Community-based research review processes

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Key Points

Community-based research review processes (CRPs) are a form of ethical review that engage communities more meaningfully in the research process.

Through CRPs, communities actively shape and review the research process. CRPs aim to minimise harm, strengthen accountability, ensure that communities benefit from the research, and empower communities to determine which research projects are carried out. They can take different forms, depending in part on the existence and functionality of local institutional review systems, and can in all cases be an important complement to formal institutional reviews.

CRPs require explicit recognition of diverse forms of knowledge and a commitment from researchers to work in meaningful partnership with communities.

Important good practices include commitments to accessible dissemination that ensures communities involved in the research meaningfully own the findings. This requires planning for the entire life cycle of the project, beyond design and data collection alone.

Common challenges that can arise in CRPs include: 1) Challenges in ensuring meaningful informed consent; and 2) Imbalances of decision-making power and access to resources within communities, and between researchers and communities.

Being aware of these challenges and taking steps to mitigate them in the design stage and throughout the project, can help to support more ethical and meaningful research.

WHAT ARE COMMUNITY-BASED RESEARCH REVIEW PROCESSES?

Community-based research review processes (CRPs) are a form of ethical review that centrally involve the communities with whom research is being carried out. They present an alternative or complementary approach to conventional institutional ethical review processes. Conventional approaches to ethical review are traditionally carried out in universities or research institutes, often far removed from the communities directly affected by and involved in research.[1]

CRPs are part of a broad range of participatory research approaches, that consider communities as 'agents of change'. These approaches emphasise that researchers should seek collaboration and partnership with communities instead of engaging in research on or in communities. Participatory research approaches invite researchers and communities to co-create, co-facilitate, co-analyse, and co-disseminate research.[2] Participatory approaches can contribute to addressing historic and existing power dynamics, and ultimately shifting imbalances.

CRPs have a specific role within participatory research to review proposed research plans, determine relevance and compatibility, decide whether a particular project should receive approval from the community to proceed, and holding researchers accountable for their work with communities.

CRPs have three central aims:
1. To ensure that research is both relevant and beneficial for communities;
2. To foster 'a stronger community voice in determining which studies to approve'; and
3. To facilitate opportunities for 'capacity building' and sustainable research collaborations.[3]

There are three primary types of CRPs:

1. General research guidance:
Some CPRs establish standing community guidelines. These are 'documents developed by, with, or for communities to outline ethical behaviour or research conduct'.[4] They typically last beyond the lifetime of an individual research study or project. These may be particularly important in 'over-researched' communities where extensive study has taken place, often with limited community ownership.[5]

2. Formalised review boards:
Some CRPs take the form of community review boards. These are like conventional institutional review boards (IRBs), but they specifically review projects involving a particular community, emphasising the research priorities of that community.[6] This involves establishing a committee of reviewers from the community who review research projects seeking their engagement. They aim to ensure compatibility with community priorities and participation preferences.

3. Project-specific advisory boards:
CRPs sometimes take the form of community advisory boards. These are normally established by a specific institution or research grant after funding is secured.[7] They focus on recruiting participants, reviewing research proposals, engaging in awareness and advocacy within the community and acting as a bridge between the specific research project and the community.

While conventional approaches to ethical review are often far removed from the communities directly affected by, and involved in, research, community-based research review processes (CRPs) are a form of ethical review that centrally involve communities with whom research is being carried out.

1. Glass and Kaufert, 2007; Brunger and Bull, 2011; Cross, Pickering and Hickey, 2015.
2. Kwan and Walsh, 2018; Shore, 2007, p. 32; Cross, Pickering and Hickey, 2015, p. 1008; Chambers, 1994.
3. Shore et al., 2011, p. S362.
4. Doerksen et al., 2024, p. 8.
5. Koen, Wassenaar and Mamotte, 2017.
6. Doerksen et al., 2024.
7. *Ibid*.

WHY ARE CRPs BENEFICIAL?

CRPs are important for five key reasons:

1. Input into design:
CRPs help to ensure greater community representation in the review and approval of research projects. In traditional approaches to ethical review, institutional boards review and approve planned research, potentially in a different country or continent to where the research actually takes place. Members of the community where research is planned to take place often have little or no say in what research is carried out, how it is designed and implemented, and who is involved. CRPs can help to address this imbalance,[8] and hold researchers accountable to communities.

2. Safeguarding and minimising harm:
CRPs can help minimise harm and risks for collaborating communities involved in the research. Community involvement is critical to protect and safeguard the rights and welfare of community collaborators. This is especially relevant in cases where research may involve sensitive or taboo subjects, risk traumatising or otherwise harming participants, or put participants at risk of reprisals or exclusion in their communities. External researchers may have insufficient understanding of these risks and how to mitigate them. CRPs should aim to establish checks and balances to ensure accountability and minimise harm.[9]

3. Ownership of results:
CRPs can establish guidelines or requirements ensuring that research findings are disseminated in meaningful, accessible and ethical ways.[10] Even when research is carried out ethically, researchers may fail to meaningfully communicate and disseminate research findings among participants and wider communities, while others may do so in inappropriate or insensitive ways. This can limit the utility of research within the communities where it has the greatest potential impact, and in some cases, even constitute unethical research practice.

4. Recognise and support community expertise:
Participatory research approaches in general require recognition of diverse forms of expertise, and a commitment to co-creating knowledge. CRPs specifically can play a role in identifying and recognising local expertise – from project logistics to navigating sensitive issues in the community – and ensuring this informs decisions on the ethical and appropriate conduct of research. CRPs can also help to strengthen existing research capacities within communities where studies take place. CRPs may encourage or require investments into training research staff in a way that supports their capacity to access research funding directly, and take part in, undertake, and lead projects.[11]

5. Feasibility:
Meaningful community engagement and buy-in through CRP processes can support the smooth implementation and operations of research projects, by identifying barriers or resistance to participation, and promoting ethical approaches to overcoming these. CRPs may be particularly useful in conflict-affected, post-conflict, and insecure research contexts. Such contexts may not have established national-level legislation on research ethics, and those that do exist may be ad hoc, functioning only intermittently, or subject to interferences.

CRPs can help minimise harm and risks for collaborating communities involved in the research, and safeguard the rights and welfare of community collaborators.

They may also be susceptible to rapidly changing environmental, political, and security factors that can affect how a research project is undertaken.[12] Wherever possible, CRPs should serve as a complementary approach to all available formal ethical review processes, including international institutional review where available, to support greater community engagement.

8. Shore et al., 2015.
9. *Ibid*.
10. *Ibid*.
11. *Ibid*.
12. Tapscott and Machón, 2024.

WHAT ARE THE STEPS INVOLVED IN CREATING AND UNDERTAKING THE CRP PROCESS?

Where a CRP body does not already exist, the steps below can be followed to support its establishment among the community and its role in a research project. In this brief, we primarily focus on CRPs' roles in design and review of proposed projects, and encourage readers to engage with wider guidance on participatory approaches to later implementation, dissemination and beyond.

Where available, researchers should make use of existing contextual and conflict analyses, as well as context-specific guidance on conflict sensitivity and do no harm measures. Researchers must also consult trusted local stakeholders identified in this process to avoid potential detrimental effects.

A deep understanding of community power dynamics is critical given the potential for community-based processes to be biased or partial if these are not taken into account, and for research to ultimately do harm.

Identify who 'the community' is.
Before engaging in the research process, it is essential to clearly establish *who is the community*.[13] The definition of the community, and who to approach as representatives where no CRP currently exists, will depend on the broad research questions the study intends to address.

On a practical level, researchers should consider, among other relevant factors:

1. Place – is the community geographically defined as a town, village, neighbourhood, or area? and

2. People – who makes up the community of interest in terms of key groups or demographics?

More fundamentally, researchers also need to carefully consider:

3. Power – who among the intended community has authority and power in decision-making; who is marginalised, over-researched and/or traditionally excluded from decision-making; and what steps can be taken to ensure community engagement is inclusive and reflective of these dynamics? The question of power is crucial and requires careful consideration. A deep understanding of community dynamics is critical given the potential for community-based processes to be biased or partial if these are not taken into account, and for research to ultimately do harm.

Establish dialogue.
Before the research begins, community representatives and researchers should engage in exchanges exploring 1) what does the community think should be emphasised in a community review; and 2) how should a community review be different from an institutional review?[14]

To accomplish this, the CRP should establish a platform for dialogue between researchers, community groups, and research partners 'about the design of the study, community needs, and the ethical principles that undergird responsible conduct of research.'[15]

This means setting up regular meetings or discussion forums with community representatives to discuss key aspects of the project (i.e. project design, implementation, and findings). Feedback from meetings should be recorded via meeting minutes or other archival formats (i.e. audio recording subject to consent from those involved) and integrated into the project design and outputs.

13. Cross, Pickering and Hickey, 2015, p. 1008; Key, 2017, p. 991.
14. Brunger and Bull, 2011.
15. Cross, Pickering and Hickey, 2015, p. 1012.

WHAT ARE THE STEPS INVOLVED IN CREATING AND UNDERTAKING THE CRP PROCESS? (CONT'D)

Consider the suitability of the proposed research.

In reviewing research, CRP members should consider the following questions:[16]

1. Does the proposed research align with the research priorities set by our community?

2. Does the community have the capacity to participate in this research at this time and through the proposed lifetime of the project? Are community resources – including time, expertise and inputs – already committed or over-extended in other initiatives or research projects?

3. What is the potential for the proposed project to do harm, or result in unintended consequences (positive and negative) in the community, and to whom?

4. What is the potential for the proposed project to benefit members of the community, and who would be affected?

Identify measures that minimise barriers to meaningful participation.

Strong community participation, both in the research and more narrowly in CRP processes, necessarily creates demands on community members' time. Not all members may be in a position to participate equally and as fully as a result. CRPs should consider what barriers might prevent meaningful participation across groups, and what appropriate incentives are relevant and culturally sensitive to overcome these in the review process. In considering resources, CRP members might advise on the appropriateness of budgeting for stipend, travel, childcare, among other expenses as deemed necessary for that community.[17] To the extent possible, the project should adopt a flexible budget to account for culturally relevant expenses deemed necessary by the community to undertake the research.

CRPs can also advise on the appropriateness and accessibility of information, consent and wider project materials, that might otherwise prevent or limit community participation. For example, the CRP can co-develop a list of key terms to use when discussing the research with communities to ensure cultural sensitivity and accessibility of research communications.

CRP members should consider whether the proposed research aligns with the research priorities set by their community. Who is likely to benefit, and what is the potential for harm?

16. Adapted from Brunger and Bull, 2011, p. 138.
17. Shore et al., 2015, p. 1297.

WHAT ARE THE GOOD PRACTICES ORGANISATIONS AND RESEARCHERS SHOULD FOLLOW?

Effective CRPs prioritise benefit-sharing, resource-sharing, transparency, relationship building, and mutual trust in the following ways:[18]

Deep contextual analysis and understanding: Understand that communities are complex, with their own internal norms and power dynamics. These must be approached in a way that neither idealises nor minimises their value to the research review process.

A deep and nuanced understanding of the community must preface engagement in any review process to avoid unintended consequences, especially when studying marginalisation and sensitive topics with potential for diverse impacts. This can be accomplished by consulting trusted local experts and stakeholders to ensure the very first steps of identifying and empowering community voices in the review process are taken carefully.

Relationship-building and mutual trust: Establishing mutual trust requires a long-term commitment to partnership and relationship-building between researchers and community collaborators in several ways:

1. From the outset, engaging with key stakeholders who have longstanding relationships with communities, who are trusted by members of the community, and who have vast contextual knowledge can be a starting point for meaningful collaboration.

2. Building trust involves 'learning to communicate across differences' – including not only language differences, but also differences in socioeconomic, geographical, and methodological backgrounds between parties involved.[19]

3. Keeping regular contact, integrating opportunities for consistent feedback and follow-up, centring community knowledge, expressing a genuine interest in the well-being of the community and respect of their culture, traditions, and forms of knowledge production are all key factors essential for building mutual trust.

4. Finally, adopting as much flexibility as possible within the research design and approach are also essential for building mutual trust.[20] While researchers are often subject to fixed or relatively inflexible timeframes set by funders or required for logistical reasons, wherever possible, timeframes and planning should be flexible, and include contingencies if additional time is required.

While researchers inevitably face constraints, it is important to emphasise flexibility. Earlier efforts to build mutual trust can be significantly undermined if, for example, research plans are not flexible enough to allow time to prevent, understand and address issues if they arise.

Pursue longer-term institutional reform: Researchers should also pursue lasting change addressing systemic imbalances in conventional research ethics processes, starting in their own institutions.

Many of the barriers to more inclusive ethical review processes are structural in nature.
Researchers can take steps to improve ethical standards for community-based research, such as: 1) document learning from CRPs; 2) support exchanges on CRPs and research ethics processes within home institutions; 3) identify opportunities for CRPs to have a say in how institutional processes operate; and/or 4) facilitate access to funding opportunities for CRPs through institutional channels.[21]

Researchers can also exchange information on the practical realities of conducting ethical research with meaningful community engagement, and use examples of good practice to advocate on behalf of inclusive and participatory approaches in institutional ethical processes that may be unfamiliar with, or resistant to, these approaches.[22]

18. Buchanan et al., 2008; Brunger and Bull, 2011; del Campo et al., 2013; Cross, Pickering and Hickey, 2015; Kwan and Walsh, 2018.
19. Cross, Pickering and Hickey, 2015, p. 1015.
20. Ibid, p. 1016.
21. Flicker et al. 2007; Shore et al., 2011.
22. Kwan and Walsh, 2018.

WHAT ARE THE COMMON CHALLENGES, PITFALLS AND MISTAKES AND HOW TO AVOID THEM?

Navigating within-community power dynamics. Communities are not homogenous and different members, stakeholders and groups often have different interests and values. These differences can map onto existing power dynamics and inequalities, and shape the research priorities of different members. For example, research about educational inequality or marginalised groups' access to healthcare may threaten the status quo and be opposed by dominant groups, while minorities in the very same community may welcome it. Researchers should carefully consider the issue of potential misuse of leadership and gatekeeping when considering how CRPs review and approve proposed research.[23] There is no universal guidance for navigating these complexities, but investing time and resources in understanding community dynamics and questions of conflict sensitivity, as well as the expertise of trusted stakeholders, can help researchers to avoid reproducing or deepening existing inequalities.

Communities are not homogenous and different members and groups often have different interests and values. For example, research about marginalisation and inequality may be opposed by dominant groups, while others may welcome it.

Ensuring truly informed consent. Ensuring meaningfully informed consent, and sequencing consent-seeking processes from the collective to the individual, are key, interrelated challenges that can arise in CRPs. On the one hand, notions of collective rights and community consent may resonate deeply with some communities, though this approach is at odds with conventional research ethics protocols, which tend to prioritise individual consent and consideration for risks to individuals.[24]

Community-based consent may also raise issues related to the different risks that might be faced by the community collectively, compared with risks to (different) individual participants.[25] On the other hand, seeking individual consent alone may mean that participants who have questions about the research, or may have a fuller understanding of it through discussion with other community members, may feel unable to question or challenge researchers, especially where a power imbalance between research team members and the community exists.

Approaches that look for consent at multiple levels, and at multiple stages, can help researchers navigate this.[26] Kwan and Walsh give numerous examples of researchers seeking consent from communities collectively, and individuals, and repeatedly revisiting the question to ensure ongoing consent.[27] Ensuring participants also know and feel comfortable exercising their right to withdraw themselves and their contributions from the study and any limitations on this – such as timeframes in which results will be published – can also help ensure consent is meaningful and actively exercised.

Addressing power dynamics. Researcher-community power imbalances may include differences in decision-making power, socioeconomic backgrounds, access to institutional resources, financial gain, and project benefits. Studies often do not sufficiently reflect on 'prior inequalities' and the importance of equitable distribution of budgeting and resources when designing and implementing research projects.[28] For example, CRPs require reflection on how to navigate differences in financial benefits between payroll versus volunteer project members.[29] CRP studies should engage in transparent and open discussions about challenges in ensuring equitable partnership, including distribution of resources and project benefits.[30]

23. Glass and Kaufert, 2007.
24. *Ibid*.; Shore et al., 2011.
25. Key, 2017, p. 995.
26. Kwan and Walsh, 2018, p. 379.
27. *Ibid*.
28. Flicker et al., 2007, p. 485; Kwan and Walsh, 2018.
29. Flicker et al., 2007.
30. Kwan and Walsh, 2018, pp. 370, 376.

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About the SoCap Project

The Role of Social Capital in Urban F agile and Conflict-Affected Contexts (SoCap) project is a three-year research project funded by Irish Aid and undertaken in partnership with Concern Worldwide. It systematically analyses the interactions between social capital, resilience, the urban environment, and conflict and fragility among marginalised urban populations in Haiti, Somalia and Somaliland.

This mixed-methods research aims to understand how pathways that translate social capital to resilience among marginalised urban groups are both fostered and thwarted, to identify practical leverage points for operational and policy actors.

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