wonderful, I see you, I think that would be the main value for the project.
Research	The theoretical literature require the researchers to protect the participants from any harm that they may experience. The researchers should ensure that the participants, if community members did not discuss the principle.		
Researcher	Moral Authority	Community members agreed that activities should take place with some ethical guidelines that have moral power. The researchers should be responsible and should be able to give through the discussion about the community leaders responsible around helping the women and the children who were a victim of DV.	Q: The question was, if you were a character that is an authority, in the year 2015, by a person or someone who has a role in your community, who can be like a leader, may be the president may, who makes decisions, sign of orders, being in the way, you as a leader what would you do about it? M2: Well, I want to continue. The authority is helping to the women, therefore, that is a community that is several activities. In fact, to meet with us there, to make a theoretical decision to discuss how that role of authority. Researcher sign cannot be an authority regarding a question and believing both to those of us, that is a decision but then often, to solve every the problems of authority. That would be. W: What would we do as a leader if we were involved in this case? M1: Well, I think that in why there is a decision to the community, we think that the authority, as someone government, have confidence here justice or judge, then we can involve it in the same community without causing any expense, without having to think that and without wanting that someone when the women can use "law", because when we would have a good he way there, it'll be well says "no" here, the health authority, that be the decision to try to refer to the community. Q: The case is not about, do I think that in the community is the main thing this case is about. Now, if there is no solution, then, the more competent authorities, because women have more rights, children have more rights and we all have rights as human beings. Then all these authorities have to analyze why the lady left her house to go to another house. That is why there is dialogue, to talk with dialogue with women what has been and analyze because as a leader. And the approach was to check when the women was. Then the government is there, but having allowed the doctor to go up and come to the house, then he should have done justice, because otherwise something could have happened in the house of the partner, for the government allowing the wife to be in the house and knowing and being that the woman is assaulted. Then the government is there for having allowed the aggressor to go to the house. I am going to be honest, I am not the authority in my house, after that in my house, I am not the authority, then, I am I change my responsibility.
		Respect	Both community members and theoretical literature highlighted that participants should be treated with respect and dignity. Participants should have their rights of being treated as human being and the researchers should not cause any discomfort for the participants.
Living People Their Rights	Respect		
	Provide Support		
Community Collaboration	Healthy		
	Respect		
Community Collaboration	Justice		
	Dialogue	Theoretical literature argued that researchers should include the community leader and members in planning and implementing the project. This could be done by conducting a stakeholder analysis to understand how community members can take role in the project and consult with community leaders to improve the project to the community.	Q: Can you mention, can someone mention a value? M1: Respect. E: As, respect. M1: Compliance, honesty. W: Good, good afternoon, as a stakeholder I work in collaboration with my people and with the other stakeholder, we collaborate with respect with the partner. That is all. E: There always been working in collaboration with the authorities of my community and, therefore, we have been working well, with respect, respect to all members and so we work well. I just want to say that. M1: Also, respect and trust. Respect (07:37) again and trust also (07:38-40). M1: Good afternoon, One of the values, how I have a role to be honest, for me, as a leader in my community, you deserve, either municipal or from the state (08:00) and they come to my community and (08:00).
Community Collaboration	Compliance	Community members emphasized on the importance of communication between the community members and the researchers to achieve the common goals. Researchers should also respect the participants and try to build trust with them.	
	Trust		
Community Collaboration	Communication and collaboration between activities		
	Trust		
Researcher Responsibility	Justice		
	Dialogue		
Researcher Responsibility	Compliance		
	Honesty		
Researcher Responsibility	Respect	Both community members and theoretical literature emphasize give the researchers the responsibility of being honest and respectful for the participants.	M: Therefore, from, the value is more, to be respectful. Q: Good afternoon, I know that is very important, we talk to the about respect. Well, as the most word of honor is healthy respect both the children yourself, because, well, I am respectful as I am, I do not respect for others because after I know, because a respect. That is why I respect, for the fact is responsibility, which is very important for each one of us, then there is responsibility, which is who rights called by each one of us, there is respect, confidentiality and confidence. W: Why confidence? M: My confidence, for example, if we are someone who is rich, we have to give this confidence, we have to respect the person. E: How, the other person did not have to make for him and even after the agreement which he is the house when she is with the children, because when women, if she leaves the house, they should register and the signs or maybe have identified her signs. W: Have more respect for our children, parents and authorities. Respect (07:37) respect, we will respect the others, the authorities, to have more with us authorities. E: What are you going to talk? Yes, respect? W: Good afternoon everyone, there values values, honesty, integrity, tolerance. M: Yes, I think it's a bad attitude because, after, at the same time we know that he is an aggressor... Actually, as the colleague that we respect neither in my group, sometimes people act like that whenever they see think, especially when they are with others in the group so in the way, because someone healthy is not going to act like this, it is very difficult, then we can not be here, well, you will have good relationships and that, then, you will have to that we think to talk with the person. In fact there are more competent authorities, who can refer you to talk to him later. I think that trying to give a person, it is an attitude that is able to be. M1: Respect and love. M1: Well, I have put in their values, respect, confidence, justice and commitment.
	Respect		
Researcher Responsibility	Trust		
	Being Honest		
Researcher Responsibility	Being Honest		
	Taking Responsibility		
Impact of Research on Stakeholder (Theoretical)	Not already covered by the community members but overlaps with the principles of research and its harm.		
Not covered by the theoretical literature for research	Learning		
Not covered by the theoretical literature for research	Honesty	These values were not covered well by the theoretical literature.	M2: But, because it was talking about values, I think (7:37) because love, care, we are culturally respecting that, but love. My approach is because with love I have a second way, respect to everything (07:48-51). That is my opinion of me, I do not know what the colleagues will say.
Not covered by the theoretical literature for research	Reflection		M3: Obviously, when I say, as you say, we have, we do change our sign? That's why there is respect to ourselves and continue our knowledge. That's it.